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# CHILDREN'S SSI POLICY

# HEARING

BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY
AND FAMILY POLICY

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED FIFTH CONGRESS

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# CHILDREN'S SSI POLICY

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## TUESDAY, JULY 7, 1998

U.S. SENATE,
SUBCOMMITTEE ON SOCIAL SECURITY
AND FAMILY POLICY
COMMITTEE ON FINANCE,
*Washington, DC.*

The hearing was convened, pursuant to notice, at 2:00 p.m., in room SD–215, Dirksen Senate Office Building, Hon. John H. Chafee, (chairman of the subcommittee) presiding.

Also present: Senators Breaux and Conrad.

## OPENING STATEMENT OF HON. JOHN H. CHAFEE, A U.S. SENATOR FROM RHODE ISLAND, CHAIRMAN OF THE SUBCOMMITTEE

Senator CHAFEE. Good afternoon. I want to welcome everyone to this hearing on the children's component of the Supplemental Security Income program, so called SSI.

This program has undergone tremendous change in the last 2 years, and this hearing gives us an opportunity to examine how these changes have affected the children and their families who rely on Supplemental Security Income.

Before we begin, I would like to take a minute to quickly review where we are with the regulations on the Children's SSI program. As most of you know, the welfare reform law enacted by Congress 2 years ago included significant changes to the Children's SSI program. For the first time, Congress put into the law a definition of childhood disability.

This new disability standard tightened the eligibility requirements for the Children's SSI program and resulted in nearly 148,000 children losing their SSI benefits. Fortunately, 22,000 of these children were reinstated, but only after having gone through a laborious appeals process.

There are two major issues which we will focus on today. The first, is the implementation process of the new disability standard. Many people have raised legitimate concerns about the way the standard is being implemented and whether beneficiaries are being treated fairly.

For example—and this is astonishing—in some States, 78 percent of the children are being terminated, and in others, only 38 percent are being terminated. This wide variation in termination rates suggests that something is askew, is not being done totally correctly. We have also heard reports about families not getting correct information about their right to appeal termination decisions.

Several of us on this committee shared our concerns with Commissioner Apfel several months back regarding the implementation of these regulations. The Commissioner, and I want to pay tribute to him, responded quickly and announced that SSA, that is, the Social Security Administration, would automatically review 45,000 cases that were terminated and would notify the other 75,000 families of their right to appeal Social Security's decision to terminate their benefits.

Commissioner Apfel acknowledged that some mistakes may have been made in the implementation process and he is eager to correct these errors. Again, I want to salute the Commissioner for his testimony and his efforts in this regard.

I am enormously sympathetic to the job the Social Security Administration has in implementing this complex set of regulations. The agency's disability examiners are forced to make very subjective and complicated decisions, so I understand that mistakes can, and indeed they will, be made. However, our first priority, it seems to me, must be the protection of these children and their families.

Given the challenges these families face on a daily basis, I believe it is incumbent upon us to do anything we can to prevent any additional stress. I know we have all reviewed some of these cases that have been written up, and they are very, very difficult on the parents, or the parent, trying to care for these children.

The other major concerns I have, is the regulations written by the Social Security Administration to implement the new disability standard made eligibility for the SSI program too strict.

I know many in this committee share my concern, in particular, Senator Conrad. We will hear today about many children who no longer qualify for the SSI program because they are not considered disabled enough.

I must say that I believe many, if not most, of these families deserve every penny that they can get from SSI. These are, in most instances, very low income families, where often one parent must quit working to stay at home with a disabled child because nobody else can or will care for them. The maximum payment is $484 a month, so these families are hardly getting rich off this program.

What alternatives are we giving these families who lose their benefits? They may end up on the State's cash assistance program. But they can only get on that for 2 years, under the new welfare reform laws that we put in.

If the parents must go to work, who is going to care for the children? We already have a child care crisis. Never mind these children with these difficulties; anybody trying to have a child cared for, the child is in perfectly good shape, the parent can pay a decent amount of money, but even in those instances, it is hard to find proper child care.

Forcing these parents of these disabled children into the workforce will only exacerbate the problem. Will some of these children be forced into institutions, and is that what we think is best? All of these issues concern us, and that is why we are here today.

I am so pleased that we have the Commissioner here who, as I say, I believe has worked hard on these programs and deserves our sympathetic concerns, because they are not easy.

I look forward to hearing the testimony of the distinguished panelists we have here this afternoon as we explore the answer to some of these questions.

I am delighted that the Ranking Member is here. Senator Breaux?

## OPENING STATEMENT OF HON. JOHN BREAUX, A U.S. SENATOR FROM LOUISIANA

Senator BREAUX. Thank you, Mr. Chairman, for having these hearings and for your leadership in assuring that people are treated fairly. In the last Congress, we spent a great deal of our time working on welfare reform. This Congress, we will be taking a closer look at what we did and implementation of what we did, and whether it is being implemented the way that Congress intended or whether it is not being implemented in the way that we thought we were requiring when the legislation was passed.

So I think that these hearings to follow up on the implementation of these programs is incredibly important. It is important that we just do not pass legislation and forget it, but that we come back and take the opportunity to find out what is happening and how what we legislated affects the daily lives of people.

It is clear that changes were made in how we were going to handle SSI. I think the whole effort was to ensure that people—children, particularly—who are truly disabled are being cared for, and that those that are not are not under the guidelines of the program.

If you have anyone in a program that is not qualified to be in the program, it makes it that much more difficult for those who are truly needed to get what they need in order to help them through difficult times.

So it is a very difficult thing to legislate on. I mean, you have to have humans involved in the process to make decisions based on what is correct, with the legislation being the ultimate guideline.

Anyway, this is an opportunity for us to see if what we adopted in the last Congress is being implemented as we felt it should be implemented to ensure that truly disadvantaged and disabled children are adequately taken care of.

That is a goal that I think, whether we are Democrat or Republican, we all share in and all are committed to making sure that that type of service is provided in this country at this time. Hopefully, these hearings will shed new light on where we are and what still needs to be done.

I thank the Chairman for having the hearings.

Senator CHAFEE. Well, thank you, Senator Breaux.

I want to say, Mr. Apfel, I hope in your testimony, if you think that there are changes that we should make to make your job an easier one to do, I hope you will give us those suggestions because we are anxious to make this whole program work better than it is, in some instances.

So why don't you go to it with your testimony, Mr. Apfel.

## STATEMENT OF HON. KENNETH S. APFEL, COMMISSIONER OF SOCIAL SECURITY, WASHINGTON, DC

Commissioner APFEL. Thank you very much, Mr. Chairman, Senator Breaux. I can assure you that the 65,000 employees at Social Security, including myself, and the 15,000 employees in the State Disability Determination system have that same priority in mind, and that is the assurance of fair and effective services for these disabled kids.

Thank you for inviting me here today to address this very important topic. Over this past quarter century, the SSI program has helped families of children with disabilities meet their special needs. It has become part of an important safety net for some of our most vulnerable families.

As you know, families with disabled children face challenges and bear burdens unknown to most of us. When those families also live in poverty, the strains on the family can be severe.

These families and the American public need to know that their government is making accurate decisions about eligibility for vital benefits. That is why, during my confirmation hearing, I pledged a top-to-bottom review of SSA's implementation of the 1996 childhood disability legislation.

We needed to know whether the law and the regulations were being applied fairly. We needed to be able to assure the President, the Congress, and the American people that every child is receiving a thorough and accurate assessment of his or her eligibility for benefits. That review was completed in December. Basically, we found that SSA and the States overall had done a good job, but that there were some problems.

We identified three specific areas of concern. First, children classified in our records as having mental retardation. Second, the quality of some aspects of our case processing. Third, the adequacy of the notices that we sent to families explaining their rights to appeal and to receive benefit continuation.

As a result of our findings, I directed the State DDSs to review the cases of approximately 36,000 children whose benefits were ceased, and to renotify about 75,000 families in which their right to appeal may not have been clearly understood.

We believe that, at the end of the process, three-quarters of those children who had benefits ceased will have received at least two separate evaluations of their eligibility, either as a result of their original appeals or other reviews.

Let me briefly summarize specific findings and subsequent agency actions. Of approximately one million children on the rolls in December of 1996, about 407,000 were coded in our computer system with a primary diagnosis of mental retardation.

Eighty percent of those children, about 325,000, met our listings for mental retardation and were not subject to the redetermination under the new law. Of the 80,000 cases that were redetermined, we found that many of these children did not actually have mental retardation.

Our data carried this diagnosis code because of our computer coding limitations and, frankly, some coding errors that were in the system. We have been working to establish more accurate computer coding of our disability cases.

But our quality assurance data also showed that some children with the code of mental retardation may have had their eligibility ceased incorrectly. I, therefore, ordered a review of all redeterminations for children that SSA had coded as having mental retardation and whose benefits were ceased.

The review of approximately 14,000 such cases began in March. About 2,600 have now been completed, and about one-third have been revised and benefit payments to the child continued.

The second area of concern was quality of case processing. Our quality assurance reviews found that the accuracy of both continuance and cessation determinations was above the regulatory threshold for most States.

Senator CHAFEE. Would you hold on one minute, Mr. Apfel? You are summarizing your statement?

Commissioner APFEL. Yes. I thought you had my summary.

Senator CHAFEE. Well, I am with you half the time.

Commissioner APFEL. All right.

Senator CHAFEE. It is that other half that worries me. [Laughter.]

Commissioner APFEL. There are large paragraphs that are taken out of the testimony.

Senator CHAFEE. Let me find what page you are on now in the summary. All right. Go ahead.

Commissioner APFEL. You can have mine, when I am through.

Senator CHAFEE. Let me see. What page are you on?

Commissioner APFEL. Page three, fourth paragraph.

Senator CHAFEE. Gee, you only have four pages.

Commissioner APFEL. Three pages. Short.

Senator CHAFEE. All right. Go ahead.

Commissioner APFEL. The second area of concern, Mr. Chairman, was the quality of case processing. Our quality assurance reviews found that the accuracy of both continuance and cessation determinations was above the regulatory threshold for most States, but in many States there was lower than average cessation accuracy for certain categories of cases.

I, therefore, directed all States to review some of the redetermination cessations that did not have the mental retardation code and which have the highest likelihood of error.

We have now completed about 4,000 of about 22,000 cessation reviews for processing quality concerns, and about 14 percent have been revised to continuance of benefit payments.

Where continuance accuracy was found to be below the threshold, we will give childhood disability cases first priority for reviews. Plans are being made to review those continuance cases in FY 1999.

The final area of concern, Mr. Chairman, was the adequacy of our benefit notices. When Social Security sends notices telling families that 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 appeals process. They are also told how to obtain information about attorney representation.

However, concerns were raised that our cessation notices were hard to understand. So, in February, the Social Security Administration sent special notices in simpler language to approximately 63,000 families of children who lost SSI eligibility and who had not appealed. We sent similar notices to the 12,000 families who had requested a reconsideration but who did not request continuation of benefit payments.

As a result of those notices, more than 22,000 additional families have requested that we reconsider our original determination to cease benefit payments. More than 65 percent have also asked for benefit continuation, and about 5,200 families that had previously appealed the cessation determination but had not requested benefits to be continued have now done so.

It is also important to note that we conducted training at all levels for staff making adjudicatory decisions. The training focused on the areas of greatest concerns from the top-to-bottom review. We have developed unprecedented safeguards to assure that our adjudication is consistent and our policy is nationally understood.

The American public should also realize that, thanks to the urging of President Clinton and this committee, last summer Congress passed an amendment as part of the Balanced Budget Act which ensured that children who lose disability payments remain eligible for Medicaid benefits. SSA is working closely with the Health Care Financing Administration and the States to make sure that Medicaid coverage continues for these children.

In conclusion, I would note that at the time interim final regulations were published, we estimated that about 135,000 children who were on the rolls in December 1996 would eventually lose SSI disability benefits. We now estimate that, when all reviews and appeals are completed, the number of children losing benefits will be about 100,000.

I want to emphasize that these reviews have been about children, not numbers, and consequently we have taken steps above and beyond normal to protect their rights. I am committed to providing fair and equitable administration of the SSI Disability program for all children, now and in the future.

The actions I have taken as a result of this review of SSI Childhood Disability will improve the agency's ability to meet that objective. You have my pledge that I will continue to ensure that children with severe impairments receive the benefits for which they qualify.

As you can see, I got the length of the statement right. The light just went off. [Laughter.]

[The prepared statement of Commissioner Apfel appears in the appendix.]

Senator CHAFEE. Well, you are a veteran here. Thank you very much. That is extremely interesting. I remember when you had that estimate of the 135,000.

Last June, just this past month, a number of us sent you a letter, dated June 24, regarding the proposed House legislation which, among other things, would apply a two-mark standard to all of the medical listings used to determine whether children are eligible for SSI. They had that two-mark standard.

What is your position on that proposal?

Commissioner **APFEL**. Mr. Chairman, the administration strongly opposes legislation establishing a two-marked standard for all listings. The listings have different histories behind them; some are medical, some rely on functionality, some rely on the pervasive nature of a particular disability, such as mental retardation. If we look at, say, cancer listings, children's cancer cases only have medical requirements.

Now, do kids with cancer meet functional tests? Some of them may not, but these kids are really sick. So we believe that establishing a two-marked standard for all listings is inappropriate and we would oppose such an effort.

Senator **CHAFEE**. Now, I am concerned about the children who are being reviewed at the age of 18 and the very high rate of denial for them. I think it is in the high 50s. Children under 18 are eligible for the SSI program about 70 percent of the time, on the basis of the listings, then it drops to 56 percent when they get to be age 18.

Your data shows that over 73 percent of these children have mental impairments, including mental retardation. Do you have any views why the children, when they are below 18, meet the standard, but no longer need it when they read so called adulthood, or are over 18? What changes?

Commissioner **APFEL**. Mr. Chairman, there is a very real reason, there is a different standard that applies at age 18. The law requires that, at age 18, children who were already on the rolls receive a de novo review, a brand-new review, as if they were applying for the first time for benefits under the adult standard. The adult standard is the one that is used at that point in time.

If you look at the adult standard, it is a very tough standard for disability. It is particularly tough for young adults. The way that the disability program works, by the time an adult is 59, 60, 62, 63 years old, the threshold questions that would have to be asked to meet the disability test are more lenient than they are for younger people.

By the time someone is in their 60s, if they are barely able to engage in their own particular job, then they could become eligible for disability. At younger ages, it is a much tougher test.

So what happens at age 18, under law, is that individuals are required to pass the adult test for the first time. By law, we have to review under this tougher standard all cases including a child who attains age 18 .

Senator **CHAFEE**. Do you think it makes sense?

Commissioner **APFEL**. I think it does. I think there are questions as to whether we should do a better job for kids age 16 and 17 preparing for this step. I think that is an important question that we need to look at.

But at age 18, this is after school, this is basically, for many people, entering into the world of work. I think that the separate standard, the adult standard, makes sense, if not at 18, then at 19. I do not know. It seems to me that it is about right in terms of that adult standard at about that age.

Senator **CHAFEE**. Senator Breaux?

Senator **BREAUX**. Thank you, Mr. Chairman. Thank you, Ken, for being with us. You had a lot of numbers and I was getting lost in all the numbers. Can you give us the figures? How many children did we have SSI qualified before we passed the changes, and how many actually were terminated off the program after?

Commissioner APFEL. All right. The SSI program, prior to the implementation of welfare reform, had about one million kids on the rolls. If you look over here at the chart, you will see that that has significantly increased since 1990, which did raise the specter about whether the program should be tightened.

Senator BREAUX. So the real spiking of increase started in 1990 and went up until it reached a peak in about 1996, is that the number?

Commissioner APFEL. In 1996, at about one million kids.

Senator BREAUX. And then welfare reform——

Senator CHAFEE. The figure over to the left, is that 1990, the first column?

Senator BREAUX. Yes.

Commissioner APFEL. Yes.

Senator BREAUX. And then welfare reform, when did it actually begin?

Commissioner APFEL. 1997.

Senator BREAUX. 1997 is when it kicked in. Yes. So you had the real drop from 1996 to 1997.

Commissioner APFEL. That is correct.

Senator BREAUX. All right. So a million before. Then, I am sorry, how many did it drop to?

Commissioner APFEL. The law required us to review about 288,000 of the million kids on the rolls. At the initial level, originally, about 150,000 had been terminated from the program.

Senator BREAUX. 150,000.

Commissioner APFEL. About 150,000. Based on re-reviews since that time, we are now down to about 125,000 who have been terminated. Our projection is, by the time we complete all of our re-reviews, and our reconsiderations, and our appeals, we will be down to about 100,000.

Senator BREAUX. One hundred thousand from the one million, total?

Commissioner APFEL. One hundred thousand from the one million, total.

Senator BREAUX. Which would be removed because of questions about mental competency.

Commissioner APFEL. Or physical competencies, or mental retardation.

Senator BREAUX. You look at physical impairments as well as the mental impairments?

Commissioner APFEL. Right.

Senator BREAUX. All right.

Commissioner APFEL. The statutory change affected, potentially, about 288,000 of the 1 million cases. The other 722,000, roughly, were unaffected by the legislation and continued. Of the 1 million, 400,000 of these were children with mental retardation; 320,000 were absolutely untouched, not reviewed, and about 80,000 mental retardation cases were reviewed.

Senator BREAUX. The 100,000, what would you categorize their being removed from SSI rolls is due to?

Commissioner APFEL. Specifically, about 10 percent were due to income changes, non-medical reasons, and about 90 percent were due to the new standard, the tougher eligibility standard.

Senator BREAUX. For the mental disability, or for physical, in general?

Commissioner APFEL. I would say that, from the mental side, it is probably about 70 percent.

Senator BREAUX. That is what I was trying to figure out. Seventy percent of the 90 percent would be because of the changes in the mental retardation standard.

Commissioner APFEL. And maladaptive and other emotional problems, learning disabilities, et cetera.

Senator BREAUX. But mental as opposed to physical impairments.

Commissioner APFEL. As opposed to physical, that is correct.

Senator BREAUX. Senator Chafee asked this question. Does it make any sense to have one standard below 18 and a different standard when, the next day, you are 18 or 19 years old? Would it not make it simpler to have one test that takes into consideration the age of the person, but, I mean, the standard would be the same?

Commissioner APFEL. Well, actually, I do not. If we were going to say whether this 4-year-old can engage in substantial gainful employment, I do not think it is a relevant test.

Senator BREAUX. No, that is obvious. But being able to adapt to society at 4 years old means one thing, being able to adapt to society at 20 years old means something else. But the test, is being able to adapt to society.

Commissioner APFEL. The childhood standard is based both on medical conditions, say, children's cancer, as well as functional limitations, the whole broad-based area of functional limitations.

My own belief is that, if we look out years into the future—and this is going to take years—functionality ought to be the basis for a lot of our disability determinations, the ability of the individual to be able to function in society, not just his or her pure medical condition. But that is a very broad, a very significant, and a very lengthy process. Before we could ever move over to the entire disability program being based on functionality——

Senator BREAUX. Obviously, I am not a psychiatrist or psychologist and have no training in that area. But does the medical profession support that, in general? I mean, it would seem to me that a 15-year-old being able to function in society is a test.

Being able to function in society at 30 or 65 is the standard; can that person function as a normal 15-year-old, a normal 30-year-old, or a normal 65-year-old? The standard being, able to function in society.

The 15-year-old would be required to do different things, as his peers do at 15, or at 30, or at 65, but the standard is being able to function in society. Are you arguing that there should be a different standard depending on the age?

Commissioner APFEL. I do not think that we have the technical expertise to solely rely, for adults, on functionality as an assessment of whether somebody should be on the disability rolls. I think it is one of the areas that we need to look at. There is a lot of research. We have a major research effort under way to look at functionality, but I do not think it——

Senator BREAUX. I would argue that this is not as much a political question as it is a medical question. I mean, I think that a reasonable standard is a person's ability to function in society. Different ages require different things to be done to be able to function in society, but that is a question we will reserve for later.

What about the Medicaid coverage? I think it would ensure, in the last Congress, that children who lost their SSI Disability benefits as a result of the changes we made would continue to remain eligible for Medicaid, as I understand it.

Commissioner APFEL. That is correct.

Senator BREAUX. Now, also, I think in my State, if you lose SSI, you lose Medicaid. Have they not complied with that?

Commissioner APFEL. In terms of SSI kids, I would certainly hope not. It is my understanding, working with the Health Care Financing Administration, we have provided information to each of the States and to the Health Care Financing Administration of any child who has lost benefits.

Senator BREAUX. Is that being clearly communicated to all the State Medicaid offices?

Commissioner APFEL. Absolutely. HCFA has, as recently as about six weeks ago, sent out a major issuance to all States clarifying roles and responsibility for this coverage. There have been some individual problems in a few States, and it has been my understanding that virtually every one of those has been corrected. But if not, I would urge the committee to get that information to me.

Senator BREAUX. Let me ask you a final question. On any of the children that were getting benefits that you determined should not have been under the new standards, are any of them being required to pay back benefits that they received before the determination came that they now are no longer eligible.

Commissioner APFEL. Under law, there is a requirement to repay, but there is also under law a waiver, which is a very broad-based waiver.

Senator BREAUX. So, of the 100,000 that have been determined not to be eligible under the new standards, how many of them were granted a waiver and how many of them are being ordered to repay some of their benefits?

Commissioner APFEL. I will get you that specific number to date, but I think you will find that a vast, vast majority have been provided with this waiver.

Senator BREAUX. I would think that would be very important, because I really just find that the Internal Revenue Service and other agencies, they overpay someone, then they find out about our mistake, meaning the government's mistake, then they send you a bill for umpteen thousands of dollars, of which a family, particularly on SSI, cannot afford to pay.

I mean, it is just that you cannot get blood out of a turnip, particularly when it is our mistake or it is because of a change in the law or the standard. But Congress instituted that we did not send a bill to someone and say, you send us, please, $16,497.16. I mean, they cannot do it.

Commissioner APFEL. In the case of a redetermination, there would not have been an overpayment in the past, it would be in the case of an appeal.

Senator BREAUX. Prospectively.

Commissioner APFEL. But even then, the vast majority do not have to repay. We will try to get you the number that exists on this.

[The information follows:]

SSA did not consider children whose Supplemental Security Income (SSI) payments were ceased to be overpaid, unless the cessation was appealed, payment continuation requested, and the cessation subsequently upheld. In those cases, as in other overpayment cases, SSA considers the beneficiary "without fault" (the primary factor in determining whether to grant waiver) in creating the overpayment, if the beneficiary acted in good faith to appeal the disability redetermination. While the supplemental security record does not contain easily obtainable data on the number of waiver approvals, since SSI children usually cannot afford to repay the money (the secondary factor in determining whether to grant waiver), SSA approves their requests in most cases.

Senator BREAUX. Do not spend a lot of time on it. I was just thinking, apparently what you are doing is the correct approach to it. I mean, I think that is the right way to go.

I know that there was abuse in this program. I know unscrupulous operators who were actually encouraging families to try and get their children qualified for SSI benefits, particularly because of mental disabilities. For every one of those, that means there is less for someone who is truly disabled. So I think what you are doing is correct and I think the way you are pursuing it is appropriate and proper. Congratulations.

Commissioner APFEL. Thank you.

Senator CHAFEE. Mr. Apfel, how do you arrive at the monthly payment? From my notes here, it indicated that the monthly maximum was $484. What would make that change? I do not think anybody——

Commissioner APFEL. The $484 would be the maximum, with virtually no income in the family. The way the SSI kids program works, the eligibility is income related, so the higher the family's income, the lower that benefit would be. Benefits go all the way up to about 180, 185 percent of the poverty level. So it is not solely for individuals below poverty, it is also for those who are near poverty.

Senator CHAFEE. Oh, I see. So what would make it go up, would be if the poverty level increased.

Commissioner APFEL. Well, if the individual's income was, say, at 130, 160 percent of the poverty level, rather than getting the full benefit, they would be getting a reduced benefit. So the amount they would be receiving would be based upon the income in the family.

If somebody has income that exceeds the poverty level by 300 percent they would not be eligible for SSI kids' benefits for the family. But the individuals with incomes at, say, 150 percent of the poverty level would receive benefits, but at a lower amount.

Senator CHAFEE. What struck me, was the disparity between the States when they did the reviews. Some States, I think it was in the 70s that there were rejections, and in other States it was 35, or something.

Now, the people who do the reviews, they are all your people, are they not? They might be from the State, but they are not on the State payroll, they are on your payroll, are they not?

Commissioner APFEL. Well, no. The initial determinations are done by State employees, through the State Disability Determination systems, but they are part of the Social Security family.

The Social Security Administration is 65,000 individuals working in 1,300 field offices around the country, plus 15,000 State workers who are working in State Disability Units, and they actually make the determinations under the guidance and the guidelines of the Social Security Administration. We work very closely with them. You will be hearing from the head of one of the Disability Determination Units, I think, later at this hearing.

If I could say, Senator, on the point of differences, that was one of the areas that troubled me greatly as well. Part of the reasons for the differences among States has to do with different case characteristics: the poverty level in that State, the number of families that would be going on the rolls, the age of the children that would be going on the rolls.

If I could give you an example which I think helped me greatly, back when we had the old system, the old Individualized Functional Assessment or IFA, we determined eligibility through the old listings or through the IFA system that was established back in the early 1990s. Some States put a lot of people on the rolls through that new system, not the listings. The all the IFA cases had to be re-reviewed under welfare reform.

Any State that had put a lot of people on the rolls based on IFA, many of whom would have been eligible based on the listings, would have a very high continuation rate, for example. Another State with very low levels of people using the IFA might very easily have a higher cessation rate, and more denials of benefits.

In addition, back in the 1990s when the standard was three moderates to be able to get benefits, it was a looser standard and it was not as tightly crisp in terms of the definitions.

So now that there is a tighter definition, you will see some of the States that have put on large numbers of children through the three moderates with the higher denial rates. So, some of the reasons for State-by-State differences are very clear.

Senator CHAFEE. Thank you. Senator Conrad, any questions?

Senator CONRAD. Thank you, Mr. Chairman. I appreciate very much your holding this hearing, and I think it is critically important.

It is good to have you here, Commissioner Apfel. We certainly appreciate working with you.

Senator Chafee and I have worked on this issue for an extended period of time and we have been very concerned with what we have seen, because all too often we have seen kids knocked off the rolls that we think legitimately deserve support. I must say, that concern continues.

I am very concerned still with the huge variances among State termination rates, ranging from 36 percent to as high as 80 percent. I am interested in what your views is as to the explanation for this significant variance.

I see, for example, in Texas that their termination rate is 79 percent. In my own home State of North Dakota, it is 69 percent. We have other States that are as low as 36 percent. What do you think accounts for this dramatic range in termination rates?

Commissioner APFEL. We did a regression analysis to try to break out some of those differences. Some of the differences are due to case characteristics, in terms of the poverty levels within the State, the age of the individuals who are undergoing the reviews, as well as the characteristics of those individuals. But it is also due, as I indicated to Senator Chafee, to the manner in which individuals came onto the rolls in the first place using the old IFA eligibility screen versus the listings, the pure listings.

This is not true in all cases, but in many cases, States that used the IFA a lot to bring people on the rolls could have many of those individuals eligible for the listings, and, therefore, you would have a high continuation rate in those cases.

So when I first saw the differences among States, I was deeply troubled, as I indicated here last fall. I believe that a lot of it is due to several factors that are understandable. Not all of it, certainly, but a lot of it.

I also would point out, Senator, that in States with high termination rates we also have high appeal rates. We are also going in, looking at, and reopening cases in several areas in those States.

Senator CONRAD. What is the rate nationally for overturning initial determinations on appeal?

Commissioner APFEL. We are now at about 40 percent. It is still early in the process. We did a top-to-bottom review, and we have done retraining. It was all aimed at making sure that each one of these kids received a full, fair evaluation, both those who are going to be in the appeals process and those whose cases were going to be reopened.

So I am not surprised at the 40 percent rate, and that is one of the reasons why I think we will be down to no more than 100,000 children terminated. My belief is that it will probably be lower than that in the end after we are through with the whole process.

Senator CONRAD. Does it not tell us that there is something wrong with the system when we have got a rate of reversal of 40 percent? I mean, it strikes me as extraordinarily high to have a system where, when people file appeals, 40 percent are overturned. It tells me that the initial work done is missing the mark.

Commissioner APFEL. Senator, I would attribute that in no small measure to the actions that we took over the course of the last 6 months to improve this program, to ensure the legitimacy of these efforts, to ensure that kids that came off had full appeal rights restored and every one of them had a chance to reappeal well after the fact. The reopening of cases on our own, the training that we went through, all this led to a different climate in terms of adjudicating these cases. So, it does not surprise me that we have a high level of appeal and reversal.

Senator CONRAD. You take it as a positive sign in the sense that people are getting a chance, in fact, to be objectively reviewed and returned, where appropriate.

Commissioner APFEL. Right. I would also say that, in the long run, there is an issue. We ought to have in our disability eligibility system a much more unified system from beginning to end. We ought to have higher approvals at the front end and lower approvals at the back end of the appeals process.

That is our long-range goal in process unification, to be able to unify our entire disability eligibility system so that, at the front end, people would get more accurate and positive decisions, and at the later end at the appeals, there would be fewer reversals. That is our long-term goal for the system. That is hard work. It is a lot of training and a lot of activities.

But, basically, your key point about having a system that had fewer reversals, I agree with fully. The way to do that is to unify the whole system. In the long run, that is our goal.

Senator CONRAD. And to do the training that is necessary to accomplish that goal.

Commissioner APFEL. Absolutely.

Senator CONRAD. I must say, it does tell me there is something wrong with the system, or at least there was something wrong with the system, that we have a 40 percent overturn on appeal of the initial determination.

Commissioner APFEL. Well, I would hope you would think that there is something right with the system. What we have done is gone back in, taken a look, reopened, reevaluated, provided full information, and we see those termination numbers coming down.

Senator CONRAD. Well, I agree with you to this extent. I am obviously pleased that people are being restored to benefits they have been denied wrongfully. Obviously, that is a good thing. It is a bad thing that they were denied in the first instance, and I think you would agree with that as well. Obviously, the system was not working appropriately when the initial determinations were made.

Commissioner APFEL. If I could put the history on that, again, if you will remember back, the legislation called for every case to be decided within a year from the date of enactment. There was intense pressure on the agency and on the States to move quickly and rapidly.

The SSI kids' program, as Senator Chafee pointed out, is a tough program to administer. Evaluating children is a hard line of work. I have spent a lot of time dealing with disability examiners individually on this. It is an easier task, to some extent, with adults than it is with kids.

Also, this is a program that has been changed quite significantly now twice over the course of the 1990s, starting in the early 1990s with the *Zebley* court decision. You will be hearing about the importance of the legislation.

I think *Zebley* did some very, very positive things, because a lot of kids who should have been served by this program were not being served, but then other changes came again in welfare reform.

So we have had a lot of changes and an intense pressure to move very quickly. I think we have conquered a lot of the problems in terms of some of the decisions that were made, and I hope to continue to work with this committee to improve again.

Senator CONRAD. Can I ask a final question, Mr. Chairman? When do you expect final regulations to be issued, and do you expect any changes in the regulations based on the comments from members who disagree with the two-marked standard?

Commissioner APFEL. Are there members that disagree, Senator Conrad and Senator Chafee?

Senator CONRAD. I think some of us, at least, are here today.

Commissioner APFEL. I think you are. Very candidly, I do not think that we will see final regulations in the near future. I think that is due to a couple of very major factors. One, there are a lot of comments on a lot of different issues that have to be sorted through very carefully.

Two, given the fact that we are now in the process of the top-to-bottom review, I think we are gaining new information which I think we should be able to share with the committee, with the Congress, with the American public about who these kids are. I think that is really what is necessary before making any final determinations.

One of the things I wanted to point out, Senator——

Senator CONRAD. Can I just interrupt you there briefly. When you say, "who these kids are," what are you finding? I am looking at statistics that suggest overwhelmingly that children who suffered from mental disorders or mental retardation represent the vast majority of those who have lost benefits. Is that consistent with your findings?

Commissioner APFEL. We are overturning a number of cessations in the mental retardation area. Most of the cases that we were required to review were in the areas of mental retardation and other mental problems, maladaptive behavior, et cetera. But a number of those cessations are being overturned. We are looking very carefully at those children to determine how and why they are coming back on, and how and why they are not.

If I could remind the committee, we did a study of 150 cases that we provided to the committee to answer the question, "who are these kids?" While we are still in the process of the top-to-bottom review, we expect that many of these children, some significant proportion, will come back on the rolls.

But I would like to go back in and take the cases of children who, after the review, are still off the rolls—at that point in time we are maybe talking about 100 cases instead of 150—and provide that information on a more extensive basis to the committee this winter—it is going to take until that time to get everything done—to give the committee a better picture about who these children are.

It might be good to work with the outside world to ensure that everyone agrees that these are good descriptions of who these children are. I think that is important information for the Congress to be able to assess other changes and future changes to the program.

Senator CONRAD. Thank you. I thank the Chairman.

Senator CHAFEE. Thank you, Senator Conrad.

Well, thank you, Commissioner. I want to say again that this subcommittee is here to be of assistance to you. We want this program to succeed. If there are things that come along that you think are in the statute that are not helpful to you, if you can consult with us, it is not an antagonistic position we are in, as far as you are concerned. We are all dedicated to trying to make this program work even better, and we appreciate the work that you have done.

I think it is terribly important we bear in mind that, in most instances, these people are low-income people, they are not the most sophisticated people in the world as far as appeals go and things like that.

They are individuals who, if there are two parents in the household, two parents probably have to work to make things go. Their chances of placing these children in a day care setting of some type that they can be cared for, the opportunities for that are not very good. So these parents have a terrible time, a very, very difficult time.

Thank you very much, Mr. Commissioner.

Commissioner APFEL. Happy to be here.

Senator CHAFEE. Now, if the next panel can come forward and if they could take their seats. I have to respond to a call back here one moment, and I will be right along in one minute.

[Whereupon, at 2:50 p.m., the hearing was recessed to reconvene at 2:54 p.m.]

Senator CONRAD. Mr. Chairman, was that House members calling to withdraw their legislation after Mr. Apfel's testimony? [Laughter.]

Senator CHAFEE. They know his position, anyway.

This next panel has Jonathan Stein, general counsel, Community Legal Services; Dawn Wardyga, from Barrington, whom I have had the privilege of knowing over several years; and Michael Brennan.

So why don't you start, Mr. Stein.

## STATEMENT OF JONATHAN STEIN, GENERAL COUNSEL, COMMUNITY LEGAL SERVICES, INC,, PHILADELPHIA, PA

Mr. STEIN. Yes. Thank you. Good afternoon, Senators Chafee and Conrad, and thank you for the opportunity to testify, and also for holding this very important hearing this afternoon. Thank you also, Senators, for your very strong leadership in protecting children with disabilities.

We also wish to acknowledge and thank Commissioner Apfel for his several steps to address some of the worst abuses in last year's reviews of close to 300,000 on SSI, including his review of thousands of denials to children with mental retardation, and the sending out of well over 60,000 new notices of appeal.

But, unfortunately, Mr. Apfel has been restrained by the policies in the interim final rules set in motion by his predecessor. These policies founder on an overly-strict misreading of the new SSI law.

Having addressed some problems in MR cases in the appeals process, Mr. Apfel now has to act to remedy other equally serious problems in the Disability process that are the subject of my testimony today.

I will limit my oral testimony, in the interest of time, to five key points. First, a little common sense would go a long way in resolving many of the problems we see in how SSA has implemented the SSI Child Disability changes mandated by Congress.

If SSA simply looked at the whole child in assessing whether the child meets the new SSI test, many of these problems would disappear. SSA is statutorily required to look at the "combined effects" of the impairments for SSI and Social Security Disability claimants. This requirement applies to children as well.

Second, with the exception of our recommendation relating to reviews of children turning age 18, and I am very happy that those children are getting scrutiny this afternoon, every one of our recommendations can be accomplished without direct Congressional intervention. They are modest, they are reasonable, they are easy-to-implement modifications that would set this program back on the correct course.

Third, Ms. Wardyga from Rhode Island Family Voices will tell you the stories of disabled children who have been harmed by the current interim final regulations. These few stories are representative of nearly 150,000 children who have been terminated in the last year, with another close to 35,000 children turning age 18 who were also terminated, and yet still another 335,000 children whose first applications for SSI Disability have been denied this past year and a half.

If you add these three groups together, the children under 18 terminated, the 18-year-olds, and the new applicants, they total one-half million children denied SSI in the last year and a half.

What is most unsettling, is that many of the children behind these numbers and behind the stories appended in our written testimony are so disabled, that anyone in this room or on Main Street, American would immediately recognize it.

They would ask, why are Social Security's eligibility rules so inflexible and overly strict? They would ask, why is there nothing in SSA's rules allowing for the measurement of disorders that affect eating, breathing, digesting, eliminating, stamina, strength and endurance, and the ability to resist disease and function in the world?

Four. Our recommendations on the common sense rules needed are summarized on page one of my written statement. Very briefly, they would require SSA to advise its interim rules to establish a test of severity that does not rely on the listings and that is midway between the prior IFA test and the listings.

Congress intended this to establish a test of disability that was more severe than the IFA test, but certainly less draconian than the listings level severity test in place in the interim rules today.

Second, we would ask that SSA realistically evaluate the whole child, as is already required by the existing Act, requiring a look at the combined effects of impairments.

Third, we would ask that SSA use a common sense approach in evaluating seriously disabled children. By not arbitrarily ignoring children who are less than "marked," a so-called marked or nothing view of disability.

Also, by not prejudicing the physically disabled child by limiting the functional assessments, as they are limited today, to a fixed number of largely mental disorder criteria. This is irrational and against sound medical evaluation to ignore anything less than marked, and to so prejudice physically disabled children.

Further, we would ask that SSA, in its rules, uncouple two medically and scientifically separate areas of functioning, communication and cognition, as nationally recognized medical experts have urged upon the agency, and as Dr. Cooke, I understand, may soon address in his testimony.

We also would ask that SSA evaluate children age three to six developmentally, as is done with infants zero to three. This development assessment information is available, but yet SSA's rules do not provide for that.

We would further ask SSA to revise its interim rules and instructions on the use of monies in dedicated bank accounts, another aspect of the new law, to make sure that basic necessities of life—food, clothing and shelter—for a child can be utilized.

Lack of definition and training has led to denial of use of these retroactive monies for necessities of life and for expenditures that, indeed, relate to the child's impairment.

Our last administrative suggestion would be an immediate priority to give to policy clarifications and retraining of DDS and OHA staff, and application of the new policies to promote legality and uniformity.

My very last, and fifth point, if you will permit me, just deals with the 18-year-olds. They have been terminated, you are right, Senator Chafee, at very high rates of termination. They have been singled out. This is the only group of disabled children or adults who do not get the medical improvement test. We think this is a lapse in the law that was overlooked.

We honestly believe that Congress did not want to deprive these children of a movie, a longitudinal view of their disability, instead of looking simply on a snapshot view of what that child turning 18 looks like on 1 day for perhaps 15 minutes at age 18, which is what the current test really provides.

We urge the Congress to adopt the medical improvement test, and perhaps other protections, for children turning 18 who do not miraculously get cured or suddenly turn not disabled when they turn 18.

One last thought on these age 18 children, those who have musculoskeletal problems, and we know those are chronic problems that stay, often, for the rest of their lives. The children with those types of problems at age 18, 72 percent of them are being terminated at age 18, even though that is the kind of chronic problem that just does not disappear overnight at age 18. So there are some serious problems there, and I think the medical improvement test would be one procedural safeguard.

Let me conclude my testimony there. Thank you again for this opportunity.

Senator CHAFEE. Well, thank you very much, Mr. Stein.

[The prepared statement of Mr. Stein appears in the appendix.]

Senator CHAFEE. Now, Dawn Wardyga from Barrington, Rhode Island. We welcome you here.

## STATEMENT OF DAWN WARDYGA, FAMILY VOICES OF RHODE ISLAND, BARRINGTON, RI

Ms. WARDYGA. Thank you, Senator Chafee and Senator Conrad. Thanks for the opportunity to provide testimony this afternoon on behalf of children with chronic illnesses and disabilities and their families from across the United States.

As a mother of six children, one of whom had suffered a severe brain injury during his birth leaving him permanently and totally disabled, I know all too well the overwhelming barriers that families of children with special health care needs face on a daily basis.

In my work as project director for Family Voices of Rhode Island, I have worked with many families directly affected by the recent changes in the SSI program, both in the State of Rhode Island, and in many other States across the Nation.

The SSI program has made, and continues to make, the lives of the children who qualify, and their families, a bit more secure. The supports provided by SSI enables families to care for their children at home and meet many of their special needs.

Many parents of children with disabilities are unable to work due to the responsibilities of caring for their child, or, if they are able to work, it is usually part-time, with limited income, as they must be on-call at all times and ready to respond to their child's latest crisis.

In many States, although not all, becoming eligible for the SSI program automatically provides children with a Medicaid card which provides families the security of knowing that they will be able to access the medical care and related services that their children require.

In many cases, the related Medicaid coverage fills the enormous gap that their commercial health insurance leaves behind in meeting their complex needs. These families, on their best days, have more than their share of issues to deal with.

This has been a complicated and unsettling time for families, most of whom had to struggle to get their children on the program in the first place.

The recent changes currently being implemented within the SSI program under the Welfare Reform Act of 1996 have impacted this vulnerable population in disturbing ways in every State across the Nation.

In some States, families who have lost their SSI benefits are being forced to relinquish custody of their children, especially those with emotional/behavioral disabilities, in an effort to obtain the necessary services for them.

I hope to illustrate some of the real hardships resulting from these changes and its impact on families. As I share these examples with you, we should all be thinking about several of the problems with the way in which Social Security has implemented the current law and how we can improve it to truly meet the needs of those it is intended to support.

SSA determined that a 12-year-old New York boy who suffers from ADHD, Attention Deficit/Hyperactivity Disorder, serious behavioral problems, and a 5-year delay in his reading level, is not eligible for SSI.

This decision was made, despite the fact that adjudicators found that a child had a marked problem in social functioning, as well as significant, but not marked, problems in three of the four remaining areas.

SSA's finding that the child has a marked social functioning problem was based on a well-documented history of extremely aggressive and violent behavior.

The child's records indicate that he has been suspended from school on numerous occasions and that he has a chronic history of disrupting his classmates and disrespecting teachers and other authority figures.

SSA's finding that the child has a significant problem with his ability to concentrate was based on reports from teachers and the school psychologist, which consistently indicate that the child is easily distracted, often off task, and has difficulty completing assignments.

SSA's findings that he has a significant problem in cognitive/communicative functioning was based on a record which indicates that he was enrolled in a self-contained special education class and he was reading at a second grade level, when children his age normally are entering the seventh grade.

The results of his most recent educational achievement testing indicate that he scored in the lowest one to four percentile in the areas of vocabulary, word identification, and reading comprehension.

SSA found a significant problem in personal functioning, as the child is still unable to bathe himself or brush his teeth without assistance and supervision from his mother.

This case illustrates the problems with SSA's rigid interpretation of the new definition of childhood disability. This child clearly has very significant problems in many areas. How can SSA conclude he has marked problems in only one area, while his problems in the other three functioning areas does not meet the criteria of disability under the new law?

Courtney is an 8-year-old North Dakotan girl who was born with a severe heart defect. At age 3 months, she suffered a brain bleed, or stroke, that left her partially paralyzed on her right side. She does not qualify for Medicaid, as hers is a farm family and must use an asset form in North Dakota.

Her parents use her SSI to purchase her health insurance and pay for other medical bills, medications for her condition, purchase special shoes, orthotics, et cetera. Hers was a case recently redetermined and, thankfully, continued in the program. Her mother shared her fear of losing Courtney's benefits and her family's inability to provide for her special needs without the support of the SSI program.

Senator CHAFEE. Do not let the bell bother you. You go ahead.

Ms. WARDYGA. Thank you. She lives in fear of continued periodic——

Senator CHAFEE. We have got a Rhode Island witness talking about a North Dakota girl. I think you are on pretty safe grounds. [Laughter.]

Ms. WARDYGA. Thank you. That was strategy.

She lives in fear of continued periodic reviews which may disqualify Courtney from the program, and threats to her family's stability in the event of future benefit losses. Courtney's medical and mobility issues are expected to be lifelong.

These few cases—and as you can see, I am not following exactly from the testimony because of the time—are only a brief sampling of how families with children with disabilities are faring under the SSI program. There are several concerns that these examples raise.

One, is the new regulations are too restrictive, denying access to SSI for children who are truly disabled. How many new applications have been denied since the new law took effect based on the new eligibility criteria and prior to the second opportunity for appeals, when some of the problems with the new law were acknowledged by SSA? How do we reach those children who have already been turned away?

Number two. What is happening to the thousands of children with severe disabilities across the country who have lost benefits, is anyone monitoring how they are doing?

Number three. What about the related Medicaid issues; is HCFA aggressively enforcing the grandfathering provisions to continue Medicaid in the 1997 Balanced Budget Act? Are children, in fact, maintaining Medicaid eligibility after losing SSI? Are they being required to enter managed care, and if so, what are those outcomes? How are families being informed of these changes, and their options, if any? Are they aware that the level and continuity of care should be protected under the law?

Number four. Do families truly understand this redetermination process and their rights under the law? How many families never receive notices or were unable to read them? How many families did not appeal, based on misunderstood information or overwhelming fear of owing the U.S. Government thousands of dollars that they knew they could not possibly pay?

Number five. Is SSA providing adequate training to its staff in addressing the complex implementation issues? Is printed information provided in other languages, and are interpreters provided for families who need them?

In closing, I would like to add that the children and families that we are concerned with today are no different, in many ways, than any other family. We have the same dreams, goals, and expectations for our children and families that all families share. Our families simply have to work harder to accomplish many of these goals.

The SSI program is just one piece, and an invaluable one, of an extremely complex puzzle that supports children with disabilities and their families in their own homes.

This program must be protected so that our families have the same opportunities to meet our children's needs and care for them in their own homes that all American families enjoy.

Senator CHAFEE. Thank you very much.

[The prepared statement of Ms. Wardyga appears in the appendix.]

Senator CHAFEE. Now, Mr. Brennan, president-elect, National Council of Disability Determination Directors.

## STATEMENT OF MICHAEL BRENNAN, PRESIDENT-ELECT, NATIONAL COUNCIL OF DISABILITY DETERMINATION DIRECTORS, LINCOLN, NE

Mr. BRENNAN. Mr. Chairman, Senator Conrad, on behalf of the National Council of Disability Determination Directors, thank you for the opportunity to appear here today to present our views regarding the process of redetermining the eligibility of some children for disability benefits.

These redetermination were required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. The NCDDD is a professional organization of the directors and other management staff of the State Disability Determination Services agencies. The DDSs participate in the Disability program by making the initial determinations of eligibility for disability benefits.

I want to begin by observing that the DDSs are not policy making components in the Disability program. That responsibility is reserved for the Social Security Administration. Our job is to apply the policy created by SSA to individual cases at the field level.

From this perspective, the following is the view of the NCDDD regarding the status of the eligibility redetermination process required by the welfare reform legislation.

The legislation rescinded the previous definition of disability for children and replaced it with a more stringent standard. The intent of the legislation clearly was that fewer children would qualify for benefits than would have qualified under the previous standard.

SSA established the regulation for implementing the Congressional intent. In our view, the regulation reasonably comports with the statutory language. SSA provided instructions and training in the application of the new standard.

DDSs were asked to apply the new standard to a large workload in a short period of time. While this was a major undertaking, DDSs recognized the importance of making correct decisions on these cases, which involve some of our country's most vulnerable citizens.

Accordingly, DDS has devoted significant resources to assure the accurate completion of these cases. Likewise, SSA devoted substantial resources to the evaluation of the work completed by the DDSs.

Overall, SSA's findings were that the great majority of cases were processed correctly, that is, in accordance with the new standard. The case reviews found that more than 93 percent of the cases in which recipients were determined not to be eligible under the new standard were done correctly. This does not mean that 7 percent were done incorrectly, since some of the case returns were simply differences in judgment.

Even though SSA found the great majority of redetermination to comport with the SSA standard, we all acknowledged the unique importance of this particular group of cases. Accordingly, Commissioner Apfel initiated a special review of the redetermination process. DDS participants were included in this special review to a much larger extent than in the issuance of the original instructions.

The review identified some areas of concern. These especially included cases involving mental retardation, some aspects of developing evidence, and the explanation of appeal rights.

In order to reduce the likelihood that benefits to disabled children might have been incorrectly terminated, SSA implemented a series of remedies unique to this special caseload.

These remedies include the reworking of some cases, the extension and expansion of appeal rights, the issuance of a new ruling on speech and cognitive impairments, additional training to DDS adjudicators, and policy clarifications.

The fact that some cases are being reworked does not indicate a widespread misapplication of the new standard. Rather, this is a result of SSA's and DDS's collective intent to take extra and unusual actions to assure that possible errors are identified and corrected.

The reworking of these cases is going well in the DDSs, but too few cases have been completed to report meaningful results.

In summary, the NCDDD believes that the policies created by SSA are reasonably in compliance with the statute, that the work performed by the DDSs were substantially in compliance with SSA's instructions, that there were some indications that a minority of cases may not have been processed correctly, that accurately processing the cases of impaired children is so important as to require unusual levels of effort, and that SSA and the DDSs are working together to identify, remedy, and rectify any errors.

Mr. Chairman, thank you again for the opportunity to be here today.

Senator CHAFEE. Well, thank you, Mr. Brennan. I do not think any of us think this is an easy job that you have. It is a very, very difficult job. Let me ask you this. You do not physically see the applicants, do you? You do not actually see the applicants. Do you work from some kind of a summary, like the summaries we saw in here that Ms. Wardyga had, and others?

Mr. BRENNAN. In some of the cases we do not see the applicants, but in these redetermination, at the reconsideration step, there is a face-to-face hearing by a disability hearing officer, who is a DDS employee. So we do see them face to face at that step.

Senator CHAFEE. I see. Both Senator Conrad and I asked the Commissioner about this wide swing between the different States when it came to the review of the cases, the difference between a 35 percent rejection rate and a 70 plus percent. How do you account for that?

Mr. BRENNAN. I think that there is not any single answer to that. I think the Commissioner touched on some of it with these redetermination claims. It depended on how they went on the rolls. He referred to some DDSs putting more individuals on the rolls by use of the IFA, even if they met or equaled and they could have put them on without an IFA. There were some DDSs that did that.

Senator CHAFEE. Thus, the rejection rate would presumably be higher in that case, would it not?

Mr. BRENNAN. No, the rejection rate in that case would be lower. The continuance rate would be higher, simply because there would be some cases that met or equaled that were done as IFAs. The IFAs were re-reviewed as part of this legislation.

There are other factors, though, that go above and beyond that. In my personal experience, I worked in the Maryland DDS for 20 years before I moved to the District of Columbia DDS. I was impressed, I was surprised, by the difference in claim in impairments, difference in claim in population, and we are only 40 miles away.

I think some of it has to do with the medical community. I found that the medical community, for example, in the District is much more responsive and helpful than they were in Maryland. I do not know why that is.

I find that the advocacy community in the District plays an important role. We work closely with the advocates and I think that is helpful. But, again, there are a number of different factors that are involved. I do not think there is any single explanation.

Senator CHAFEE. Could we go back to the question we asked before. I did not quite understand. It seems to me, when the standards were less strictly enforced more children came on the rolls, when they came in with the new rules that were tighter, a higher percentage of those would go off than they would be in another State. Am I mixed up there?

Mr. BRENNAN. No. I think you were talking about the variation in continuance rates, or the variation in cessation rates between the States, some being as high as 70 percent, some being as low as 35 percent.

Senator CHAFEE. Yes. The States that took a lot of children on the rolls, I would think when they reviewed them, those States would have a higher percentage go off the rolls. Is that right?

Mr. BRENNAN. Let me explain it again, because I think I am talking about continuance rates and you might have been talking about cessation rates.

Senator CHAFEE. Yes. I was talking about the cessation rates.

Mr. BRENNAN. All right. Again, the explanation is the same. The distinction is between whether somebody is continued or not.

Senator CHAFEE. I see. Yes.

Mr. BRENNAN. Under the *Zebley* standard, there was the step called the IFA, the Individual Functional Assessment. There were some DDSs that, in a sequential evaluation procedure, went through the meets and equals, even though a case may have met the listings, and went to the IFA step. There were a number of reasons for doing that, one of which was to be better able to explain the rationale for their decision.

When the IFA was eliminated and those cases were re-reviewed, the likelihood of somebody who met the listing coming on was not the same as if it was a straight IFA.

Senator CHAFEE. I see.

Mr. BRENNAN. Does that help?

Senator CHAFEE. Yes, I get it.

Now, Ms. Wardyga, in your testimony you talked about parents in some instances having to relinquish custody. I was not quite sure what you were talking about.

Ms. WARDYGA. In some of the States, I have spoken to families, and this especially affects some of the kids with ADHD, emotional, and behavioral disorders. Some of the kids that have been ceased from the SSI rolls, their families are having a hard time accessing services for them. Obviously, because of their diagnoses and the symptoms related to those diagnoses, there are several behavioral issues in there.

Some of these parents are actually being told in their States that the only options that they have, because now the child does not have SSI and they are unable to access services, that the only way to get those services for those children is to actually turn them over to the Child Protective Agency, or, in some cases, even the juvenile justice system.

Now, you and I go back a long way. You wonder where these kids wind up. It is an issue, and I have heard it from several States, and it is an option that is thrown out there because the families cannot find services for their kids. They no longer have that safety net, the support of the SSI program.

So when they are faced with a choice, do they leave their child without the services that they need or do they relinquish custody, then in most cases they are going to opt to get that child the care they need and take whatever means it takes to get them there.

Senator CHAFEE. I must say, that is a rather shocking suggestion.

Ms. WARDYGA. It sure is.

Senator CHAFEE. Senator Conrad?

Senator CONRAD. Thank you, Mr. Chairman. Maybe I could go to you, Ms. Wardyga. Am I pronouncing it correctly?

Ms. WARDYGA. Yes. Very good.

Senator CONRAD. I want to follow up on that. Do we actually know of cases where parents have relinquished the parental rights to their child in order to give them services?

Ms. WARDYGA. I do not know if they have actually taken the step yet. What I have heard is, because they know that I have been working on this SSI issue, is this is the situation we are in, I do not know what to do with this.

Senator CONRAD. Who is saying those things to you, are parents saying that to you?

Ms. WARDYGA. Parents. Parents.

Senator CONRAD. Parents are saying to you, it has been suggested to us that we give up the parental rights to our child in order to get them services that they are otherwise denied?

Ms. WARDYGA. Absolutely.

Senator CONRAD. To get them care that they are otherwise denied.

Ms. WARDYGA. Right.

Senator CONRAD. That is what parents have told you?

Ms. WARDYGA. Absolutely. No different than the medical model from, I would say, 10 to 12 years ago when families with kids who had medical issues, technology dependency, before the days of the Medicaid waiver program, that basically your option was, you take your child home without the support services, or, if you relinquish custody, there is public help for you. That is basically what the options are. I am hearing those same stories as a result of the changes in the SSI.

Senator CONRAD. Tell us, which States are involved?

Ms. WARDYGA. There are two that have come to me already, and I have heard from other States that they have heard it happen. At least three, actually. I have heard Louisiana is one where this is an issue, Nebraska is another one that comes up, and I think Georgia was the third one that I had heard about. It is very disturbing, I mean, when you think about, how can you help these families.

Senator CONRAD. That is a rather extraordinary thing, to say that to a parent. Now, these are State employees saying to families, you relinquish your parental rights, basically you turn your child over to the State so they can get care that they would otherwise be denied?

Ms. WARDYGA. That is the way those stories are being transferred to me, that when they go looking for the services and they have tried every public avenue they can get at, they are told that if their child is out of their care and in the care of the State, then SSI or whatever other services kick in to protect that child.

Senator CONRAD. Mr. Brennan, do you have any knowledge of this? Have you heard this suggestion from your people operating in these States?

Mr. BRENNAN. No, sir, I have not. I have not heard any of that at all.

Senator CONRAD. Mr. Stein, is this something you have heard?

Mr. STEIN. No. A lot of other problems have surfaced, but that is not yet in our consciousness, although this does appear very disturbing.

Senator CONRAD. I would like to ask you, Mr. Stein, can you give us some example of cases that you believe demonstrate the problems of the two-marked standard that has been adopted by SSA? I mean, actual cases of children.

Mr. STEIN. Yes, Senator.

Senator CONRAD. Give us examples of children who are being eliminated, who are being denied assistance, who are being denied care, because of this standard.

Mr. STEIN. Many are appended to my written testimony. A child like Steven, who is on page 17 of our written testimony, with an IQ of 75. He is in a special education class with eight students and he is failing the special education class.

That child, because the 75 IQ is just above the marked level of 70, that counts for nothing, as if that child had a 140 IQ. That is how inflexible and arbitrary is the so-called marked standard. If it is anything less than marked, and a child with an IQ in the low 70's may be there, that essentially counts for nothing in the process that is being used across the country.

There is a child like Terrence, a 6-year-old, on page 29 of our testimony, who has Hirschsprung's disease, which is a lack of a full colon that leads to uncontrollable diarrhea. Because of the functional areas used are largely mental area criteria, there is no physical criterion that is extant in Social Security that deals with someone with uncontrollable diarrhea. You have to show that, somehow, that affects a social area, the mental area, the personal area, or cognition, or communication. That is, again, how arbitrary things are.

Another area is where Social Security has combined these two areas of cognition and communication into one area, so that a Vermont child, MG, at page 19 of our testimony, or Mildred, age 17, at page 25. They have Iqs in the 60's. A 66 IQ is what MG and Mildred have. And they have another serious communication problem. MG has severe deficits in expressive language. She is at the first/second grade level, even though she is 12 years old.

Mildred is age 17. In addition to her 66 IQ, she has serious visual problems and eye movement. She gets headache as a result, she has double vision. Yet, because Social Security has put these two areas of problems into one, these children do not make two marked. They are viewed as one marked.

Their 66 IQ and this other separate communication problem counts as one marked. Because this is an arbitrary two-marked standard that SSI has come up with in their intramurals, these children, MG and Mildred, have been terminated from the SSI program. They are typical of thousands and thousands of others.

A last example, Senator, is Warren, at page 13 of our testimony. This child has four or five major problems, a congenital heart condition, Wolff-Parkinson-White disease, a serious mood disorder, a mental problem, a severe expressive and receptive language delay problem, and uncontrollable, impulsive behaviors, including self-inflicted injuries.

The DDS has said none of those are marked, and because not each of those are marked, we are going to count them as zero. So this child has four separate major problems. They do not put them together, they do not look at the whole child.

They do not weigh the combined effects of impairments as the existing law still requires, and this child is said to have no marked because anything close to marked, 90 percent to marked, means zero in this current rather arbitrary system that we are living with in these interim rules.

Senator CONRAD. Mr. Brennan, if I could ask you, just to follow up on Mr. Stein's examples, do you think that the standard that is being applied is the appropriate standard?

You have already testify that you belief that the standard meets the statutory requirements, the legal requirements. I am asking you the broader, more philosophical question. Do you think it is the appropriate standard, given the examples that Mr. Stein and Ms. Wardyga have provided us?

Mr. BRENNAN. It is difficult to say. I did anticipate that question and I surveyed some of our DDS administrators and some of the adjudicators. The responses that I got, the consensus was, we have had no problems continuing children we think are severely disabled.

Let me clarify a little bit about that. I know Mr. Stein referred to the functional part of the listings and the fact that there was no way to assess the diarrhea. But I want to make the distinction here between the mental listings and the physical listings. The mental listings are unique in that all of the areas considered are functional.

When you assess severity with a mental impairment, you are looking at function. With the diarrhea, I would be looking at weight loss, I would be looking to see what the height was, I would be looking at other physical aspects before you even get into function.

Senator CONRAD. Well, if I could, how about a child with an IQ of 66; is that child not severely disabled?

Mr. BRENNAN. An IQ of 66 alone? I would say they have a marked deficit in cognition. That is what our policy says.

Senator CONRAD. I know what the policy says. I am asking you the broader question: is that the right policy?

Mr. BRENNAN. I am not sure it is the right policy. Again, I spend a significant portion of my time as an administrator ensuring that we apply the policy that we have been given in an evenhanded manner.

Senator CONRAD. No, I understand all that. But that is the question I am asking. I am asking you if that is the right standard. I mean, I must tell you, when I hear a child has an IQ of 66 and they do not find that child severely disabled, I mean, I do not understand that.

Mr. BRENNAN. What we found, Senator, is that there are some kids with an IQ of 72 that are very disabled, and there are some with an IQ of 62 that function well. So we have got the dilemma of trying to sort through that to determine which ones truly meet the standard for eligibility. It is not easy.

Senator CONRAD. No, I understand it is not easy. I must tell you, if a child has got an IQ of 62, their prospects for functioning in this society are not very high. I do not know of many children with an IQ of 62 that can make it in this society. I really do not. I do not know how you could.

If that is where we are with this policy, then I really have to question the policy. I know you are stuck with it. It is not something that is your decision. But you are there in the front lines, in the trenches, and should be able to form a judgment about this probably as well as anyone, and that is why I asked the question.

I thank the Chair.

Senator CHAFEE. Thank you, Senator Conrad.

I want to thank the panel very much. I appreciate it. Ms. Wardyga came all the way from Rhode Island, and others have made an effort to come a distance. So, thank you all very, very much.

Mr. STEIN. Senator, would you permit a brief response on the State differentials?

Senator CHAFEE. Yes, please do.

Mr. STEIN. I know you have asked that of the witnesses. My short answer is, I do not think that Commissioner Apfel has really satisfactorily answered your question.

I think there is a serious dilemma of major differences across the country where States are cutting off children, have cut off children, 100 percent more than other States. His answer basically is to you that some States have used the IFA test, that is no longer, more often to qualify children than others.

That only would suggest that, yes, in those States the absolute numbers of children cut off should be greater in other States where the IFA test was not used as much. it does not lead to the current facts that the percentage of cessations, therefore, must be much higher in those States, like Texas and Louisiana. I think when you get beyond that, you see that answer of the Commissioner does not really respond to your question.

I think you can look at other things, like lack of training of staff, the inadequacy of training of staff around the country. What is marked? The agency, when it deals with a child who is on a second grade reading level who should be at the eighth grade does not tell any of the States what marked means, which is one of many examples of the need for training.

We do know that, in some States, there was a great misunderstanding of the new law. They thought that all children with behavior problems must be cut off when, in fact, that is not what Congress did.

So I think the explanation really lies in some serious problems of application of the new law, not in the response you have gotten so far.

Senator CHAFEE. All right. Fine. Well, thank you very much. I thank all of you.

Now, the next panel is Dr. Cooke, chairman, Scientific Advisory Board, Joseph P. Kennedy, Jr. Foundation, former pediatrician and chief, Johns Hopkins; Laurie Humphries, M.D., American Academy of Child and Adolescent Psychiatry; and Dr. James Perrin, on behalf of the American Academy of Pediatrics in Boston.

Why don't we take them in the order I read them, starting with Dr. Cooke. Welcome, Doctor. Glad you are here.

## STATEMENT OF ROBERT COOKE, M.D., CHAIRMAN, SCIENTIFIC ADVISORY BOARD, JOSEPH P. KENNEDY JR. FOUNDATION; FORMER PEDIATRICIAN AND CHIEF, JOHNS HOPKINS UNIVERSITY, WASHINGTON, DC

Dr. COOKE. Thank you very much, Senator Chafee. I want to express my appreciation to the members of the Senate Finance Committee for this hearing and for your particular interest and energies in this direction. In addition to being a professional in this field for some 40 years, I am also the father of two profoundly retarded children.

The statistics of terminations and approvals have been provided by a number of the previous persons, and I will not review those.

Let me condense my remarks, in the 5 minutes allotted, to six points. One, the standards adopted, two marked impairments or two functional limitations, is rigid, harsh, and in conflict with modern developmental pediatrics and neurology.

The regulations do not recognize the amplifier effect of one impairment or functional limitations on another, especially low IQ. For example, a child with an IQ of 120 and moderate attention disorder, I do not consider markedly disabled.

A child with an IQ of 71 with the same degree of Attention Deficit Disorder is markedly limited in functioning, but would not qualify under the existing rules because there would not be two severe limitations.

A child, and I have taken care of a number of these, with moderate cerebral palsy, moderate asthma, moderate attention problems, moderate cognitive difficulties, is tremendously impaired, and yet would not be eligible under the present two-marked restrictions.

The second point I would like to make, is that the separation, as Mr. Stein referred, of cognition and communication runs in the face of testimony by experts in speech and hearing, experts in neurology, experts in developmental pediatrics.

They are different areas of the brain, they are different functions, and at the present time are combined as a single domain which will disqualify a number of children who should be eligible for SSI.

We carried out a review of 150 cases submitted to us by the Social Security Administration. This was a panel of developmental pediatricians, neurologists, fairly eminent people, and I carried it out also.

This review of cases that have been terminated, randomly sampled, when they were reviewed by SSA, seven were overturned by the SSA Central Bureau. When our group looked at this, there were somewhere between 20 and 40 that we felt should have been reversed, or there was inadequate information to make an appropriate decision. So in the process of execution of the interim rules, there is, I think, enormous discrepancy.

Now, how is that possible? The quality assurance data that comes from SSA talks about 90 percent accuracy. So we investigated what this quality assurance program of SSA was. It is not a quality assurance program. It is not at all like anything we ever carry out in a hospital or in a clinic.

It is basically an accuracy check of a paper trail, or in the carrying out of rules of evidence. It is not an analysis of egregious errors. It is not an analysis of why one State may have a very high termination rate, and another State a very low one.

So the quality assurance program, to me, in SSA, has to be radically revised to be much more in concert with the medical model.

An additional test of disability, it seems to me, that ought to be recognized is the degree of dependency on the family, what I call the burden on the family. If the mother or father cannot work because the child has to be cared for a large part of the day, requiring long periods of feeding or administration of medications and so forth, that parent cannot work and that vitiates the whole intent of the Welfare Reform Act.

In terms of the disqualification of the 18-year-olds using adult standards, I certainly agree that the medical test of improvement is important. I also believe, however, that before anyone is terminated, there ought to be an adequate evaluation by the Office of Vocational Rehabilitation, they ought to receive treatment services, if this is important, to prepare them for the future before any termination of benefits.

In summary, I believe that the long-term, carefully performed review of the criteria and process for termination of childhood SSI benefits should be undertaken. Thank you.

Senator CHAFEE. Thank you very much, Dr. Cooke.

[The prepared statement of Dr. Cooke appears in the appendix.]

Senator CHAFEE. Now, Dr. Humphries?

## STATEMENT OF LAURIE HUMPHRIES, M.D., AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY, LEXINGTON, KY

Dr. HUMPHRIES. Mr. Chairman, I am Dr. Laurie Humphries. I am a child and adolescent psychiatrist from Lexington, Kentucky, and I am a member of the American Academy of Child and Adolescent Psychiatry. Thank you for this opportunity to testify before this subcommittee on the new standard for eligibility for SSI.

I see firsthand patients who are disabled and the problems they face with this new standard. I believe that many children with mental illness will lose benefits as a result of the 1996 welfare reform law that made major changes in the SSI standard for assessing eligibility for children and adolescents with mental illness.

The current standards now in regulation should, in theory, capture children with mental illnesses, but, in fact, it is penalizing these children by setting a level of severity that is too high for the intent of the law.

How do we know this? First, there is a problem with under-recognition. It is estimated that between 15 to 25 percent of children evaluated have significant psychosocial problems requiring some type of intervention, yet, fewer than 1 in 5 of these at-risk children are identified as needing help. Nearly one-half of these at-risk children are severely disabled by their mental health problems and need constant care and attention.

Second, there is really a tremendous problem with stigma. Parents fear that they will be blamed for their child's illness, and that they are concerned about their child being labeled with a psychiatric disorder. We have a long way to go in this country before there is an equal public acceptance of mental and physical illness.

Third, children and adolescents do have mental illnesses. Emotional disorders do not discriminate across social, racial, or economic backgrounds. Research shows that they are real illnesses and they are not the result of bad parenting or a child's poor social skills.

Research is helping us to understand the brain and development in environmental influences and how prevention and treatment can reduce the later effects of more significant problems. Children and adolescents with mental illness face emotion and social impairments requiring a lifetime of treatment, rehabilitation, and therapy.

Now, most of my patients use the SSI benefit to provide transportation to and from treatment. I live in Kentucky. This is not Boston, DC, New York, or Los Angeles. Without transportation, the child loses access to mental health care, which interrupts treatment and limits the services the child needs.

The new standard for determining SSI eligibility is too harsh for children with mental illnesses. This new standard was opposed by many clinicians who are trained to treat the most severe causes and cases of mental illness.

For example, I know, in talking to a colleague yesterday from the State of Mississippi, that a child was denied the SSI benefit. What happened, was that child has schizophrenia. She hallucinates. She hears voices that tell her to hurt herself and to hurt others.

She lost her Medicaid card with the benefit. They had to stop the medication. Her hallucinations, which were well under control, came back and now she is psychotic again. Senator, that is not the intent of the law.

In summary, the current regulations are too harsh for children and adolescents with mental illnesses, and a review should be done on the standard and its impact on children and adolescents with mental illnesses.

Thank you, Senator.

Senator CHAFEE. Well, thank you, Dr. Humphries.

[The prepared statement of Dr. Humphries appears in the appendix.]

Senator CHAFEE. Dr. Perrin?

## STATEMENT OF JAMES PERRIN, M.D., ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS, BOSTON, MA

Dr. PERRIN. Good afternoon, Chairman Chafee. Thank you very much for letting me be here to represent the American Academy of Pediatrics and its 53,000 pediatric members.

I am a general pediatrician, and also an academic who, over the last two and a half decades, has focused a major portion of my time working with children with special health care needs and their families. I also formerly chaired the Academy's Committee on Children With Disabilities.

We are very, very grateful to you and your colleagues for your commitment to the issues of children with disabilities and to exploring the impact of recent changes to the program for children. Like you, the Academy is deeply concerned that SSI benefits remain available for children who need them.

The AAP strongly supports the SSI program for children, and has been troubled that children are being denied benefits to which they are entitled. This is a critical link between medical and social services for children with disabilities who are mainly in low-income families.

I have seen myself many children with spinal deformities, developmental disabilities, leukemia, chronic bleeding problems, severe childhood arthritis, and for those families, SSI provides the financial support and access to medical care that allows families to raise their children effectively at home and helps to ensure their best long-term functioning.

Over the last several years, the SSI program has been under intense scrutiny. The rapid growth in the number of children and adolescents receiving benefits since the early 1990's, as well as anecdotal reports of fraud and abuse of the program, were key factors in the 1996 Congressional modifications.

The AAP strongly supported the policy changes, however, that led to the expansions in the SSI program and believe strongly that the incidence of fraud and abuse in the program is negligible.

My specific remarks today focus on three areas. First, there is a need for in-depth information and analysis of the SSI program. Throughout the Congressional debate, the Academy expressed deep concerns that the changes sought by Congress did not reflect a thorough understanding of the SSI program, but, instead, focused on problems associated with a small number of enrolled children and adolescents. The limited understanding of many members of Congress of the SSI program was, in part, due to a lack of information about the program.

From the beginning and to the present, neither basic nor longitudinal information has been adequately collected regarding the children being served by the SSI program, including its impact on households and children.

Although the Academy generally supported the administration in its interpretation of changes in the SSI legislation in 1996 and 1997, we are concerned about the apparent inability of the administration to provide satisfactory information documenting the fair and safe implementation of these changes.

There is a necessity to understand how the SSI program affects children with disabilities, and whether it can better encourage the long-term involvement of young people with disabilities in employment and other adult activities. Absent this information, policy changes may once again be made without an understanding of the program and the policy that it implements.

Second, there is a need to modify the determination of disability in three key areas. First, the medical listings must be updated to current standards. There have been many improvements in the diagnosis and treatment of children since 1977, when the Social Security Administration published the diagnostic criteria for determining childhood eligibility. To reflect these diagnostic advances, we recommend a top-to-bottom review and revision of the childhood medical listings.

Second, children must be included in current and future SSA disability determination reforms. Children are not small adults, and disabilities affect their functional capabilities quite differently from how they affect adults.

To date, children have been excluded from SSA's process to reform the ways in which the disability among adults is determined. Commissioner Apfel talked about an approach of functionality.

That approach is not now being applied to children, and similar research is not going on about how to make this approach work effectively with children. There must be specific attention directed to children's issues in this reform process.

Third, and other people have said similar things, the functional equivalence component of SSI must be fully developed. The Supreme Court *Zebley* decision in 1990 led to the publication of the new childhood disability regulations. However, even within that, the functional equivalent provision of those regulations has not been effectively developed.

Third, the transition of adolescents with disabilities to adulthood should be further developed, an area others have spoken about. Although many young people with disabilities will require substantial ongoing services, many others with proper education and rehabilitative services can become increasingly independent. Achieving the goals of increased independence requires imaginative use of the incentives in the SSI program.

These incentives should be linked with providing young people appropriate services and guidance early in their adolescent career—13, 14, not 17 and 18—to maximize growth and development. The age 18 problem discussed today is a major one.

Let me close by providing several specific recommendations. These are expanded in our written testimony. The Social Security Administration should develop an effective mechanism for ongoing monitoring of the children and adolescents in the SSI program; a top-to-bottom review and revision of the childhood medical listings; a commitment to develop new methods to assess functional abilities in the context of disability rather than relying on medical listings alone, comparable to the efforts currently going on for adults.

Modifications to the medical listings should include criteria that would enable children with multiple disabilities, not simply a two-marked standard of assessment to be eligible for, or remain in, the SSI program, regardless of diagnosis.

These are our recommendations, and we would be glad to answer further questions. We strongly urge the administration and the Congress to adopt a "first, do no harm" standard when reviewing the SSI program for children.

The population served by this program is among the most important and vulnerable in America, and we must be diligent in the implementation of changes to this important program so that we do not harm children and adolescents in the process. Thank you very much.

[The prepared statement of Dr. Perrin appears in the appendix.]

Senator CHAFEE. Thank you very much, Doctor. Those are good points. I think it is in point three on page five. You say, "The Social

Security Administration should develop an effective mechanism for ongoing monitoring of the children and adolescents in the SSI program."

I can see that. But suppose they take somebody off the program, then that person is not monitored any more. That might be the very person that might ought to come back on the program. Am I missing something or am I right?

Dr. PERRIN. I think you are right on target, Senator Chafee. That is an important group of people to be monitoring as well. We know very little about what happens to families when they do get SSI benefits.

We know very little about what happens to families when they lose SSI benefits. We have a lot of statistics about large numbers of categories of people, but very little data at the level of the individual child and family and what happens at both of those steps in the process. We need to have that information.

Senator CHAFEE. I thought, Dr. Cooke, you made a good point when you were talking about a child with a normal IQ and Attention Deficit Disorder is one case, and that same child with the Attention Deficit Disorder and a lower IQ is an entirely different case.

Dr. COOKE. Absolutely. Severely disabled, with that combination, yet it would not qualify under the present rules.

Senator CHAFEE. Dr. Humphries, when diagnosing a child's mental impairment, is it pretty important to know about the child's functional limitations?

Dr. HUMPHRIES. Yes, sir, it is. One of the things, as a child and adolescent psychiatrist, we are well aware of, is that you have to really assess the child from multiple standpoints. You need to know what that child looks like in the school setting, you need to know what they are like in their community, in their home, how do they function at camp. Often, children with different types of structure look differently. For example, if you are in a self-contained classroom and you have got eight students in that classroom and you have got an aide, then that child may function well. But, my goodness, look what you are doing to get that level of function.

Then that child may attend summer camp and may literally flunk out because they cannot attend to anything. It is a normal situation, but their function in a camp setting, without that added structure, and they literally sort of fall apart because of the cognitive problems and the mental problems that they have.

Senator CHAFEE. Now, Dr. Perrin, you said the listings should be revised. These listings embrace such criteria as recurrent hospitalizations and major medical interventions.

Should the SSA's revisions not take into account current medical practice, such as decreased use of hospitalization and fewer emergency visits as a result of managed care, or increased reliance? In other words, have you taken these other things into account when you talk about when you were dealing with your listings?

Dr. PERRIN. Senator, I think there are two or three elements to that that are important to keep in mind.

Senator CHAFEE. I am sorry. I was looking at you, Dr. Humphries, as I addressed the question to Dr. Perrin. I do not have double vision. I am sorry. Go ahead, Doctor.

Dr. PERRIN. I think there are two or three elements there, Senator Chafee. First of all, within the medical listings themselves there are a large number of listings that are currently very much out of date medically. They talk about the functioning of the pulmonary system, the lung system. We are not using criteria that are used today to diagnose disabilities or capabilities in lung functioning. That is just one example.

So one can go through the entire set of listings and say, these are really not taking into account modern information about how children can be measured with respect to their clinical status.

But, importantly, the issue of the use of hospitalization or the use of emergency departments, those are really not good measures, frankly, of functioning any more, although the asthma listing has, in fact, used those kinds of indicators about, does this child have enough asthma to be considered severely disabled as a result of asthma. That just is not very appropriate to be using it any more.

But that is exactly why we also recommend not only the revision of the medical listings, but also this same degree of intent to develop a high-quality measure of child functional impairment. That is currently being done for adults, but no similar work is going on for children. That way we will be able to, in fact, look at how children are functioning as a result of having a chronic condition.

Senator CHAFEE. Well, thank you all very much. I want to ask one question. I feel I have got three experts in front of me. There were other experts in the other panels. But if you had your choice of taking one big step in the preventative area, whether it be better prenatal care, or getting rid of lead paint, or whatever it might be, prevention, what would you do?

Let us say you are king or queen and you have got some money, and you want to take one big step prevention-wise in connection with the mentally retarded, emotionally disturbed, or terrifically handicapped children, what would you do? I will start with you, Dr. Humphries?

Dr. HUMPHRIES. Well, that is an important question because I think that is where we need, Senator, to really look at how to prevent this. That is, I think, probably what we are all in this for.

Senator CHAFEE. Because when I looked at those cases that Mr. Stein had assembled, they are really very heart-rending cases. We are all familiar with them, you certainly more than I. To some extent, I am familiar with these cases from the work I have done on this over many, many years. All right. What should we do, prevention-wise?

Dr. HUMPHRIES. One of the things I think I would say, is early recognition and treatment. In my area, this is something that I see not happening. Frankly, the more severe standards you have for this make it more difficult for us actually to make a diagnosis and start treatment in a child. The more stringent, harsh standards we have with the SSI Disability, set the stage.

What, in effect, is going to happen, is that this actually is a counter effort to prevention, especially secondary and tertiary prevention that we talk about in medicine. So, one of the things I think we need to do, what you, the Senate, can do in the overview, is really take very seriously the recommendations that we have had today.

One, make a child evaluation a child evaluation. I asked, from the Kentucky administration, for a copy of a CE, that is, a consultative examiner. I got an adult psychiatric evaluation form to actually go by to evaluate children and adolescents. That should not be. We should not be using the same form for children and adolescents as we use for adults.

That is my personal experience, and I can show you my packet. These are two different things, adult evaluation and child evaluation. I am board certified in both, and I know. Your committee can do something about that, to make sure that SSA really follows through. That is one thing.

I think the other thing I have heard again and again, is we must separate out communication and cognition. That really is a major issue. When you are a child and adolescent psychiatrist, you are looking at lines of development that are different.

In effect, it would be like asking a pediatric surgeon to evaluate only the right leg of a child. I mean, that is absurd; every child has two legs. Well, to say that we have to put together the cognitive and communication area is bizarre. I will say that.

So one of the things your committee can do, is to look at the SSA and how these regulations are actually being enforced. That is one of the things that I think we could do as citizens to really try to increase prevention.

Senator CHAFEE. All right. Dr. Perrin?

Dr. PERRIN. I would love to defer to Dr. Cooke. Bob has been one of the world's experts on prevention in mental retardation.

Senator CHAFEE. Well, I was going to get to Dr. Cooke. I will get to him.

Dr. PERRIN. I will go ahead, but I know he is going to tell us what really to do. I think that the notion is really early intervention. These are not new ideas, Senator Chafee.

I think we know a great deal as pediatricians about the fact that providing services to children and to families, not just to children alone, early in the careers of children who have different kinds of disabilities pays off. These are children who are much more capable once they get to school, to participate in school. We really know that these are effective ways of trying to improve things for children.

I put in a similar plea about the notion of providing comprehensive, long-term, family-based planning services for young adolescents with disabilities. We think about the problem of age 18; that is far too late to be thinking about the problem.

We need to be providing the kind of high-quality planning with the young person at age 12, 13, or 14 so she gets the right kinds of service. Not only SSI, but the right kinds of training, education, experience, and support, so by the time she does achieve age 18, she is, in fact, a pretty capable young person, despite disability.

So, early intervention, as well, I would offer you.

Senator CHAFEE. All right, Doctor. Dr. Cooke?

Dr. COOKE. Well, I am going to cheat a little bit and give you more than one, if I might.

Senator CHAFEE. Well, we will give you dispensation. All right.

Dr. COOKE. Early assessment has been indicated. The CHIP program, which is going to make a great impact on children's health, and the necessity for very expert, early developmental assessments so early intervention becomes possible. That, I think, is critical.

Certainly, adolescent pregnancy is an area which can make a very significant difference. Fetal alcohol, is another. I would put the very low birth weight baby, which is common in an adolescent pregnancy, but now is very much preventable with the treatment of infection in pregnancy. I think you will see a marked reduction in the severe problems from the very low birth weight babies if we apply the present knowledge.

So I am cheating a little in giving you more than one.

Senator CHAFEE. No, no. You qualify. All right. Thank you all very, very much. You have been very helpful to us. I appreciated a great deal your coming. That completes the hearing.

[Whereupon, at 4:06 p.m., the hearing was concluded.]

# APPENDIX

## ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

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### PREPARED STATEMENT OF KENNETH S. APFEL

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to address this most important topic. 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 full 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, more commonly known as the welfare reform law.

#### THE TOP-TO-BOTTOM REVIEW

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.

Where specific problems were identified, I ordered that the Agency undertake immediate, corrective actions. And, because of my concern for the welfare of children, a concern I know is shared by you, the President, and the American people, the Social Security Administration (SSA) is taking steps above and beyond normal actions to ensure that every child receives a thorough and accurate assessment of his or her eligibility for benefits.

The review, which was completed in December 1997, showed that overall SSA and the SSA-funded State Disability Determination Services (DDSs), which make disability determinations for the Agency, have done a good job. Of the approximately one million children receiving SSI benefits as of December 1996 based on disability, about 288,000 were subject to redetermination under the new law, and most of these were handled properly. After screening out the cases that were inaccurately coded as needing a review, there were about 264,000 cases requiring a review. As of May 30, 1998, we had made initial redetermination determinations for 245,349 children. We have continued benefits to 147,933 children, or 54.1 percent of all the decisions we have made. However, the review also found some inconsistencies in the application of the rules and in compliance with SSA instructions. The review identified three specific areas of concern: processing of children's cases classified in SSA's records as having mental retardation; the quality of some aspects of case processing; and the adequacy of the information SSA was providing beneficiaries on their rights to appeal a cessation determination and to request that benefits be continued through the Administrative Law Judge hearing level.

As a result of the review's findings, I directed the State DDSs to review the cases of approximately 36,000 children whose benefits were ceased. Where our quality assurance information has identified problems with the accuracy of our decisions to continue benefits, we will give childhood disability cases priority review. In addition, on February 18, 1998, we renotified approximately 75,000 children whose representative payees may not have understood their rights to appeal the determination to terminate their benefits or to request benefit continuation.

In March, we completed training for virtually all of our 15,000 adjudicators, including administrative law judges, on childhood issues that were problematic in adjudicating these claims, such as mental retardation and evaluation of maladaptive behaviors, in preparation for conducting the re-reviews. Although we originally expected to have the initial re-reviews completed by the end of this fiscal year, we are finding that more time may be needed in some cases to complete development of the medical evidence and to ensure that each child receives a fair and accurate new determination.

On March 30th, we published a new Social Security Ruling clarifying how to determine medical equivalence in childhood disability cases involving both cognition and speech disorders. Our adjudicators have been trained on this Ruling. In developing all of the training, and the Ruling, we had many discussions with individual medical experts and childhood advocates and took into account their comments. Moreover, we have conducted additional training, specifically geared to types of issues relevant to a particular State's needs. I am confident that as a result of these training efforts, our determinations will be even more accurate and consistent.

We have also developed unprecedented safeguards to ensure that our adjudication is consistent and our policy is nationally understood. This includes an enhanced and comprehensive quality review plan. These efforts will ensure early understanding by all components of the right way to do cases, provide timely and consistent feedback on deficient cases, initiate timely central policy guidance and clarification, and ensure national dissemination of all policy clarifications.

In addition, I have directed that SSA conduct a study comparing the group of children losing SSI benefits to a group of children retaining SSI after implementation of welfare reform. This study will consist of two parts. The first part is an examination of existing data held by SSA, the Census Bureau and HHS. The second part is the development of a limited number of case studies to supplement the statistical information. These case studies-along with the statistical information—will improve our knowledge of the effects of welfare reform on children with disabilities and their families. The results will be available by the end of FY 1999 and will help the design of our second research project on childhood disability.

A second research project on childhood disability will be a nationally representative survey of 2,000 families of children with disabilities, which will provide a more comprehensive evaluation of the impact of removing certain children with disabilities from SSI under welfare reform. A round of follow-up interviews will be conducted after one year to provide longitudinal data about a range of outcomes similar to the first study, such as use of medical care, quality of life, parental labor force participation, and cost of care. This type of data has not previously been available.

SSA is also going to conduct a clinical study directed at evaluating the most effective approach for assessing functioning in some children. This study will begin in FY 1999 and continue through FY 2001.

At this point, I'd like to tell you about specific findings in the three areas covered by the review.

## MENTAL RETARDATION

Of the approximately one million children on the rolls in December 1996, about 407,000 (almost 41 percent of all children on the rolls) were coded in SSA's computer system as having a primary diagnosis of mental retardation. Eighty percent of these children (over 325,000 children) had impairments that had already been found to meet SSA's listings for mental retardation and were not subject to redetermination under the new law. Therefore, SSA conducted redeterminations on only 20 percent of the children (almost 80,000 children) who were coded on SSA's data systems as having mental retardation.

To begin, I'd like to draw a distinction between low IQ scores and mental retardation. Mental retardation is characterized by significantly subaverage general intellectual functioning accompanied by significant limitations in adaptive functioning. Children with low IQ scores who do not have limitations in adaptive functioning do not have mental retardation, although they may have another disabling impairment. In other words, we look at each child's ability to function as a whole-we do not base our determinations solely on IQ scores.

During the redetermination process, concerns were raised that benefits to children with IQ scores in the range of 60 to 70 were being ceased erroneously because of misapplication of the listings, and that benefits to children with mental retardation who have IQ scores above 70 were being ceased because of adjudicator failure to consider the range of error inherent in all test scores and to consider all of the evidence.

SSA found that in a large number of the cases with the computer code for mental retardation, the children did not actually have mental retardation, and were never thought to have mental retardation, but were only shown in SSA's data with this diagnosis code because of limitations in our coding capacities and, frankly, coding errors. 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 mental retardation. This occurred because codes do not exist for all possible impairments. In such cases, our adjudicators are instructed to choose a code for a "closely analogous" impairment. As a result, DDSs have used the mental retardation code for other impairments.

In 1994, SSA established additional codes for certain impairments, including learning disabilities, which were often coded as mental retardation. In connection with the top-to-bottom review, another new code was established in October 1997, for "borderline intellectual functioning," another impairment that was often coded as mental retardation.

However, SSA's quality assurance data showed that some decisions to cease benefits to children SSA correctly coded as having mental retardation were deficient in some way. This means that some children appropriately identified as having mental retardation may have had their eligibility ceased incorrectly. Similar problems exist for children with mental retardation whose applications for benefits were denied after the enactment of the welfare reform legislation on August 22, 1996. As a result of these findings I have directed that SSA, through the DDSs, review the cases of all children, whose benefits were ceased or denied after the passage of welfare reform, that SSA coded as having mental retardation. These reviews began at the end of March.

## QUALITY OF CASE PROCESSING

SSA defines an accurate case as one that is free of both documentation and decisional errors. Therefore, a case may be found to be inaccurate because the adjudicator did not fully document his or her decision. Full documentation does not necessarily mean that the determination would change.

Our quality assurance process found that in most States the accuracy of both continuance and cessation determinations was above the rate of accuracy that SSA requires. However, quality assurance data also showed lower than average cessation accuracy for certain categories of cases in many States.

Based on this finding I directed that all States will also review a portion of their redetermination workloads that did not have the code for mental retardation. SSA has identified the types of cases that each State will review. The reviews will be of cessations in those categories of cases which, based on the data from our quality assurance review, have the highest likelihood of error. Where continuance accuracy was found to be below the threshold, we have given childhood disability cases first priority for reviews. Plans are being made to review these continuance cases in FY 1999.

The report also identified problems in cases where eligibility 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 notices initiating the disability redetermination, does not take the child to a consultative medical examination, or otherwise does not cooperate in processing the claim without good cause.

Before eligibility is ceased, however, SSA's 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. SSA sampled cases in States with the highest rates of cessation for "failure to cooperate." SSA found that in a large number of the cases either all of the contacts required had not been attempted or the contact efforts were not documented in the case file.

Therefore, I have directed that SSA review the cases of all children whose benefits were ceased based on "failure to cooperate" in which a request for reconsideration was not filed. Most of these reviews have already been completed. These reviews will ensure that all required contacts and follow-ups are made and documented in case files.

## ADEQUACY OF INFORMATION

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, about how to obtain information concerning attorney representation.

I would like to note that, in many of these families, English is not the first language, further adding to problems with understanding appeals rights. In order to provide the best service to all of our customers, and to reduce reliance on outside interpreters, SSA has recently focused on hiring more bilingual employees as one of its key change initiatives. In the last five fiscal years, SSA hired over 1,700 full-time bilingual employees to serve the public in our field offices and teleservice centers. As a result, SSA's own employees are currently capable of translating and interpreting in at least 22 different languages.

On February 18th, SSA sent special notices in simpler language to approximately 75,000 families (or other representative payees) of children whose eligibility for SSI has ceased, and who have not appealed, and also to families who have requested reconsideration, but who did not request continuation of benefit payments. These notices restated our determination regarding the child's eligibility under the new disability standard. In addition, the notices provided a clearer explanation of the child's right to appeal our determination and to request benefit continuation while the appeal is being considered.

I recognize that this step goes above and beyond normal actions. However, concerns were raised that the cessation notice was hard to understand and that SSA was not providing beneficiaries with an accurate and comprehensive explanation of their rights to file an appeal or request benefit continuation. We ascertained that in some instances inconsistent or incomplete information led to some individuals having an inadequate understanding of their appeal rights. Therefore, I determined that these concerns should be heeded.

As a result of these notices, more than 22,000 of these families have requested that we reconsider our original determination to cease benefits to their children. Over 65 percent of these families have also requested benefit continuation. Additionally, about 5,200 of the families that had previously appealed the cessation determination, but did not request benefit continuation, have now done so.

At this point, we are very early in the review process. As of May 30th we have completed processing on 7,300 of the approximately 36,000 cases subject to re-review.

About 2,600 of the 14,000 cases coded as MR have been completed. Of these cases, a third were revised to continuance. We have completed about 4,600 of 22,000 other targeted cessations. Of these, about 14 percent became continuances after reopening.

Mr. Chairman, it would be inappropriate to assume that these percentages will not change as more cases are worked. These are preliminary results and we have many more reviews to complete. We fully expect the percentages of cessations and allowances to change as more cases are processed. What we are seeing from these early reviews, however, is consistent with our projections that about 100,000 children will ultimately lose benefits.

## MEDICAID COVERAGE

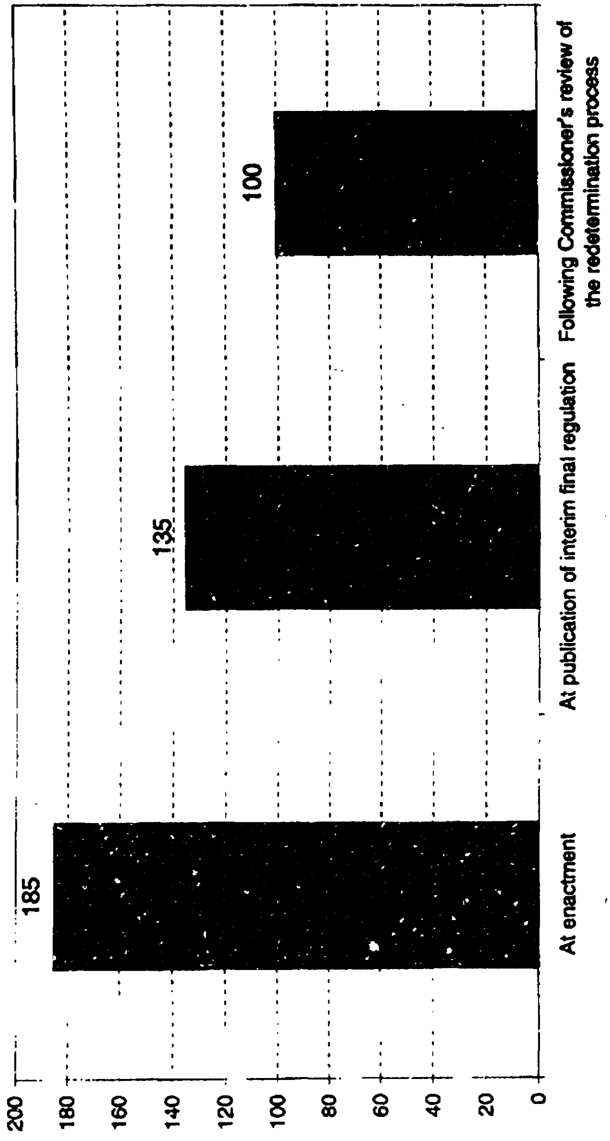
Thanks to the urging of President Clinton, last summer Congress passed an amendment as part of the Balanced Budget Act which ensured that children who lose SSI disability benefits as a result of the changes due to welfare reform continue to remain eligible for Medicaid benefits. SSA is working closely with the Health Care Financing Administration (HCFA) and the States to make sure that Medicaid coverage continues for these children. In order to accomplish this, we have provided to HCFA, and made available to all 50 States, lists of children whose SSI eligibility ended due to changes mandated by welfare reform. Additionally, HCFA is working with SSA to write guidelines for States to help ensure that these children continue to receive Medicaid.

## CONCLUSION

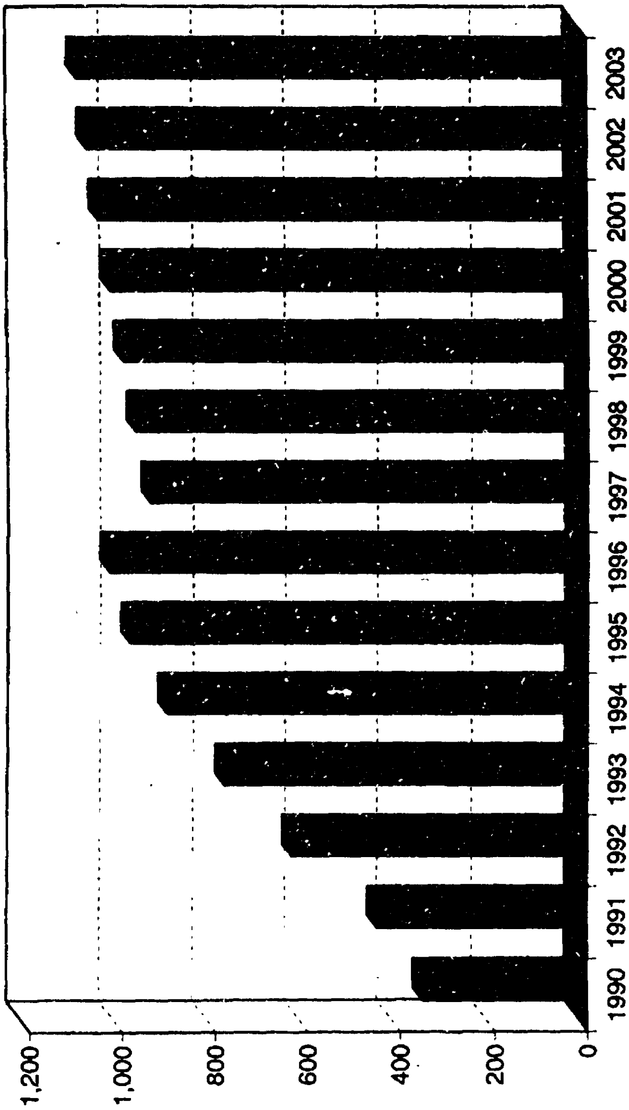
At the time the interim final regulations were published, SSA estimated that, of the approximately one million children receiving benefits as of December 1996, 135,000 would eventually be determined ineligible for SSI benefits. Now that the redeterminations are mostly completed, and in view of the actions dictated by the findings of the top-to-bottom review, the estimate was revised downward to about 100,000 children when all actions including appeals are completed. This represents approximately 10 percent of the children on the rolls in December 1996. This estimate is consistent with the lower range estimate of the Congressional Budget Office in June 1995. I believe that, based on the early results of our re-reviews, the estimate is still accurate. I want to emphasize that the SSI childhood disability program continues—and will continue—to help many families of children with disabilities meet their special needs. I am committed to providing fair and equitable administration of the SSI disability program for all children now and in the future. More than 3 out of 4 of those children whose benefits were initially ceased will have received at least 2 separate evaluations of their continuing eligibility. This means that all of these children are receiving the fair and accurate review they deserve. The actions I have taken as a result of this review of SSI childhood disability program issues will improve the Agency's ability to meet that objective. You have my pledge that I will continue to ensure that children with severe disabilities receive the benefits for which they qualify.

**Estimated numbers of SSI disabled children in payment status as of August 1996 who will ultimately be terminated under the provisions of P.L. 104-193**

*(In thousands)*



Social Security Administration
Office of the Chief Actuary
July 6, 1998



Disabled children receiving Federal SSI payments (In thousands)

Source: *1998 SSI Annual Report*

Social Security Administration
Office of the Chief Actuary
July 6, 1998

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PREPARED STATEMENT OF ROBERT E. COOKE, MD

I wish to thank Senator Chafee for inviting me here today to testify, and I also want to thank Chairman Gramm, Senator Rockefeller, and the other distinguished Members of the Committee.

I am Robert E. Cooke, MD, former Pediatrician in Chief of the Johns Hopkins Hospital for 17 years, during which time I had the opportunity to play a major role in the creation of the National Institute of Child Health and Human Development (NICHD), the University Affiliated Facilities (UAF) and I was the architect of Head Start as Chairman of the original planning committee.

As a pediatrician and Fellow of the American Academy of Pediatrics, Distinguished Fellow of the American Psychiatric Association, and Chairman of the Scientific Advisory Board of the Joseph P. Kennedy, Jr. Foundation, I have devoted most of my professional life to helping families, rich and poor, with severely disabled children. More importantly, however, I appear today as a father of two profoundly retarded daughters—one now deceased.

It is most rewarding to appreciate the great interest of the Senate Finance Committee and many other members of Congress on the issue of disallowance of Supplemental Security Income (SSI) benefits for children as a consequence of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PL 104-193) and the promulgation and implementation of the "interim" regulations by the Social Security Administration.

As of May 30, 1998, 245,349 children have been reevaluated out of the 998,280 child recipients of SSI at the demand of Congress to reassess those children who received SSI based on the Individual Functional Assessment (IFA) and "maladaptive behavior." Of that number only 147,933, which is 54%, have been continued and 125,740 (46%) have been terminated, which is far more than anticipated by many members of Congress, and particularly members of this Committee, who have expressed their concern to the Administration. In addition 56.7% of the 61,402 adolescents turning age 18 have been removed from SSI based on adult criteria even though many had been qualified previously under the very strict Listings level criteria.

In addition, of the approximately 508,000 new applicants for SSI as of May 30, 1998, only 34% have been allowed using SSA's strict eligibility criteria and over 100,000 fewer new applications have been filed than in previous years, further reducing the number of disabled children receiving benefits. In short, not only have the rules become more strict, but also many in the agency mistakenly believe that they must crack down on SSI children. This has had a chilling effect on families and goes far beyond what many Members of Congress intended when passing the legislation. Many of the children who have lost their SSI are extremely disabled and no reasonable, scientifically and individually sound system could possibly disqualify them.

For example:

> A 13 year old girl in Louisiana with a properly performed IQ of 55 and ADHD and major depression requiring hospitalization was cut off;
>
> A 10 year old boy in Illinois with an IQ of 62 with ADHD, failing grades in school, and asthma requiring inhalation therapy several times a day was dropped because a subsequent IQ test a few weeks later was used to disqualify him, even though professional ethics and IQ test publishers caution against readministering the same IQ test due to a practice effect, which causes IQ scores to be artificially inflated.

Furthermore, a random sample consisting of 151 cases whose benefits were terminated (20 because of failure to cooperate) was reviewed by the central office of SSA in the fall of 1997. It reversed 7 cases. However, a review of the same cases by several nationally known experts in developmental pediatrics and child neurology, including myself, identified 20 to 47 cases that were either lacking sufficient evidence to disqualify or clearly should have been reversed and benefits continued.

These statistics and examples illustrate the fact that the regulations are inappropriate and are not grounded in the developmental sciences nor in expert clinical practice. They do not take into consideration the totality of the child in relation to his or her impairments. Decisions are based on Listings in large part derived from adult Listings or equivalence to Listings and not on developmental standards. They are rigid, inflexible and not based on current scientific knowledge.

For example, the Listings specify that a child with an IQ of 69 and another marked limitation qualifies. However, a similar child with IQ 71 does not qualify under that standard. Clearly such a judgment is in contradiction to all known testing variability. Yet a senior psychologist in the SSA, when discussing this range of variation (standard error of measurement—SEM) stated, not jokingly, that one half of the children in this situation would benefit and the other half would be out of luck. Such a viewpoint is not an acceptable reason for ignoring test variation in the USA where fairness is a fundamental moral principle. As the Government Accounting Office has recently pointed out, consistency is important but science and reason are even more so.

The Institute of Medicine (IOM) and the World Health Organization (WHO) have used the following paradigm of Disability.

| | Pathology | Impairment | Functional Limitation | Disability |
|---|---|---|---|---|
| Example: | Meningitis | Deafness | Communication deficit | School Failure |

Such a paradigm recognizes the end point as Disability which is the summation of pathology, impairment, and functional limitation:—whether it be one, two, three or more limitations. Unfortunately, the SSI regulations ignore the scientific fact that there are additive and even multiplier effects of limitations and impairments, especially cognitive limitations. SSA's standard of "two marked functional limitations" as a requirement of receiving benefits ignores the scientific and clinical evidence behind the IOM paradigm of Disability, namely that a combination of impairments or functional limitations in a child—only one of which is marked—may be more disabling than two marked limitations in another child.

For example, a child with moderate cerebral palsy, moderate asthma, moderate attention disorder, and moderate learning problems would not be eligible under SSA's rules because none of the impairments or functional limitations, even though severe in combination, reach the marked standard.

A child with an IQ of 75 and moderate attention problems will be markedly incapacitated in school and at home and should be considered disabled and eligible for SSI. However, a child with an IQ an 120 and the same level of attention problems is not disabled. This is so because limited cognitive ability severely limits a person's capacity to compensate for other limitations.

Based on the latest reports from SSA, which covers 98% of the original case load, large differentials still exist amongst the states—41% termination rates in Pennsylvania and California; versus 76-79% in Arkansas, Texas, Louisiana, and Mississippi (which were already among the strictest states before the new law and therefore should have terminated benefits for far fewer children than other states). The review of new applicants denied benefits also show substantial state variations, yet SSA has offered no adequate explanation for these differences despite the agency being questioned about these differentials by Senators during the September confirmation hearing for Mr. Apfel.

In addition, the failure to Cooperate (FTC) cut off rates, a measure of ineffectiveness at reaching families, is five times as high in New York and Illinois as in Michigan and several other states—it is unlikely that parents in Illinois are less cooperative than parents in Michigan. Likewise, accuracy rates as part of so called Quality Assurance in several states are significantly below SSA's national standards.

These data sound bleak. Indeed, the American Academy of Pediatrics, in a recent newsletter states: "A year after implementation of the new SSI regulations, the Academy is deeply concerned about the large number of children and adolescents who are losing these benefits in substantially larger numbers than had been initially predicted—the state-by-state discrepancies are very troubling."

However, there is some hope for improvement. Commissioner Apfel has taken aggressive steps to rectify, in part, some systemic problems in implementation of the regulations, short of taking the additional and necessary next step of modifying the regulations to meet more closely the intent of Congress.

For example, Commissioner Apfel ordered an automatic review of all children with mental retardation who have lost SSI or been denied SSI upon initial application; the reopening of the appeals process for all who did not appeal the termination of benefits within the proscribed 60 days; and the SEM has been recognized in standardized testing. Furthermore, with the assistance of Deputy Commissioner Susan Daniels, Chief Counsel Arthur Fried, and Acting Associate Commissioner Ken Nibali and Barry Eigen, a revision of training programs and manuals for adjudicators in the areas of mental retardation and behavior disorders have been carried out. And while much more needs to be accomplished, these steps deserve our continued support.

Nevertheless, despite these efforts, a severe systematic problem still exists, best summarized in a quote attributed to me years ago, "A child is not a small adult" to which I now add, "A child is more than the sum of his or her individual parts."

In 1996, the Congress adopted a somewhat more stringent test of childhood disability which required the child to have functional limitations that are "marked and severe." The Listings remained the same but the SSA, in its new regulations, arbitrarily interpreted the statutory test as "two marked and severe functional limitations," thus adding the requirement that a child must have at least "two marked" limitations.

One problem appears to be semantic and lies in the use of the term functional limitations. The common plural use of the term functional limitations implies the need for more than one limitation. Yet often in common parlance, one says "a child has limitations"—without necessarily meaning the child, has 1, 2, 3, or more specific limitations. Thus, I believe the intent of Congress for eligibility was that a child be found eligible if he or she is "markedly limited in functioning." Such terminology, "markedly limited in functioning" rather than SSA's term "2 marked functional limitations," is in-line with the IOM and WHO paradigm of disability in that it clearly expresses the true developmental approach—that is, looking at the whole child and not simply a collection of organs or systems as is SSA's current policy.

The SSA has appropriately recognized the validity of two standard deviations below the mean—or the bottom 2% of the population—as "marked and severe" limitation and three standard deviations below the mean, or the bottom 0.13%, as an indication of "extreme" limitation. Thus, by using the phrase "markedly limited in functioning" instead of SSA outdated and ridged standard of "2 marked functional limitations," a low-income or poor disabled child whose overall functioning was found to be two standard deviations (at the bottom 2%) or more below his or her same-age peers would be found eligible for SSI.

Another problem is that SSA, looking for a quick way to measure function, has adopted the functional areas used in the mental disorder Listings, even though they are not particularly useful to evaluating other disabilities, especially physical disabilities. In addition, SSA has combined the two domains of cognitive limitations and communicative functioning into a single area of mental functioning. The result has been that a child with significant communication problems (not just speech) and impaired cognition is not considered to have two marked limitations under SSA's standard even though experts in neurology and communication science have testified repeatedly that these are two separate areas of brain function. SSA considers limitations in communication separately in neurological disorders, cerebral palsy and epilepsy, but not in cognitive impairment. Thus, SSA should revise its "interim" rules and separate out communication/cognition as two separate domains of functioning to reflect the views of medical science.

Another systemic problem in the SSI process is the so called "quality assurance" system. SSA's policy of sampling adjudicated cases and reviewing them for errors in complying with rules of record keeping and decision making is far removed from "quality assurance" as carried out by hospitals and clinics (and private industry). SSI cases that have been terminated egregiously should prompt intensive investigation as to what went wrong, just as with the death of a baby in a premature nursery, or when an infection is contracted in the hospital. States with extreme approval or disapproval rates should also prompt investigation, whether or not their compliance with the rules is judged to be adequate. "Quality assurance" by SSA needs radical overhaul.

In addition, while the potential for employment makes no sense when applied to evaluation of a three or even a nine year old child, employability is highly relevant for the now statutorily mandated evaluation of 18 year olds who are to be judged by adult criteria. Thus, Congress should additionally mandate that the Office of Vocational Rehabilitation (OVR) carry out an evaluation of the employability of such teens before the termination of benefits as they graduate to adult standards. Furthermore, even though the law defines disability as "the inability to engage in any substantial gainful activity by reason of a any medically determinable physical or mental impairment. . . ." SSA's current standard of ability to do sedentary work as a criterion looks at only physical disability and ignores completely the problem of limitation in mental functioning. Is a 19 year old who is unable to follow directions, can not use public transportation and is a danger to self or others employable? SSA needs to address this issue.

If the Congress reconsiders the criteria for eligibility of children for SSI, it must recognize a self evident fact that all children, well or disabled, are dependent upon their families for assistance. But children with disabilities are far more dependent, creating a greater financial, time consuming, emotional burden on the family than the average child.

The existing regulations in no way acknowledge this fact. What is badly needed is a Congressionally mandated long-term rewrite of childhood disability regulations which takes into consideration the burden on the family in addition to existing criteria. Objective scales exist. A child who needs frequent attention from another person for bodily functions, marked feeding difficulties or supervision far in excess of that needed by the average child of the same age in order to avoid substantial dangers to himself or others imposes a burden on the family that should be recognized.

If a single parent, for example, must devote a large part of his or her time in caring for the child and thus is unable to work and earn enough to support the child, then the very essence of the Welfare Reform Act of 1996 is vitiated. Institutionalization or foster placement then becomes a costly alternative to home care. Even dissolution of the family may result, with even greater moral cost to society.

In summary, I would like to make 5 points:

1. The standards applied by SSA via their "interim" regulations in their evaluation of children are far too rigid and bureaucratic and they are in conflict with modern knowledge derived from the developmental pediatric, neurological and psychological sciences.
2. The implementation of these standards has been inconsistent and erratic from state to state and from case to case with many severely disabled children being unfairly terminated from SSI benefits and new cases being denied that should be eligible.
3. The regulations fail address the additive and even the multiplier effect of several limitations and impairments, especially cognitive limitations.
4. In the transition from child criteria to adult criteria for eligibility for 18 year olds, employability is an important criterion and not just capacity to do sedentary work. Protections such as the medical improvement test and evaluation by OVR are needed.
5. In the criteria for childhood disability, the burden on the family should be added to medical and psychological criteria.

To correct these problems the SSA should:

1. Revisit the intent of Congress and revise its interim regulations as soon as possible.
2. Provide a random sample of 150 cases disqualified by the reevaluation now in progress, as well as new cases so that review by outside experts can be carried out.
3. In its adjudication process, SSA should revise the interim regulations to consider the totality of the child's limitations—the Gestalt—not just the separate impairments, as well as the additive effects of several limitations, particularly cognitive limitations.
4. Add protections for children turning age 18 such as a medical improvement test and OVR evaluation.
5. Give consideration to the "burden on the family" as an additional criterion for eligibility for children.
6. Consider the concept of "limitation in functioning" in the revised regulations as the meaning of the statutory term "marked and severe functional limitations."

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## PREPARED STATEMENT OF LAURIE HUMPHRIES, M.D.

### INTRODUCTION

Mr. Chairman, I am Dr. Laurie Humphries, a child and adolescent psychiatrist from Lexington, Kentucky and a member of the American Academy of Child and Adolescent Psychiatry. The Academy is an association of child and adolescent psychiatrists who are physicians who have completed a general psychiatry residency and a two-year residency training program in child and adolescent psychiatry. Child and adolescent psychiatrists are uniquely qualified to integrate knowledge about human behavior and development from biological, psychological, familial, social, and cultural perspectives in scientific humanistic, and collaborative approaches to diagnosis, treatment and the promotion of mental health. Thank you for the opportunity to testify before this subcommittee on the new standard of eligibility for Supplemental Security Income (SSI). It is timely for me to testify on this issue because I recently served as a consultant for an AACAP publication entitled "Guidelines for Reviewing SSI Disability Benefits for Children and Adolescents with Mental Disorders." I also see first hand, many patients who are disabled and the problems they face with the new standard. I believe that many children with mental illness will lose benefits as a result of the 1996 Welfare Reform law that made major changes to the SSI standard for assessing eligibility for children and adolescents with serious emotional disturbances. The current standard, now in regulation, should, in theory capture children with mental illnesses, but in fact it is penalizing these children by setting a level of severity that is too high for the intent of the law.

## IMPACT ON CHILDREN AND ADOLESCENTS WITH MENTAL DISORDERS

How do we know this? Let us look first at the prevalence rate for children and adolescents with serious emotional disturbances. Five studies funded by NIMH on the identification of mental health problems have consistently identified under-recognition as a major barrier to receiving proper care. It is estimated that between 15 and 25 percent of children evaluated in primary care offices have significant psycho-social problems requiring some type of intervention; yet fewer than one in five of these at-risk children are identified as needing help. Nearly half of these at-risk children are severely disabled by their mental health problems and need constant care and attention. Among these children are many whose families are low income and who need the federal assistance of the SSI program.

In addition to financial or income difficulties, there are the day-to-day barriers to accessing mental health care. Parents often face difficult decisions in even accessing the mental health care system because they fear they will be blamed for their child's illness. Caregivers are often concerned about their child being labeled with a psychiatric disorder. We have a long way to go in this country before there is equal public acceptance of mental and physical illness. The overall discussion of the SSI program has not always recognized the effect of a mental illness on a family especially on a family's emotional and physical resources. Just as children and adolescents may become physically ill they may also experience serious mental illnesses. Losing SSI benefits underminds family stability that is already threatened by the demands of the child's mental illness.

Children and adolescents do have mental illnesses. Emotional disorders do not discriminate across social, racial or economic backgrounds. Research shows that these are real illnesses and are not a result of bad parenting or the child's poor social skills. Research is helping us understand brain development, environmental influences and how prevention and treatment can reduce the effects of later more significant problems. Children and adolescents with emotional and social impairments often face a life time of treatment, rehabilitation and therapy. Without treatment and services research shows:

- forty-two percent of youth with serious emotional disturbances earn a high school diploma as opposed to fifty percent of all youth with physical disabilities and seventy-six percent of similarly aged youth in the general population.
- twenty percent of students with serious emotional disorders are arrested or have some involvement with the juvenile justice system at least once before they leave school as opposed to nine percent of students with disabilities and six percent of all students.

## WHAT IS THE PURPOSE OF THE SSI PROGRAM?

SSI benefits are intended to help families face these consequences. Families use benefits to help pay for food, clothing, transportation and shelter for their low-income families living with a child with severe disabilities like mental illnesses. Common sense tells us that families raising children with these illnesses have higher expenses, less income, and need as much support as possible. Raising a child with mental illness often requires a parent to remain home and forego employment. Some parents must refuse better jobs to protect their child's current health benefits or to remain in a school district that has the necessary educational services for their child. Although public or private health insurance covers some medical costs, families may face extraordinary out-of-pocket expenses related to the child's mental illness. All these factors drain the family income and explain the higher expenses of raising a child with a serious disability.

Most parents in my state use the SSI benefit to provide transportation to and from treatment. Without transportation, the child loses access to mental health care which interrupts the treatment and limits the services the child needs.

If eligible children lose their SSI benefits, many families will not have the resources to care for their child at home. In some cases a family may be forced to surrender custody to guarantee proper care for their children, either through the foster care system or state institutions at a higher cost to taxpayers.

## ASSESSMENT OF THE NEW STANDARD

The new standard for determining SSI eligibility is too harsh for children with mental illnesses. In reviewing my own cases and talking with others, there appears to be a series of cases where SSI eligibility was lost and the children end up being hospitalized. In effect, the new standard is removing the eligibility of children with mental impairments who need access to home and community-based services. When they can not access these services, the alternative can be emergency room and hospital care. This represents a penny-wise and pound foolish philosophy with our most precious resources—our children. This new standard was opposed by many clinicians who are trained to treat the most severe cases of mental illnesses. Paradoxically, the children who have been denied benefits are those who were responding well to treatment and services. For example, often when a seriously disturbed child is in a self-contained special education class with a teacher's aide and other supports and resources, the school will report to the SSA that the child is functioning well at school, and SSI benefits are denied. Then, in addition to losing the SSI benefit, the child will lose his/her medical card, and the family cannot afford the medications needed to maintain function. After this, the child becomes more disturbed and the family finds that they must reapply for SSI while accessing emergency room care or hospital care.

To be very specific, the new standard also combines two very different areas of functioning, communication and cognition. I recognize that this is part of the mental impairment listings, but it is unfair to the children whose limitations may make them eligible if these two areas are judged independently. Cognitive functioning and communicative functioning independently influence mental illnesses. Clinically, it is common for a child to have a cognitive disorder, such as a learning disorder in the area of mathematics. Another example is for a child to have communication disorders, such as an articulation disorder or expressive language disorder, which is related to another clinical problem called conduct disorder.

## RECOMMENDATIONS

Evaluators must not look at the child solely on the severity of one or two functional limitations but on the overall disabling effect of a combination of functional limitations. The SSA should ensure monitoring of the new standard and fair interpretation of the current rules. SSA commissioner, Kenneth Apfel, recently reviewed the implementation of the new SSI childhood disability legislation. A similar review should be done on the standard and its impact for children and adolescents with mental illnesses. The interim final regulations should not be finalized until there has been a proper assessment of the standard and whether its required level of severity is appropriate.

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## Prepared Statement of Hon. Daniel Patrick Moynihan

I thank Senator Chafee for convening this hearing. The children receiving SSI are among the most vulnerable children in our country and changes in law and regulations concerning them merit our closest attention here in the Senate.

The continuing arguments over the meaning of the 1996 statutory changes and implementing regulations suggest the complexity of the issues involved in SSI for children. We should move cautiously here. I understand that some in the House have suggested revisiting the statute to further tighten eligibility standards. I believe we should be sure we have properly implemented the 1996 changes first. Hearings like this help us explore all the questions raised by the 1996 law. I thank all those who will share their views with us.

I thank Commissioner Apfel for his efforts on this and look forward to his testimony.

Again, thank you.

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## Prepared Statement of James Perrin, MD

Good Afternoon, Chairman Chafee. My name is Jim Perrin, MD, and I am pleased to be here today to represent the American Academy of Pediatrics and its 53,000 pediatrician members. As both a primary care pediatrician and an academic researcher, my career has been devoted to helping children and adolescents receive optimal health care and services. Over the last few decades, a major focus of my work has been working with children with special health care needs and their families. I was also a member of the National Commission on Childhood Disability and I have chaired the Children's Committee of the National Academy of Social Insurance Disability Policy Panel.

The AAP is grateful for your commitment to the issue of children with disabilities and to exploring the impact of recent changes to the Supplemental Security Income (SSI) program for children. Like you, the AAP is concerned that SSI benefits be available for children who need them. SSI is a program that helps children with disabilities and we have been troubled that children are being hurt by the denial of benefits to which they are entitled.

The American Academy of Pediatrics strongly supports the SSI program for children. Pediatricians, by the very nature of our work, are advocates for children's health and well being. We regularly care for children and adolescents with a spectrum of chronic or disabling conditions. Whether it is a child with one—or several—special health care needs such as asthma, mental retardation, cerebral palsy or attention deficit disorder, a pediatrician is often a parent or caregiver's first, and ongoing source of medical and social assistance for their child.

As front-line caregivers, pediatricians assess children's needs every day. We have seen the value of the SSI program for many families having extra demands and carrying major additional expenses as a result of having a child with a major disability. SSI is viewed as a critical link between medical and social services for children with disabilities. We must be sure this program is available for those in need.

A child with a chronic illness or other disabling conditions may require a broad range of medical and community services to increase their ability to participate in educational and social activities. The typical child eligible for SSI has significant physical, developmental, or mental disabilities. Most children with disabilities will survive to adulthood, and, with appropriate preventive and habilitative services, can become functioning and productive adults. The SSI program plays a vital role in the care and treatment of such children who are in low-income families.

Over the last several years, the SSI program has been under intense scrutiny by the Congress. Concerns over the rapidly increasing number of children enrolling in the program, anecdotal stories of fraud and abuse, and the budget expenditures related to the burgeoning rolls prompted Congress to make changes to the program.

The AAP strongly supported the policy changes that led to expansions in the SSI program for children and adolescents and believes that the incidence of fraud and abuse of the program is negligible. Prior to changes in program management and the development of newer methods of assessment which addressed the functional impact of disabling conditions, children and adolescents with disabling conditions were only half as likely as adults with similarly disabling conditions to receive SSI benefits. The program growth has in large part but not fully redressed this inequity in access to benefits.

The congressional debate was not easy, nor were the solutions reached ideal. The AAP, along with a number of other children's advocacy organizations, expressed deep concerns that the changes sought by Congress did not reflect a thorough understanding of the SSI program for children, but instead focused on problems associated with a small number of enrolled children and adolescents.

The results of Congress' actions and the Social Security Administration's (Administration) implementation of the new law are being discussed at this hearing today. The reasons of HOW and WHY we got to this point are less important to review than WHAT the impact is of those changes and WHAT Congress and the Administration need to be considering for children with disabilities from this point forward.

I would like to concentrate my remarks for the AAP on three areas: (1) the need for in-depth information and analysis of the SSI program, (2) the need to modify the medical listings and to assess functioning in children and adolescents, and (3) the importance of focusing attention on transition to adulthood of adolescents with disabilities.

### I. NEED FOR INDEPTH INFORMATION AND ANALYSIS:

AAP believes that all programs serving children need to be evaluated on an ongoing basis and based on findings, be modified as necessary to serve the intended population better.

Growth in the number of children and adolescents receiving SSI benefits since the early 1990's was a cause of concern for the Congress and a factor in the 1996 modifications made to the program. Several appropriate reasons explain much of the rapid program growth. These include: program changes to provide equivalent treatment of children's claims as was provided for claims from adults (the *Zebley* Supreme Court decision from 1990), revised and updated childhood mental disorders listings, outreach efforts required by part of title XVI of the Social Security Act, and the increase in the number of children whose families met income requirements.

However, from the beginning of the SSI program and throughout this rapid expansion period neither basic, nor especially longitudinal, information was adequately collected regarding the children being served and the basic impact of this program on households and children. Thus, the 1995 National Commission on Childhood Disability, mandated by Congress, suffered also from inadequate information on which to make recommendations regarding the children's programs.

The continuing changes to SSI with the likelihood of other long-term policy changes, make it critical to collect accurate program data quickly and to develop systems for ongoing monitoring. There is a lack of information—a void that must be filled in short order to develop methods to assess the current changes in the program, as well as to monitor the efforts and benefits of this program for children and adolescents over time.

There is a necessity to understand how the SSI program affects children with disabilities and their families and whether it can better encourage the long-term involvement of young people with disabilities in employment and other adult activities. Although these determinations may be complex, they will help to answer questions that have had substantial policy relevance over the past several years.

The Social Security Administration needs to monitor several components of SSI that are critical to children. This will require a significant commitment of time and resources. However, without this crucial information the effectiveness and long-term benefits of the program in serving children can not be adequately evaluated. Absent this information, policy changes may, once again, be made without a clear picture of who will be affected by the changes and the impact those changes will have on children with disabilities.

Some critical components that should be explored, many in an ongoing manner, are:

The redetermination process:

- Has training of Social Security personnel been adequate to accomplish consistent evaluation of children with difficult to assess conditions?

The appeals process:

- How have families understood the appeals process?
- Are families accessing the appeals process?
- What kind of assistance has been given to families who seek to appeal decisions?
- What is the cost to the SSI for the denial, appeal and approval process?

Benefits:

- What are the direct effects of the loss (or receipt) of benefits on household structure, income, health, and parental labor force participation?
- How do families use their benefits?
- How well do benefits for children with disabilities link families with other needed services?
- How successful have these benefits and programs been in strengthening families and their ability to provide appropriate care for their child with disabilities?

Transitions:

- To what degree have other public programs, including Medicaid, helped families connect to necessary services once SSI benefits have ended?

## II. NEED TO MODIFY THE MEDICAL LISTINGS:

In 1977, the Social Security Administration published diagnostic criteria for determining eligibility for children, criteria that formed the basis of disability determination for over a decade.

We have learned much about childhood disabilities in the last two decades. New technologies have greatly improved diagnosis, treatment, and long-term outcomes for children with disabilities. Many of the medical listings for children are now clinically inappropriate and well out of date and thus discriminate against many children. Evaluation techniques have improved a great deal and the understanding of the functional aspects of children with disabilities has grown significantly.

*Medical listings must be updated to current standards.* We recommend a top-to-bottom review and revision of the childhood medical listings.

Though the medical listings for children should provide a basis for evaluation, they can not be seen in isolation. In addition to the need for a diagnostic approach to disability evaluation, there is a very critical functional component that must be integrated into the overall assessment of a child.

*Children should be included in current and future Social Security Administration disability determination reforms.* The Social Security Administration is deeply involved in a process to reform the ways in which disability among adults is determined, including the development of new methods to assess functioning among adults and the functional limitations caused by disabling conditions. So far, children have been excluded from this process. They too need major reform in the ways of determining disability, but the differences in the conditions that cause disability for children and adolescents, in the developmental consequences of disabling conditions, and the likelihood of improvement among many childhood disabling conditions make clear the need for specific attention directed to the children's issues in this process of reform.

Children are not small adults, and disabilities affect their functional capabilities differently from how they affect adults. As an example, functional abilities tend to be relatively static among older populations on SSI; the dynamic processes of childhood and adolescence mean that functional abilities may change dramatically, especially if appropriate preventive and treatment services are provided. Children must be considered and included specifically in the process redesign.

*The "functional equivalence" component of SSI must be fully developed.* As a result of the Supreme Court case in 1990 (the *Zebley* Decision), the SSA published a new childhood disability regulation which included a functional equivalency provision. Though this functional equivalent provision has been in regulation for 7 years, it has not been developed effectively.

One critical reason for emphasizing functional equivalence is the need to assure that children with multiple disabilities, of which only one condition may be severe enough to meet a medical listing, can still be assessed with respect to their multiple problems. This is a basic notion in the Supreme Court *Zebley* decision concerning children with multiple disabilities.

## III. TRANSITION OF ADOLESCENTS WITH DISABILITIES TO ADULTHOOD:

A key concern throughout all the recent discussions of the child and adolescent SSI program has been how to maximize the independence of young people with disabilities when they become adults. Although many young people with disabilities will require substantial ongoing services, many others, with proper education and habilitative services, can become increasingly independent, lead productive lives, pursue education, and in almost all ways succeed as do other members of their age group.

As indicated in the reports of the National Commission on Childhood Disability and the Disability Policy Panel of the National Academy of Social Insurance, achieving these goals requires imaginative use of the incentives in the SSI program. These incentives should be linked with providing young people appropriate services and guidance early in their adolescent career to maximize growth and development.

We applaud recent efforts by the Social Security Administration to coordinate services in some states and to experiment in these ways. We see these resource linkages directed toward young people with disabilities as one of the more promising efforts to achieving long-term capabilities.

Let me provide several recommendations:

- The Social Security Administration should develop an effective mechanism for ongoing monitoring of the children and adolescents in the SSI program. Monitoring should address basic questions including changes in the child's health and disability status, health care utilization of the child and other members of the household, household income, household health insurance coverage, and parental labor force participation. In addition, there should be an evaluation of how families use their SSI benefits.
- The Social Security Administration must commit itself to developing new methods to assess functional abilities in the context of disability rather than relying on medical listings alone. There is the need to preserve and expand the step of "functionally equaling" the medical listings, which currently exist in the regulations. The administration must strengthen methods to use functional limitations in determining a child's disability.
- The AAP recommends a marked and severe functional limitation test which adds categories for age-appropriate physical stamina and basic physical functioning—areas the AAP believes were absent from previous assessment methods.
- Modifications to the medical listings should include criteria that would enable children with multiple disabilities, not simply a "two marked" standard of assessment, to be eligible for, or remain in, the SSI program regardless of diagnosis. This addition supports the basic notions in the Supreme Court *Zebley* decision concerning children with multiple disabilities.
- The AAP recommends that the Social Security Administration continue to pursue innovative incentives and coordination of services for adolescents with disabilities as they transition into adulthood.
- The SSI program for children and adolescents merits the same level of attention from Congress, the Administration, and outside agencies as has gone into the disability process design. Thus, we further recommend that the Institute of Medicine and its Board on Children and Families undertake a study of the several program options, some indicated above, that can improve the use of these public resources for the benefit of children with disabilities and their families.

The American Academy of Pediatrics strongly urges the Social Security Administration and the Congress to adopt a "First Do No Harm" standard when reviewing the SSI program for children. The population of children served by the SSI program is among the most vulnerable. We must be diligent in the implementation and changes to this important program so that we do not harm children in the process.

Thank you for the opportunity to share the perspective of the American Academy of Pediatrics this afternoon. I would be pleased to respond to any questions you may have.

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## PREPARED STATEMENT OF JONATHAN M. STEIN

Senators Chafee and Breaux and fellow Senators, thank you for the opportunity to offer this statement this afternoon. Having monitored the SSI children's disability program and represented families across the nation almost from the inception of the program in 1974, we are concerned that too many seriously disabled children, especially the multiply impaired, are being denied on application or terminated from the SSI program.

We are here this afternoon to state simply that seriously disabled children and their families are facing a very trying situation and real hardship today as a result of the Administration's application of the new law. Some simple, reasonable and straightforward administrative changes would solve almost all of the problems detailed in this written testimony. If the Administration is not able to solve these problems, then Congress will need to step in to ensure that the statute is properly and fairly implemented. While the Administration has to date indicated some concern, nothing has been done to correct the problems addressed in our recommendations.

We **recommend** that the agency's "interim final rules" issued in February 1997 be revised to:

1. De-link the test to Listings-level severity to establish a severity threshold between the prior IFA test and the Listings as intended by Congress.
2. Realistically evaluate the whole child as required by the existing "combined effects of impairments" language in the Act.
3. Use a common sense approach to evaluating seriously disabled children, by not arbitrarily ignoring problems in all children that are less than "marked" and by not prejudicing the physically disabled by limiting functional assessments to a fixed number of largely mental disorder criteria.
4. Decoupling the two medically and scientifically separate areas of functioning, communication and cognition, as nationally recognized medical-experts have urged upon the agency.
5. Evaluate children aged 3-6 developmentally, as is now done with infants 0-3.
6. Re-establish the statutory longitudinally sounder medical improvement test for reviews of children turning 18, and mandate vocational rehabilitation assessments and placements for them before termination from SSI (the sole recommendation requiring statutory amendment).
7. Revise interim rules and instructions to provide for use of dedicated bank account monies to cover necessities for the child.
8. Give an immediate priority to policy clarifications and retraining of DDS and OHA staff in application of the new policies.

To his credit, Commissioner Apfel has taken several steps to address some of the abuses in last year's review process, especially those concerning children with mental retardation and severe behavioral disorders, and problems in the appeals process. But to date SSA has failed to remedy abuses suffered by new applicants, failed to require a broader set of trainings and policy clarifications and, most importantly, failed to address the major policy failings that are the main subject of my testimony today.

We start first with the disturbing statistics: close to 150,000 children have been terminated this past year (a number reduced by successful appeals of terminations). Another 335,000 new applicants--many with pronounced disabilities--have been denied as a direct result of the Administration's interpretation and application of the 1996 SSI law. This translates into 66% of new applicants are being denied.

As of May 30, 1998, 41% (or 21,835 children) of reconsideration appeals by children terminated this past year under the reviews ordered by Congress have led to reversals and award of benefits. No governmental process that makes disability determinations with a 40% reversal rate is functioning efficiently or fairly.

Equally disturbing, and earlier presented to this Committee at Mr. Apfel's September 1997 confirmation hearing, are the irrational state differentials in child cessation rates from highs in Texas (78.7%) and Mississippi (76.1%) to lows in Pennsylvania (40.8%) and California (40.9%).[1] These discrepancies have never been adequately explained or remedied by SSA.

What is most unsettling, however, is that many of the children behind the above numbers are so disabled that anyone in this room or on Main Street America will immediately recognize it. They would ask, "Why are Social Security's eligibility rules so inflexible and overly strict?" and "Why is there nothing in SSA's rules allowing for the measurement of disorders that affect eating, breathing, digesting, eliminating, stamina, strength and endurance and the ability to resist disease and function in the world?"

Please take the time to read the sample cases we have provided of children denied SSI disability benefits. Their stories tell of serious injustice, not minor process "errors" or a few misapplications of policy. These are real cases of children with extremely grave problems who can't leap the new hurdles SSA has placed before them.

The recently enacted statutory test conditions eligibility on the presence of "marked and severe functional limitations." Although perhaps intentionally imprecise, the new law did give the executive branch the discretion to supplement the discredited, out-of-date and extreme Medical Listings of Childhood Impairments with a sound and fair functional test that would have been somewhat tighter than the previous Individualized Functional Assessment test. We say "somewhat" tighter because then-Majority Leader Bob Dole, in shaping the final version, assured members of the Senate that the program would receive a "tune-up," not a major cutback in eligibility. See 141 Cong. Rec. S 13613 (Sept. 14, 1995).

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[1] A state-by-state breakdown of overall cessation rates is attached.

Instead of a fine tuning, SSA came up with a narrow and inflexible test. The test is grafted onto the much-criticized existing Medical Listings.[2] In order to qualify under the current test, a child's condition must "meet" a Listing of Impairment, or a child's condition must "equal" a Listing by showing that there are "marked" deficiencies in at least two of five broad areas of function that are almost exclusively relevant to children with mental disorders (thereby additionally disadvantaging physically disabled children). Those broad areas of function are: cognitive/communicative, motor, personal, social and deficiencies in concentration, persistence or pace.

Where a sensible test would allow weighing all the things wrong with the child, SSA only considers impairments that cause a "marked" loss of function in one or more of the five broad areas and gives "0" weight to anything that is "less than marked." This means that a child's 72 IQ, which is "less than marked," is virtually irrelevant under the new test as SSA has implemented it. Such a child is treated by SSA as if he or she were the same as a child with a 140 IQ for purposes of determining disability.

Other problems of arbitrariness and inflexibility abound, as set out below and in the case narratives.

We believe that there are several interrelated problems with SSA's approach:

1. It is built almost exclusively on the much criticized, inadequate Listings;

2. The totality of children's problems are ignored;

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[2] The U.S. Supreme Court critiqued the childhood Listings on several grounds which, although Congress has modified the legal standard, still bear remembering:

> [T]he listings obviously do not cover all illnesses and abnormalities that actually can be disabling.... There are, as yet, no specific listings for many well-known, childhood impairments.... [T]he listings also exclude...actual effects on [the child] — such as pain, consequences of medication, and other symptoms that vary greatly with the individual.... [T]he equivalence [to the Listings] analysis excludes claimants who have unlisted impairments, or combinations of impairments, that do not fulfill all the criteria for any one listed impairment. Sullivan v. Zebley, 493 U.S. 521, 533-34, 110 S. Ct. 885, 893 (1990).

The Court continued in a critique that is as relevant today as it was in 1990, given SSA's reliance on the Listings or their "equivalents":

> Empirical evidence suggests that the rigidity of the Secretary's listings-only approach has a severe impact on child claimants. There are many rare childhood diseases that cannot meaningfully be compared with any of the listings.... Moreover, the listings-only approach disregards factors such as pain, side effects of medication, feeding problems, dependence on medical equipment, confinement at home, and frequent hospitalizations, that vary with each individual case.... [C]hildren with multiple impairments, young children who cannot be subjected to the clinical tests required by the listings criteria, and children whose impairments have a severe functional impact but do not match listings criteria are often denied benefits. 493 U.S. at 535, 110 S. Ct. at 894.

3. The two "marked" or nothing approach fails to properly weigh combinations of impairments;

4. The five broad areas of function don't adequately measure many disabling conditions;

5. SSA fails to evaluate children aged 3-6 developmentally;

6. Much more needs to be done to retrain SSA staff.

The problem starts with SSA's misreading of what Congress did. The Senate version of the new test prevailed over the 1995 House version that would have restricted the standard to a "meets or equals" the Listing test. See H.R. 4, sec. 602(A)(1)(ii)(II). The Senate then substituted a "functional limitations" test and defined disability as a "marked and severe" loss of function. In the process of consideration the more restrictive requirement that an impairment be "marked, severe and pervasive" was dropped.

Confirming the compromise that produced the final version of the law that Listings-level severity was not called for, Senators, including from this Committee, within a month of final passage of the new welfare law, wrote the President. See, e.g., Letter of Sen. John Chafee (Sept. 17, 1996) (attached); Sen. Kent Conrad (Sept. 4, 1996) (attached); Sen. Tom Daschle (Oct. 4, 1996); and Sen. William Cohen (Oct. 8, 1996). Ten Senators again wrote the President after publication of the interim rules. (Letter of Apr. 14, 1997 attached).

Not only did the Congress reject the "meets or equals" Listings test, as was contained in the House version, it also did not codify a "two marked" standard which Congress could have easily done by legislating "two marked and severe functional limitations."

The Conference Report unfortunately confused the matter providing that "in those areas of the [Medical Impairment] Listings 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 (July 30, 1996). The problems with this "expectation" include the fact that most of the Listings do not include "domains" of childhood functioning and most don't even include the term "marked." Notwithstanding this, the Report's "expectation" has been translated into a wooden, overly rigid policy that has been used to enshrine the Listings in ways that were never intended by Congress. Indeed, now it is being used to attack the Listings themselves, arguing that some of the Listings are too lenient. This is absurd as we shall see.

Furthermore,"marked" has no definition in the statute or legislative history, and SSA's regulatory one, i.e., tests that show two standard deviations below the norm, is largely irrelevant to most of the evidence that comes in for a child disability evaluation, because most of the evidence is not part of a quantifiable test.

Nevertheless, SSA has developed regulations without the benefit of public comment and enshrined a test that every child must "meet or equal" a Listing as if the Congress had enacted this aspect of the rejected House bill. And by reading much too much into the conference language, SSA ruled that "equals" the listing means showing "two marked" limitations in the "areas" of cognition/communication, motor, social, personal, or concentration, persistence or pace.

62 Fed. Reg. 6408, 6410 (Feb. 11, 1997). (These regulations, issued as "interim final rules," received close to 200 public comments, almost all critical of the rules as overly strict, inflexible and not consistent with congressional intent. Since April 1997, SSA has shown no sign of responding to the comments with relevant changes to the rules.)

The cases of children who meet the new statutory test of "marked and severe functional limitations" but who have been improperly denied under SSA's interpretation of this law establish the following **major problems** with the current regulatory test:

1. **The Listings-based test**, i.e., "meets or equals a Listing," incorporates all of the major weaknesses of the Listings. Those Listings are inexact, uneven, maddeningly vague at times; and often outdated. They often measure severity in terms of the need for emergency treatment, even where conscientious parents often can forestall such drastic interventions. For example, the diabetes listing requires "recent, recurrent hospitalizations with acidosis" (Listing § 109.08 (A)) which excludes many fragile diabetic children who most doctors and lay people would consider disabled by any reasonable standard. Thus, a child who avoids repeated trips to the emergency room or hospital because of the dedication and vigilance of her parents will fail to meet this criteria or similar extreme criteria for other impairments. Especially in these days of aggressive cost cutting by insurers, it is unfair and unreasonable to determine eligibility based on the number of hospital admissions.

2. **Totality of child's problems ignored.** The regulatory test simply does not look at the overall picture of the child with multiple problems or disabilities. By counting or weighing only functional deficits rising to the "marked" level, SSA effectively excludes a host of serious, debilitating effects that do not rise to "marked".

For example, take the case of Warren, who has a congenital heart condition (Wolff-Parkinson-White disease), a mood disorder, severe expressive and receptive language delays, and uncontrolled impulsive behaviors, including self-inflicted injuries. (See narrative below, p. 13). SSA has concluded that Warren has no "marked" deficits in any broad functional area, and based on the approach it has adopted cannot give any weight to Warren's multiple problems, even though the totality of his condition makes this boy seriously disabled. His condition is far more debilitating than that of many children with two marked impairments.

This "marked or nothing" policy violates the statutory directive that SSA "shall consider the combined effect of all of the individual's impairments without regard to whether any such impairment, if considered separately, would be of such severity....The combined impact of the impairments shall be considered throughout the disability determination process." 42 U.S.C. § 1382c(a)(3)(F).

3. **Inflexibility of "marked" standard; anything less, however close to "marked," is "0" and not material to the determination.** The inflexibility of the "two marked" functional limitations rule means that anything "less than marked," however serious or debilitating, counts for nothing under the rules. This is totally irrational, against common sense and sound medical evaluation practice.

For example, Steven, a 10 year old from Illinois, who has an IQ of 75 (see narrative below, p. 17), is classified as having a "less than marked" cognitive impairment that counts as nothing in the SSA evaluation despite the fact that Steven is getting failing grades even though he is in a learning support class with only 8 other students.

Other problems abound with the "marked" line SSA has struck, including their inability to translate for adjudicators what "marked" means. While there is a clear definition of "marked" for impairments that can be measured by standardized testing, the majority of impairments are not amenable to such testing. Yet, despite the fact that it is requiring two marked impairments for children under the 1996 law, SSA lacks a precise definition of what constitutes a marked impairment; in the absence of such clarity we often see children held to extreme standards, particularly in the motor skills area, where anything less than the complete inability to walk is generally considered to be less than marked.

Now the picture has been further confused by a GAO report criticizing the Listing as being too soft on children with mental retardation, since some of the Listings criteria for retardation "only" require a diagnosis of retardation, an IQ between 60 and 70, and another "significant" impairment. According to some, this isn't enough since the only marked impairment that such a child has is in the cognitive area. Such criticism shows the ultimate bankruptcy of relying solely on a "two marked" approach, as if this had some scientific or logical validity and as if all "marked" impairments were equal in weight. One does not need to be a mental health expert to understand that a cognitive impairment such as an IQ in the mentally deficient range can be much more debilitating overall than many impairments in other areas. Ask the parent of any child with mental retardation if their child isn't disabled enough because they "only" have one "marked" impairment in the cognitive area and you will quickly get set straight.

4. **The five "broad areas of function" don't adequately measure function for many seriously disabled children.** SSA admits that their "functional equals" assessment (the "equivalency" evaluation that purports to supplement the Listings) simply borrowed the four functional areas from the "Category of Impairments, Mental" and added a motor skills domain. (The broad areas are 1) cognition/communication (two areas combined as one); 2) social; 3) personal; and 4) concentration, persistence or pace; and 5) motor). In so doing, SSA even combined two areas, the cognitive and communicative, solely because they were so combined in the Mental Impairment Listings. This combination hurts all those children who previously had both conditions at the marked level since, instead of meeting the test by having two marked, they are now magically transformed into children who "only" have marked limitation.

In borrowing from the Mental Impairment Listing, SSA took a set of mental disorder criteria developed solely to evaluate one narrow set of conditions and broadened it to encompass a whole panoply of conditions. Merely adding motor function hardly makes up for the inappropriateness of evaluating all conditions with a yardstick designed to measure only one specific set of conditions.

**a. The physically disabled cannot be fairly evaluated.** Four of the five "areas" relate solely to mental disorders; only the motor area is directly relevant to the physically disabled child. Thus, 6 year old Terrence, (see narrative below, p. 29), who has Hirschsprung's disease, -an impairment of the colon resulting in uncontrollable diarrhea, has no physically-related area relevant to his condition. This deficiency explains his September 1997 denial, despite a very severe disability. Similarly, 10 year old Anna (see narrative below, p. 24), with severe asthma and gastroesophageal reflux disorder, is also prejudiced because there are no areas of functioning that readily address her problems. In short, nothing in the regulations readily allows for the measurement of disorders that affect eating, breathing, digesting, eliminating, stamina, strength and endurance and the ability to resist disease and to function in the world.

SSA's denial data confirms this critique, as children, for example, with physical respiratory impairments, have the highest denial rates, 81%; versus a 64% overall average rate. Assessing childhood disabilities using only the four mental disorder criteria plus a motor criterion cannot fairly measure children with breathing and stamina problems.

The National Academy of Social Insurance 1996 Report, Restructuring the SSI Disability Program for Children and Adolescents was critical of SSA for using "essentially the same criteria for assessing [physical] function as the mental disorder listings." These mental health concepts were found to be inappropriate for children with both mental and physical impairments and for children with only physical impairments. The Report urged "appropriate criteria" be established, including measurements of neurological deficits, stamina and endurance, medical fragility, vulnerability to disease, and the need for special equipment. (Report at pp. 27-29). Unfortunately, in adopting the interim rules, SSA never re-examined how it evaluated children with physical problems (such as in breathing, eating, digesting and eliminating), and has yet to respond to the many critical commentators who recommended expansion of the five "broad functional areas of function."

**b. Combining "cognition" and "communication" into one broad area prejudices children with two separate problems.** As we have seen, SSA requires marked limitations in two different areas of functioning. This presents a particular problem for children with a combination of cognitive and communicative disorders since the two have been combined into one broad area. When SSA combined cognition and communication into one broad area, it made hundreds, or even thousands, of children ineligible, even though they would otherwise have qualified as having two separate and distinct marked impairments. Thus, children like MG in Vermont (see narrative below, p. 19), a 12 year old who has an IQ of 66 and severe deficits in expressive language, and Mildred, a 17 year old who also has an IQ of 66, along with significant visual impairments in eye movement and tracking (see narrative below, p. 25), are denied benefits. Despite considerable criticism from the medical community, including a team of nationally renowned pediatric, neurological, and cognitive experts assembled for SSA by Mrs. Eunice Kennedy Shriver and the Joseph P. Kennedy, Jr. Foundation, SSA continues to lump these two areas together. Separate parts of the brain control cognition and communication, and a myriad of very separate diseases and conditions affect these two distinct areas, yet the unfair combination continues, and the denials of these children mount up.[3]

**c. SSA's "functional areas" policy is so rigid that two different impairments impacting on one "area" are given no additional weight.** Many of the most disabled children have multiple impairments and, given the interconnectedness of these problems, a particular functional "area"

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[3] SSA's recently issued Social Security Ruling on cognition and speech problems addresses the combined conditions of only a very few children who have a cognitive impairment and a physically-caused problem with speaking ability. This Ruling does not purport to address the wider panoply of communication disorders to which many children are susceptible and it therefore provides no guidance on how to evaluate these far more prevalent examples of cognitive and communicative impairments.

may be doubly impacted. Thus, young Anna (4narrative below, p. 23), with reflux disorder and asthma, was denied despite her severe, ulcer-like cramps and shortened asthmatic breathing. Even if an SSA adjudicator evaluated her physical disabilities as "motor" function limitations (the approach advocated by SSA HQ, but rarely carried out in the field), by saying her conditions restricted her motor activities, both because her cramps made her unlikely to be able to move around and her asthma robbed her of her stamina, she still would not qualify because she would only have one marked—not two, as required. Yet her two problems combined are much worse than either taken individually. However, these two independent and debilitating problems are counted as one since there is only one truly physically-related functional "area" and SSA has no rule that takes into account two or more impairments affecting one broad area of function.

**5. SSA refuses to evaluate children aged 3-6 developmentally.** SSA stops its developmental assessment of children at age 3, despite the existence of developmental assessments that are available through Early Intervention programs and day care programs such as Head Start, which assess developmental skills through age 5. Rather than resort to the arbitrary and deficient "two marked" out of five functional areas, SSA could continue to assess these children aged 3-6 using the existing developmental indices they use for younger children and infants. They don't, however, much to the detriment of many pre-school aged children.

**6. Much more needs to be done by SSA in training their staff and in addressing implementation issues.** During the last two years, extraordinary misunderstandings have come to light at all levels of SSA and state DDSs as they have applied the new law and rules. Commissioner Apfel has done much to address some of the worst problems and we applaud his efforts to correct these problems. To take just one example, among many, some DDS staff, some Social Security Administrative Law Judges, and even, at one point, some of SSA's own Quality Assurance staff believed, and many still do to this day, that Congress had directed that all children with mental illnesses that manifested themselves in behavioral problems were to be terminated. Of course, Congress had done nothing of the kind; rather Congress had merely directed the Secretary to modify a sub-criterion of the Listings to avoid double-counting such behavioral problems. Commissioner Apfel's recently announced remedies corrected this misunderstanding and ordered the re-review of terminations involving behavioral problems, but nothing was done for those applicants who were already denied eligibility based upon the same policy misinterpretation.

SSA's recent April 1998 training, which Commissioner Apfel will refer to at today's hearing as part of his "top to bottom" review, comes a year after close to 300,000 children were hurriedly reviewed and, all too often, terminated. Although sorely needed, the training was limited to mental retardation and children with severe emotional problems. SSA tabled training in other drastically needed areas indefinitely.

For example, training is needed in how to apply the functional area of "concentration, persistence or pace" (for which there is no measure or guideline of the requisite level of impairment that corresponds to the fuzzy "marked" standard; instead, adjudicators are merely to determine whether there are "frequent" failures in this area. And "frequent" itself has never been adequately defined.)

Moreover, there is a need to conform the functional assessment form used by adjudicators to guide decision making to the regulations themselves. (For example, the "other factors" regulation allows adjudicators to consider complicating factors but the form makes no mention of the relevance of these factors; or how--or whether--an adjudicator can ever consider a 12 year old who is reading at a $2^{nd}$ grade level to have a "marked" impairment of cognitive functioning.

SSA staff has recognized the need for such training and policy clarification, but the agency needs to commit itself to working to get this done right and quickly.

There are two other changes to the SSI program that Congress made in the 1996 legislation which SSA policy has implemented in ways that are contrary to the intention of Congress. First, SSA has allowed an inordinately high rate of 18 year olds to be terminated from SSI without accumulating data to justify the wide differences among the State rates of these cessations. Moreover, denying the Medical Improvement test only to SSI recipients who turn 18, while utilizing it for all other continuing disability reviews, specifically encourages disparate treatment of 18 year olds. Congress must reconsider its decision to treat current childhood recipients who turn 18 as if they were new adult applicants. All current recipients undergoing a disability review, regardless of their age, deserve to be evaluated under the same Medical Improvement test.

In addition, we recommend that Congress and the Commissioner mandate that SSA refer to State Vocational Rehabilitation agencies all childhood recipients prior to their redetermination when they become 18. Such a measure will allow the young adult's condition to be fully evaluated and to identify those who can be assisted to find work without terminating those who can not be assisted and who are therefore not truly employable.

Second, SSA has also permitted arbitrary restrictions by local field office staff on the dedicated account funds that are now required for all lump sum payments made to children recipients that exceed 6 times the federal benefit rate. Although Congress intended this requirement of dedicated funds to place more control over how these monies were utilized to benefit the disabled child, it surely could not have intended that child recipients would be unable to use the funds entirely. We have heard from families who have been told by SSA field office staff that they are not permitted to spend this money at all.

**1. Children turning 18 have been unfairly dropped from the program.** The new law mandated that every year into the future all children turning 18 be reviewed de novo. Almost 35,000 or 57% of the 18 year olds reviewed (in addition to the nearly 150,00 children under age 18) have been cut off, without even the benefit of grandfathered Medicaid status. The 57% cessation rate is a very alarming and unanticipated rate, given that this is a group that includes a very large number who were found to meet the Listings on initial allowance and who should therefore also have qualified even under the new statutory test.

Furthermore, there is a very high rate (close to 10%) of "failure to cooperate" for those 18 year olds with mental disorders. SSA itself acknowledges this is a suspect grounds for termination. (We fear that the failure-to-cooperate assessment is more a measure of mental illness than a intentional abandonment of a person's claim, given the clustering of cases in this area.)

Everyone should be troubled by the very high cessation rate for 18 year olds who have serious disabilities, such as endocrine system problems (81%), musculoskeletal conditions (72%)

and immune disorders (65%). These conditions seldom improve at age 18 and there is no sound medical explanation for this high rate of cessations for conditions that rarely improve. Note also that a large majority (about 75%) of these young adults were previously found eligible because they met a Listing criteria, not because they met the former IFA test (the new law mandates reviews for all children turning 18 and does not differentiate between those found eligible through the Listings rather than the IFA test).

In fact, the requirement that all 18 year olds get a de novo review puts them in the same unfair position that claimants found themselves in prior to the adoption of the medical improvement standard in 1984. The fact that a majority of these young adults initially met a Listing is compelling enough reason to require that SSA review their disability under the Medical Improvement test which is intended to measure the degree to which a disabling condition has gotten better over time.

**a. Denying 18 year olds the protections afforded by the Medical Improvement Test encourages disparate treatment**

The law fails to extend the longstanding "medical improvement" test for these young adults. Everyone else reviewed, those aged 1 to 17, and those aged 19 to 65, has the basic protection of this test. If Congress continues these mandated reviews, it should at least extend the basic protection of the medical improvement test to all redeterminations to prevent arbitrary terminations. Many people look better on a particular day if you take a snapshot. What is needed is a "movie" that shows their real condition over time; the medical improvement test would insure a fairer review.

Part of the explanation for the extraordinarily high rate of terminations for 18 year olds may be due to the misunderstandings at state DDSs, where each agency seems to have had its own understanding of what the new law required. How else can one explain the continuing extraordinary state-by-state differences in cessation rates such as Louisiana (77%) and North Dakota (40%)? We believe that many DDSs have mistakenly assumed that the new law simply meant that teenagers turning 18 should not be continued on SSI as adults. This also represents a gross misunderstanding of the law that Congress actually passed.

Unless this misunderstanding is corrected or the medical improvement test legislated, every year the unfair treatment of this population will continue.

**b. Mandatory referral to State Vocational Rehabilitation agencies for all SSI recipients over age 16 will enhance their employability and better serve Congressional purpose**

One way to promote the employability of 17-18 year olds and to lessen the hardship imposed on disabled childhood recipients by their abrupt terminations from SSI when they turn 18 would be to take advantage of the vocational rehabilitation provisions already contained in the statute, 42 U.S.C. § 1382d(a), and in SSA's regulations, 20 C.F.R. § 416.1710. The statute and regulations require SSA to "make provision for referral" of 16 to 64 year old recipients to vocational rehabilitation services. This requirement has thus far only sporadically been implemented. Yet, referral to vocational rehabilitation services offers a viable means for easing young adults off SSI and into the workforce. Making the referral to a State Vocational

Rehabilitation agency for services and requiring a vocational assessment should be mandatory policy for SSA and a complete, valid vocational assessment should be a pre-condition to any action to terminate 18 year olds.

Vocational rehabilitation provides valuable job skills and training, which greatly increase the individual's ability to acquire and retain employment. The need for these rehabilitative services is great. For example, consider the plight of a young person who turns 18 but who has only completed the tenth grade because of limitations imposed by a disability. When redetermined under the adult standard, this youngster may be found able to be no longer disabled based on a combination of the "snapshot" approach and the strict criteria used in evaluating the disability case of younger adults However, this young adult has not completed high school and may thus be permanently impeded from employment because of his educational deficits and lack of skills. Moreover, it is highly likely that this young adult will also lack any relevant job skills. Even though this youngster may be found not disabled under SSA's adult standard, he or she will never be able to overcome the effects of the limitations imposed by the disability which resulted in being unable to keep pace with peers and being unable to complete school. Future career opportunities will be severely limited for this young adult by the lack of education and subsequent lack of vocational rehabilitation. A better approach would be to give this youngster the vocational help needed to obtain employment.

Current SSA policy fails to assist the 18 year old to move into work settings with whatever supports are needed. Instead, current policy cuts them off of all supports, including Medicaid. Such assistance is invaluable for these young adults who could for the first time take advantage of SSI's work incentives to help them obtain and retain jobs. Instead, current policy cuts them off of all supports, including Medicaid.

Certainly, vocational rehabilitation services may remain available to young adults despite being ineligible for SSI, but the delay in accessing these services creates an undue but avoidable hardship on the individual recipient. If SSA referred every young person to vocational training before their seventeenth birthday, then more of those who can benefit from this training will actually be prepared for employment.

The statute and regulations provide the requirement that once referred to vocational rehabilitation, an individual may not refuse to participate in vocational rehabilitation if they wish to continue to remain eligible for SSI. 42 U.S.C. § 1382d(c), 20 C.F.R. § 416.1715. Therefore, it is in the best interests of both SSI recipients and SSA to require referral to vocational rehabilitation services for all childhood SSI recipients between the ages of 16 and 18.

The Congress should enact legislation that requires SSA to make referrals to the State Vocational Rehabilitation agencies for evaluations of all SSI recipients over age 16. The law should also mandate that SSA cannot terminate an SSI recipient when he or she becomes 18 unless there is a recent, valid vocational assessment that demonstrates that the individual is realistically employable. In the absence of legislation, the Commissioner could adopt this as a policy and we will urge him to do so, hopefully with your support.

**2. Abuses in the application of the new law's provisions for Dedicated Bank Account expenditures.** The 1996 welfare law also contained a provision requiring dedicated bank accounts for child disability awards of six months or more of benefits, and severe restrictions on the use of the money. Sec. 213 of Pub. L. 104-193. The legislation named a number of impairment-related uses for the money, and gave the Commissioner broad discretion to allow expenditures for "any other item or service that the Commissioner determines to be appropriate." Sec. 213(a)(2). Unfortunately, the agency has not exercised its discretion in a helpful way.

To date, SSA has allowed field offices to make arbitrary restrictions on use of the money that directly contravene the best interests of the disabled child and the child's basic needs for food, clothing, utilities and shelter. Despite a SSA Program Circular issued in March 1998 that was in response to advocates' criticisms about these abuses, field office staff continue to abuse this discretion. No training has been done to make sure that field office staff are aware of this new policy. Consequently, a family we know of is economically insecure because the parents who must devote extra time caring for a disabled child are told that account monies can't be used to pay 3 months back rent and overdue utility bills, some of which pay to run electrical equipment for the child.

Instead, SSA staff has told such families that the money can be used only if the family is about to be evicted or if the utilities are about to be shut off. Similar restrictions on these accounts have arisen in efforts to buy a home, even in the child's name, where that would provide the child safe and decent housing and protect the funds in an asset for the child's future. SSA staff's interpretation of the law threatens vital housing and utility needs of the child with disabilities and usurps parental authority.

SSA field office staff continue to second guess appropriate expenditures for the child, or require impossible accountings -- for instance, how much of a utility bill specifically goes for usage by the child? This has put SSA staff in an awkward position with very little objective guidance. Furthermore, as late as May 1998, we heard from families that SSA field office staff told them they could not spend the money at all until their child turned 18. If SSA staff continue to prohibit expenditures for a need as extreme as preventing homelessness because they feel the law restrains them, then the Program Circular remedy alone obviously was insufficient. It is clear that SSA must now revise the interim rules issued without prior public comment almost two years ago.

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Below are case narratives of children denied or terminated from SSI which call for substantive revision of the interim rules currently in place.[4]

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[4] We submitted these case examples of deficiencies in policy implementation to the Commissioner in April 1998. We understand that SSA staff at the Office of Disability have reviewed the specifics in each child's case to determine whether the decisions were correct. It is likely that some of the children whose stories are outlined in the following pages were subsequently found eligible. However, this unusual form of heightened review by the central office is not available to all the other children who are either being terminated or being denied eligibility. We present them as we submitted them to the Commissioner in April because they reflect a representative sample of the seriously disabled children whose lives are being affected by the SSA's deficient policies and practical misapplications of the new statutory disability standard.

## CHILDHOOD SSI CASES

### WARREN--8 YEAR OLD PENNSYLVANIA BOY WITH MOOD DISORDER, EXPRESSIVE LANGUAGE DISORDER, AND ADHD

**Warren** is an 8 year old with Wolff-Parkinson-White disease (i.e., a condition causing irregular heartbeat), Mood Disorder, Attention Deficit Hyperactivity Disorder ("ADHD"), and severe expressive and receptive language delays. He currently receives 40+ hours weekly of wrap-around services (i.e., in-school and in-home therapeutic behavioral intervention services) in addition to 4 hours of behavioral specialist interventions each week (i.e., in-home family therapy and parent skills training). These therapeutic services are intended to help Warren improve his lack of impulse control. Due to his heart condition, Warren is unable to take many of the medications available that might further help control his impulsive behaviors. In school, Warren receives mostly Cs and Ds, with particularly low achievement in such behavioral categories as "completes assignments" and "demonstrates responsibility."

Warren is extremely self-conscious and easily embarrassed. He routinely engages in ritualized behaviors, such as making noises, tapping a pencil, pacing, picking at his clothes and fingers, cutting up papers which he accumulates in a corner in his room but does not otherwise use. He often scratches at his face while watching television. He picks at the skin on his fingers until it bleeds; this has led to scars forming on his skin. He demonstrates other forms of self-injurious behaviors like taking his mother's pills; last year, he stuck a pencil in his hand and needed emergency care to prevent permanent damage to the hand.

Warren needs constant supervision to ensure that he completes tasks or does not try to hurt himself again. He demonstrates careless and impulsive problem-solving, has serious difficulties concentrating, and rapidly skips from one activity to another. Because of significant speech delays, he has great difficulty expressing himself and consequently other children pick on him. He often responds to this teasing by running away from the other children. He plays mostly with 5 or 6 year old children. He talks to himself in his sleep and has had numerous nightmares in the past several months. He receives speech therapy twice a week. According to his therapist, Warren's mother is "extremely concerned and supportive and has been a leader in [Warren's] receiving necessary evaluations and care."

Warren's mother was employed for a number of years as a chemical technician. She became disabled following hip replacement surgery in 1993. Warren has one older brother, who is 18. Although Warren's brother graduated from high school, he has a learning disability and can only read at a 3rd grade level. Warren's mother is determined to provide whatever she can for Warren so that he is not passed along in school like his brother was and so that Warren does not end up being unable to read when he graduates from school.

After a reconsideration hearing, the state DDS determined that Warren had "less than marked" limitations in all areas and that he was not disabled under the new childhood disability standard since his impairments do not impose "marked and severe functional limitation."

## MARCUS--13 YEAR OLD MISSISSIPPI BOY WITH LIFE-THREATENING HEART CONDITION DIES AFTER BEING TERMINATED AS "NOT DISABLED"

**Marcus** was a 13 year old with a congenital heart defect. Marcus was cut from SSI in July 1997 because the DDS determined that his condition did not meet the new "marked and severe" standard for childhood disability. Tragically, Marcus died from this heart condition on December 4, 1997, after suffering from hypertrophic cardiomyopathy and a series of mini-strokes. At the time of his death, Marcus was on a waiting list to receive a heart transplant.

Marcus' cardiac condition required open heart surgery when he was 10 months old. The condition had been described by his grandparents as "a hole in his heart" so that the valves in Marcus's heart had to be "switched around." Marcus again had open heart surgery in August 1997 because of leakage, inefficient valve flow, and fluid build-up. His annual checkup in August had revealed that Marcus's heart was causing very serious complications. Because of the treatment required for this condition, Marcus was unable to attend school in the Fall of 1997.

His grandparents, who were Marcus' guardians, did not appeal the SSI termination because they believed that if their appeal was unsuccessful then they would have to pay back all of the money from the period when Marcus first became eligible and started receiving SSI benefits. This was their interpretation of Social Security's termination letter they received in the summer 1997 notifying them that Marcus' SSI would be terminated because he was "no longer disabled."

For Marcus' grandparents, the termination of Marcus' SSI benefits was a great hardship. They live in rural Mississippi, a 2 hour trip to Memphis, and they had to be in Memphis much of the time between August and December 1997 for the intensive health treatment that Marcus required. Their traveling and stays in Memphis caused Marcus' grandparents to miss much work and to suffer other financial hardships, in addition to the emotional strain of watching Marcus' condition deteriorate so rapidly and fatally.

## SANDY--13-YEAR-OLD LOUISIANA GIRL WITH MENTAL RETARDATION AND ADHD

**Sandy** is a 13 year old with mental retardation and ADHD. Sandy has an IQ of 55. The DDS had Sandy re-evaluated at a consultative examination as part of the redetermination process mandated by the 1996 welfare law. The DDS psychologist diagnosed mental retardation but failed to provide current test scores. However, another consultative psychologist corroborated the diagnosis and noted that Sandy had also recently been hospitalized for major depression. The psychologist suggested an additional diagnosis for Sandy of oppositional defiant disorder. Records confirm that Sandy continues to perform very poorly academically (making virtually all Fs and Ds), and presents severe behavioral problems (disruptive behavior, truancy, inattention and hyperactivity), and is socially isolated. Sandy continues to take medication for ADHD and depression.

Upon reconsideration, the DDS affirmed its initial decision to terminate Sandy's SSI. The DDS determined that Sandy had "marked" limitation in concentration, persistence, or pace and "less than marked" in all other areas despite the fact that SSA regulations specify that an IQ below 59 is an "extreme" limitation and presumptively meets a Listing. In evaluating Sandy's cognitive functioning, however, the DDS relied not on the psychological test results on record, but rather on a comment contained in Sandy's recent hospitalization records that suggested Sandy's intelligence "seemed average [from her demeanor]."[5]

## ERNEST--7 YEAR OLD PENNSYLVANIA BOY WITH ASTHMA AND ADHD

Ernest is a 7 year old with severe asthma and ADHD. Ernest takes several different asthma medications daily, including steroidal inhalants, which cause his hyperactive behavior to worsen. He has difficulty concentrating generally, but is unable to concentrate at all for about ½ hour after inhaling his asthma medication. In the last year, Ernest was hospitalized twice for pneumonia-like symptoms. He has persistent wheezing and never has symptom-free periods of shortness of breath. He receives daily treatments with bronchodilators. He has had emergency treatment for his asthma at least four times since June 1997, followed each time by week-long doses of corticosteroid treatment.

Due to his asthma, Ernest frequently misses school. When at school, he is not permitted to go outside to play like the other children and he does not participate in gym activities. Because he must inhale his medications at lunch time as well, he also misses the company of other children during this important period for socializing.

Ernest is in the first grade, where his poor attendance is creating learning deficiencies and his uncontrolled hyperactive behavior is becoming problematic for both his teacher and the other students in his class. Ernest takes Ritalin for his hyperactivity. However, the hyperactivity and impulsivity are no longer confined to brief periods following inhalation of his asthma medication and Ernest's mother has begun taking him to a

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[5] This is exactly the type of misapplication of the regulations that SSA training in March 1998 addressed. We can only hope that the adjudicator who reviews Sandy's case on appeal recognizes the absurdity of the situation when a child with an "extreme" limitation does not qualify.

psychotherapist regularly. In the past year, Ernest has gone from being a generally happy, sociable child to a sad and lonely one and he is having difficulty understanding why.

Despite meeting listings level severity for his asthmatic condition alone, and without considering the combined effects of Ernest's asthma and ADHD, the DDS determined that Ernest has "less than marked" limitations in all functional areas.

### TAQEE--8 YEAR OLD PENNSYLVANIA BOY WITH ADHD, LEAD POISONING, AND ANEMIA

**Taqee** is an 8 year old who is diagnosed with ADHD, lead poisoning, enuresis (bed wetting), and anemia. Taqee has a history of hyperactive behavior, impulsivity, and poor attention that have severely limited his social and personal functioning. He frequently is unable to complete tasks in a timely manner.

Taqee was diagnosed with lead poisoning when he was 3 years old. Taqee had several inpatient chelations (i.e., intravenous treatment for lead poisoning) and receives ongoing treatment for Class III lead poisoning. When he was 5 years old, following much treatment and after his family moved to a more "lead-free environment," Taqee was downgraded to a "moderate risk" level of lead poisoning. He remains at risk of long-term adverse effects from the lead poisoning, such as cognitive deficits and encephalopathy, which may be manifested in symptomatology similar to ADHD. Taqee frequently has spontaneous nosebleeds, and due to his anemic condition he must take iron supplements daily.

His teacher reports that Taqee has difficulties sitting in his seat; he constantly taps his pencil on his desk. He calls out inappropriately in class and becomes anxious or angry when he must wait his turn. Unlike other children in the class who may become impatient, Taqee's behavior has been so disruptive that his teacher must have Taqee sit next to her in order to help him control himself. Taqee has a history of impulsive behaviors, including head banging, breaking toys, running wildly, threatening to harm himself, and refusing to eat. His teacher reports that Taqee is "always falling down and having accidents." He has been taken to the emergency room a number of times after falling and injuring himself. His teacher also reports that Taqee has poor attention, is "distracted very easily," and he is "extremely forgetful and unfocused." He routinely experiences difficulties completing tasks because he is easily frustrated. His teacher reports that Taqee completes assignments "60% of the time."

Taqee demonstrates poor social judgment and low self-esteem. His teacher reports that Taqee has been "getting into more fights" with his classmates. He has no friends away from school because other children in his neighborhood are afraid of his impulsive behaviors. When he is frustrated, he will sometimes break his toys or throw things.

In addition, despite an elaborate behavioral modification system involving alarms and moisture-sensitive apparatus, Taqee continues to wet his bed almost nightly. His pediatrician has ruled out a bladder or other genito-urinary tract problem. Although his parents follow the remedial plan recommended by the family's therapist to have Taqee clean his own bedclothes, his bed wetting persists. The DDS determined that Taqee has "less than marked" limitations in all functional areas.

### STEVEN--10 YEAR OLD ILLINOIS BOY WITH MENTAL RETARDATION, ASTHMA, AND ADHD

**Steven** is a 10 year old boy with mental retardation, chronic asthma, and ADHD. Steven has an IQ of 62, which was recorded this past year as part of an evaluation at school. He has been in learning support classes since beginning school. His teachers this year report that he is unable to sit still in his chair, does not complete assignments, and generally distracts the entire class of 9 students. His grades are Ds and Fs this year. He must inhale several doses of medications for his asthma every day. He uses a nebulizer several times a day as well. Some of the medication for his asthma makes him feel nervous inside, which makes him even more agitated and hyperactive than he is already.

The DDS had Steven re-evaluated at a consultative examination one month after the evaluation done by the school. Steven recorded an IQ of 75. The DDS concluded that Steven therefore had "less than marked" cognitive limitations, despite the low grades and academic difficulties he was experiencing in a learning support class. The DDS did not factor in the psychometrically recognized phenomena of the "practice effect" of repeated administrations of a test within a short period of time, nor the standard of error of measurement, which provides a range of accuracy within 5 points of a reported score. Children commonly score 8-10 points higher on a test they were recently administered and all psychometric tests have some error in their measurement ranges. Without considering either phenomena, the DDS concluded that Steven had "marked" limitations in concentration, persistence, or pace and "less than marked" in all other areas. Therefore, the only "combined effects" of Steven's ADHD and asthma recognized by the DDS was in the lone area of concentration, persistence, or pace and he was found not disabled.

### KATINA--9 YEAR OLD PENNSYLVANIA GIRL WITH LEARNING DISORDER AND SPEECH DISORDER

**Katina** is a 9 year old with poor visual-motor coordination, a learning disorder, and severe speech and language deficits. Results from a speech and language evaluation showed that Katina had extreme expressive and receptive language delays, articulation deficiencies, and difficulty retaining information. Because cognitive and communicative disorders are lumped into one "area" under SSA's rules, SSA considers her to have only <u>one</u> "marked" impairment, despite <u>both</u> cognitive <u>and</u> communicative problems. She scored in the lowest 1% on all tests administered and her language development is ranked at less than the 5 year old level. A psychological report from her school confirmed this assessment and showed Katina has difficulties with memory, visual-motor coordination, and severe delays in language and speech. Katina attends weekly speech therapy and is in special education classes for math and reading.

Katina has great difficulty expressing herself. Because of her poor visual-motor integration, she is sometimes physically clumsy. She has few friends because when she becomes frustrated she is prone to cry and this is upsetting to her peers who do not know how to deal with Katina's erratic emotional expression. She was denied benefits by the DDS as a new applicant.[6]

## SERETA–3 YEAR OLD NEW YORK GIRL WITH MENTAL RETARDATION AND MILD HEARING LOSS

**Sereta** is a 3 year old with a developmental quotient of 60 (i.e., cognitive development more than 2 standard deviations below the norm). She has mild hearing loss in her better ear with middle ear pathology and a history of chronic otitis media in both ears. Her speech is extremely delayed (scores at age equivalent of 12 months) and she has significant impairment of expressive and receptive language skills (scores at age equivalent of 14 months). She is not fully toilet trained, rarely engages in play with other children, is unable to consistently mimic behavior. She rarely responds to questions verbally. She cannot identify colors, name common objects or most body parts. She has difficulty understanding pronouns, common verbs, or following two-step directions. She rarely used more than 3 word sentences; she usually jabbers.

The DDS rated Sereta's limitations as "marked" in the cognitive/communicative area and "less than marked" in all other areas. Despite the separate etiology of her cognitive deficiencies and her language deficits, the DDS determined that her cognitive deficits were not an accurate reflection of her functional limitations because they were "double weighted" due to Sereta's inability to respond verbally. In addition, because Sereta lives in a bilingual household, the DDS reasoned that a bilingual environment tends to lower scores for speech development, a dubious proposition at best. She was denied benefits as a new applicant.[7]

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[6] Katina was recently awarded benefits at the Administrative Law Judge level of appeal.

[7] Sereta was recently awarded benefits at the Administrative Law Judge level of appeal.

## MG--12 YEAR OLD VERMONT GIRL WITH MENTAL RETARDATION DEVELOPMENTAL DELAYS IN LANGUAGE AND SPEECH

MG is a 12 year old girl who lives in rural Vermont with her mother, father, and four siblings. Her father is a self-employed lumberjack. Her mother assists in the family business and takes care of their five children. MG suffered a closed head injury at 4 years of age. In 1993, she became eligible for SSI after a finding that she had impairments in cognitive development, communicative development and deficiencies in concentration, persistence and pace. In the redetermination of her benefits in 1997, MG was determined no longer disabled because her impairments were "less than marked" in all functional levels. MG is currently in the 6th grade and receives special education services.

MG's head injury has seriously interfered with her activities of daily living, particularly in the school setting. Her teachers state that, despite their best efforts, she functions on a 2nd grade level. Teachers also report she has a short attention span, even in one-to-one situations. MG is unable to remain focused or to finish a task independently, even work at the 2nd grade level. She cannot respond appropriately to changes in routine.

When recently assessed by a neuropsychologist, MG scored an IQ of 66. According to this assessment, MG functions at the kindergarten to first grade level in oral language and auditory processing. Her other test scores showed that her perceptual organization and perceptual speed both fell two standard deviations below the normal range for children her age. Her expressive language was found to be in the severely impaired range which is not separately calculated under the interim rules because it falls in the same "functional area" as cognition. (The one "area" is called cognition/communication.) Her skills in reading, writing, and math all fell two standard deviations below normal. In her testing of attention, concentration, information processing, and vigilance she scored well below average. In the testing of vigilance, she was both inattentive and impulsive, recording a score 4 standard deviations below the norm, which is beyond the "extreme" limitation as defined by SSA regulations.

It is quite clear from neuropsychological testing and from comments from her teachers that MG's head injury has profoundly interfered with her functioning in cognition, communication, and concentration, persistence and pace. Her parents are hopeful that MG will continue her eligibility for SSI so that they will have the resources to have MG more thoroughly evaluated and treated. They fear that without further testing and more intensive educational and behavioral supports, MG will be unable to become a productive member of society.

## JEFFREY--10 YEAR OLD WEST VIRGINIA BOY WITH MENTAL RETARDATION AND ADHD

Jeffrey is a 10 year old boy with mental retardation and ADHD. Jeffrey has an IQ of 66. He is unable to match clothes or put on his socks without assistance. He has been unable to learn how to tie his shoes. He has great difficulty completing activities and needs constant supervision and encouragement to complete his homework. He frequently gets up in the middle of the night and wanders through the house, waking up the rest of his family. The family has been unable to remedy this behavior despite adhering to the recommended therapeutic interventions. When Jeffrey's case was reviewed, the West Virginia DDS determined that he was no longer disabled because although he had "marked" cognitive limitations, he had "less than marked" limitations in all other areas.

Jeffrey has had two DDS reconsideration hearings. At the present time, the DDS believes that the SSA Quality Assurance reviewers have indicated that there is insufficient evidence to find that Jeffrey meets the new disability standard for children.

## HANNAH--3 YEAR OLD LOUISIANA GIRL WITH DEVELOPMENTAL DELAYS AND SEVERE SPEECH IMPAIRMENT

Hannah is a 3 year old who was born prematurely. Besides neurological deficits from a complicated birth she has had a series of severe ear infections. She has bi-lateral sensorineural hearing loss that requires hearing aids in both ears. Because of her severe hearing impairment she has considerable language deficits. When she was 17 months old, she was evaluated for early intervention services. Testing at that time revealed Hanna had social development of 7 months, adaptive self-help skills of 8 months, and communication development of 10½ months.

When Hannah was 19 months old, a speech pathologist found Hannah's play skills were at the 9-12 month level and her language skills were below the 9 month level. She had no meaningful spoken language and was diagnosed with "moderate to severe expressive and receptive language delays." Under the new childhood disability standards, Hannah's hearing and communication impairments are evaluated in the same functional area; thus she was found to have one "marked" limitation only in the combined area of cognition/communication and "less than marked" in all other areas. The Louisiana DDS denied her benefits.

## DUSTIN--6 YEAR OLD LOUISIANA BOY WITH PERVASIVE DEVELOPMENTAL DELAYS, MENTAL RETARDATION AND ADHD

Dustin is a 6 year old who has had developmental delays and other problems since he was 3 years old. He was diagnosed with Pervasive Developmental Disorder, ADHD, and mental retardation. Dustin has an IQ of 65. When he was 5 years old, standardized testing showed that he was functioning at the 28 month level for receptive and expressive language, less than half his chronological age at the time of testing of 60+ months. According to SSA regulations, this disparity between functional limitation and performance demonstrates an "extreme" impairment, and is presumptively of "listings level severity." In addition, Dustin scored at the 42 month level in social skill development.

Nevertheless, despite the record showing "extreme" limitations in expressive and receptive language, the DDS determined that Dustin was no longer disabled under the new childhood disability standard. Because the new standard conflates the cognitive and communicative areas, the DDS determined that Dustin had "marked" limitations only in the cognitive/communicative area and "less than marked" in all other functional areas. The new childhood standards do not allow for the combined effect of limitations in cognition and communication. Therefore, his IQ of 65, which is "marked," and his language scores, which should have been rated as "extreme," were only counted as "marked" under the cognitive/communicative functional area.

## CLETE–12 YEAR OLD PENNSYLVANIA BOY WITH HYPOTONIA AND SEVERE LANGUAGE DEFICITS

Clete is a 12 year old boy terminated by the DDS from SSI despite his congenital hypotonia (i.e., muscle tone deficiencies) and neurologically-based deficits in language development, attention and comprehension, gross and fine motor coordination, and significant impairments of visual-motor integration. He has a history of learning disorders in math and written expression. He also has a history of hearing deficits and was hospitalized a number of times when younger due to problems with his eyes. Although many of Clete's physical impairments were corrected by surgery, his hearing has recently regressed. He continues to have visual-motor difficulties.

Clete attends an ungraded 6th grade class. Although due to special education his math skills are now adequate, his writing skills remain severely deficient because Clete is unable to appropriately hold and manipulate a pen or pencil. In addition, at 12 years of age, Clete continues to have difficulty with some daily living skills because of poor muscle tone. For example, he has difficulty holding eating utensils and must be reminded not to simply eat with his hands. His poor muscle tone frequently results in the food falling off when he uses the proper utensils. He is unstable when climbing steps and often falters or staggers; he frequently falls when walking or running. Because of his overall physical clumsiness, Clete is frequently teased by his peers at school. His friends are mostly much younger children.

Despite an average IQ, Clete has difficulties with comprehension, following directions, and assimilating new information, he is easily frustrated when he cannot complete tasks or grasp academic material. He has great difficulty completing most of his school and homework, and requires constant adult supervision to ensure that he completes these assignments. He also needs supervision to finish dressing or doing chores because he is distracted easily and cannot concentrate on one activity for long.

## NICHOLAS—9½ YEAR OLD PENNSYLVANIA BOY WITH DEVELOPMENTAL DELAYS & LANGUAGE DISORDER

Nicholas is a 9½ year old terminated from SSI despite his having developmental delays, language disorder, asthma, and possible organic deficits of the brain. His speech is dysarthric and he receives speech therapy at school. Nicholas has insomnia, anxiety, impaired memory. He exhibits poor impulse control, low frustration tolerance, and psychomotor agitation. Nicholas has trouble concentrating and cannot read or write age-appropriately. He has difficulty dressing himself, often putting his clothes on inside-out; he has problems tying his shoes correctly. He becomes frustrated easily and when upset he will punch himself in the face. When he is corrected by an adult, he runs away and hides. Occasionally, he tries to run away from his mother. He recently walked into traffic without looking and was almost hit. His eyes twitch involuntarily. He repeated kindergarten. He now attends an ungraded learning disability class.

Nicholas has been experiencing increasing behavioral and social problems at home and school. His teacher recently complained about his behavior and ordered him kept at home if he could not control himself. At home, Nicholas sometimes refuses to get dressed. Frequently, his mother must force him to wash himself when he refuses. The DDS determined that Nicholas had marked cognitive impairment but "less than marked" limitations in all other areas of functioning.

## ANDREW—14 YEAR OLD PENNSYLVANIA BOY WITH ADHD

Andrew is a 14 year old with Attention Deficit Hyperactivity Disorder. He has been receiving psychiatric treatment and medication for this condition since he was 5 years old. When he was 11 years old he made a suicide attempt. He currently attends a seriously emotionally disturbed ("SED") class in school where he is repeating the 6th grade, despite extra tutoring and summer school work. He has few friends and is seldom allowed to go out on his own because of his poor impulse control.

Andrew is basically unable to function independently and needs almost constant adult supervision. He rarely completes tasks unless an adult consistently reminds him because he has trouble organizing, planning, and in following directions. Despite medication, he continues to have difficulty controlling his hyperactivity and frequently exhibits inappropriate disruptive behaviors, both in school and at home. He is sometimes destructive of property. Andrew was terminated from SSI by the Pennsylvania DDS.

## DERRICK--11 YEAR OLD PENNSYLVANIA BOY WITH MENTAL RETARDATION, SPEECH DEFICITS, AND ADJUSTMENT DISORDER

Derrick is an 11 year old terminated by the Pennsylvania DDS despite his having mental retardation, a learning disorder, severely delayed expressive and receptive language development, deficits in visual-motor integration, and an adjustment disorder. He is in a learning support class and receives speech therapy. Although in a 5th grade class, he reads on a 2nd grade level and does math on a 4th grade level. Because of his difficulties with speech, Derrick has trouble asking for help and unless his teacher inquires Derrick does not indicate that he is having problems comprehending and retaining new information. Current language skills testing reveals that Derrick's language development is between the 5½ and 6 year level. He is unable to concentrate or stay focused for periods longer than a few minutes.

Derrick rarely completes his homework unless his mother sits by his side and provides constant encouragement. He has similar problems completing assignments while in school and is easily frustrated when he does not grasp the subject being taught. He has a special seat near the teacher to provide one-on-one attention. He is able to do routine activities, like dressing and brushing his teeth, but consistently needs to be reminded to finish one activity before moving on to another. He currently attends individual psychotherapy sessions weekly for an adjustment disorder because he has difficulties expressing his emotions. Despite having an IQ of 70 and delayed language skills development at half his chronological age, the state DDS concluded that Derrick had only "marked" cognitive impairment and was "less than marked" in all other functional areas.

## JASON--15 YEAR OLD PENNSYLVANIA BOY WITH BIPOLAR DISORDER

Jason is a 15 year old with manic-depressive ("bipolar") disorder. Jason has recently been suicidal, for which he was hospitalized for several weeks this past Fall. He receives wrap-around services (i.e., in-school and in-home therapeutic behavioral interventions) to help motivate him to engage in different activities and to complete tasks. He attends a school for severely emotionally disturbed children. He has sleep disturbances, poor eating habits, and occasionally does irrational or dangerous things, such as running aimlessly in heavily trafficked areas.

Jason can be grandiose or apathetic, depending on his mood. When he is depressed he can be suicidal. He generally lacks interest in all activities. He has no friends. His family is very worried about his future because medicine does not seem to control his mood swings. His family never knows what to expect from Jason's behavior.

The Pennsylvania DDS determined that Jason did not meet the new disability test and cut him from SSI.[8]

### DAMIAN--17 YEAR OLD PENNSYLVANIA BOY WITH SCHIZOAFFECTIVE DISORDER AND LEARNING DISORDER

Damian is a 17½ year old with schizoaffective disorder, depression, borderline intellectual functioning, a learning disorder, Duchenne's dystrophy, and chronic headaches. He daily has diffuse, aching head pain often accompanied by nausea and photophobia (sensitivity to light). He has a history of audial hallucinations. He stopped attending school a year ago because other boys threatened to hurt him badly; he was too afraid to return to school after several prior attacks made by this same group of five boys.

Damian was hit by a car when he was 6 years old. At that time, he suffered closed head trauma resulting in cognitive deficits and subsequently Damian attended special education classes until last year. He still cannot read or write and he rarely engages in verbal interactions with others. He has poor appetite and sleep disturbances. He has attended individual psychotherapy periodically over the past few years. He currently takes medication for his mood disorder and hallucinations. He also sees a neurologist for treatment for his chronic headaches. Damian was found not disabled under the new law and terminated from SSI.

### ANNA--10 YEAR OLD PENNSYLVANIA GIRL WITH ASTHMA AND REFLUX DISORDER

Anna is a 10 year old with asthma and gastroesophageal reflux disorder (i.e., an ulcer-type disorder of the upper gastrointestinal area). She was hospitalized once during the past year for an asthmatic attack. During the past year, she has also had several short-term courses of treatment with steroidal medication to control asthmatic attacks. Each day she must take several medications for asthma and several for the reflux disorder.

Anna is unable to participate in physical activities and must adhere to a special diet to avoid stomach cramps and severe heartburn. She often misses school because of the combination of shortness of breath caused by the asthma and chest pains caused by the reflux. There is no broad "area of function" under SSA's rules on "functional equivalence" to the Listings that directly measures her limitations. Both affect her ability to engage in "motor" functioning. Therefore, they are seen as overlapping, affecting only <u>one</u> "area." SSA's rules offer no other "areas" to capture her problems. Anna was determined not disabled by the DDS and terminated from SSI.

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[8] Jason was reinstated to continuing benefits at the Administrative Law Judge level of appeal.

## MILDRED--17 YEAR OLD PENNSYLVANIA GIRL WITH MENTAL RETARDATION AND VISUAL PROBLEMS

Mildred is a 17 year old with mental retardation and significant problems of impairment of eye tracking and teaming. Mildred has an IQ of 66. Her eye teaming problem results in a tendency for her eyes to turn inward. Because Mildred has inadequate ability to compensate for this trait, which diminishes her visual efficiency and visual processing, she has trouble controlling her eye movements. The problem with her impaired eyesight causes double vision and frequent headaches. She often loses her place when trying to copy from the blackboard, skips words when trying to read, and can't sustain visual tasks for any prolonged period without pain. Mildred consistently has difficulties with visual processing and visual-motor integration. Her visual difficulties only compound the cognitive problems she has processing and analyzing new information. Despite valiant effort, Mildred is unable to keep pace with other children in her learning support class because of her visual processing deficiencies.

The DDS determined that Mildred's condition was "marked" in cognitive limitations but "less than marked" in all other areas. There is no functional "area" for vision problems and the Listings of Childhood Impairments do not touch on her particular visual dysfunction. Despite the pain and obvious difficulties imposed by her visual processing deficiencies, the DDS concluded that because Mildred's visual acuity was corrected with lenses the remainder of her vision problems did not constitute any additional limitation. According to the DDS, Mildred's visual-motor integration deficits were factored in under the cognitive limitations and did not amount to an additional significant limitation, even though she is much more disabled than another child with an IQ of 66 would be who did not have an additional visual deficiency. Found not to be disabled under the new law, Mildred was terminated from SSI by the Pennsylvania DDS.

## ATIFA--12 YEAR OLD PENNSYLVANIA GIRL WITH MENTAL RETARDATION AND ASTHMA

Atifa is a 12 year old with mental retardation and asthma who was cut from SSI as not disabled under the new law. Atifa is easily distractable, irritable, and has low tolerance for frustration. Atifa has difficulties with learning and retaining new information. She is in special education classes. Her reading scores place her four or five grades behind her chronological age; for example, her 9 year old brother reads to her. Her parents spend a great deal of time and energy helping Atifa with her homework, practicing her reading, and developing other skills. Her parents have purchased numerous learning games that they play with Atifa to help bolster her self-confidence, keep her attentive, and provide encouraging feedback on her successes at these activities.

Her teachers report that Atifa has poor concentration, does not always persist in completing her schoolwork, is not assertive, and sometimes has problems interacting with peers. At home and around her neighborhood, she plays with children younger than her.

Because of her asthma, Atifa is unable to participate in gym or go outdoors on days when the weather causes her shortness of breath. She can't keep up with other children.

## JONI--7 YEAR OLD PENNSYLVANIA GIRL WITH HEARING LOSS, SPEECH DELAYS, AND ADHD

Joni is a 7 year old child with conductive hearing loss, speech delays, lead poisoning, and attention deficit hyperactivity disorder who was denied by the DDS as a new applicant under the amended law. She has moderate receptive and expressive language delays with a 25 decibel conductive hearing loss. She has a history of hyperactivity, impulsivity, disturbed sleeping patterns, aggressive behaviors with peers and adults, and poor concentration and persistence.

Joni has severely underdeveloped social skills and difficulties with concentration and persistence. A teacher's report shows that Joni manifests significant limitations of her hearing, concentration, and attention as well as exhibiting recurrent aggressive behaviors toward her peers. According to her teachers this year, Joni's "attention span is extremely short." The difficulties with her hearing are not attributable to the adenotonsillar hypertrophy and recurrent otitis media because both conditions were surgically corrected by a tonsillectomy and bilateral myringotomy in February 1996. Because she is developing more aggressive behaviors, Joni's family has begun therapy for her at their local mental health clinic.

It is evident that Joni's functional and behavioral limitations, as well as her expressive and receptive language skills, were not remedied by the surgical corrections to her adenoids and tonsils. In addition, according to her teacher, Joni continues to need assistance with learning sight vocabulary, and her attention span is extremely short. She is unable to attend to most tasks, rarely completes assignments, and is easily distracted--she is often talking out loud when other children are trying to concentrate on their school work.

## RANDY--12 YEAR OLD LOUISIANA BOY WITH ORGANIC MENTAL DISORDER

Randy is a 12 year old with organic mental disorder. At age 8, he was placed in a highly structured special educational classroom for emotionally and behaviorally disturbed children, with his "special educational curriculum needs" determined to be in the areas of "social" and "academic/cognitive." SSA had, via its Appeals Council, found undisputable evidence that the child suffered from an organic mental disorder--listing 112.02, due to the medically documented persistence of developmental delay (despite IQ scores in the 90's), and personality disturbance and impairment of impulse control (aggression, hostility, destructive behavior, mood swings).

As a consequence of Public Law 104-193, the SSA in May of 1997 issued a notice to Randy terminating his SSI, having concluded that he was no longer disabled under the new definition of disability (not because his condition had improved). In fact, the evidence considered by the agency showed that the child's condition is essentially the same in 1997 as it was in 1993. Randy remained in the same highly structured special educational classroom for severely emotionally and behaviorally disturbed children and his "special educational curriculum needs" were still in the areas of "academic/cognitive" and "social." At the request of the agency, his teacher filled out a "school function form" in April of 1997 describing the child's functioning even in the highly structured behavioral management program utilized at school. She described his "aggression" toward his peers and even adults, his "hyperactivity and destructive behavior," his moodiness, and his inability to maintain close peer relationships. The most recent in-depth school evaluation of his academic performance indicated that the child's behavior (aggression, impulsiveness, distractibility, disruptiveness) continued to have a "significant adverse impact" on his educational performance. Psychological testing by a consultative psychologist hired by the agency found that his IQ scores had lowered to the 70's.

The child's mother requested redetermination of the agency's cessation decision. The SSA officer who reviewed Randy's case accepted the validity of the psychologist's IQ scores and accepted school reports that he functions 2 grades below age level. However, she concluded that although the child is markedly limited in the area of social functioning, he is "less than markedly" limited in the area of cognitive functioning. The SSA reviewer concluded that the child's impairments do not meet or equal a listed impairment. The child's mother has requested a hearing before an administrative law judge.

## 12-YEAR-OLD NEW YORK BOY WITH ADHD, SERIOUS BEHAVIORAL PROBLEMS, AND READING AT SECOND GRADE LEVEL

SSA has recently determined that a 12-year-old Brooklyn boy who suffers from Attention Deficit Hyperactivity Disorder ("ADHD"), serious behavioral problems and a 5-year delay in his reading level is not eligible for SSI under the new law. This decision was made despite the fact that SSA adjudicators found that the child had a "marked" problem in social functioning as well as significant (but "less than marked") problems in three of the four remaining areas. (The functioning areas where the child was found to have significant but "less than marked" problems were concentration, persistence or pace, cognitive/communicative functioning and personal functioning.)

SSA's finding that the child has a "marked" social functioning problem was based on a well-documented history of extremely aggressive and violent behavior. In fact, the child's records indicate that he has been suspended from school on numerous occasions and that he has a chronic history of disrupting his classmates and disrespecting teachers and other authority figures.

SSA's finding that the child has a significant but less than marked problem with his ability to concentrate was based on reports from teachers and school psychologists which consistently indicated that the child is "easily distracted," often "off task" and has "difficulty completing assignments."

SSA's finding that the child has a significant but less than marked problem in cognitive/communicative functioning was based on a record which indicates that the child was enrolled in a self-contained special education class and that he was reading at only a second grade level at a time when children of his age would normally have been about to enter the seventh grade. In addition, the results of the child's most recent educational achievement testing indicate that he scored in the lowest 1-4 percentile in the fundamental areas of vocabulary, word identification and reading comprehension.

Finally, in regard to personal functioning, the record indicates that SSA found a significant but less than marked problem in this area due to the fact that despite being 12 years old, the child is still unable to bathe himself or brush his teeth without assistance and supervision from his mother.

The facts of this case exemplify the problems with SSA's rigid interpretation of the new definition of childhood disability. In order to be found eligible for SSI, this interpretation mandates that a child have a "marked" level impairment in at least two of the five functional areas without taking into consideration the possibility that the combination of significant (but less than marked) problems in other functioning areas might be equivalent to a two "marked" finding. Here, it is difficult to believe that a child who has marked problems in social functioning, as well as the very serious problems summarized above in three other functioning areas, does not have an overall impairment level which is equivalent to the mandated "two marked" standard.

## TEXAS--10 YEAR OLD GIRL WITH HIRSCHSPRUNG'S DISEASE AND MENTAL RETARDATION

This 10-year-old girl was awarded SSI benefits in January 1993 with an onset date of August, 1987. At the time, she met the listing 112.11 A and B. She was born with Hirschsprung's disease with enterocolitis, which required several major surgeries because most of her colon was missing. She continues to need daily enemas (which require about two hours of her mother's time to perform) in order to function and prevent bowel obstruction. She was diagnosed with ADHD in December, 1992. Currently, she exhibits a learning disability in math and reading while attending the fourth grade. She attends special education classes and has limitations in the areas of cognitive/communicative and concentration, persistence or pace.

In June, 1997, a redetermination was made and the child was found by SSA not to be disabled. A reconsideration hearing was held, and she was still found not disabled. She is currently awaiting a hearing date before an ALJ. **(Note: Texas led the country with the highest percentage of child disability cessations, 79%.)**

## JB--15 YEAR OLD WEST VIRGINIA BOY WITH DEPRESSION AND ADHD

**JB** turned 15 in May. He is in the 8th grade in special education classes. He also has severe asthma. About two years ago, he began engaging in anti-social behavior and threw two dogs off a roof. He also has been diagnosed as suffering from major depression and a conduct disorder. He has been suicidal, resulting in inpatient hospitalization in the past. About a year or so ago, one psychiatrist who treated him, felt that his problems with concentration were more likely related to depression. He was diagnosed with ADHD at age 8. He was taken off Ritalin and placed on Paxil. His IQ scores have run the gamut from 82, in May, 1990; 92 in August, 1991; and 69 in September, 1996. The West Virginia DDS determined him not disabled.

## TERRENCE--6 YEAR-OLD OHIO BOY WITH RARE HIRSCHSPRUNG'S DISEASE CAUSING UNCONTROLLABLE DIARRHEA

**Terrence** is a 6-year-old boy who suffers from Hirschsprung's disease, a congenital condition affecting the colon. Because of the disease, Terrence has episodes of explosive, uncontrollable diarrhea. He has to wear diapers. He misses a lot of school; he is sent home when he soils himself or he does not attend at all because of stomach distention and pain. He is ridiculed at school and called "Stinky" because of his condition. He has no friends. The doctor feels that Terrence has limitations in cognition, social, and personal areas of functioning.

The Social Security Administration denied Terrence's initial SSI claim on September 2, 1997. Terrence's mother has requested reconsideration; that appeal is still pending. Terrence is obviously a child who has a severe impairment. He is disabled. His daily functioning revolves around his condition although there is no "area of function" that deals directly with his problem, which instead must be evaluated in terms of social and personal limitations. He does not have a "normal" life in any sense of the word. This is a child who should receive SSI and related Medicaid coverage.

## CHRISTOPHER--9 YEAR OLD OHIO BOY WITH ADHD, SPEECH DISORDER, AND LANGUAGE-BASED LEARNING DISORDER

**Christopher** is a 9-year-old with ADHD, a speech articulation disorder, and a language-based learning disorder. Chris applied for SSI in November of 1994. Evaluations by Children's Hospital Medical Center confirmed that he had ADHD with a very limited attention span, and inability to maintain attention and concentration. This was in spite of the use of Ritalin and later Clonidine. According to Chris's treating doctors, he has significant limitations in cognitive, social, and personal/behavioral functioning as well as ability to maintain concentration, persistence, and pace. In addition, he has significant limitations in communicative functioning due to his speech articulation disorder.

In a decision of May 2, 1996, a Social Security Administrative Law Judge found that Chris H.'s impairments met the level of severity required by listing 1112.11 (ADHD) and listing 112.10 (Pervasive Developmental Disorders). Chris was found disabled and awarded SSI.

On July 30, 1997, the Social Security Administration sent a disability redetermination decision to Christopher. The finding was that his speech, social skills, attention span, and his ability to care for his personal needs were limited, but each one in separation was not so limited that he is disabled. Even though Christopher H. was found to have Listings-level impairments in May of 1996, the Social Security Administration's determination made in the Spring of 1997 under the new SSI law was that he no longer had a severe impairment.

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CHAIRMAN, COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

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September 17, 1996

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

Dear Mr. President:

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

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

The debate over this issue was heated at times, but, ultimately, we reached a compromise on the definition of childhood disability in September, 1995. That definition became part of the overall Congressional compromise on SSI, and was included in the first two versions of welfare reform approved by Congress and then finally in the bill enacted in August.✓The compromise is notable in two ways. First, it preserves a broad functional approach, <u>beyond</u> the "Listings of Impairments," in measuring childhood disability. Second, it specifically <u>does not</u> establish the listings level of severity, or any equivalent level of severity, as the measure to be used in assessing childhood disability.

The enclosed Senate colloquy between those of us involved in this compromise is important in understanding the meaning of the new definition. This colloquy was not entered into lightly. Rather, it was the subject of much negotiation and was key to the final language of the definition regarding "physical and mental impairment, which results in marked and severe functional limitations" after dropping the requirement that the effect of the impairment also be "pervasive".

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The Honorable Bill Clinton
September 17, 1996
Page two

It is certainly appropriate for SSA, as the regulatory agency, to adopt a disability test that is stricter than the old Individualized Functional Assessment (IFA), but which is not at the very strict level of the "Listings." The proposal put forward by several disability advocates and organizations with considerable expertise – a one marked/one moderate level – is an acceptable and reasonable approach that fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require that these limitations be pervasive.

The Congressional Budget Office (CBO) has also acknowledged that SSA would have a great deal of flexibility in meeting the requirements of the new law. The enclosed Senate Finance Committee report shows that CBO estimated that the new definition of childhood disability could bar anywhere from 10-28 percent of children from the program, depending upon the regulatory interpretation of the new definition.

I know that you will do everything in your power to ensure that children with severe disabilities who are truly deserving are not harmed by the changes in the new welfare law. Thank you in advance for your attention to this matter. Please do not hesitate to contact me if I may be of any further assistance.

Sincerely,

John H. Chafee

John H. Chafee

JHC:bd

cc: Secretary Shalala
Commissioner Chater

KENT CONRAD
NORTH DAKOTA
202-224-2043

COMM
AGRICULTURE,
AND FO
FINA
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INDIAN A

United States Senate
WASHINGTON, DC 20510-3403

September 4, 1996

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

Dear Mr. President:

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

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

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

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

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

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

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

Sincerely,

KENT CONRAD
United States Senate

KC:wmah

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

United States Senate
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

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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

Ed Kennedy
Senator Edward Kennedy

Jay Rockefeller
Senator John D Rockefeller IV

Max Baucus
Senator Max Baucus

Chris Dodd
Senator Christopher Dodd

John Chafee
Senator John Chafee

Tom Harkin
Senator Tom Harkin

Jim Jeffords
Senator James Jeffords

Patrick Leahy
Senator Patrick Leahy

Tom Daschle
Senator Tom Daschle

## SSI Childhood Disability Cessations, New Initial Allowances, and Reconsideration Appeal Reversals Cumulative Through 3/28/98

| State (DDS) | Initial Cease Rate (%) | Total Ceased | New Initial Allowance Rates (%) | Recon Reversal Rate (%) |
|---|---|---|---|---|
| **National Totals** | **60.3** | **147,468** | **33.4*** | **43.0**** |
| Texas | 78.8 | 9,111 | 28.1 | 36.7 |
| Mississippi | 77.4 | 4,579 | 20.1 | 43.1 |
| Montana | 77.3 | 368 | 36.4 | 34.1 |
| Arkansas | 76.9 | 4,339 | 21.2 | 26.2 |
| Louisiana | 76.9 | 8,706 | 18.9 | 23.0 |
| Iowa | 76.7 | 1,273 | 33.2 | 65.0 |
| Oklahoma | 76.1 | 1,236 | 28.9 | 15.5 |
| Kansas | 75.5 | 1,819 | 29.1 | 27.4 |
| Tennessee | 74.3 | 4,046 | 29.5 | 27.9 |
| Alabama | 73.6 | 4,997 | 24.3 | 13.2 |
| Missouri | 72.7 | 4,342 | 23.6 | 23.3 |
| South Carolina | 70.5 | 2,742 | 30.6 | 40.1 |
| Rhode Island | 69.7 | 560 | 32.7 | 37.8 |
| Georgia | 69.7 | 3,263 | 29.8 | 32.0 |
| Illinois | 69.4 | 8,759 | 33.2 | 86.2 |
| North Dakota | 69.0 | 127 | 42.1 | 41.7 |
| Nebraska | 68.6 | 614 | 34.4 | 34.7 |
| Wisconsin | 67.2 | 3,950 | 33.1 | 45.2 |
| New Mexico | 66.9 | 846 | 32.2 | 29.0 |
| Ohio | 66.1 | 8,679 | 33.4 | 46.3 |
| West Virginia | 65.2 | 1,363 | 28.7 | 17.3 |
| New York | 62.6 | 15,639 | 29.9 | 52.8 |
| Indiana | 61.0 | 3,028 | 35.9 | 26.3 |

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*The pre-Zebley, 1989 new initial allowance rate, when a similar Listings-level policy was in use, was 42%.

**Historical reversal rates at reconsideration ("recon"), the first step of appeal, are about 10%.

| State (DDS) | Initial Cease Rate (%) | Total Ceased | New Initial Allowance Rates (%) | Recon Reversal Rate (%) |
|---|---|---|---|---|
| Florida | 59.9 | 8,407 | 30.3 | 26.4 |
| Utah | 59.9 | 537 | 53.6 | 63.6 |
| Maine | 58.8 | 297 | 36.0 | 77.6 |
| New Hampshire | 58.6 | 171 | 43.8 | 64.5 |
| Connecticut | 56.8 | 687 | 36.6 | 61.8 |
| Colorado | 56.1 | 993 | 47.2 | 47.7 |
| Idaho | 56.0 | 598 | 41.9 | 28.3 |
| Wyoming | 55.3 | 182 | 29.4 | 50.0 |
| Maryland | 53.2 | 1,630 | 42.1 | 47.4 |
| Virginia | 53.0 | 4,194 | 34.2 | 45.7 |
| Vermont | 52.7 | 196 | 41.6 | 52.4 |
| Massachusetts | 50.9 | 2,252 | 41.7 | 44.4 |
| Michigan | 50.4 | 6,468 | 32.9 | 61.7 |
| Delaware | 49.2 | 245 | 41.8 | 95.5 |
| Arizona | 48.7 | 1,281 | 44.7 | 55.4 |
| Alaska | 47.9 | 90 | 56.9 | 90.9 |
| Washington | 47.0 | 1,232 | 52.0 | 73.0 |
| New Jersey | 45.4 | 2,381 | 39.7 | 52.6 |
| South Dakota | 45.1 | 245 | 38.1 | 46.9 |
| Kentucky | 44.5 | 3,167 | 38.4 | 61.4 |
| North Carolina | 44.2 | 4,961 | 37.6 | 34.9 |
| Minnesota | 42.3 | 1,316 | 52.2 | 35.4 |
| Oregon | 41.6 | 475 | 50.9 | 85.7 |
| Nevada | 41.5 | 230 | 47.9 | 48.6 |
| California | 40.9 | 5,374 | 49.0 | 46.0 |
| Pennsylvania | 40.8 | 5,230 | 33.0 | 32.9 |
| Hawaii | 38.0 | 30 | 57.6 | 100.0 |
| D.C. | 35.1 | 212 | 46.3 | 100.0 |

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

## PREPARED STATEMENT OF DAWN WARDYGA

Thank you for the opportunity to provide testimony this afternoon on behalf of children with chronic illnesses and disabilities and their families from across the United States. As a mother of six children, one of whom had suffered a severe brain injury during his birth, leaving him permanently and totally disabled, I know, all too well, the overwhelming barriers that families of children with special health care needs face on a daily basis. In my work as Project Director for Family Voices of Rhode Island, I've worked with many families directly affected by the recent changes in the SSI program, both in the State of Rhode Island and many other states across the nation.

The SSI program has made, and continues to make, the lives of the children who qualify and their families a bit more secure. The supports provided by SSI enable families to care for their children at home and meet many of their special needs. Many parents of children with disabilities are unable to work due to the responsibilities of caring for their child or, if they are able to work, it is usually part time with limited income, as they must be "on call" at all times and ready to respond to their child's latest crisis.

In many states, although not all, becoming eligible for the SSI program automatically provides children with a Medicaid card, which provides families the security of knowing that they will be able to access the medical care and related services that their children require. In many cases, the related Medicaid coverage fills the enormous gap that their commercial health insurance leaves behind in meeting their complex needs. These families, on their best days, have more than their share of issues to deal with.

This has been a complicated and unsettling time for families, most of whom had to struggle to get their children on the program in the first place! The recent changes currently being implemented within the SSI program under the Welfare Reform Act of 1996 have impacted this vulnerable population in disturbing ways in every state across the nation. In some states, families who have lost their SSI benefits are being forced to relinquish custody of their children, especially those with emotional/behavioral disabilities, in an effort to obtain the necessary services for them. I hope to illustrate some of the real hardship resulting from these changes and its impact on families. As I share these examples with you, we should all be thinking about several of the problems with the way in which Social Security has implemented the current law and how we can improve it to truly meet the needs of those it is intended to support.

Sandy is a 13-year-old from Louisiana with mental retardation and Attention Deficit Hyperactivity Disorder (ADHD). She has an IQ of 55. The Disability Determination Service had Sandy evaluated as part of the redetermination process mandated by the new welfare law. The DDS psychologist diagnosed mental retardation but failed to provide current test scores. However, another psychologist corroborated the diagnosis and noted that Sandy had also recently been hospitalized for major depression. The second psychologist suggested an additional diagnosis for Sandy of oppositional defiant disorder. Records confirm that Sandy continues to perform poorly academically (all F's and D's) and presents severe behavioral problems (disruptive behavior, truancy, inattention and hyperactivity) and is socially isolated. Records show that Sandy continues to take medication for ADHD and depression. Upon reconsideration the DDS affirmed its initial decision to terminate Sandy's SSI. They determined that Sandy had marked limitation in concentration, persistence or pace and less than marked in all other areas despite the fact that SSA regulations consider an IQ below 59 to be an extreme limitation and to presumptively meet one of the listings. In evaluating Sandy's cognitive functioning, however, the DDS relied not on the psychological test results on record, but on a comment contained in Sandy's recent hospitalization records that suggested her intelligence seemed average, from her demeanor.

SSA also determined that a 12-year-old New York boy who suffers from ADHD, serious behavioral problems and a five year delay in his reading level is not eligible for SSI. This decision was made despite the fact that adjudicators found that the child had a marked problem in social functioning as well as significant problems in three of the four remaining areas. SSA's finding that the child has a marked social functioning problem was based on a well-documented history of extremely aggressive and violent behavior. The child's records indicate that he has been suspended from school on numerous occasions and that he has a chronic history of disrupting his classmates and disrespecting teachers and other authority figures. SSA's finding that the child has a significant problem with his ability to concentrate was based on reports from teachers and the school psychologist which consistently indicate that the child is easily distracted, often off task and has difficulty completing assignments. SSA's finding that he has a significant problem in cognitive/communicative functioning was based on a record which indicates that he was enrolled in a self-contained special education class and he was reading at a second grade level when children his age normally are entering the seventh grade. The results of his most recent educational achievement testing indicate that he scored in the lowest 1-4 percentile in the areas of vocabulary, word identification and reading comprehension. SSA found a significant problem in personal functioning as the child is still unable to bathe himself or brush his teeth without assistance and supervision from his mother. This case illustrates the problems with SSA's rigid interpretation of the new definition of childhood disability. This child clearly has very significant problems in many areas. How can SSA conclude he has marked problems in only one area while his problems in the other three functioning areas does not meet the criteria of disability under the new law?

Courtney is an 8-year-old North Dakota girl who was born with a severe heart defect. At age 3 months she suffered a brain bleed, or stroke, that left her partially paralyzed on her right side. She does not qualify for Medicaid as hers is a farm family and must use an asset form in North Dakota. Her parents use her SSI to purchase her health insurance and pay for other medical bills, medications for her condition, purchase special shoes and orthotics, etc. Hers was a case recently redetermined and, thankfully, continued in the program. Her mother shared her fear of losing Courtney's benefits and her family's inability to provide for her special needs without the support of the SSI program. She lives in fear of continued periodic reviews which may disqualify Courtney from the program and threats to her family's stability in the event of future benefit losses. Courtney's medical and mobility issues are expected to be life long.

Stephanie is a 14-year-old from Iowa who was diagnosed with an inoperable brain tumor at the age of three years. She endured extensive chemotherapy at that time which caused considerable liver damage and halted the production of her growth hormones. Her care includes growth hormone injections, given by her mother, six times per week and she must be evaluated every three months to keep the tumor under control. Stephanie is significantly developmentally delayed and her mobility is substantially limited due to the effects of her illness. She is enrolled in a special education program to meet her special needs. In August of 1996, two years after her parents separated, Stephanie's mother filed a claim for SSI benefits as the family income was then reduced to $1100.00 per month for her family of three (Stephanie has one younger sibling). Three months later, Stephanie was denied benefits at which time her mother was advised by SSA to hire an attorney, at her own expense, and appeal the decision. Sixteen months later, in March of 1998, Stephanie finally qualified for benefits and, in June, was issued a $3100.00 check, retroactive to her initial filing date. Stephanie's mother had to cash in a life insurance policy for its cash value of approximately $400.00 as a means to support her children during this lengthy process. Stephanie will be receiving $180.00 per month from the SSI program and is now eligible for Medicaid in her state. Although her mother received notification of her SSI and Medicaid eligibility last March, she still has not received a Medicaid card nor has she received any guidance as to how to access the services her daughter needs. This particular case raises many troubling issues as to the SSI and Medicaid programs and what they should be doing to help families navigate their way through the system in caring for their children with special needs.

Marcus, a 13-year-old Mississippi boy with a congenital heart defect, was determined ineligible for SSI in July 1997 when the DDS determined that his condition did not meet the new marked and severe standard for childhood disability. His condition required open heart surgery when he was 10-months-old. The condition had been described by his grandparents as a hole in his heart and that the valves in his heart had to be switched around. Marcus again had open heart surgery in August 1997 because of leakage, inefficient valve flow and fluid build-up. His annual checkup in August had revealed that his heart was causing serious complications. Because of the treatment required for this condition, Marcus was unable to attend school in the fall of 1997 and he was placed on a waiting list to receive a heart transplant. His grandparents, Marcus's guardians, did not appeal the SSI termination because they believed that if their appeal was unsuccessful, they would have to pay back all of the money that he had ever received from SSI. This was their interpretation of Social Security's letter received in the summer of 1997 notifying them that Marcus's SSI would be terminated because he was no longer disabled under the new standard. The loss of SSI benefits to this family created great hardship for his grandparents. The family lives in rural Mississippi, a two hour trip to Memphis where Marcus received the intensive health treatment his condition required. Their trips to Memphis caused Marcus's grandparents to miss much work and suffer other financial hardships in addition to the emotional strain of watching his condition deteriorate so rapidly. Marcus died from his heart condition on December 4, 1997, after suffering from hypertrophic cardiomyopathy and a series of mini-strokes.

These few cases are only a brief sampling of how families with children with disabilities are faring under the SSI program. There are several concerns that these examples raise:

1. The new regulations are too restrictive, denying access to SSI for children who are truly disabled. How many new applications have been denied since the new law took effect, based on the new eligibility criteria and prior to the second opportunity for appeals, when some of the problems with the new law were acknowledged by SSA? How do we reach those children who have already been turned away?
2. What is happening to the thousands of children with severe disabilities across the country who have lost benefits? Is anyone monitoring how they are doing?
3. What about the related Medicaid issues? Is HCFA aggressively enforcing the grand fathering provisions to continue Medicaid in the 1997 Balanced Budget Act? Are children, in fact, maintaining Medicaid eligibility after losing SSI? Are they being required to enter managed care and, if so, what are those outcomes? How are families being informed of these changes and their options, if any? Are they aware that the level and continuity of care should be protected under the law?
4. Do families truly understand this redetermination process and their rights under the law? How many families never received notices or were unable to read them? How many families did not appeal based on misunderstood information or overwhelming fear of owing the United States government thousands of dollars that they knew they couldn't possibly pay?
5. Is SSA providing adequate training to its staff in addressing the complex implementation issues? Is printed information provided in other languages and are interpreters provided for families who need them?

In closing, I'd like to add that the children and families that we are concerned with today are no different in many ways than any other American family. We have the same dreams, goals and expectations for our children and families that all families share. Our families simply have to work harder to accomplish many of these goals. The SSI program is just one piece, and an invaluable one, of an extremely complex puzzle that supports children with disabilities and their families in their own homes. This program must be protected so that our families have the same opportunities to meet our children's needs and care for them, in their own homes, that all American families enjoy.

# COMMUNICATIONS

## STATEMENT OF THE AMERICAN BAR ASSOCIATION

[SUBMITTED BY JEROME J. SHESTACK, PRESIDENT]

Dear Mr. Chairman and Members of the Subcommittee:

I am Jerome J. Shestack, a lawyer in private practice in Philadelphia, Pennsylvania and the current President of the American Bar Association. We applaud your leadership on a matter that is profoundly important to thousands of our nation's most vulnerable citizens—poor children with physical and mental disabilities. On behalf of the ABA, I am pleased to submit this statement in conjunction with the July 7, 1998 Oversight Hearing on the Implementation of the SSI Childhood Disability Standard.

The American Bar Association, with a membership of 392,000, including 346,000 lawyer members, is concerned in general about the rights of every citizen for access to justice and has been particularly concerned with access to justice for those least able to protect their rights. The Association has worked actively over the years to promote the efficacy and fairness of the Supplemental Security Income (SSI) Program for low-income aged, blind and disabled persons.

In keeping with this tradition, the ABA Board of Governors authorized emergency funding in 1996 to initiate our Children's SSI Project. This Project was designed to insure that the 264,000 children whose SSI disability status would be reviewed as a result of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRA) would have access to free legal advice and representation. In a matter of months, our SSI Project was able to organize thousands of attorneys and paralegals throughout the country who volunteered to represent children with their meritorious SSI appeals.

Working closely with children's advocates in every state, the ABA Children's SSI Project learned a great deal about SSA's implementation of the new childhood disability standard. Unfortunately, much of what we discovered was extremely distressing. Early reports indicated huge discrepancies in SSI termination rates from state to state. For example, SSA data issued on November 8, 1997 revealed that Mississippi had terminated 80% of the children's SSI cases it had reviewed. In contrast, Washington DC, had a termination rate of 35%. Huge variations were evident across the nation—children with disabilities in one state were more than twice as likely to lose their SSI benefits as children in another state. In addition to this troubling statistical data, we heard numerous reports from our state and local contacts that SSA personnel, working in field offices and staffing the agency's toll-free phone number, were providing misinformation to families about their appeal rights. In some cases, SSA personnel actively discouraged parents from appealing termination decisions.

As I am sure you are aware, in addition to key leaders in Congress, the ABA and other national organizations and children's advocates brought these matters to the attention of newly appointed SSA Commissioner Kenneth Apfel in the fall of 1997. After taking stock of these concerns, the Commissioner investigated the cause of the problems and designed a plan to remedy them. In his December 1997 Review of the Implementation of the New Childhood Disability Standard, Commissioner Apfel agreed to make several important changes in his agency's handling of children's SSI cases.

The American Bar Association lauds the Commissioner for the significant steps he initiated as a result of his Review. We appreciate his hard work and his willingness to work closely and openly with our Association and with children's advocates. We recognize that under his leadership much has been done to address initial missteps by broadly reinitiating review of a large number of individual cases. Unfortunately, all the good intentions and the initial efforts of the new Commissioner have not yet been able to rectify many problems stemming from the implementation of the new childhood disability standard.

It is imperative that we identify and address the remaining issues and problems now, because thousands of children who are involved in the SSA review process seek prompt, fair and consistent resolution of their appeals. Similarly, many children with physical and mental impairments who are applying for SSI benefits deserve speedy and accurate processing of their initial applications. SSA must continue to tackle the serious problems that have plagued its implementation of the new childhood disability standard and, indeed, must make dramatic improvements in the near future.

Among significant, ongoing problems, we call your attention to the following:

1. *Continued Variations in Termination Rates.* Recent data from SSA reveals continuing wide disparities in children's SSI termination rates from state-to-state and region-to region. For example, SSI children who reside in California are much less likely to lose their benefits than children in Texas, where the 80% termination rate is the highest in the country. States in the South and the Midwest have disproportionately high termination rates. SSA has never provided a valid reason for these discrepancies. SSA must promptly investigate the reasons for the variations and insure that all children are treated fairly and consistently, wherever they may live.
2. *Problems With "Second Chance Notices."* Some SSI families report that they did not receive "Second Chance Notices" sent out by the Social Security Administration in February 1998. Others report that their notices contained incorrect information concerning their appeal rights The Social Security Administration needs to liberally construe its "good cause" provisions for late filing of appeals to insure that all SSI families are given a fair chance to present their child's case. SSA should issue an advisory to all case-handlers, reminding them about "good cause"exceptions for late appeals.
3. *Need for Legal Representation for SSI Families.* Recent data from SSA indicates that more than 102,000 families have now appealed termination of their children's SSI benefits. Many of these families did not receive from SSA information about the availability of free legal assistance with their appeals. In forty-six states, ABA Children's SSI hotline numbers provide free legal advice and representation to families. SSA should take immediate steps to disseminate information about free legal help to all claimants who have filed appeals. SSA should also insure that all field offices, state disability determination service (DDS) and Office of Hearing and Appeals personnel have updated lists of ABA Children's SSI hotline numbers, and encourage staff to refer claimants to these resources.
4. *Quality of DDS Case Development.* Many redetermination decisions that resulted in children losing SSI benefits were issued hastily, with scant evidence of the child's mental and physical condition in the administrative file. A number of files lacked important medical, psychological or school records that could have been obtained with more effort by DDS case handlers. Some children's cases needed additional development, requiring that DDS secure comprehensive consultative examinations by doctors or psychologists. SSA needs to insure that all DDS personnel take the necessary time to insure thorough case development. Furthermore, DDS medical advisors (many of whom work on a contractual basis) should be required to receive training on the new childhood disability standard before handling children's cases.

In sum, SSA must continue its work to insure that children with disabilities across the country are evaluated in accordance with one consistent SSI childhood disability standard administered by trained case handlers, with input from qualified medical advisors. All SSI families must also receive full due process rights, should their child's benefits be terminated or application denied. At a minimum, families must receive termination or denial notices that are readily comprehensible and advise families of the availability for free legal help in their communities.

The ABA appreciates the opportunity to submit these comments for the Subcommittee's consideration. Thank you for your leadership and determination to address the plight of the thousands of families with disabled children who desperately need the support and security afforded by an efficient and compassionate SSI program.

**The Arc of the United States**
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# HEARING ON

# CHILDREN'S SSI POLICY

SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY

July 7, 1998

Statement for the Record
of

**The Arc of the United States**

Contact:

Marty Ford
Governmental Affairs Office
The Arc of the United States
1730 K Street, NW Suite 1212
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The Arc

*a national organization*
*on mental retardation*
formerly Association for
Retarded Citizens of the United States

The Arc of the United States appreciates the opportunity to comment on the implementation of the eligibility standard for children in the Supplemental Security Income program, as revised by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193). We are especially grateful for the leadership and commitment to the children's SSI issues shown by Subcommittee Chairman John Chafee and Senator Kent Conrad. With the help of Committee Members and other Senators, you have continued to give serious attention to the children's SSI program and the children and families who are affected by the changes in the law. We commend you for your continued dedication to ensuring that the program works for its intended beneficiaries and for supporting the future potential of the children who could benefit from SSI.

The Arc of the United States is a national organization on mental retardation. Formerly known as the Association for Retarded Citizens, The Arc is a voluntary membership organization made up of approximately 140,000 people with mental retardation, their families, friends, professionals, and other interested people forming more than 1,100 state and local chapters across the country.

The Arc is vitally interested in the implementation of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Over 937,000 children and adults with mental retardation under age 65 depend upon the income supports of the Supplemental Security Income program; they constitute 38 percent of children and 24 percent of adults receiving SSI. We are concerned about the potential impact of the rules on children with mental retardation whose cases have been reviewed under these new rules and those who will apply for SSI in the future.

The Arc believes that implementation of the changes enacted in PRWORA must be viewed in two separate, but broad, categories. First, the standard adopted by the Social Security Administration to implement the new eligibility language must be examined for its impact on children and for whether it meets the intent of Congress. (Parts I and II below) Second, SSA's procedures and practice for carrying out the changes in the regulations must be addressed. (Part III below)

## I. NEW CHILDHOOD DISABILITY STANDARD: Listings Level Standard is Too Severe and Does Not Reflect Congressional Intent

The Arc is deeply disappointed in the interim final regulations for childhood disability determinations in the SSI program as published on February 11, 1997. The eligibility standard established by the Social Security Administration to implement the law is far more severe than required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. We believe that it is clear from a strong legislative history that the new statutory definition of childhood disability gives SSA the flexibility to tighten the eligibility criteria, yet protect and include more children than will be included by SSA's current approach. In addition, within the interim final regulation, there are a number of serious flaws which will harm children with severe disabilities.

While we praise Commissioner Ken Apfel for SSA's recent thorough review of the children's SSI program and for his placement of priority emphasis on the children's issues early in his tenure (see below), we believe that he must reassess the standard which was adopted before his tenure. The standard is simply too harsh, too bureaucratic and rigid, and it ignores current scientific, medical, and educational knowledge and practice, as well as core principles of childhood development. The standard is also far more severe than required by PRWORA. Commissioner Apfel's current estimate is that, when all reviews and re-reviews are completed, 100,000 children will have been removed from the SSI program. In addition, over 335,000 children have been denied initial eligibility since August of 1996, and the numbers of applications are declining. Some of those children would have been eligible under prior law. Currently, 66 percent of children who applied for SSI are denied.

The Arc, along with member organizations of the Consortium for Citizens with Disabilities and other advocates, worked very hard with Members of this Committee and others to ensure that, if PRWORA were signed into law, the definition of disability for children in the SSI program would be fair. In fact, the new statutory language requires that a child have a "medically determinable physical or mental impairment **which results in marked and severe functional limitations**" (emphasis on new statutory language) -- the first time that the Social Security statute has recognized the importance of functional assessments for children.

We believed, along with Senators Chafee, Conrad, and others who crafted the new definition, that the language gave SSA room to develop a new approach to functional assessment and to tighten the eligibility criteria without a wholesale overhaul of the disability standard for children. As you recall, this intent was noted in a floor colloquy (September 14, 1995) between Senators Dole, Chafee, and Conrad and in letters to President Clinton prior to the publication of these new regulations (Senators Chafee, Conrad, Daschle, Moseley-Braun, Harkin, and Cohen,) and a letter from Sen. Wellstone to Secretary Shalala).

We believe that these Senators' interpretations of Senate action, the colloquy between then-Majority Leader Dole and Senators Conrad and Chafee, and the acceptability of another, less-severe standard (including a "one marked/one moderate" standard) are very crucial to the children who are being adversely affected by the interim final rules. It is clear that these Senators, through their own negotiations on the new definition, believed that they were not establishing a "listings level" standard for the childhood disability program. Since the critical statutory language was the result of intensive Senate negotiations which rejected the House "listings" approach, the interpretations of these Senators should have been given great weight by SSA. This is especially important since there is clearly flexibility within the statutory definition for agency interpretation (CBO estimates noted a substantial range for agency discretion).

Despite strong legislative history to the contrary, SSA has adopted a very high standard of disability for children. A child must show an impairment that "meets" or "medically equals" the listings or that "functionally equals" the listings. The interim final regulations of February

1997 describe how a child can prove that an impairment functionally equals the listing. For children who cannot prove their disability through some specific functional equivalence categories (limitations of specific functions; episodic impairments; and limitations related to treatment or medication effects), the regulations require showing that the impairment(s) results in "marked" limitations in two of three to five areas of childhood functioning (depending on the child's age) or in extreme limitations in one area. Known as the "two-marked" standard, this regulation prohibits eligibility for a child who has marked limitations in one area along with significant or moderate limitations in another area(s). In addition, children could have significant or moderate limitations in three to five areas of functioning and still be excluded.

Even within the structure of a two-marked standard, we believe that the interim final regulations have some other serious problems built into them. The problems include: the combination of cognition and communication as one area of functioning; failure to include more areas of functioning for 1 to 3 year olds ("personal" area and "concentration, persistence, and pace"); failure to address standard error of measurement for IQs; failure to include non-motor aspects of physical functioning; and failure to give guidance on "other factors", among other issues.

At the direction of Commissioner Apfel, the training materials for SSA and state disability determination service (DDS) staff on the interim final regulations have attempted to address some of these issues within the context of certain impairments. We believe that they must be addressed as part of the actual regulations so that the criteria are available to the public, including applicants and their representatives.

From our long experience with children and adults with mental retardation, we believe that the children who were correctly eligible for SSI prior to the passage of PRWORA but who will ultimately be found ineligible under the interim final regulations are indeed children with severe disabilities. As this Committee is aware, SSA's standard not only affects children eligible as of August 1996, it also affects all children who apply for SSI in the future. They are children who will need substantial help, beyond that needed by the typical child, from their families, their school systems, their communities, and our society in general.

Attached is a page describing two children who have lost eligibility under the new rules. While we think these are likely to be typical stories, we recognize the limitations of examples that do not rely on documentation reviewed by SSA.

We believe that it is critical for SSA to reassess the severity of disability for the children who are being dropped from SSI under the interim final regulation. We believe that SSA should conduct a new study of 150 to 200 children who were previously eligible but who no longer qualify under SSA's regulation. These children should be described in sufficient detail for SSA, the Congress, and the general public to understand the nature of the children's limitations in their attempts to function in their families, their schools, and their communities at large. It would also be useful for SSA to indicate whether the particular child described would likely have qualified for the program if SSA had adopted a "one marked/one moderate" standard in the regulations. With this information, SSA and Congress can better assess the real impact of the 1997 regulations. SSA should present only those children whose cases were decided correctly in SSA's view.

While this is an oversight hearing on the current regulations and the implementation of the children's SSI program, it is important to note here the proposal that has surfaced on the House side in response to the GAO's May 6 letter to Representative Clay Shaw, Chairman of the Ways and Means Subcommittee on Human Resources. The proposal would require SSA to revise all of its childhood listings to ensure that the minimum criteria that a child must meet would equate to a two-marked standard.

Based on the notion of ensuring consistency raised by GAO, the House proposal actually would go much farther than the changes in PRWORA. The proposal would affect children who have in the past become eligible through the listings and who, essentially, were not the subject of discussion or debate in the development of PRWORA. GAO indicates that SSA has identified a list of 28 listings that do not meet the two-marked standard. Several of these listings involve children who have IQs in the 60 to 70 range (already a marked impairment) along with another significant limitation. These listings represent children who have been admitted to the SSI program for more than a decade, certainly since long before the *Zebley* case was even argued before the US Supreme Court. A quick look at the Code of Federal Regulations in the mid-80s reveals listings of equivalent severity to those on the list of 28.

In addition to the two-marked provision, two other proposals have surfaced on the House side which would reduce the importance of using functional evidence in deciding cases for both children and adults and which would reduce the value of evidence which comes from the person's treating physician or other sources. Both of these proposals would serve to undercut efforts to ensure a complete picture of a child (or adult) prior to making a decision about eligibility and, in particular, seem to fly in the face of the new statutory language adopted in PRWORA requiring children to have a physical or mental impairment resulting in marked and severe *functional* limitations.

We urge the Finance Committee to oppose any such proposals which might come before you.

## II. IMPACT ON CHILDREN AND THEIR FUTURE LIVES

Over the past two decades, Congress has recognized the value of early intervention in a child's life to ameliorate or reduce the long-term effects of disabling impairments. These values have been given life and implemented through various services such as the Individuals with Disabilities Education Act and the Early and Periodic Screening, Diagnosis, and Treatment program in Medicaid as well as through SSI's financial assistance low-income families raising children with severe disabilities.

While this Congress continues to look at the efficacy of the childhood eligibility criteria for SSI, it is important to step back and look at the whole picture. K. Charlie Lakin, Lynda Anderson, and Robert Prouty of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota have developed a paper summarizing changes in out-of-home placements for children and youth with mental retardation since the implementation of SSI and IDEA. Their findings are dramatic.

> The steady decline in the number of children and youth receiving out-of-home MR/DD [mental retardation/developmental disabilities] residential services demonstrates powerful effects of social policies introduced in the mid-1970s to support children and youth in their own homes and communities. **The number of children and youth receiving out-of-home MR/DD residential services in the U.S. has been reduced to less than 30% of the number 20 years earlier,** even as the total number of children and youth less than 22 years old increased by 4% and the total number of persons receiving out-of-home MR/DD residential services increased by 37%. (emphasis added)
>
> Another indicator of the impact of the mid-1970s commitment to children and youth with mental retardation was that in just 6 years between 1972 and 1978, the average age of first admission to MR/DD residential settings increased from 13.95 years to 18.02 years....

Lakin and colleagues' policy research brief, *Children and Youth Receiving Residential Services for Persons with Developmental Disabilities Outside Their Family Home: Trends from 1977 to 1997,* includes data by state on these important trends. The policy brief also discusses the positive financial impact of reduced out-of-home placements. The paper is included with this statement for the record.

## III. SSA's POLICIES AND PRACTICES

The Arc commends Commissioner Apfel for his administrative leadership in thoroughly reviewing the childhood SSI program and in initiating remedial actions where agency actions or inaction may have been harmful.

Upon taking his oath of office, Commissioner Apfel placed high priority on a complete study of the implementation of the interim final regulations regarding childhood eligibility. Within his first few months in office, Commissioner Apfel had published a report on his findings, including a review of 151 cases of children denied continued eligibility; conducted training for SSA and DDS staff; called for automatic review of certain classes of cases; and notified all affected families of a new opportunity to appeal or to request benefits pending appeal. While The Arc believes that these were necessary actions and remedies in light of the concerns raised about the implementation of the regulations across the country, we believe that Commissioner Apfel's actions were bold and important steps to send a message to families, SSA employees, and DDS employees that children would be treated fairly within the law.

As Members of this Committee know, numerous concerns had been raised about the administrative interpretation and implementation of the interim standard ("two-marked") and about the potentially widespread, reported violations of due process for families seeking to appeal their cases or request benefits pending appeal. The re-reviews of certain cases and the new opportunities offered for appeal were critical for re-establishing trust and credibility in the system. We are pleased to see in SSA's *SSI Welfare Reform Childhood Status Report Through May 30, 1998* that appeals rates and benefit continuation rates "have increased significantly in the past month due to re-noticing of ceased beneficiaries who had not appealed."

We recognize the complexity of the issues, the size of the agency, and the number of new applications and continuing disability reviews which face SSA and the state DDS agencies everyday. Therefore, we recognize that, despite Commissioner's Apfel's best efforts in the initial review of the children's SSI program, there will continue to be issues which must be addressed. In the months following his swearing-in, Commissioner Apfel has ensured an open door with SSA officials, making it possible for advocates to convey concerns about developing policy, obtain statistical and other information, alert the agency to developing trends, and otherwise conduct an on-going dialogue with the agency in matters relating the interests of beneficiaries. We commend Commissioner Apfel for his open-door policy.

For purposes of this hearing, we note that there remain some outstanding concerns about the implementation of the new statutory provisions regarding the reviews of disability for children turning 18. There is a very high rate of denial of these 18-year olds (over 56 percent) for the adult program at the initial DDS decision. Since children are eligible for the SSI program about 70 percent of the time on the basis of the listings, this rate seems exceptionally higher than would be expected. SSA's data shows that over 73 percent of these children have mental impairments, including mental retardation. We are hopeful that Commissioner Apfel will place new priority on studying the data regarding the 18-year olds to determine what may be happening and that he will commit to take action as necessary to remedy any problems identified.

## IV. RECOMMENDATIONS

The Arc commends this Subcommittee for its attention to the children's SSI program. Based on the above, we believe that there are several things that must be done to improve the way SSI assists children and their families. They include:

- **The interim final regulations must be revised to better reflect Congressional intent and to include at least children whose impairments cause marked limitations in one area of functioning and moderate limitations in another area of functioning (one marked/one moderate).** Over the long run, since the marked and moderate designations flow from past and current methods of looking at disability, we believe that it is not even necessary to retain such terminology if SSA were to essentially start from "scratch" and devise another, comprehensive, up-to-date approach to assessing disability.

- **SSA should conduct another 150 to 200 case review as described above to educate the Congress and the public about the true ramifications of the standard adopted in the interim final regulations.**

- **SSA should address the flaws within the current interim standard, as outlined in the attached comments from the Consortium for Citizens with Disabilities Social Security Task Force** (submitted to SSA on April 10, 1997). These flaws should be fixed under the current interim standard and should not be allowed to carry forward into any revised standard. Again, they would include at least looking at the whole child and his/her combination of impairments (removing the all-or-nothing approach) and expanding the number of areas of functioning to be taken into account (adding neurological problems, medical fragility, and vulnerability to disease). These are but a few of the recommendations regarding the current interim regulations.

- **SSA should continue to assess the impact of the regulations and report to Congress, particularly on the issues regarding 18-year olds and the re-reviews of children with mental retardation.**

Again, The Arc thanks Chairman Chafee for conducting this hearing and for continued dedication to ensuring that the SSI program works for low income children with disabilities. We would be pleased to provide further information on the above.

## Children Dropped from SSI Due to Changes in Eligibility Standard

1. John is a 10 year old child who has severe hearing loss and mental retardation. After 6 surgeries, he has approximately 50 percent hearing. He is scheduled for another four surgeries. John also has underdeveloped motor skills. For example, this April was the first time that John was able to ride a bike without training wheels.

Concentration is another major obstacle for John. He is unable to sit still to do work or even eat. He is constantly moving around. John's disabilities have made it hard for him to learn. He does have special classes at school, but is still unable to read.

John's parents are trying to do everything they can to help John develop his skills so he can be a healthy, productive adult. For example, John attends a special after-school program where tutors help him do homework and practice academic skills.

His stepfather works full-time but earns a very low wage. SSI has been a saving grace in John's young life. The benefits have allowed his mother to be home with him and his brothers and sisters and to help him with homework, learning to read, and developing motor skills.

Further, the SSI benefits have allowed John's parents to apply for and receive Medicaid for John. The medical insurance has given John the chance to gain some of or all of his hearing back through surgery that is too expensive for the family to cover. Lastly, SSI benefits have allowed the family to buy medication for John which is not available through Medicaid.

2. Judy is an eleven year old child who lives on a farm. Her father died, so her mother takes care of Judy alone. Judy has mental retardation with an IQ between 60 and 70. In addition she has asthma that requires medication and an inhaler. She attends a school for children with developmental disabilities.

Because of Judy's mental retardation, she needs one-on-one attention when trying to read and write. Still, basic skills like reading and writing are a struggle for her. Often, she becomes frustrated and upset because academics are so hard for her.

Judy also has emotional problems. She has difficulty controlling her temper and exhibits uncontrollable aggression towards others around her, even towards her mother. Judy's mother tries to provide Judy with loving emotional support, but this attention and care often is not enough to control her.

Judy and her mother are struggling to live on Social Security survivor benefits from Judy's father. The additional SSI benefits have been a lifeline for the family. Further, Judy's eligibility for SSI benefits has assisted her with eligibility for Medicaid which provides essential medication and health care for her asthma.

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UNIVERSITY OF MINNESOTA

Policy
Research Brief

RESEARCH AND
TRAINING CENTER
ON COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

# Children and Youth Receiving Residential Services for Persons with Developmental Disabilities Outside Their Family Home: Trends from 1977 to 1997

*This Policy Research Brief was prepared by K.Charlie Lakin, Lynda Anderson, and Robert Prouty of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. This brief summarizes changes in out-of-home placements of children and youth with mental retardation since the implementation of the SSI and IDEA entitlements. Very special thanks go to the many state officials who generously responded to a request for the reported data on a very short timeline.*

## ■ Introduction

Since 1974, the Supplemental Security Income (SSI) program has been administered by the Social Security Administration (SSA) to provide cash assistance to persons who are aged, have disabilities, or are blind and who meet standards of financial need. In most states, SSI recipients are also automatically eligible for Medicaid and for all medical and rehabilitation services included in the state Medicaid benefit package. Persons eligible for SSI include children with mental retardation who live in families that meet the established standard of financial need. Children's SSI has been one of the cornerstones of a national commitment to support children and youth with disabilities in their families and communities. Another key entitlement program in the national commitment to children, families, and community has been the Individuals with Disabilities Education Act (IDEA). Since 1976, IDEA has assured a free and appropriate public education to all children with disabilities to the largest extent possible in the least restrictive educational environment of their local communities.

In recent years, there has been growing concern and sometimes outright skepticism within Congress and from other critics of U.S. domestic policy as to whether these national commitments to children and youth with disabilities yield tangible and valuable results. Presumably based on the assumption that they do not, Congress in Public Law 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, established a stricter standard for disability among children and youth to reduce enrollments and expenditures in the Children's SSI program.

The Social Security Administration estimated that approximately 135,000 children and youth would lose their benefits as a result of these changes. The single largest group of children and youth receiving SSI are those coded as having mental retardation. They made up approximately 41% of the nearly one million Children's SSI recipients in 1996. In 1997, based on its interpretation of Public Law 104-193, the Social Security Administration notified approximately 80,000 of the 407,000 Children's SSI recipients indicated to have mental retardation that their eligibility would be re-evaluated. Initial redeterminations denied continua-

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.

The College of Education
& Human Development

tion of benefits to about 57% of those who were reevaluated.

Substantial debate about SSA's interpretation of Congressional intent and about its specific methodologies of assessing mental retardation has ensued. Often lost in these debates is the more general discussion of social outcomes that may derive from societal commitments to supporting children and youth with mental retardation in their families and communities.

This brief report summarizes changes in out-of-home placements of children and youth with mental retardation since the implementation of the SSI and IDEA entitlements. Specifically, these statistics show the numbers of children (0-14 years) and youth (15-21 years) with mental retardation living in out-of-home residential settings provided under the administrative authority of state mental retardation/developmental disabilities (MR/DD) agencies. Statistics are reported for 1977, 1987, and 1997 to show trends in such out-of-home placements. These statistics in each of the three reporting years exclude those children and youth with mental retardation placed out of natural or adoptive homes into foster care financed by local child welfare agencies, residential schools financed by education agencies, juvenile correction facilities, and other residential settings other than those financed by state MR/DD agencies. The statistics reported do include the out-of-home placements of a substantial majority of children and youth with mental retardation living outside of their natural or adoptive homes and they include statistics for the same types of programs in all three years reported. They do, therefore, provide a key indicator of one of the most important outcomes intended in the enhanced support for children with mental retardation and their families since the mid-1970s.

## ■ Method of Study

Statistics contained in this report derive from three distinct data collection efforts. Statistics for 1977 were gathered as part of a national survey of all state MR/DD agency financed, licensed or operated residential settings for persons with mental retardation operating on June 30, 1977. This survey, conducted by the Research and Training Center on Community Living at the University of Minnesota, yielded state-by-state and national population statistics on the number of persons ages 0-14, 15-21, and various adult age categories living in "MR/DD residential settings" (Lakin, Hill & Bruininks, 1985). The statistics for 1987 are based on estimates from the 1987 National Medical Expenditure Survey (NMES), Institutional Populations Component (Lakin, Hill, Chen & Stephens, 1989). This study, sponsored by the federal Agency for Health Care Policy and Research, included a random sample of 3,618 residents of a stratified sample of 700 state licensed and state-operated residential facilities. Individual records for each of the sample members included date of birth. An age was computed for each subject from this variable and categorized into the same age breakdowns available from the 1977 survey. The NMES was a national sample that did not permit state-by-state estimates. Because the NMES sample frame excluded settings with two or fewer residents and underrepresented those with six or fewer residents, NMES age distribution estimates were applied to national statistics for the total number of persons receiving MR/DD residential services outside their family homes from a separate survey of each individual state (Lakin et al.,1989)..

The statistics for 1997 were gathered from a direct survey of all 51 states. This survey was conducted in response to a request from the Social Security Administration to update statistics from 1977 and 1987 regarding numbers of children and youth receiving out-of-home MR/DD residential services. Specifically, state officials were asked to provide 1997 statistics on the number of children and youth 0-14 years and 15-21 years receiving out-of-home residential services through agencies licensed, operated, or funded by the state MR/DD program agency. Concurrently, states were reporting statistics on the total number of persons receiving residential services as part of an annual residential services data collection program (Prouty & Lakin, 1998). The survey of the number of children and youth receiving out-of-home services was conducted over a six-week period in December and January 1997-1998. It requested statistics as of June 30, 1997. Altogether, 49 states with 97.2% of the nation's total population of persons receiving MR/DD residential services responded to the request. Estimates of the number of children and youth in the non-reporting states (with 2.8% of residents with MR/DD nationwide) were made applying the same average ratio of children and youth to total residents as reported by the other 49 states.

The response rate to the 1997 survey was remarkably high, given the detail and timelines of the data request. It demonstrates how in recent years states have substantially increased the capacity of their management of information systems to provide such specific information. The fact that the responding states provide residential services to 97.2% of the total number of people receiving such services nationwide suggests that national estimates derived from the reported data should be considered highly reliable.

**Table 1: Children, Youth, and Adults Receiving Public and Private Out-of-Home Residential Services Sponsored by Developmental Disabilities Agencies**

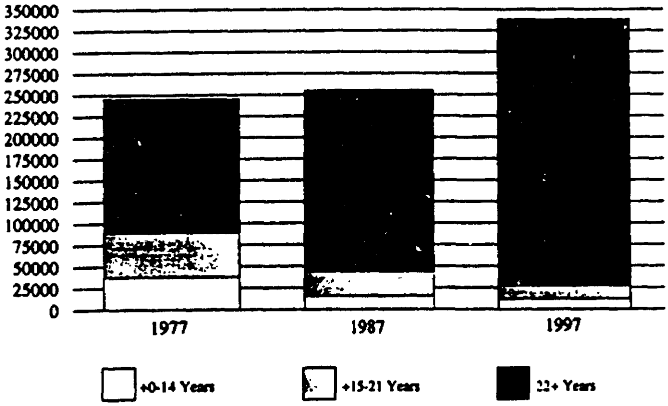
| Age | 1977 | 1987 | 1997 |
|---|---|---|---|
| 0-14 | 38,161 (15.4%) | 15,085 (5.9%) | 11,403 (3.4%) |
| 15-21 | 52,781 (21.3%) | 31,448 (12.3%) | 14,438 (4.3%) |
| 22+ | 156,854 (63.3%) | 209,140 (81.8%) | 312,641 (92.3%) |
| Total | 247,796 (100%) | 255,673 (100%) | 338,482 (100%) |

## Results of the Study

Table 1 and Figure 1 present the total number of children (0-14 years), youth (15-21 years), and adults receiving MR/DD residential services in 1977, 1987, and 1997. As shown in 1977 (at the very beginning of the federal commitment to supporting children and youth in their families and communities), there were 90,942 children and youth in MR/DD residential settings. Of these young persons, about 38,200 were 14 years or younger and 52,800 were 15-21 years old. In 1977, children and youth made up 36.7% of the 247,796 persons receiving MR/DD residential services, and 15.4% of all persons in MR/DD residential settings were children 14 years and younger.

By 1987, just over a decade into the major national commitment to supporting children and youth with mental retardation in home and community, the number of children and youth living out-of-home in MR/DD facilities had decreased by nearly one-half (48.8%) to an estimated 46,533. Even more impressively, the number of children 14 years and younger had been reduced to an estimated 15,085. This was only 39.5% of the 1977 total. The number of youth with mental retardation 15-21 years old living out-of-home decreased by about 21,000 to an estimated 31,450. In 1987, children and youth 21 years and

**Figure 1: Children, Youth, and Adults Receiving Public and Private Out-Of-Home Residential Services Sponsored by State Mental Retardation/Developmental Disabilities Agencies**



younger made up only 18.2% of all persons receiving out of home MR/DD residential services. This compares with 36.7% in 1977.

Between 1987 and 1997 the earlier trend continued. In 1997, there were an estimated 11,403 children 14 years and younger and 14,438 youth 15-21 years in out-of-home MR/DD settings. The estimated total of 25,842 children and youth 0-21 years living in out-of-home MR/DD residential settings was 44.5% less than in 1987. The rate of decrease between 1987 and 1997 was only slightly less than the rate of decrease between 1977 and 1987 (48.8%).

In the 20 years between 1977 and 1997, the number of children and youth receiving out-of-home MR/DD residential services decreased by over 65,000 persons and 71.6 %. The number of children birth to 14 years decreased by 70.1% to 3.4% of all people receiving MR/DD residential services. The number of youth 15-21 years decreased by 72.6% to 4.3% of all people receiving MR/DD residential services. As shown in Table 2, decreases occurred in every state. (Idaho's lower reported number of children in 1977 was due to partial reporting.)

## Discussion and Recommendations

The statistics reported in this *Policy Research Brief* document a substantial decrease in the number of U.S. children and youth with mental retardation removed from their families and placed in residential settings for persons with mental retardation and related conditions.

The steady decline in the number of children and youth receiving out-of-home MR/DD residential services demonstrates powerful effects of social policies introduced in the mid-1970s to support children and youth in their own homes and communities. The number of children and youth receiving out-of-home MR/DD residential services in the U.S. has been reduced to less than 30% of the number 20 years earlier, even as the total number of children and youth less than 22 years old increased by 4% and the total number of persons receiving out-of-home MR/DD residential services increased by 37%.

Another indicator of the impact of the mid-1970s commitment to children and youth with mental retardation was that in just 6 years between 1972 and 1978, the average age of first admission to MR/DD residential settings increased from 13.95 years to 18.02 years (Lakin, Hill, Hauber & Bruininks, 1982).

In 1996, there were an estimated 87,000 people with mental retardation waiting for out-of-home residential services in the United States (Prouty & Lakin, 1997). Waiting lists are viewed as a growing national problem. It is remarkable to consider what would be the lengths of waiting lists today if MR/DD residential settings still housed the 91,000 children and youth who lived in them in 1977. If it were not for the success of SSI, IDEA, and other federal and state programs that have assisted families to keep their children with mental retardation at home, the number of people waiting for MR/DD residential services might be nearly double what it is today.

When Congress was considering Public Law 104-193, the Congressional Research Service estimated that the bill would yield "savings" of about $7.4 billion over 6 years, or about $1.23 billion per year (Soloman-Fears, 1996). Based on Social Security Administration projections, about 45,300 of the projected 135,000 discontinued children and youth would be individuals listed as having mental retardation, although these original estimates have since been revised downward by about one-quarter (Social Security Administration, 1998). Therefore, about one-third of the 6-year SSI savings or $1.9-2.5 billion or $310-415 million per year might be assumed to come from discontinued benefits to children and youth with mental retardation. But what is overlooked in these estimated "savings" is the surety that there are also "costs" associated with the discontinuation of important cash assistance. Although Medicaid eligibility was restored for SSI children whose cash benefits were discontinued, such is not the case for those children and youth denied SSI in the future.

Because of the reduced commitment to children and youth with mental retardation, some unknown number of them will enter out-of-home residential care. One way to examine the potential impacts of such outcomes is to consider the cost-related benefits and the expenditures for the programs and policies that have contributed to the remarkable decreases in the number of children and youth with mental retardation receiving out-of-home residential services. (Unfortunately, it is impossible to isolate individual programs such as SSI from the broad set of commitments that this society has made to children with disabilities and their families. However, SSI and IDEA are, by far, the largest and broadest in scope of those commitments

**Table 2: Children and Youth with MR/DD Living Outside the Homes of Their Natural or Adoptive Families as a Percentage of All People with MR/DD Receiving MR/DD Services in 1977 and 1997**

| | 1977 | | | 1997 | | | | |
|---|---|---|---|---|---|---|---|---|
| State | Total Residents in MR/DD Services | 0-21 Year Olds in MR/DD Residential Services | 0-21 as % of Total | Total Residents in MR/DD Services | Ages Birth -14 Years | Ages 15-21 Years | 0-21 Year Olds in MR/DD Residential Services | 0-21 as % of Total |
| AL | 2,106 | 415 | 19.7% | 3,210 | 19 | 108 | 127 | 4.0% |
| AK | 243 | 169 | 69.5% | 697 | 18 | 39 | 57 | 8.2% |
| AZ | 1,453 | 667 | 45.9% | 3,016 | 378 | 281 | 659 | 21.9% |
| AR | 1,901 b | 1,150 | 60.5% | 2,822 a | 130 | 267 | 397 | 14.1% |
| CA | 26,179 | 12,644 | 48.3% | 41,584 | 4,587 | 2,360 | 6,947 | 16.7% |
| CO | 2,651 | 1,052 | 39.7% | 3,910 | DNF | DNF | 263 | 6.7% |
| CT | 4,497 | 1,533 | 34.1% | 6,326 | 50 | 158 | 208 | 3.3% |
| DE | 810 | 412 | 50.9% | 752 | 19 | 6 | 25 | 3.3% |
| DC | 75 e | 64 | 85.3% | 1,875 | 2 | 6 | 8 | 0.4% |
| FL | 8,103 | 4,295 | 53.0% | 10,463 | 370 | 527 | 897 | 8.6% |
| GA | 3,327 | 1,251 | 37.6% | 3,557 a | 175 | 221 | 396 | 11.1% |
| HI | 384 e | 98 | 25.5% | 1,071 | 20 | 31 | 51 i | 4.8% |
| ID | 811 d | 173 | 21.3% | 2,417 | DNF | DNF | 321 | 13.3% |
| IL | 13,398 | 4,756 | 35.5% | 13,077 a | 463 | 678 | 1,141 | 8.7% |
| IN | 4,856 | 1,923 | 39.6% | 7,600 | 400 | 458 | 858 | 11.3% |
| IA | 3,499 | 1,410 | 40.3% | 8,048 a | 168 f | 295 f | 463 | 5.8% |
| KS | 2,708 | 980 | 36.2% | 2,783 a | 46 | 180 | 226 | 8.1% |
| KY | 1,659 | 667 | 40.2% | 653 h | DNF | DNF | 25 h | 3.8% |
| LA | 4,449 | 2,171 | 48.8% | 8,011 a | 196 | 581 | 777 | 9.7% |
| ME | 1,493 | 372 | 24.9% | 2,314 | DNF | DNF | 94 | 4.1% |
| MD | 3,372 | 1,281 | 38.0% | 4,880 | 25 | 78 | 103 | 2.1% |
| MA | 7,723 | 2,016 | 26.1% | 8,602 | 67 | 251 | 318 | 3.7% |
| MI | 12,648 | 4,111 | 32.5% | 11,890 | 127 | 394 | 521 | 4.4% |
| MN | 6,182 | 1,626 | 26.3% | 10,990 a | 170 | 545 | 715 | 6.5% |
| MS | 2,138 c | 671 | 31.4% | 2,860 | 74 | 118 | 192 | 6.7% |
| MO | 6,505 | 2,700 | 41.5% | 6,611 | 180 | 366 | 546 | 8.3% |
| MT | 765 | 194 | 25.3% | 1,752 | 121 | 68 | 189 | 10.8% |
| NE | 2,298 | 678 | 29.5% | 2,359 e | 44 | 98 | 142 | 8.1% |
| NV | 247 | 144 | 58.4% | 553 a | 12 | 23 | 35 | 5.4% |
| NH | 836 | 275 | 32.9% | 1,628 | 7 | 52 | 59 | 3.6% |
| NJ | 9,314 | 3,502 | 37.6% | 9,432 | 176 | 450 | 626 | 6.6% |
| NM | 793 | 370 | 46.6% | 2,038 a | 35 | 64 | 99 | 4.9% |
| NY | 26,552 | 6,824 | 25.7% | 34,782 | 537 | 1,201 | 1,738 | 5.0% |
| NC | 4,424 | 1,637 | 37.0% | 7,566 | DNF | DNF | DNF | DNF |
| ND | 1,376 | 299 | 21.7% | 1,922 | DNF | DNF | DNF | DNF |
| OH | 10,818 | 3,689 | 34.1% | 15,891 | 203 | 457 | 660 | 4.2% |
| OK | 2,132 b,d | 1,671 | 78.4% | 4,439 | 99 | 117 | 216 | 4.9% |
| OR | 2,607 | 1,004 | 38.5% | 3,900 a | 190 | 300 j | 490 | 12.6% |
| PA | 16,705 | 6,014 | 36.0% | 18,275 | 244 | 513 | 757 | 4.1% |
| RI | 992 d | 183 | 18.4% | 1,351 | 0 | 0 | 0 | 0% |
| SC | 4,126 | 1,593 | 38.6% | 4,592 | 103 | 351 | 454 | 9.9% |
| SD | 1,177 | 395 | 33.6% | 2,031 | 24 | 202 | 226 | 11.1% |
| TN | 3,206 | 1,125 | 35.1% | 4,386 | 47 | 126 | 173 | 3.9% |
| TX | 14,906 | 6,052 | 40.6% | 17,571 | DNF | DNF | 1,423 g | 8.1% |
| UT | 1,380 | 472 | 34.2% | 2,378 | 73 | 183 | 256 | 10.8% |
| VT | 921 | 281 | 30.5% | 915 | 16 | 48 | 64 | 7.0% |
| VA | 4,717 | 1,665 | 35.3% | 3,373 a | DNF | DNF | 387 g | 11.5% |
| WA | 4,428 | 1,519 | 34.3% | 6,626 | 16 | 105 | 121 | 1.8% |
| WV | 1,006 | 374 | 37.2% | 1,917 | 1 | 9 | 10 | 0.5% |
| WI | 5,649 | 2,192 | 38.8% | 17,468 | 261 | 213 | 474 | 2.7% |
| WY | 631 c | 115 | 18.2% | 976 | 18 | 21 | 39 | 4.0% |
| Reported U.S. Total | 247,796 c | 90,942 | 36.8% | 327,106 | 9,911 | 12,549 | 24,973 | 7.6% |
| Estimated U.S. Total | | | | 338,482 | 11,403 | 14,438 | 25,842 | 7.6% |

a indicates 1996 data
b excludes facilities with 1-6 residents
c excludes facilities with 16-63 residents
d excludes facilities with 64-299 residents
e excludes facilities with 300+ residents
f indicates estimate
g 1997 statistics include ICF/MR Residents only
h indicates only children and youth living in state-operated facilities
i does not include birth through three years of age
j does not include people over age 18
k 0-21 total is greater than combined 0-14 and 15-21 total because six states could only provide combined 0-21

affecting children with disabilities.)

Nationwide, the average annual per person costs of Medicaid-financed residential programs in 1996, including the SSI benefit for Medicaid Home and Community Based Services (waiver) recipients, was $50,750 (Prouty & Lakin, 1997). The average federal SSI benefit in 1996 for children and youth with mental retardation was an estimated $5,600. If the 90,942 children and youth with mental retardation in out-of-home residential services had not been affected by the social interventions of family and community support that began with SSI in 1974, it might be assumed that the number of children and youth living in out-of-home MR/DD settings in 1997 would have grown proportionally to the growth of children and youth in the society as a whole (+3.5%) and today might number about 94,125 children and youth. Expenditures for these individuals based on the 1996 average Medicaid long-term care expenditures for persons with mental retardation would have been an estimated $4.8 billion.

But, instead of the projected scenario, in 1997 the number of children and youth living out-of-home in MR/DD settings were an estimated 25,842 individuals. Based on 1996 Medicaid reimbursements, expenditures for these individuals was an estimated $1.3 billion, or about $3.5 billion less than the estimated expenditures had out-of-home placement rates for children and youth with mental retardation remained at their 1977 levels. If the SSI alone were sufficient to produce such a result, the $2.25 billion spent on federal SSI benefits for the estimated 407,000 children with mental retardation on SSI rolls in mid-1997 would have yielded a substantial cost-benefit of about $1.25 billion per year. But, of course, SSI was only one of a number of significant commitments made in the mid-1970s and early 1980s to value families and communities as the preferred option for nurturing children and youth with mental retardation (and other disabilities). Other programs providing support for such ideals included the Education for All Handicapped Children Act of 1976 (now IDEA as amended), the Medicaid Home and Community Based Services ("waiver") authority in 1981, the Adoption Assistance and Child Welfare Act of 1980 and the emergence of state family subsidy and support programs which began in the 1970s and by 1996 had reached $500 million in annual expenditures (Braddock, Hemp, Parish & Westrich, 1998).

Although the savings projected for PL 104-193 do not reflect other costs that will be incurred as a result, costs that will be much more heavily borne by state and local governments, it appears unlikely that there is an absolute federal "cost benefit" that can be attributed to the support programs that have dramatically reduced out-of-home placements of children and youth with mental retardation over the past 20 years. But the benefits of keeping children and youth in families and communities have not always been viewed in terms of cost benefit. In establishing SSI and IDEA entitlements, the Congress of a generation ago wanted to provide as many children as possible the opportunity, if not the right, to benefit from typical developmental experiences of childhood, growing up in a family and going to a community school. By the standards of this previous generation of Congress, remarkable, albeit fragile, outcomes were attained. But the commitment to sustain these outcomes seems ever more in doubt.

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## ■ Related Publications

*The following are available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 624-4512. Please write or call for a catalog or for cost and ordering information.*

- *Family Needs Survey Results: Responses from Parents of Youth Children with Disabilities (Report #90-2)* (1990). Compiled by C.J. Gilman, S.D. Johnson, and K. McGrew. A summary of the results of a structured interview administered to 57 parents of children ages 3-10 with moderate to severe developmental disabilities. The survey gathered information about their current and future needs for information, sources of informal and formal service support, and involvement in school and non-school based activities, as well as perceived sources of stress and obstacles to adequate child care and other community services.
- *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1996 (Report #49)* (1997). Edited by K.C. Lakin and R.W. Prouty. A report providing statistics on persons with developmental disabilities in state, non-state, and Medicaid-funded residential programs in the United States for the fiscal year ending June 30, 1996.
- *Status and Changes in Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program: Results from Analysis of the Online Survey Certification and Reporting System (Report #47)* (1995). By K.C. Lakin and S.A. Larson. A report summarizing facility and resident information for the most recent surveys of Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) in the OSCAR database as of January 1994. It also compares the characteristics of ICFs-MR in the OSCAR databases with the findings of a 1982 survey of all ICFs-MR.
- *Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities (Report #44)* (1994). By K.C. Lakin and T. Morgan. A report on the current status of national and state information systems on residential services for persons with developmental disabilities. The report gives summaries of the types of information collected, how this information can be accessed, and suggests supports that would assist states in improving, utilizing, and sharing their data collection systems.
- *IMPACT: Feature Issue on Institution Closures.* This newsletter focuses on a critically important step in honoring the full citizenship of persons with developmental disabilities: the closing of institutions. Includes articles by self-advocates, policymakers, service providers, parents, and researchers.
- *IMPACT: Feature Issue on Supported Living.* In this newsletter, many leaders in the development of supported living describe the challenges and rewards of a new relationship between those who need and provide assistance.

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April 10, 1997

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

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

Dear Acting Commissioner Callahan:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

RECOMMENDATION:

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

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

## II. SUBSTANTIVE ISSUES WITHIN THE STANDARD

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

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

1. <u>Cognition and Communication Should Be Assessed Separately</u>

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

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

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

<u>**RECOMMENDATION:**</u>

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

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

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

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

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

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

### RECOMMENDATION:

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

## 3. Measurement of IQ Must Include Room for Measurement Error

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

RECOMMENDATION:

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

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

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

RECOMMENDATION

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

5. "Other factors" Need Better Link to Functional Assessment

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

RECOMMENDATION

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

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

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

RECOMMENDATION

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

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

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

### RECOMMENDATION

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

## III. IMPLEMENTATION ISSUES

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

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

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

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

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The undersigned organizations urge the Social Security Administration to publish new regulations incorporating the changes suggested above.

Thank you for the opportunity to submit comments on these regulations. If you have any questions on the above, please contact Marty Ford (The Arc, 202/785-3388) or Rhoda Schulzinger (Bazelon Center for Mental Health Law, 202/467-5730).

Sincerely,

Marty Ford
Marty Ford
The Arc of the United States

Rhoda Schulzinger
Rhoda Schulzinger
Bazelon Center for Mental Health Law

Tony Young
Tony Young
United Cerebral Palsy
Associations, Inc.

Paul Seifert
Paul Seifert
International Association of Psychosocial
Rehabilitation Services

Co-Chairs, CCD Task Force on Social Security

**ON BEHALF OF:**

American Academy of Child & Adolescent Psychiatry
American Association of University Affiliated Programs
American Association on Mental Retardation
American Network of Community Options and Resources
American Psychological Association
American Rehabilitation Association
Association of Maternal and Child Health Programs
Autism Society of America
Bazelon Center for Mental Health Law
Brain Injury Association
Council for Exceptional Children
Division for Early Childhood of the Council for Exceptional Children
Epilepsy Foundation of America
International Association of Psychosocial Rehabilitation Services
Joseph P. Kennedy, Jr. Foundation
Learning Disability Association of America
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Council for Community Behavioral Healthcare
National Easter Seal Society
National Mental Health Association
National Parent Network on Disabilities
Paralyzed Veterans of American
Spina Bifida Association of America
The Arc of the United States
United Cerebral Palsy Associations, Inc.

neglect will no longer be protected CAPTA's immunity for reporting. ( good-faith reports will be protected.

Finally, we have clarified the definition of child abuse or neglect to provide additional guidance and assistance to States as they endeavor to protect children from abuse and neglect.

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

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

### STUDENT AID

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

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

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

### CHILDREN'S SSI

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

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

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

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

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

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

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

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

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

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

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

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

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

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

BEST AVAILABLE COPY

But I think there may be some difference of opinion about the purpose of the program. The SSI program was originally started to provide a small cash income to individuals who cannot work because of age or disability. But the children's SSI program had a somewhat different purpose—to help poor families with the extra costs of having a child with a disability. It seems the program has expanded without much Congressional attention. In my view, we need to revisit the purpose of the SSI program. The Finance Committee has not tackled this problem yet, but it should and I believe it will. But the Senate decision to retain the cash benefit is clearly an important difference from the House.

Mr. CONRAD. I would like to join in the comments of both of my colleagues regarding the cash benefit nature of the SSI program. This provision is critically important, and I commend the Majority Leader for including it in the amendment. If I might address one additional question to the majority leader, it is the intent of this Senator and other supporters of this amendment on both sides of the aisle that this amendment is the position of the Senate, and that it will be vigorously defended in conference with the House of Representatives. Will the majority leader insist on this provision during conference with the House?

Mr. DOLE. This is a bipartisan compromise with broad support, and in my view it should be a position to which the Senate should firmly hold in conference.

Mr. CONRAD. Base on these assurances, I am pleased to support the compromise we have developed on children's SSI. This is not everything I had hoped to achieve, but it is critically important that the Senate enter conference with a solid unified position.

Mr. WARNER. Mr. President, I am pleased to rise as one of the original cosponsors of the Republican leadership welfare reform bill.

We have entered this historic debate because the 30-year War on Poverty remains a war, but the nation is losing. According to recent analysis, aggregate government spending on welfare programs over the last 30 years has surpassed $5.4 trillion, an expenditure that exceeds our national debt.

Despite this spending, America's national poverty rate remains at about the same level as 1965, the year that President Johnson launched the War on Poverty.

Despite the best of intentions, we have a welfare system that "traps" children and families in a cycle of dependency, and that encourages behavior leading to indefinite reliance on welfare. It fosters a lifestyle that is in direct opposition to the motivators that propel others to get up and go to work every day.

The Republican leadership's bill emphasizes work, families and genuine hope for the future while giving the States greater responsibility—and flexibility—for managing welfare.

This measure has been a long time coming, and I do not just mean this summer. Our distinguished colleague from Colorado, Senator HANK BROWN, did an outstanding job in 1993 and 1994 as chairman of the Republican Welfare Reform Task Force. Health Care Reform diverted the Senate, but it did not diminish the value of their work. Much of what we are considering today is built directly on the strong foundation of Senator BROWN's early proposals.

I also think back to the 1986 State of the Union Address of President Ronald Reagan. That year he proposed Welfare Reform. This was another step. The Reagan welfare reform plan, the Family Security Act of 1988, was guided to enactment by the fine hand of the then Finance Committee Chairman, Senator MOYNIHAN of New York, who is now serving with such distinction as the comanager of this bill.

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

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

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

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

Governor Allen, with his great courtesy, personally journeyed to Washington on September 12 to deliver a thoughtful and, in my judgment, immensely helpful letter on what he believes the Senate should accomplish in welfare reform.

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

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

COMMONWEALTH OF VIRGINIA,
OFFICE OF THE GOVERNOR,
September 12, 1995.

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

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

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

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

Experience shows that the States are perfectly capable of taking this responsibility and exercising it wisely for our citizens. Virginia's landmark welfare reform legislation is a prime example. Our plan applies to the entire AFDC caseload, with a work requirement for 8,000 of our 74,000 cases. It incorporates common-sense principles into the welfare system by rewarding responsible behavior and providing compassionate, but temporary, assistance for those in need.

In addition to providing opportunity and support to recipients, the program is expected to save the taxpayers more than $120 million over the first five years. Already, we have had a significant drop in our caseload. Restrictive maintenance-of-effort requirements rob States of the ability to share in these savings and the incentives to achieve them. They should be opposed.

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

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

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

JOHN H. CHAFEE
RHODE ISLAND

[illegible] COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

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INTERNET ADDRESS:
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September 17, 1996

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

Dear Mr. President:

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

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

The debate over this issue was heated at times, but, ultimately, we reached a compromise on the definition of childhood disability in September, 1995. That definition became part of the overall Congressional compromise on SSI, and was included in the first two versions of welfare reform approved by Congress and then finally in the bill enacted in August. The compromise is notable in two ways. First, it preserves a broad functional approach, beyond the "Listings of Impairments," in measuring childhood disability. Second, it specifically does not establish the listings level of severity, or any equivalent level of severity, as the measure to be used in assessing childhood disability.

The enclosed Senate colloquy between those of us involved in this compromise is important in understanding the meaning of the new definition. This colloquy was not entered into lightly. Rather, it was the subject of much negotiation and was key to the final language of the definition regarding "physical and mental impairment, which results in marked and severe functional limitations" after dropping the requirement that the effect of the impairment also be "pervasive".

It is certainly appropriate for SSA, as the regulatory agency, to adopt a disability test that is stricter than the old Individualized Functional Assessment (IFA), but which is not at the very strict level of the "Listings." The proposal put forward by several disability advocates and organizations with considerable expertise – a one marked/one moderate level – is an acceptable and reasonable approach that fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require that these limitations be pervasive.

The Congressional Budget Office (CBO) has also acknowledged that SSA would have a great deal of flexibility in meeting the requirements of the new law. The enclosed Senate Finance Committee report shows that CBO estimated that the new definition of childhood disability could bar anywhere from 10-28 percent of children from the program, depending upon the regulatory interpretation of the new definition.

I know that you will do everything in your power to ensure that children with severe disabilities who are truly deserving are not harmed by the changes in the new welfare law. Thank you in advance for your attention to this matter. Please do not hesitate to contact me if I may be of any further assistance.

Sincerely,

John H. Chafee

John H. Chafee

JHC:bd

cc: Secretary Shalala
Commissioner Chater

KENT CONRAD
NORTH DAKOTA
[illegible]

United States Senate
WASHINGTON, DC 20510-3403

September 4, 1996

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

Dear Mr. President:

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

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

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

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

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

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

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

Sincerely,

Kent Conrad

KENT CONRAD
United States Senate

KC:wman

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

TOM DASCHLE
SOUTH DAKOTA

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

October 4, 1996

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

Dear Mr. President:

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

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

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

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

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

With best wishes, I am

Sincerely,

Tom Daschle
United States Senator

cc: The Honorable Carol Rasco
The Honorable Shirley Chater

CAROL MOSELEY-BRAUN
ILLINOIS

COMMITTEES:
BANKING, HOUSING, & URBAN AFFAIRS
FINANCE
SPECIAL AGING

United States Senate
WASHINGTON, DC 20510 1303

September 25, 1996

The Honorable Bill Clinton
President
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

I am writing regarding the Supplemental Security Income (SSI) provisions of the new welfare law. As you know, the Social Security Administration has a key role in the implementation of the children's SSI provisions. While I fully support efforts to ensure that only children wh are truly disabled receive SSI benefits, I hope that there will be adequat safeguards to ensure that those children who are, in fact, severely disabled, will not be unduly harmed by the new rules.

The Congressional Budget Office has told Congress that the new welfar law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretion that the SSA will have in implementing the broad functional limitations test used to evaluate children.

In developing policies to implement the new SSI provisions, I encourage you to carefully consider the recommendations of several nationally recognized experts of this program, including the SSI Coalition located in Chicago. The proposal put forth by the SSI Coalition is similar to that put forward by several other disability advocates--that is, a "one marked/one moderate" functional disability test. This standard is an acceptable and reasonable approach which fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require these limitations to be pervasive.

Mr. President, I know that you, too, are keenly interested in implementing the welfare bill in a way that will adequately protect children with severe disabilities. I appreciate your thoughtful consideration of this matter and look forward to hearing from you.

Sincerely,

Carol Moseley Braun

Carol Moseley-Braun
United States Senator

CMB:arc

cc: Shirley Chater

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

October 8, 1996

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

Dear Mr. President:

The recently enacted welfare reform legislation included changes to the eligibility standard for low-income children who receive Supplemental Security Income (SSI). The legislation eliminated the Individual Functional Assessment, an eligibility standard formulated for children as a result of the Supreme Court decision in Sullivan v. Zebley. The Social Security Administration (SSA) is now in the process of carrying out a directive to draft a new definition that will permit a child to receive benefits if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations."

As Chairman of the Senate Special Committee on Aging, I have worked to ensure that the SSI program is not vulnerable to false claims for disability benefits from disabled adults, immigrants, and children. However, I am concerned that as SSA carries out its mandate to revise the disability criteria, children with severe disabilities may be denied eligibility unfairly.

Congress intended that the new eligibility guidelines should be more strict than the Individual Functional Assessment; however, Congress recognized that the revised standard should continue the use of criteria which take into account functional limitations. In addition, there was no explicit directive that the new standard equal the level of severity generally found in the Listing of Medical Impairments.

Evidence of congressional intent can be found in a colloquy between Senator John Chafee and Senator Bob Dole (Cong. Rec. S13613). My colleagues noted that a definition requiring a "marked, severe, and pervasive impairment" was rejected by the conferees. When this language was proposed, the Congressional Budget Office (CBO) calculated that the number of children who would be affected could be anywhere from 10 to 28 percent of the children currently on the program. Upon further consideration, the term "pervasive" was dropped from the definition because the term implied some degree of impairment in almost all areas of a child's functioning or body systems. With the deletion of the term "pervasive," it is clear that Congress is not demanding a drastic change in the level of severity required to demonstrate eligibility for benefits. In choosing a more lenient definition, it is also clear that the number of children who ultimately lose benefits will be lower than the range cited by CBO.

The SSI program provides critical health services and financial support for families with disabled children. While the program has experienced problems, I believe that SSA has initiated steps to implement safeguards which protect against potential abuses. I know that you will do whatever you can to encourage a standard that will promote confidence in the program and will direct help to those who need it most.

With best wishes, I am

Sincerely,

Bill Cohen

William S. Cohen
Chairman

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

[illegible]

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

December 9, 1996

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

Dear Mr. President:

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

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

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

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

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

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

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

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

Sincerely,

Tom Harkin

Tom Harkin
United States Senator

PAUL D. WELLSTONE
MINNESOTA

[illegible]
[illegible]

United States Senate
WASHINGTON, DC 20510-2303

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

November 12, 1996

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

Dear Secretary Shalala:

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

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

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

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In addition, I would hope that in issuing its new eligibility standards, the Department of Health and Human Services would recognize that the medical and education communities are currently reluctant to place labels on young children. However, under strict new eligibility standards, it would not be surprising to see children with functional limitations being given severe labels and psychiatric diagnoses in order allow them to obtain needed services.

I urge the Department to set its eligibility standards in such a way that would allow children who are truly dependent on SSI to continue to receive benefits. It is ironic that the IFA was targeted in the Welfare Reform bill since functional assessments are much more reliable than medical listings, and there are great functional variations among people who carry the same medical listing. Additionally, diagnostic processes used to determine a medical listing use functional assessments.

My greatest concern is that we not reduce our commitment to keep children, particularly children with disabilities, in their family homes. In the 1970's, Congress made an assumption that the best place for a child to be raised is with his or her family. A number of commitments were made to provide financial assistance to families and an education to children with disabilities so that they could be raised at home. This has worked incredibly well. In 1965, 91,000 children lived in state institutions but now only 3,000 children remain in them. In 1977, 90,000 children lived in residential facilities, but now only 40,000 live in these facilities. In short, the number of children receiving SSI benefits have increased, but the number of children in out-of-home placements has decreased.

Again, I hope that you will take great care in establishing these standards. I firmly believe that we must not reduce our commitment to children. Thanks for your attention to the issues I have raised. I look forward to hearing from you.

Sincerely,

Paul Wellstone

Paul David Wellstone
United States Senator

PDW:sa

C V L S

Chicago
Volunteer
Legal
Services
Foundation

## Testimony on Children's SSI
## Finance Committee
## United States Senate

**Who We Are.** Founded in 1964, Chicago Volunteer Legal Services Foundation is the nation's oldest and largest *pro bono* program which provides direct legal services to individual clients. Last year, our 1,859 volunteers—assisted by a staff of 6 lawyers and 5 paralegals—provided free assistance to 11,193 low-income area residents with "everyday" legal problems. With a panel referral program and 26 free neighborhood legal clinics, CVLS fields more legal aid attorneys than all other Chicago-area programs combined.

Our agency, individual volunteers, and key staff have received an impressive array of community and bar association awards. Detailed information about our mission, membership and finances is set forth in the enclosed Annual Report fully describing our agency is enclosed with this statement.

By choice, Chicago Volunteer Legal Services Foundation (CVLS) accepts no funds from any government entity. Our donors are individuals, law firms, foundations, corporations, and law firms. CVLS has no ideology or political agenda. As far as I know, this is only the fourth time in our history that we've communicated with a legislature. This testimony follows an invitation to elaborate upon my letter which was published in the Illinois State Bar Association Newsletter (copy attached).

**CVLS & Children's SSI.** CVLS knows SSI in theory and in practice. Our attorneys and paralegals have experience as effective client representatives. In addition, we've had extensive contact with thousands of SSI recipients, representing their families in divorce, eviction, guardianship, and matters.

**SSI & the State & Income Redistribution.** The Illinois Department of Public Aid has been very aggressive in persuading/ coercing its clients for SSI. Many—probably, most—successful applicants were genuinely

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and seriously disabled. However, as time went by, many of us found an increasing number of parents of children transferring from State (IDPA) to Federal (SSI) welfare rolls openly or tacitly acknowledging that their offspring had no real disability. This was particularly noticeable in the asthma and learning/behavior disorder categories. Judging from our clientele, it was not unusual for an IDPA caseworker to "sign up" all the children in a family.

What made State officeholders happy also pleased activists who favored income redistribution. As a University of Chicago study pointed out some years ago, it is impossible for one to survive solely on one's IDPA grant. However, legislators regarded raising IDPA grants as political suicide. SSI, on the other hand, provided a realistic subsistence income. As time went by, one heard more social workers and lawyers admit that many of their recipients (again, concentrated in the above categories) were not really seriously disabled but this was the only way to increase their family incomes. This mentality is evident in some of today's advocate training materials. One text instructs volunteers that even if a case appears to lack medical merit, it should be pursued.

**Impact on Parents and Their Communities.** A fair number of the hundreds of clients we've seen were puzzled by or annoyed by having their "normal" children labeled as disordered. Other parents didn't care. They got more money and no "strings." There has never been any requirement that SSI awards must be used to directly benefit the disabled child. This means that parents could, and many did, use the extra money to fund their own lifestyles.

Over and over, clients have complained to us about neighbors using their children's grants to finance drugs, late-model cars, and boyfriends. Community residents are embarrassed when homes subsidized by SSI are found to have no food, no heat, and no one over the age of 10 when rescuers arrive at 2 AM. Marginally-employed, uninsured clients complain that that their tax dollars support a lifestyle their own children do not enjoy. Parents of genuinely disabled children have come to resent the fact that an increasing number of people equate "SSI" with "fraud". SSI's promiscuous coverage has had a corrosive effect on low-income communities. And, somewhere along the line, the distinction between genuine ADD and old-fashioned BAD has been lost.

In short, I truly believe that the majority of low-income persons recognize that there have been serious abuses in the SSI program. They will support reform that is fairly devised and implemented.

**The "Crisis".** The media predicted dire consequences of reform before *any* consequences were evident. Well-funded "projects" sprang up to redress "wrongs" before they were identified.

It is wise to prepare for future exigencies. Who can fault bar groups for trying to head off the crisis that "experts" assured them would occur? However, it's always hard to admit that a need has been overstated or that a remedy has been overblown. And it's tempting to explore how a "project" can become even bigger and more important.

**Our Own Experience.** Since we knew that many Illinois SSI recipients in certain categories had no legitimate claim, we expected many to be properly disqualified. We expressed our concerns to a number of projects in their infancy. *Pro bono* programs are killed by recruitment drives that produce eager lawyers who will get no cases—or no *good* cases. And that, at least in Chicago, is exactly what is happening now.

Our advice and concerns have not been well received. What we once thought would be a medical issue affecting individual children has become a collection of political issues with a dash of empire-building.

Sometimes we see good cases. More often we get junk. The woman who's been receiving benefits for a grandson for the past 5 years. She hasn't seen him for 3 years. The man who wants us to appeal termination of benefits for his 5 children but has no idea why they're getting SSI. How are their disorders being treated? They aren't. "There's nothing wrong with them." The mother whose "proof" of her daughter's learning disability is a teacher's report that although this 7 year-old reads at age level, "her attention sometimes wanders."

We keep hearing that someday there will be a huge flood of cases. However, a recent provider meeting in Chicago was indefinitely postponed because there has hardly been a trickle. Perhaps the parents who don't appeal know more than their would-be advocates do.

**There Are Good Cases Out There.** Yes, some genuinely disabled children are being disqualified. These vulnerable children need strong advocates. The quality of determinations in Chicago improved once school was in session and records were more accessible. The government finally did get around to issuing a notification that identified providers of free legal representation.

However, it is unfair to say that reform, major reform, was not needed. It is unfair to use children to turn SSI into a political football. Neither party has a corner on virtue. Bureaucrats and advocates both tend to excess. We urge you to try your best to eliminate rhetoric and politics from your considerations.

Thank you.

M. Lee Witte
Executive Director
Chicago Volunteer Legal Services Foundation
100 North LaSalle Street
Suite 900 Chicago, IL 60602.2405
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F: 312.332.1460

DECEMBER 1, 1997/ISBA BAR NEWS

# CVLS disgusted with SSI cases that lack merit

We're proud of the Illinois State Bar Association's leadership in recruiting pro bono attorneys to contest termination of kids' SSI disability benefits.

This was a speedy and proactive response to an apparent national crisis. That ISBA has responded so generously is a tribute to the great good will of its members. However, fair warning: All ISBA volunteers may not get cases.

Due to years of experience with SSI, the Chicago Volunteer Legal Services Foundation asked to be given cases in categories most likely to make sense. Even so, less than 50 percent of the SSI cases we receive to place with volunteers have an arguable merit.

"Disgusted" is a mild word for how we feel about the fraud, greed and neglect some of these cases reveal.

We're told that Illinois has a disproportionate number of terminations. That makes sense when one considers that most of these payees were essentially coerced by the Illinois Department of Public Aid to qualify children (and adults) for federal SSI benefits, thus removing them from IDPA rolls.

Faced with a threat of losing legitimate state aid unless you applied for the much larger federal grant, what would you do?

And isn't it true that study after study shows it would be a lot more honest for states to raise all their welfare grants to the level of SSI payments because no one can subsist on the lower payments?

Depressing and disillusioning? Maybe. But it's also a relief to see how many of these disqualifications are totally correct. And thanks to ISBA, children who are actually disabled will have lawyers.

With welfare reform upon us, we hope the bar will enter into an ongoing dialogue with the Illinois Department of Human Services to assure that the state does its best by all our impoverished youth.

So if you don't get an SSI case, don't walk away from children. Your local pro bono program should have no problem finding another type of case where you can make a big difference in a little kid's life.

M. Lee Witte, Executive Director
Chicago Volunteer Legal Services
Foundation

# THE CHAIN REACTION

AGENTS OF CHANGE
1416 - 33rd Avenue South
Seattle WA 98144
(206) 323-2040 (VOICE/FAX) Ktdolan@seanet.com

CHANGE AGENTRY - EMPOWERMENT - ENLIGHTENMENT

Senator Chaffee Hearing
SSI and Needy Blind and Disabled Children
July 7, 1998 2:00 p.m.

## TESTIMONY

My name is Katie Dolan. I live in Seattle Washington where I direct this national organization of all volunteer citizen advocates who serve in behalf of children and adults with developmental disabilities. I am the former director of the Washington State Protection & Advocacy Agency (1972 - 1986), commonly called The Troubleshooters. I have served on the National Developmental Disabilities Advisory Council, a consultant to both the Congressional Epilepsy Commission, and the Region X Social Security Administration, and am a founder of the Washington State chapter of the Autism Society of America.

In 1972, two years before SSI started, regional federal officials gave me a 3 year federal grant of $12,000 annually, to help bring families of children and adults with disabilities on to state benefits in preparation for being grandfathered on to SSI in 1974. We, subsequently, advised SSA on disability family issues.

We found families often so protective of their children with disabilities, as to be unable to verify the severity of the child's functional handicap. We had to hold "disability parties", where we made the parents stay in the kitchen fixing potluck luncheons, while Social Security Officials filled out application forms in order to "make" the child eligible. Many of the children had severe disabilities, but their parents refused to admit it! And we found that families of children with mild disabilities would fight to the death to deny their child's handicap!

The cardinal rule we taught all of our advocates:

NEVER LET A GRANDPARENT APPLY FOR SSI FOR A CHILD WITH A DISABILITY

Grandparents always believe their grand child is perfect!

I know our families, and when in the last years, I began seeing identical news accounts in newspapers and tabloid press, stating parents were 'coaching' their children to pretend to be disabled in order to get "dumb checks", I knew that was not true. No parents ever coached their child to be retarded.

- Poor families are already receiving public assistance checks from the state welfare program. Not one poor family with a child who has a disability knows how much more money they would get if their child receives SSI vs the state welfare money. Most don't even know what SSI is! Only when their caseworkers tell them to sign up their child for SSI, do they even try for it.

- SSA contracted doctors establish a child's medical eligibility, using current examinations, as well as, medical and educational records of history. Parents "teaching" their child to "pretend" to be retarded, would have nothing to do with the final establishment of medical eligibility.

- A major concern, and the most cruel, is the denial of babies with birth defects diagnosed upon birth. Since the late 70's, SSA, has been trying to say that there is no such thing as a "disabled" baby, because no baby can care for itself, feed itself, support itself; SSA used the criteria for adults to establish eligibility. Parents or agents certainly are not training babies to "pretend" to be disabled. Case after case against SSA has been won in courts throughout the country over these policies of exclusion of babies and children. Yet, SSA continues to make more restrictive rules and regs of eligibility, making up lies of cheating to justify their own cruel policies.

- Earlier in 1998, a report of an intensive study found not one case where a family had coached its child to "pretend" to be disabled. The totally manufactured data supporting this charge against poor families came out of the SSA and has been innocently accepted by some Congress members.

- Recently some states in anticipation of "welfare reform", have applied en masse for SSI for their children with unmeasurable, but mild mental retardation and learning disabilities. Many have been receiving SSI and now are being threatened with expulsion from the rolls. This is an argument between the states and SSA and should be settled at the federal level without the propaganda used by SSA to stigmatize receiving SSI. These children need support, because their mild disabilities constitute lifelong handicaps, if not treated early.

*Since the '70's, there has been a plan that the feds would, slowly but surely, take over public assistance to children and adults with disabilities on the 100% federally funded SSI program. Then the states would pick up all of the people who were poor and their children on Aid to Families with Dependent Children (AFDC), and General Assistance Unemployable, (GAU), presently 50-50 state/federal funds, but slated to be an all-state funded/regulated program.*

*Cities and municipalities have a large stake in these federal/state agreements on SSI. SSI is the fastest form of "revenue sharing" ever invented by government. Harvard University social scientist, Charles Morris pointed this out with his comment that "on the first of every month that 100% federally backed SSI check goes fast into the local economy". Somehow the recipients never receive a thank you, nor even an acknowledgement, for what they bring to their city and state. Instead they are maligned by the SSA, demeaned and even criminalized, for receiving their eligible benefits.*

*This misinformation and propaganda sent out by our formerly most revered, respected and most efficient Social Security Administration, has become the shame of America. To disallow benefits and therefore Medicaid to little babies and children with genetic disabilities, suffering illnesses and injuries, is shocking and may not be tolerated.*

*Citizens of the United States, the most generous and compassionate people in the world, do not want their country's policies to hurt children with disabilities, nor their families. Therefore, SSA has had to resort to the practice of misinformation, and propaganda against needy families who have children with disabilities. It is not a partisan issue, because it has gone on through a variety of administrations. However, it has now culminated in so vicious an attack against the most vulnerable of our society, it borders on genocide.*

*Respectfully submitted on July 6, 1998*

*Post Testimony: I would have dropped everything to come to Washington, D.C. at my own expense in order to testify. Unfortunately, the date and time of the hearing (July 7th at 2:00 p.m.), was unavailable from my Congressional delegation until 9:00 a.m. on July 6th, though I had requested the information on June 26th after reading of the Chaffee hearing in the newspaper.*

United States General Accounting Office

**GAO**

Testimony

**Before the Subcommittee on Social Security and Family Policy, Committee on Finance, U.S. Senate**

**For Release on Delivery**
**Expected at 2:00 p.m.**
**Tuesday, July 7, 1998**

# SUPPLEMENTAL SECURITY INCOME

# SSA Needs a Uniform Standard for Assessing Childhood Disability

**Statement for the Record by Cynthia M. Fagnoni,**
**Director, Income Security Issues**
**Health, Education, and Human Services Division**

Mr. Chairman and Members of the Subcommittee:

I am pleased to provide this statement for the record in which we discuss the Social Security Administration's (SSA) implementation of the new eligibility criteria for childhood disability benefits under the Supplemental Security Income (SSI) program. In 1997, almost 900,000 children younger than 18 received about $5 billion in SSI benefits. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193), commonly referred to as welfare reform, made eligibility for childhood SSI benefits more restrictive.[1] In February 1997, the Social Security Administration (SSA) published regulations to implement the new definition of disability for the SSI children's program set forth in the welfare reform law. Under the more restrictive standard, a child's impairment generally must result in marked limitations in two areas of functioning or an extreme limitation in one area. Previously, a child could be found eligible if his or her impairment resulted in one marked and one moderate limitation or three moderate limitations.

In September 1997, we reported that SSA's regulations establishing a new severity standard are consistent with the law and are well supported.[2] Since then, we have been monitoring SSA's adjudication of cases under the new regulations for 288,000 children whose eligibility was subject to review against the new standard as well as for about 370,000 new applicants. In May 1998, we reported to the Chairman of the Subcommittee on Human Resources, House Ways and Means Committee, our early findings regarding SSA's implementation of the new standard.[3] This statement summarizes and updates the report's findings. (See the list of related products on children receiving SSI disability benefits at the end of this statement.)

In summary, SSA has made considerable progress in implementing the welfare reform changes in eligibility for SSI children. It has taken important steps to safeguard fairness by identifying children whose benefits may have been terminated inappropriately and establishing remedial action to rereview their cases. However, because SSA's medical listings reflect multiple levels of severity, SSA also needs to expedite updating and modifying its medical listings to ensure that all children are

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[1] Sec. 232 of P.L. 104-193 mandates that we report to the Congress by January 1, 1999, on (1) the effect of the legislative changes on the SSI program and (2) the extra expenses incurred by families of children receiving SSI who are not covered by other public programs. This statement is based on our work to date under the first mandated study.

[2] Supplemental Security Income: Review of SSA Regulations Governing Children's Eligibility for the Program (GAO/HEHS-97-220R, Sept. 16, 1997).

[3] Supplemental Security Income: SSA Needs a Uniform Standard for Assessing Childhood Disability (GAO/HEHS-98-123, May 6, 1998).

assessed against a uniform severity standard. The need to revise the listings is a long-standing problem that we reported 3 years ago. Moreover, SSA needs to take concerted action to follow through on its plan for monitoring and continually improving the quality of decisions regarding children. Consistent with our legislative mandate, we will continue to focus our work on SSA's efforts to provide reasonable assurance that it can administer the program consistently and improve the accuracy of childhood disability decisions.

## BACKGROUND

The Congress made the eligibility criteria for children to receive SSI more restrictive in order to help ensure that only needy children with severe disabilities are eligible for benefits. From the end of 1989 through 1996, the number of children younger than 18 receiving SSI had more than tripled, from 265,000 to 955,000. This growth occurred after SSA initiated outreach efforts and issued two sets of regulations that made the eligibility criteria for children less restrictive, particularly for children with mental impairments.[4]

One regulatory change, issued in December 1990, revised and expanded SSA's medical listings for childhood mental impairments by adding such impairments as attention deficit hyperactivity disorder and incorporating functional criteria into the listings. Examples of such functional criteria include standards for assessing a child's social skills; cognition and communication skills; and the ability to concentrate, keep pace, and persist at tasks at hand. The medical listings are regulations containing examples of medical conditions, including both physical and mental impairments, 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--medical signs and symptoms and laboratory findings--of the listing. Since the listings cannot include every possible impairment or combination of impairments a person can have, SSA's rules also provide that an impairment or combination of impairments can "equal" or be "equivalent to" the severity of a listing. There are separate listings for adults and children. The childhood listings are used first in evaluating childhood claims. If the child's impairment does not meet or equal the severity of a childhood listing, the adult listings are considered.

The second regulatory change, issued in February 1991 in response to the Sullivan v. Zebley Supreme Court decision, added two new bases for finding children eligible for benefits, both of which required an assessment of a child's ability to function: functional equivalence, which was set at "listing level" severity, and an individualized functional assessment (IFA), which was set at a lower threshold of severity.

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

Functional equivalence is based on the principle that it is the functional limitations resulting from an impairment that make the child disabled, regardless of the particular medical cause. It was added as a basis for eligibility in response to the Supreme Court's determination in the Zebley case that SSA's medical listing of impairments–which had been the only basis for eligibility–was incomplete. Under functional equivalence, a child could be found eligible for benefits if the child's impairment limited his or her functional ability to the same degree as described in a listed impairment. Functional equivalence is particularly appropriate for assessing children with combinations of physical and mental impairments.

The IFA allowed children whose impairments were less severe than listing level to be found eligible if their impairments were severe enough to substantially limit their ability to act and behave in age-appropriate ways. A child was generally found eligible under the IFA if his or her impairment resulted in moderate functional limitations in three areas of functioning or a marked limitation in one area and a moderate limitation in another area.[5]

In 1995, we reported that the subjectivity of the IFA called into question SSA's ability to ensure reasonable consistency in administering the SSI program, particularly for children with behavioral and learning disorders. We suggested that the Congress consider eliminating the IFA and directing SSA to revise its medical listings.[6]

## WELFARE REFORM RESTRICTS CHILDHOOD ELIGIBILITY FOR SSI BENEFITS

Several welfare reform provisions enacted in August 1996 made the eligibility criteria for disabled children more restrictive: (1) childhood disability was redefined from an impairment comparable to one that would prevent an adult from working to an impairment that results in "marked and severe functional limitations," (2) the IFA was eliminated as a basis for determining eligibility for children, and (3) maladaptive behavior was removed from consideration when assessing a child's personal or behavioral functioning. Thus, such behavior would be considered only once–in the assessment of that child's social functioning–when determining whether the child had

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[5] Under the IFA, areas of functioning were assessed on the basis of children's ages. Social, communication, cognition, and motor skills were assessed for children of all ages. Responsiveness to stimuli was assessed in children under age 1; personal and behavioral skills were assessed for children aged 1 and older; the ability to concentrate, persist at tasks at hand, and keep pace was assessed for children aged 3 and older.

[6] Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995.)

a mental impairment severe enough to meet or equal the medical listings. The law also required SSA to redetermine the eligibility of children on the rolls who might not meet the new eligibility criteria because they received benefits on the basis of the IFA or maladaptive behavior.

### Fewer Children Are Affected by the Law Than Was Earlier Estimated

Earlier legislative proposals under consideration in 1995 might have removed from the rolls as few as 45,000 to as many as 190,000 children, according to Congressional Budget Office (CBO) estimates. After the welfare reform legislation was enacted in August 1996 but before SSA issued its regulations, CBO estimated that about 170,000 children on the rolls would no longer be eligible for benefits. After SSA issued its regulations in February 1997, CBO and SSA estimates of children who would be removed from the rolls were very close–131,000 and 135,000, respectively.

SSA identified 288,000 children as potentially affected by the changes in the eligibility criteria because they had been awarded benefits on the basis of the IFA or maladaptive behavior. Through February 28, 1998, SSA reviewed the eligibility of 272,232 of the 288,000 children. Of these, 139,693 (51.3 percent) were found eligible to continue to receive benefits and 132,539 (48.7 percent) were found ineligible. Because the number of children deemed ineligible does not yet reflect the results of all appeals, we do not yet know the final outcome on all these cases. Children initially deemed by a disability determination service to be ineligible have 60 days to request reconsideration of their case. If they continue to receive an unfavorable result, they can appeal to an SSA administrative law judge and, finally, to federal court. Recipients can elect to continue receiving benefit payments during the appeal process. Factoring in appeals and experience in conducting redeterminations so far, SSA now estimates that 100,000 children will be removed from the rolls as a result of the redeterminations.

### SSA's Review Identified Implementation Problems and Initiated Corrective Actions

In December 1997, SSA issued a report on its "top-to-bottom" review of the implementation of the new regulations to address concerns that children may have had their benefits terminated unfairly.[7] SSA found problems with the adjudication of claims for which mental retardation was the primary impairment as well as potential procedural weaknesses relating to notification of appeal rights and termination of

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[7] For more information, see SSA, Social Security: Review of SSA's Implementation of the New SSI Childhood Disability Legislation (Baltimore, Md.: 1997).

benefits for failure to cooperate with SSA requests for information needed to redetermine eligibility.

To remedy these problems, SSA decided to rereview all children whose benefits were terminated or denied on the basis of mental retardation. SSA conducted training in March 1998 to clarify how these claims should be adjudicated. Also, all cases terminated because families did not cooperate with SSA in processing the claim, such as by failing to provide requested medical information or to take the child for a consultative examination, will be rereviewed. SSA found that in two-thirds of these terminations, all the required contacts had not been made or had not been documented in the file. Finally, families of children whose benefits were terminated but did not appeal are being given an additional 60-day period in which to appeal their terminations. Notices of this right as well as the right to continue to receive benefits while the appeal is pending were sent out in February 1998.

## REGULATIONS GENERALLY SET SEVERITY AT TWO MARKED OR ONE EXTREME LIMITATION

To implement the new law, SSA issued interim final regulations establishing a new severity standard in February 1997, which we found to be consistent with the law.[8] The regulations define an impairment that results in "marked and severe functional limitations" as one that meets or medically or functionally equals one of SSA's medical listings.[9] For a child to be determined eligible for benefits under this new and stricter standard of severity, the child's impairment must generally result in marked functional limitations in two areas of functioning or an extreme limitation in one area. SSA also eliminated the IFA and removed the duplicate consideration of maladaptive behavior from the mental disorders listings.

In developing its regulations, SSA concluded that the Congress meant to establish a stricter standard of severity than "one marked, one moderate" limitation, for several reasons. The Congress eliminated the "comparable severity" standard of disability and

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

[9] Previously, the IFA afforded children whose impairments were not severe enough to meet or equal SSA's listings an additional basis on which to qualify for benefits. The IFA, which was set at a lower severity standard than the listings, was analogous to the test of residual functional capacity for adults whose impairments are not of listing level severity. Now, unlike adults, children can qualify only under the listings.

the IFA, which was created for evaluating impairments less severe than those in the medical listings. A "one marked, one moderate" standard of severity would have retained one of the standards under which children were found eligible under the IFA, which SSA stated would violate the law. Finally, SSA interpreted the conference report to mean that the Congress intended the listings to be the last step in the disability determination process for children.

### Some Children With Less Severe Disabilities Still Receive Benefits

Although SSA articulated the "two marked or one extreme" severity standard in its regulations, it did not modify its existing listings to specifically incorporate functional criteria that would reflect both the new definition of childhood disability and advances in medicine and science. For example, because of advances in treatment, some impairments no longer have as severe an effect on a child's ability to function as they once did. As a result, some listings are set below the "two marked or one extreme" threshold of severity, and cases are being adjudicated at this less severe level as well as at the "two marked or one extreme" severity level.

SSA has identified 28 listings that are most likely to enable children whose impairments result in fewer than two marked functional limitations or one extreme functional limitation to be awarded benefits. Twenty-one of the 28 listings have not been revised since March 1977. Our review shows that such less severe listings can serve as the basis for awards even though SSA rejected the "one marked, one moderate" level of severity in interpreting the "marked and severe" functional limitations required by the welfare reform law. Children who meet or medically equal these less severe listings qualify for benefits under the regulations. At the same time, SSA told us that the regulations prohibit the less severe listings from being used to determine functional equivalence. In March 1997, SSA stated that it planned to issue a Social Security ruling to clarify that only listings at the "two marked or one extreme" level were to be used in determining functional equivalence, but SSA has not yet issued such a ruling. In the absence of such clarification, some adjudicators may be using less severe listings in making functional equivalence determinations. Reviewers in SSA's Office of Program and Integrity Reviews have told us, however, that they would consider this an error.

SSA has not identified how many children may have been awarded benefits on the basis of these less severe listings. SSA told us that unreliable coding of the listings used to determine eligibility makes it difficult to quantify the extent of this problem. We do know, however, that some of the listings below the "two marked or one extreme" threshold are for prevalent impairments, including two of six listings for the most common impairment--mental retardation--and three listings for cerebral palsy, one for epilepsy, and one for asthma. Other listings below the "two marked or one extreme" threshold include one listing for juvenile rheumatoid arthritis, one for juvenile diabetes, and two for diabetes insipidus. As of June 1998, SSA had not established a schedule for updating and modifying its listings.

## SSA IS TAKING STEPS TO IMPROVE THE QUALITY OF DECISIONS ON CHILDREN

SSA's quality assurance statistics on childhood cases show uneven accuracy rates across the states. Although nationally the accuracy rate for decisions on new childhood cases and redeterminations exceeds SSA's standard of 90.6 percent, many states fall below the standard. Specifically, for decisions made on new childhood cases from June 1997 through February 1998, 5 states fell below the 90.6-percent accuracy standard for awards, and 9 states fell below the standard for denials. For redeterminations, 10 states fell below the standard for continuances, and 10 states fell below the standard for cessations. Most of the errors have been in the documentation; that is, there was some deficiency in the evidence that formed the basis for the determination. In these cases, proper documentation of the case could substantiate or reverse the decision.

Given the significant changes in adjudicating cases on the basis of the new regulations, these statistics are not surprising. Moreover, childhood cases historically have been among the more difficult cases to adjudicate. We would expect SSA to be monitoring the decisions; identifying areas of difficulty for adjudicators; and providing additional clarification, guidance, and training to improve the accuracy of decisions. In fact, this is exactly what SSA has been doing, although its training schedule was delayed slightly.

Further, on February 18, 1998, SSA issued a memorandum detailing a new quality review plan for childhood disability cases to ensure correct and consistent application of the new regulations. The plan includes special initiatives to ensure the quality of cases readjudicated in response to the top-to-bottom review, as well as initiatives to improve SSA's ongoing quality assurance reviews on childhood cases. For the first time, SSA will be drawing separate samples of new childhood claims and continuing disability reviews. This should allow SSA to provide more timely feedback and policy clarifications on the problems unique to adjudication of childhood claims. SSA also will be measuring the performance of its quality reviewers to ensure that they are accurately and consistently identifying errors. Under this effort, SSA plans to increase its sample of reviewed cases from 1,600 to 6,000 annually.

## CONCLUSIONS

SSA has made substantial progress in implementing the new childhood definition of disability through its rapid redetermination of most of these cases, its action to ensure that the redetermination process is fair, and its ongoing review of the implementation of the new regulations. However, we remain concerned about how accurately and consistently the disability determination process is working for children. Specifically, because some of SSA's listings of impairments require less than "two marked or one extreme" limitation to qualify for benefits, SSA adjudicators are not assessing all children against a uniform severity standard. This is because SSA has neither updated its listings to reflect advances in medicine and science nor modified them to reflect a single standard of severity, despite its authority to do so. Moreover, we noted the need to revise the listings 3 years ago. SSA also needs to continue its efforts to improve decisionmaking for childhood cases to better ensure that adjudicators apply the new eligibility criteria accurately and consistently.

In view of the fact that many of SSA's medical listings for children are outdated and allow eligibility to be based upon multiple standards of severity, our May 1998 report recommended that the Commissioner act immediately to update and modify its medical listings to incorporate advances in medicine and science and to reflect a uniform standard of severity. In its comments on our report, SSA officials agreed that SSA should periodically update its listings and stated that it is developing a schedule to accomplish this. The agency stated that it must consult with medical experts to ensure that the listings reflect state-of-the-art medical practice and estimates that it will take several years to complete the revision. However, the agency did not address the need for the listings to reflect a uniform severity standard.

We will continue to monitor SSA's implementation of the new eligibility criteria, including the agency's actions to update its medical listings for children, as part of our mandate to report to the Congress by 1999 on the impact of the changes to the SSI program enacted by welfare reform. As part of that effort, we are monitoring what SSA is doing to ensure the accuracy and consistency of childhood disability decisions made under the new eligibility criteria.

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Please contact me on (202) 512-7215 if you have questions about the information presented in this statement.

## RELATED GAO PRODUCTS

Supplemental Security Income: SSA Needs a Uniform Standard for Assessing Childhood Disability (GAO/HEHS-98-123, May 6, 1998).

SSA's Management Challenges: Strong Leadership Needed to Turn Plans Into Timely, Meaningful Action (GAO/T-HEHS-98-113, Mar. 12, 1998).

Supplemental Security Income: Review of SSA Regulations Governing Children's Eligibility for the Program (GAO/HEHS-97-220R, Sept. 16, 1997).

Children Receiving SSI by State (GAO/HEHS-96-144R, May 15, 1996).

SSA Initiatives to Identify Coaching (GAO/HEHS-96-96R, Mar. 5, 1996).

Supplemental Security Income: Growth and Changes in Recipient Population Call for Reexamining Program (GAO/HEHS-95-137, July 7, 1995).

Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995).

Social Security: Federal Disability Programs Face Major Issues (GAO/T-HEHS-95-97, Mar. 2, 1995).

Supplemental Security Income: Recent Growth in the Rolls Raises Fundamental Program Concerns (GAO/T-HEHS-95-67, Jan. 27, 1995).

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

(207041)

# Statement submitted for the Record
# for the U.S. Senate Finance Committee
# Social Security and Family Policy Subcommittee
# Hearing on Children's SSI Program
# Held on July 7, 1998

Submitted by
Judge David L. Bazelon Center for Mental Health Law
1101 Fifteenth Street NW, Suite 1212
Washington, DC 20005

The Judge David L. Bazelon Center for Mental Health Law, a legal advocacy organization representing people with mental disabilities, submits this statement for the record about the children's SSI program. We commend the Social Security and Family Policy Subcommittee for holding this hearing to review the status of the implementation of the interim final regulations for the children's Supplemental Security Income (SSI) program. The publication of these regulations in February 1997 has had a significant impact on the program.

The Bazelon Center has a long history of advocating on behalf of children with mental and emotional disabilities who are eligible for SSI. The Center worked with the Social Security Administration (SSA) to revise and improve the childhood mental impairment regulations that were issued in 1990 and participated in the agency's effort to develop new children's rules after the U.S. Supreme Court Zebley decision. Most recently, the Center worked to ensure that the program continue to provide cash assistance to families who want to raise their children with significant disabilities at home.

We submit this testimony to address three major areas of concern: the interim final regulations; decreased program applications; and proposals to change SSI disability rules.

## I. Interim Final Regulations

We believe that the interim final regulations for the children's SSI program establish an eligibility standard that is more severe than that required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193). We believe that the new statutory definition of childhood disability gives SSA the flexibility to establish a standard that will protect more children, especially those who have behavioral and emotional disabilities.

The very high standard of disability in the regulations requires marked limitations in two areas and will limit eligibility among children who have severe disabilities -- many of them with mental impairments -- causing great hardship to them and their families. We understand that the childhood SSI amendments were enacted, in part, because of concerns about alleged fraud among a small group of beneficiaries. However, we believe that raising the eligibility standard goes far beyond the goal of ending program abuse and causes families and children with legitimate needs for assistance to be denied benefits. We have urged the agency to leave the door open to adjust the regulations as needed to meet changing knowledge about childhood disability.

The new statutory language requires that a child have impairments resulting in "marked and severe functional limitations"-- the first time that the Social Security statute recognizes the importance of functional assessments for children. However, despite strong legislative history to the contrary, SSA adopted a very high standard of childhood disability which has already resulted in denial of benefits to over 100,000 children with severe disabilities and their families. The impact of these changes punishes children and their families and we believe, ignores the seriousness of their physical and mental limitations.

Senators Dole (R-KS), Chafee (R-RI) and Conrad (D-ND) discussed the legislative intent of the 1996 amendments in a colloquy on the Senate floor during debate on the Senate bill. Later, prior to publication of the new childhood regulations, Senators Chafee, Conrad, Daschle (D-SD), Cohen (R-ME), Moseley-Braun (D-IL) and Harkin expressed concern about the new standard in letters to President Clinton. Last month, a group of Senators expressed concern to Commissioner Apfel about SSA's strict interpretation of the new definition because "...some of us firmly believe that the 1996 statutory changes in the children's SSI program do not require a "two-marked" standard..." (6/24/98 letter from Senators Conrad, Chafee, Jeffords (R-VT), DeWine (R-OH), Rockefeller (D-WV), Kennedy (D-MA), Dodd (D-CT), Lautenberg (D-NJ), Moynihan (D-NY), Kerrey (D-NE), Baucus (D-MT), Harkin, Wellstone (D-MN), Breaux (D-LA) and Daschle.

We concur with these Senators that SSA has room to develop a new approach to functional assessment and authority to tighten the eligibility criteria without causing denial of benefits to children with severe mental impairments. The new definition did not require SSA to establish a "listings level" standard for the childhood disability program. Since the critical statutory language was the result of intensive Senate negotiations and the conference committee had rejected the House "listings" approach, the interpretations in the Senate should carry weight. There is clearly flexibility within the statutory definition for agency interpretation and there are other possible interpretations of the conference report language upon which SSA so heavily relies. We believe that the Senators' interpretations of Senate action allows the acceptability of a standard which would include children who have one marked and one moderate impairment.

II. Children's SSI Enrollment and Applications

SSA was required by law to review certain children's cases under the interim final regulations to determine if they still qualify for benefits under the new eligibility standard. SSA data from May 30, 1998 shows that 245,349 of the redeterminations are completed or almost 93% of the 264,342 mandated case reviews. Among these reviews, 147,575 children have lost benefits while 97,774 continue to qualify -- this represents a 60.1% termination rate and a 39.9% allowance rate. We are especially concerned about the impact of the new standard because children with mental disorders or mental retardation represent 82% of those who have lost benefits (121,440 children).

We are also concerned that at the first stage of the appeal process (known as reconsideration), there is a 41% reversal rate of cases that were denied after the redetermination under the new standard. Historically, the reversal rate at this stage of the appeals process is only about 10-15%. Given the high rate of reversal, we believe there is cause for concern about how the interim final regulations are being applied by the state disability adjudicators.

A second group required to have redeterminations as a result of the program changes are young people turning 18 years old. As of May 30, 1998 there were 61,402 young people in this age category whose eligibility was reviewed and over half no longer qualify for benefits -- the cessation rate for this group is 56.7% (34,803 individuals). In this age category, among those losing benefits, almost 73% have mental impairments (25,403 individuals). At the first stage of the appeal process, there is a 34.5% reversal rate of cases that were initially denied.

The top-to-bottom review of the children's SSI program requested by SSA Commissioner Apfel indicated that there were concerns about how families were notified about their appeal rights and told about their right to request benefits pending appeal of the benefit termination. Consequently, new notices were sent in February 1998 to 78,000 children giving them a second opportunity to appeal their benefit termination or to request benefits pending appeal. Families had 60 days to make these requests and SSA reports that appeals were filed in 70.5% (102,451) of the 145,408 cases where children were given the second chance to appeal and benefit continuation was requested in 67.3% of these cases (68,968 of 102,451).

Although there has been far more attention paid to the redeterminations, there is reason to be equally concerned about the allowance rate among new childhood claims. For the time period beginning in August 1996, the national allowance rate is only 34% which is significantly lower than it was when the standard was only based upon medical evidence. In 1989, prior to the Zebley decision, the allowance rate was 42.8%when the eligibility standard was more restrictive than the standard now used. Equally alarming is the declining number of initial determinations: in FY 1996 there were about 459,000 initial decisions and in FY 1997, it had dropped to 356,000. We believe that the number of initial decisions is dropping so significantly because far fewer families are applying for benefits which, if their children meet the strict eligibility criteria, remain a legal entitlement. We fear that as in the pre-Zebley days, families are not applying because they believe that so few children will qualify for benefits.

## III. Proposed Changes in SSI Disability Program

We recognize that there are still concerns about possible fraud and abuse in federal disability programs. However, we urge caution before any further statutory or regulatory changes are made. Before making further significant changes, there must be clear evidence that fraud is, in fact, evident or that the program is subject to abuse. The SSI program serves a large number of adults and children and has complex rules and regulations to guide disability adjudicators who must make extremely difficult decisions about who may qualify for benefits. Errors do occur; many of them caused by SSA itself, which is slow to enter new information into its computer systems.

We are deeply troubled by new proposals circulating on the House side that would amend the SSI program further. We are especially concerned about proposals that would (1) require all disability determinations to be based only on medical evidence, (2) give greater weight to consultative examiners, (3) to reduce benefits for individuals living in the same household, and (4) adjust the listings to require proof of two marked limitations for each qualifying condition.

We oppose the proposal to limit the evidence used to determine disability to only medical evidence because it would have a disproportionate impact on adults and children who have mental and emotional impairments. Making a determination about who qualifies for benefits should be based on the most comprehensive evidence possible to ensure that accurate decisions are made. Medical evidence alone is insufficient for an accurate decision.

Evidence of individual functioning is a key component of disability assessment for both adults and children with mental impairments because the medical evidence is not generally decisive or even the most important. Functional evidence, collected from various sources, is critical to making accurate decisions about who qualifies for disability benefits. Congress itself has repeatedly recognized this fact, most recently when it changed the definition of childhood disability to include individuals who have "a medically determinable physical or mental impairment, which results in marked and severe functional limitations." (42 U.S.C. 1382(a)(3)(C)(i) as amended by Pub. L. No. 104-193, S.211(a)).

We also strongly oppose any change to give greater weight to the evidence obtained from consultative examinations. A recent report from SSA's Office of Inspector General highlighted several problems with the consultative examination process and called it a primary area of "vulnerability in the SSI disability review process." A consultative examiner may see the individual for as little as half an hour or even a few minutes while a treating physician may have documented the individual's medical history and disability for years.

Proposals designed to reduce benefits for individuals on SSI who live with another person are extremely cruel. Such proposals may include children or adults in group homes or adults living together to conserve resources and improve their quality of life as they survive on what is a less-than-poverty level benefit. It is ironic that such a proposal should surface in the same year that a new tax break for higher income Americans is proposed to eliminate the marriage penalty. In SSI, on the other hand, the House is considering extending the marriage penalty to anyone who shares an apartment or other living arrangement with another person.

The proposal to adjust medical listings to require evidence of "two marked" limitations for each of the listings would be a harsh ratcheting up of the standard for both children and adults with certain impairments, including mental retardation. As stated above, we agree with the Senators who have stated that the 1996 amendments did not establish a standard that requires proof of two marked limitations for children and we do not believe this approach should be adopted now.

The Bazelon Center appreciates the opportunity to submit this statement for the record and commends the Subcommittee for taking a further, careful look at the operation of the SSI program for children.

# *Statement*
# *of the*
# *National Association of Disability Examiners*
# *to the*
# *Senate Finance Committee*
# *Subcommittee on Social Security and Family Policy*
# *by*
# *Debi Gardiner*
# *NADE President*
# *July 7, 1998*

Chairman Chafee and members of the Subcommittee, thank you for providing NADE this opportunity to present testimony. The problems being addressed at this hearing are important to our members. The solutions will have a significant impact on our country's future.

NADE is a professional association whose membership includes disability examiners, physicians, support staff and administrators who are employed in the state Disability Determination Service (DDS) agencies. The DDSs have responsibility for adjudicating Social Security and Supplemental Security Income (SSI) disability claims. Our membership also includes physicians, psychologists and other professionals not in the DDSs (including federal employees) who work with and are interested in the disability program. We believe the diversity of our membership and our experience in working directly with the disability program --and with the applicant --provides us with a unique understanding of this program. It is our members who are responsible for making the system work efficiently and effectively, serving both the claimant / beneficiary and the taxpaying public.

On several occasions, in previous testimonies and in correspondence with the Social Security Administration, NADE has expressed concern that the SSI program for children with disabilities may not necessarily be serving the best interests of these children. (Our January 1995 Position Paper on this subject is attached.) Children with disabilities represent some of the most vulnerable members of our society. They need, and deserve, assistance beyond that needed by the general public. NADE strongly supports actions taken by Congress in providing assistance to these children and their families. *Any such assistance, however, must serve the best interests of the individuals involved.* We are concerned that many children were being labeled "disabled" and were receiving checks who did not have a severe impairment. We have expressed concern that this practice may actually be harming the very population it was intended to help.

NADE strongly supported those provisions in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) which established a new and stricter definition of disability for children and which required the representative payee to present evidence that the child is, and has been, receiving appropriate treatment. Many children were awarded benefits as a result of the less restrictive standard of eligibility created by the 1990 Zebley Supreme Court decision. Congress wisely tightened that standard in the 1996 legislation. As a result, approximately 288,000 children who were receiving benefits had their claims reviewed to determine if they continued to meet the new standard. We supported the redetermination process as an effort to insure the integrity of the disability program.

The PRWORA was signed by the President on August 22, 1996 and the reviews were to be completed by August 22, 1997. Unfortunately, instructions for these redeterminations were delayed until February 1997. At that time DDSs throughout the country were hit with a tidal wave of childhood claims with only a six month window in which to complete the reviews. These cases were given top priority and the DDSs worked overtime to complete the reviews as quickly and as accurately as possible. Our efforts were hampered by the fact that training, instructions and notices were often received in a piecemeal fashion. When it became clear that the DDSs could not complete the redeterminations within the mandated timeframe, SSA requested a six month extension. This was granted and the DDSs were given until February 1998 ~~to~~ complete the redeterminations.

Advocates have been critical of the redetermination process. News articles and other public statements have often conveyed the impression that this workload was completed in a hasty manner with emphasis on meeting mandated timeframes at the expense of accuracy, and that severely disabled children lost benefits without due process or appropriate evaluation. NADE disagrees. The efforts of the DDSs to process this workload in a timely *and accurate* manner, despite the challenges they faced in doing so, were recognized by Commissioner Apfel following his "top to bottom" review and by the General Accounting Office.

NADE is committed to the goal that disabled individuals, *children and adults*, should receive fair and timely decisions on their claims for disability benefits. At the same time, we will continue our efforts to insure the integrity of the disability program.

Anecdotal evidence suggests that many of the children whose claims were reviewed were not receiving appropriate treatment. In the absence of treating source evidence we must rely on purchased consultative examinations. These appointments, scheduled by the DDS, were frequently not kept and often several appointments were missed. At the appeals level Hearing Officers report similar experience with missed appointments and instances of lack of cooperation from parents and guardians.

While we do not believe there were widespread errors or significant problems with the initial redetermination process, we do agree with Commissioner Apfel that actions above and beyond those normally taken are appropriate to ensure that children with disabilities receive a fair and accurate decision. However, while we supported taking a second look at some of these claims we found the instructions for processing these to be unclear, sometimes contradictory and often unrealistic. Resources --including appropriate staff, clear and timely instructions, and a meaningful Quality Review process --are essential to the success not only of the redetermination process but of the disability program as a whole.

Children are our future. They should not be political pawns. Congress and the Social Security Administration must take whatever actions are necessary to insure that the SSI childhood program is administered fairly and appropriately. While NADE believes that severely disabled children should receive benefits we are concerned that some children may not be encouraged to reach their full potential because they have been labeled "disabled." Such disincentives serve neither society nor the individual.

Again, thank you for allowing us this opportunity to present testimony.

# *Position Paper of the National Association of Disability Examiners on the SSI Program for Children with Disabilities*

MEMBERS OF THE NATIONAL ASSOCIATION of Disability Examiners (NADE) share the growing public concern that the current SSI program for children with disabilities program may not be serving childrens' best interest. We concur with the findings reported by the office of Inspector General in the October 1994 report: "Concerns about the participation of children with disabilities in the Supplemental Security Income program." We commend the initiative to establish a commission on childhood disability to conduct a "comprehensive, cross cutting policy examination of all programs affecting children with Disabilities and their families." We strongly believe that NADE, representing the front line workers in the Nation's largest disability program for children, should be represented on that commission.

Children with disabilities represent some of the most vulnerable members of our society. Whether or not there is evidence of widespread fraud and abuse in the current SSI Childhood Disability Program no substantial evidence exists to support the conclusion that granting unrestricted cash benefits provides children with means—or incentives—to grow and develop, to become independent, and ultimately, to become productive members of society.

Children with disabilities and their families need and deserve assistance beyond that needed by the general public. To accomplish that we believe the childhood disability program must be refocused—moving away from cash benefits to increased access to services and medical care and, when appropriate, financial assistance to provide for caretaker services.

Unrestricted, unmonitored cash benefits unrelated to the identification of any financial need created by the disability, are not conducive to maximizing the child's growth and development and may, in fact, be counterproductive. If cash benefits are retained, SSA must be given the tools and personnel to strengthen their current monitoring system to assure that funds are being used to provide appropriate treatment and services. And, at the very least, the law and regulations must be changed to establish a family cap on benefits.

In order to insure the integrity of the program, continuing disability reviews (CDRs) must be conducted on a timely basis.

This cannot be done without adequate funds and personnel. Not to do so, however, may promote a lifelong dependence on disability payments for those whose conditions could have improved.

Accurate, well documented initial decisions are as important to program integrity as continuing disability reviews. These, in turn, require comprehensive, detailed and descriptive information from the medical and educational communities. NADE asks that SSA increase efforts (including pro
ing the tools, staffing and funding to
state Disability Determinations Servi
to educate the medical and educatio
communities regarding our spec
documentation requirements. We
ask that SSA facilitate retrieval of do
mentation from schools and teach
through such initiatives as establ
ment of a uniform national fee for in
mation from these sources.

NADE believes the current
childhood disability program must
changed if it is to truly serve the uni
needs of children with disabilities
their families and provide children w
opportunities for acquiring the life sk
necessary to become active participa
in society. To that end we request:

*NADE representation on the comm
sion on childhood disability

*the elimination of unrestricted c
benefits

*increased access to services and me
cal care for children with disabilit
and their families

*adequate funding and personnel
ensure that CDRs can be conducted
a timely basis

*increased efforts by SSA to educate
medical and educational communi
regarding our specific documentat
requirements and to establish appro
ate compensation for information p
vided.

# TESTIMONY OF

## DOUGLAS WILLMAN, PRESIDENT
## NATIONAL COUNCIL OF DISABILITY DETERMINATIONS DIRECTORS

## BEFORE THE SUBCOMMITTEE ON SOCIAL SECURITY AND FAMILY POLICY SENATE FINANCE COMMITTEE UNITED STATES SENATE

## REGARDING CHILDREN'S SSI POLICY

July 7, 1998

Mr. Chairman and members of the subcommittee, on behalf of the National Council of Disability Determinations Directors (NCDDD), thank you for the opportunity to appear here today to present our views regarding the process of redetermining the eligibility of some children for disability benefits. These redeterminations were required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996.

The NCDDD is a professional organization of the directors and other management staff of the state Disability Determination Services agencies. The DDSs participate in the disability program by making the initial determinations of eligibility for disability benefits.

I want to begin by observing that the DDSs are not policy making components in the disability program — that responsibility is reserved to the Social Security Administration. Our job is to apply the policies created by SSA at the field level to individual cases.

From this perspective, the following is the view of the NCDDD regarding the status of the eligibility redetermination process required by the welfare reform legislation.

- The legislation rescinded the previous definition of disability for children and replaced it with a more stringent standard. The intent of the legislation clearly was that fewer children would qualify for benefits than would have qualified under the previous standard.

- SSA established a regulation for implementing the congressional intent. In our view, the regulation comports reasonably with the statutory language.

- SSA provided instructions and training in the application of the new standard.

- DDSs were asked to apply the new standard to a large workload in a short period of time. While this was a major undertaking, DDSs recognized the importance of making correct decisions on these cases which involve some our country's most vulnerable citizens. Accordingly, DDSs devoted significant resources to assure the accurate completion of these cases.

- Likewise, SSA devoted substantial resources to the evaluation of the work completed by the DDSs. Overall, SSA's findings were that the great majority of cases were processed correctly — that is, in accordance with the new standard. The case reviews found that more than 93% of the cases in which recipients were determined not to be eligible under the new standard were done correctly. It is crucial to point out that this does not mean that 7% were done incorrectly. Many of the cases classified as errors were simply differences in interpretation between the original adjudicator and the reviewer as to the amount of evidence needed to support a decision. Many such cases already have been returned to the DDSs in order to resolve the differences by obtaining the additional evidence, but many times the decision does not change.

- Even though SSA found the great majority of redeterminations to comport with the SSA standard, we all acknowledged the unique importance of this particular group of cases. Accordingly, Commissioner Apfel initiated a special review of the redetermination process. DDS participants were included in this special review to a much larger extent than in the issuance of the original instructions. The review identified some areas of concern. These especially included cases involving mental retardation, some aspects of developing evidence, and the explanation of appeal rights. In order to reduce the likelihood that benefits to disabled children might have been incorrectly terminated, SSA implemented a series of remedies unique to this special caseload. These remedies include the reworking of some cases, the extension and expansion of appeal rights, the issuance of a new ruling on speech and cognitive impairments, additional training to DDS adjudicators, and policy clarifications.

- The fact that some cases are being reworked does not indicate a widespread misapplication of the new standard. Rather, it is the result of SSA's and DDSs' collective intent to take extra and unusual actions to assure that possible errors are identified and corrected. The reworking of these cases is going well in the DDSs, but too few cases have been completed to report meaningful results. The work of the DDSs will not be completed until the face to face hearings on appealed cases have been held. These hearings are labor intensive and time consuming. We hope that we will not be placed under processing time deadlines which could compromise the effectiveness of the hearings in reaching proper decisions.

- As a part of the Commissioner's special review, SSA has agreed with a DDS proposal to establish DDS participation in the SSA quality review process. This new approach has the potential to foster greater consistency among the states and the SSA regional offices and to assure that case reviewers and policy makers have the benefit of the point of view of front line personnel.

- Our experience with the child redetermination cases has brought into sharper focus some proposals by which the service delivery infrastructure could be further improved. Because of the emphasis on cost containment, too few resources are available, both in SSA and in the DDSs, for training, policy adaptation and clarification, and giving appropriate attention to each individual case. These problems have been addressed in the case of the child redetermination workload only by the one time special initiatives undertaken by the Commissioner and by the designation of these cases as a priority workload. A greater and ongoing investment in policy adaptation and training would, in our opinion, improve the quality and consistency of case processing at the front end so that costly and disruptive remedial approaches would be less necessary.

In summary, the NCDDD believes that the policies created by SSA are reasonably in compliance with the statute, that the work performed by the DDSs was in compliance with SSA's instructions, that there were some indications that a minority of cases may not have been processed correctly, that accurately processing the cases of impaired children is so important as to require unusual levels of effort, and that SSA and DDSs are working together to identify, remedy, and rectify any errors.

Mr. Chairman, thank you again for the opportunity to be here today.

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