

***“National Dialogue on SSI Childhood Disability”***

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Good morning. I'm pleased to have the opportunity to open this important conference -- this "National Dialogue on SSI Childhood Disability." I want to thank the National Academy of Social Insurance for co-hosting this event, and especially Pam Larson, Virginia Reno and Katherine Olsen.

People often don't think about children when they think about the Social Security Administration, but everyone here knows that we do go together in many, many ways. Social Security -- the Old Age Survivors Disability Insurance program -- provides important survivor benefits and dependent benefits to 1.9 million children. Our Social Security program for kids has become part of the accepted fabric of this country. But when kids intersect with our other key program, the Supplemental Security Income program, what happens? We certainly meet very real needs for nearly a million disabled children, but we also find that questions are raised about the program's legitimacy. It's our job -- collectively -- to strengthen the legitimacy of this very important program.

Since SSI was established more than a quarter-century ago, we know it has provided vital financial support and access to health insurance to many millions of the nation's neediest people -- and this includes the families of children with severe disabilities. For these kids, the meaning of the SSI benefit is really quite simple and profound: a better life. Without it, the quality of their lives is lessened, and they are placed at higher risk.

Their issues need to be on our agenda. That is why we're holding this first National Dialogue meeting for all of us who are interested in and concerned about the welfare of poor children with disabilities.

So thank you for being part of this today. What I want to do this morning is to take a brief look at where we are -- and how we've gotten here. But I also want to look at where we think we need to go.

Let's begin long ago -- pre-*Zebley* -- when there were less than 300,000 disabled kids on the SSI rolls, and a lot of severely disabled kids were not receiving support and were not part of our system. Something had to change, and a court case helped change it. I have often said that there was so much right about the *Zebley* decision. That landmark Supreme Court decision -- I believe in my heart -- helped this nation face up to its responsibilities to disabled kids. The world is better because of *Zebley*, and SSA worked hard and led the way in looking at functional limitations and trying to reach these unserved kids.

We know the history that followed -- the rolls tripled, due mostly to the *Zebley* decision. But there also were other factors -- increasing numbers of children in poverty, outreach mandated by Congress in the SSI law, and quite frankly new and better rules for assessing mental disorders that we ourselves issued.

Then came reports of abuses, "crazy checks" and coaching, although most of the reports -- when dissected -- proved unwarranted. There also were reports that some children with much more moderate impairments were entering the rolls. And there was some truth to those reports.

For our national institutions to survive and flourish, they need broad-based legitimacy across all ages, all income groups, and over time. The SSI kids program was in real jeopardy of losing legitimacy. There was serious talk of block granting the program or of drastically rethinking its scope and mission.

That set the stage for the welfare reform changes, which thankfully repudiated drastic change but did change the definition of childhood disability. The revised standard provides that a child is considered disabled only if he or she "has an impairment which results in marked and severe functional limitations." This means meeting or equaling our medical listings. Children with more moderate disabilities were no longer eligible for SSI.

The legislation also specifically eliminated some of SSA's rules, including some rules we added in response to the *Zebley* decision and required SSA to redetermine the eligibility of about 300,000 children of the almost 1 million children receiving benefits.

Implementing this legislation in 1997 was a major undertaking for SSA, and there were very short timeframes mandated by the legislation. And more questions arose about whether our institutions were up to the challenge. And my first action as Commissioner was to direct a "top-to-bottom" review of the implementation of the SSI childhood disability provisions to assure the fairness of the implementation.

I believed then -- and I believe now -- that Congress, the President and the American people deserve to know whether the law and regulations are being applied fairly. And we need to better understand who these kids are -- those both on and off the rolls.

We reopened the cases of many children whose eligibility we had originally ceased or whose applications we had denied. We got new evidence if needed, and provided a revised decision when that was called for. We re-opened appeals and we sent special notices in simpler, non-bureaucratic language. And we gave families another chance to continue getting their benefits until their appeals were over.

The bottom line? When the new regulations were originally issued, some believed that almost 200,000 kids -- about 1 in 5 -- would lose eligibility. SSA estimated that 135,000 children would lose eligibility after all appeals. As a result of agency efforts to assure fair and accurate decisions, about 100,000 have actually been found ineligible.

Where have we come? I believe all the work that's been done over the past decade and the past two years brings us closer to getting it right. And I must say, our State disability partners are working hard with us to strengthen the program. We need a program -- America needs a program -- that gets it right and meets the needs of severely disabled kids and has broad-based legitimacy.

We're making every effort to reach out and involve as many as possible in helping us run the best childhood disability program possible. Many of these efforts are reflected by the agenda for this conference. For example:

- President Clinton proposed continuing Medicaid eligibility for children who lost eligibility for SSI as a result of the new definition of disability. There are concerns about how this provision has been implemented, and we've included that issue on the agenda. Let's talk it through.
- Through the RAND Corporation, we are assessing the effects of the changes on families and children who continued to receive benefits and who lost benefits. For children who lost eligibility, we'll be looking at the effects on family income, medical care, and overall well-being. There is a segment this morning that will report on our progress to date.
- We are conducting studies with the American Association of University-Affiliated Programs to help us understand how some children might benefit from additional or different sorts of examinations and testing, and we'll talk about that this afternoon.
- We all know that evidence from teachers and schools is critical to our assessment of disability. We have ideas for improving the quality of information we obtain while being sensitive to the pressures on the educational community. We have a very important session this afternoon on this topic.
- We're conducting studies on the transition from school to work with our colleagues in the Department of Education. There is a segment on tomorrow's agenda addressing this and other efforts we're making.

- We are using the research community, such as the National Research Council, to help us find the information we need to update our medical listings.

Now I don't believe we should move forward -- on any of those fronts -- alone. We have reached out to the community, seeking information from a number of you, such as the Kennedy Foundation, the Arc, the States, and others.

There are lots of efforts underway. But there are two efforts in particular I want to note. First, I said that the welfare reform law required us to issue implementing regulations in a very short timeframe. So, the rules we published in February of 1997 are what we call interim final rules.

We've been very busy for the past couple of years doing the various activities I've already mentioned, and we've also gained a lot of valuable experience in that time. I believe that it's now time to address the public comments and issue improved regulations, and to do it soon. What I am committed to doing is taking the experience we have under the new law as well as the comments we received on the regulation, and working very hard to issue a final regulation this year.

Now, the overall standard for review of cases set in the interim final regulations can not change. But I know we can make improvements to the processes and procedures in deciding whether and how that standard is met. Some things we are looking at include:

- Clarifying and simplifying our adjudicative rules.
- Ensuring that we are assessing children's functioning in the best way possible, including how to take the best overall look at a child considering all of the child's medical conditions.
- Clarifying our rules for determining the severity of functional limitations. And this includes, as our friend Dr. Bob Cooke keeps reminding us, remembering that we must assess children in relation to their same-age peers who do not have disabilities.

I know that you know that I take a personal interest in the SSI Kids program and in the development of these rules. We have learned a lot in the past two and a half years. As Commissioner, I've learned even more in the past several weeks. But we need more than knowledge. If we are to move forward, we need consensus. Are the stars in alignment for us to move forward? Well, we're going to find out, and I'm going to try to move heaven and earth to make the stars align.

The second effort I want to highlight relates to this forum, and what I believe it represents. As I have indicated, we have a much stronger program today than we ever had. But my goal is to work together to improve the SSI childhood disability program, including ways to improve the regulations and instructions for our thousands of dedicated State and Federal workers. This meeting represents part of our commitment to inclusiveness and the free exchange of ideas.

So in closing, I want to make a commitment. I earlier referred to this meeting as our first national dialogue on childhood disability. I believe a subject of this importance calls for an ongoing dialogue between SSA and the community -- so I offer that if you find this meeting to be of value, I propose to make this an annual event. A conference such as this offers us all an invaluable opportunity to share information with each other in order to make the program the best it can be -- in order to make certain that no child falls through the cracks.

Certainly, no child anywhere should be allowed to fall through the cracks of the system. Earlier this week I read an *Esquire Magazine* article about a young boy from Mississippi. His name was Marcus Stephens, and he was born with a congenital heart impairment that qualified him for SSI benefit payments. That SSI check made a very big difference in Marcus' life, since he was being raised by loving but certainly not wealthy grandparents.

As you may know, Marcus lost his SSI benefits when his case was reviewed after the welfare reform law was passed. And, later, he lost his life to the heart ailment he had fought throughout his 13 years.

What happened in this case? Well, human errors, not bad faith action. But what happened was a tragedy -- for Marcus and his family, and for those of us who are responsible for ensuring eligibility during the last months of his life. He should not have fallen through the cracks of the system. And Marcus' story helps focus us on the very real, very human reasons why we are all here today.

Make no mistake about it -- our goal is to do right by these kids. But also realize that the adjudication of disabling conditions of kids is not easy. It is very, very hard. Just ask a State disability examiner. Our mission must be to recognize and talk through problems with our system, and move forward. This is what I have tried to do ever since my very first day as Commissioner, and what I intend to continue to do until my last. Working together with those of you here today, and with others who have a strong interest in childhood disability issues, we can find solutions to the problems that still exist. We can do right by our kids. And we can have rock-solid institutions with broad-based legitimacy with the American people. That's why this conference is important -- to help us strengthen a program that is so vital to so many young people and to this country as a whole.

Thank you.