10

OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES

OF THE

COMMITTEE ON WAYS AND MEANS
HOUSE OF REPRESENTATIVES

ONE HUNDRED THIRD CONGRESS

FIRST SESSION

OCTOBER 14, 1993

Serial 103–45

Printed for the use of the Committee on Ways and Means

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OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

THURSDAY, OCTOBER 14, 1993

House of Representatives,
Committee on Ways and Means,
Subcommittee on Human Resources,
Washington, D.C.

The subcommittee met, pursuant to call, at 10 a.m., in room B–318, Rayburn House Office Building, Hon. Harold E. Ford (chairman of the subcommittee) presiding.

[The press releases announcing the hearing follow:]

FOR IMMEDIATE RELEASE
FRIDAY, JULY 2, 1993

PRESS RELEASE #7
SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
1102 LONGWORTH HOUSE OFFICE BLDG.
WASHINGTON, D.C. 20515
TELEPHONE: (202) 225-1721

THE HONORABLE HAROLD E. FORD (D., TENN.), CHAIRMAN, SUBCOMMITTEE ON HUMAN RESOURCES, COMMITTEE ON WAYS AND MEANS, U.S. HOUSE OF REPRESENTATIVES, ANNOUNCES AN OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

The Honorable Harold E. Ford (D., Tenn.), Chairman, Subcommittee on Human Resources, Committee on Ways and Means, U.S. House Of Representatives, today announced that the Subcommittee will hold an oversight hearing on the Supplemental Security Income program. The date of the hearing will be announced in a subsequent press release.

BACKGROUND

The Supplemental Security Income (SSI) program is authorized by title XVI of the Social Security Act. Enacted as part of the 1972 amendments to the Social Security Act (P.L. 92-603) and begun in 1974, SSI provides monthly cash payments in accordance with uniform, nationwide eligibility requirements to needy aged, blind, and disabled persons. The SSI program replaced the former Federal grants to the States for old-age assistance, aid to the blind, and aid to the permanently disabled. These Federal grants continue in Guam, Puerto Rico and the Virgin Islands; however, the Northern Mariana Islands is covered by SSI.

SCOPE OF THE HEARING

Members of the Subcommittee are interested in hearing testimony relating to:

(1) Recommendations made by the SSI Modernization Panel -

The SSI Modernization Panel was established to conduct the first comprehensive review of the SSI program since it began in 1974. The project was designed to "create a dialogue that provided a full examination of how well the SSI law, and the policies developed by SSA to implement the law, serve people with very low or no income who are over 65 or blind or otherwise disabled." The SSI Modernization Panel released a report in August 1992.

(2) The effect of the Supreme Court's decision in Sullivan v. Zebley - (Zebley)

In Zebley, the Supreme Court ruled that the Social Security Administration (SSA) was applying a standard of disability to children that was stricter than had been intended by Congress when it passed the legislation that established the SSI program. In response, SSA issued new regulations for evaluating childhood disability benefits, and the percentage of applications for children that are approved has increased. Recently, however, educators and others have criticized the SSI program for providing benefits to children whom they think are not disabled.

(3) Eligibility requirements for immigrants and substance abusers -

Recent news media reports about substance abusers and immigrants on SSI have been troubling. The problem of substance abusers receiving SSI benefits and not meeting treatment requirements has become an issue in some parts of the country. Critics have charged that SSI benefits might be enabling substance abusers to continue their addictions. Other news reports have portrayed immigrants paying middlemen to help them apply for SSI and, in some cases, defrauding the government by paying off doctors to diagnose them as mentally ill to qualify for SSI benefits.

(4) Certain criteria for establishing trusts -

Trusts may be set up for SSI recipients to shield income and assets from the SSI means tests. Although some might view this as an abuse of a welfare program, there are some instances where it might be justified.

(MORE)

For example, trusts are particularly helpful to parents of *Zebley* children, who can receive lump sum awards dating back to 1980. They are also helpful to SSI recipients who receive large awards for damages incurred in accidents.

DETAILS FOR SUBMISSION OF REQUEST TO BE HEARD:

Individuals and organizations interested in presenting oral testimony before the Subcommittee must submit their requests by telephone to Harriett Lawler, Diane Kirkland, or Karen Ponzurick [(202) 225-1721] no later than close of business Thursday, July 15, 1993, to be followed by a formal request to Janice Mays, Chief Counsel and Staff Director, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. The Subcommittee staff will notify by telephone those scheduled to appear as soon as possible after the filing deadline. Any questions concerning a scheduled appearance should be directed to the Subcommittee staff [(202) 225-1025].

It is urged that persons and organizations having a common position make every effort to designate one spokesperson to represent them in order for the Subcommittee to hear as many points of view as possible. Time for oral presentations will be strictly limited with the understanding that a more detailed statement may be included in the printed record of the hearing. (See formatting requirements below.) This process will afford more time for Members to question witnesses. In addition, witnesses may be grouped as panelists with strict time limitations for each panelist.

In order to assure the most productive use of the limited amount of time available to question witnesses, all witnesses scheduled to appear are required to submit 200 copies of their prepared statements to the Subcommittee office, B-317 Rayburn House Office Building, at least 48 hours in advance of their scheduled appearance. *Failure to comply with this requirement may result in the witness being denied the opportunity to testify in person.*

WRITTEN STATEMENTS IN LIEU OF PERSONAL APPEARANCE:

Any persons to organizations wishing to submit a written statement for the printed record of the hearing should submit at least six (6) copies of their statements by close of business, two weeks after the day of the scheduled hearing, to Janice Mays, Chief Counsel and Staff Director, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. If those filing written statements wish to have their statements distributed to the press and interested public, they may deliver 100 additional copies for this purpose to the Subcommittee office, room B-317 Rayburn House Office Building, on or before the day of the hearing.

FORMATTING REQUIREMENTS:

Each statement presented for printing to the Committee by a witness, any written statement or exhibit submitted for the printed record or any written comments in response to a request for written comments must conform to the guidelines listed below. Any statement or exhibit not in compliance with these guidelines will not be printed, but will be maintained in the Committee files for review and use by the Committee.

1. All statements and any accompanying exhibits for printing must be typed in single space on legal-size paper and may not exceed a total of 10 pages.

2. Copies of whole documents submitted as exhibit material will not be accepted for printing. Instead, exhibit material should be referenced and quoted or paraphrased. All exhibit material not meeting these specifications will be maintained in the Committee files for review and use by the Committee.

3. Statements must contain the name and capacity in which the witness will appear or, for written comments, the name and capacity of the person submitting the statement, as well as any clients or persons, or any organization for whom the witness appears or for whom the statement is submitted.

4. A supplemental sheet must accompany each statement listing the name, full address, a telephone number where the witness or the designated representative may be reached and a topical outline or summary of the comments and recommendations in the full statement. This supplemental sheet will not be included in the printed record.

The above restrictions and limitations apply only to material being submitted for printing. Statements and exhibits or supplementary material submitted solely for distribution to the Members, the press and the public during the course of a public hearing may be submitted in other forms.

* * * *

FOR IMMEDIATE RELEASE
FRIDAY, OCTOBER 8, 1993

PRESS RELEASE #9
SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
1102 LONGWORTH HOUSE OFFICE BLDG.
WASHINGTON, D.C. 20515
TELEPHONE: (202) 225-1025

THE HONORABLE HAROLD E. FORD (D., TENN.), CHAIRMAN, SUBCOMMITTEE ON HUMAN RESOURCES, COMMITTEE ON WAYS AND MEANS, U.S. HOUSE OF REPRESENTATIVES, ANNOUNCES A DATE FOR AN OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

The Honorable Harold E. Ford (D., Tenn.), Chairman, Subcommittee on Human Resources, Committee on Ways and Means, U.S. House of Representatives, today announced the date for the oversight hearing on the Supplemental Security Income program. (See Press Release #7, dated July 2, 1993.) The hearing will be held on Thursday, October 14, 1993, beginning at 10:00 a.m., in room B-318 Rayburn House Office Building.

As indicated in Press Release #7, the final date for submitting requests to testify orally was Thursday, July 15, 1993. Persons submitting written statements for the record should submit at least six (6) copies by the close of business, Thursday, October 28, 1993, to Janice Mays, Chief Counsel and Staff Director, Committee on Ways and Means, U.S. House of Representatives, 1102 Longworth House Office Building, Washington, D.C. 20515. If those filing written statements for the record of the printed hearing wish to have their statements distributed to the press and the interested public, they may provide 100 additional copies for this purpose to the Subcommittee office, room B-317 Rayburn House Office Building, before the hearing begins.

*****

Chairman FORD. The Subcommittee on Human Resources of the Ways and Means Committee will come to order.

Today, the subcommittee holds an oversight hearing on the supplemental security income program. This program has received attention lately regarding the provision that was being considered as a means of partially financing an extension of emergency unemployment compensation. I anticipate holding hearings in the future that will cover not only the treatment of immigrants and aliens, but also substance abusers in the SSI program.

At 8 percent per year, the SSI program is one of the most rapidly growing Federal entitlement programs. Part of this growth is due to the impact of the 1990 decision of the Supreme Court in *Sullivan* v. *Zebley*. This case made nearly a half million children potentially eligible for lump-sum retroactive benefits by ruling that the Social Security Administration must apply a standard of disability to children that is comparable to that applied to adults. But perhaps a more lasting force behind this trend is the underlying growth of the disabled population of all ages on Supplemental Security Income.

This hearing will address various issues, including the recommendations of the SSI modernization project, the impact of the *Zebley* decision, and services to clients. Members of the modernization project were appointed by the Bush administration to conduct the first comprehensive review of the SSI program since it began in 1974. In August of 1992, a report was released documenting the findings of the project and recommendations by its panelists. Today, I look forward to the testimony of the distinguished chairman of the SSI modernization project, Dr. Arthur Flemming.

I am also pleased and encouraged by the response to the subcommittee's call for public witnesses on this subject. With more than 50 requests to testify, the subcommittee could not accommodate all who wanted to present testimony. I encourage those not on the witness list, however, to submit their written testimony to this subcommittee. Meanwhile, I am going to ask witnesses today to summarize their testimony in 5 minutes. If we adhere to this rule, as being set by the chairman, all witnesses will have a fair opportunity to be heard today.

Let us begin with our first witnesses. I open this subcommittee, thinking that there might be a vote on the House floor on the Journal, but undoubtedly that is not the case. I think there are members who are not here yet, but we are going to proceed. We have members listed first on the agenda. Many of them are waiting to see whether or not we have a recorded vote. I would like to call to the witness stand at this time the witness from the Social Security Administration, Hon. Lawrence H. Thompson, Principal Deputy Commissioner, along with Hon. Arthur S. Flemming, chair of the SSI Modernization Panel, former Secretary of Health, Education and Welfare.

Dorcas Hardy is a witness who is testifying later today. We have not received copies of testimony you will be giving today. We would like to have that because the press release indicates that the copies of your written testimony must be received in advance.

And also Stephanie Shelton, who will be testifying, we have not received your testimony. We would like to have it, also, so we can make it available to the public.

As chairman of the subcommittee, I am very pleased, Dr. Thompson, to have you and Dr. Flemming testify before the subcommittee. I am one who has worked very closely with the SSA implementing policy changes in the SSI program. I am delighted, and I know I speak for both sides of the aisle, to have such distinguished witnesses who are going to be testifying today, and at this time, the Chair will recognize Dr. Thompson, first.

STATEMENT OF LAWRENCE H. THOMPSON, PRINCIPAL DEPUTY COMMISSIONER, SOCIAL SECURITY ADMINISTRATION

Mr. THOMPSON. Thank you, Mr. Chairman. SSI is one of the most valuable lifelines our Nation offers to its citizens who have the greatest need. Millions of people have been able to achieve a greater degree of comfort and security and have been able to lead their lives with dignity because of SSI. I appreciate the opportunity to bring you up to date on several of the issues concerning SSA's administration of this vitally important program.

This morning, I want to discuss briefly four issues: SSI modernization, *Zebley*-related childhood disability, trusts, and payments to aliens and substance abusers. And in order to be brief, I would like to submit my full written testimony for the record.

Chairman FORD. It will be made a part of the record, sir. All testimony should be summarized within the 5-minute limit. The written testimony will, in fact, be made a part of the record today.

You may proceed.

Mr. THOMPSON. Thank you, Mr. Chairman.

Chairman FORD. Thank you.

Mr. THOMPSON. Let me begin by bringing you up to date on the SSI modernization project, and I want to start by praising the work of Arthur Flemming, who is here sitting beside me, a man whose passion for public service has been demonstrated yet again in his work on behalf of SSI modernization. He and 20 other experts in the program and related public policy areas held public meetings throughout the country to gather comments on an SSI program that had been in operation for 18 years without a comprehensive outside review.

Their final report identified over 50 options for changes that were supported by a majority of the experts. Of that list, the experts designated four options they believe deserving of priority attention for congressional action. Those 4 options are: one, increasing the benefit amount incrementally over 5 years to 120 percent of poverty; second, increasing resource limits; third, eliminating consideration of food, clothing, and shelter as income; and fourth, increasing SSA staffing, including State disability determination service agencies, by 6,000 employees.

Each of these options would require authorizing legislation or the appropriation of additional funds; and the cost of all four could be over $80 billion for the first 5 years.

We are evaluating the final report and the public comments and are using them in our ongoing efforts to improve the SSI program.

On the issue of childhood disability, as you said, in 1990 the Supreme Court decided *Sullivan* v. *Zebley*. The decision required SSA to dramatically revise the rules used to decide whether children are disabled and eligible for SSI benefits.

In the interests of time, I won't review in detail the process used by SSA to comply with the Supreme Court decision, although the decision is discussed in my written testimony. I would just say that the new rules, which were developed in consultation with many experts and advocates in numerous fields relating to childhood disability, are both state of the art and based on standard pediatric practices for evaluating children.

After publishing the rules in early 1991, SSA notified over 452,000 children who were denied benefits, or had their benefits terminated, since January 1, 1983, that they could come in for a reconsideration.

Public comments on the rules published in February 1991 were almost unanimously favorable. However, they are still relatively new, and it would not be unreasonable to expect that we will want to refine them or change them as we gain experience and insight through adjudications, public feedback, and ongoing monitoring and study.

We are continuing to gather information about the program, looking at the kinds of changes that have occurred and tracking cases to understand the effects of the new rules. We are carefully monitoring the quality of our adjudications and are providing training and written instructions as necessary. We are now also doing a study looking at children with learning disabilities and behavioral disorders. Our ongoing reviews, together with a recently initiated audit by the HHS Office of Inspector General to evaluate the program's vulnerability to abuse, should help us to pinpoint any problem areas and to take appropriate action.

Let me speak briefly about trusts. Under current rules, if an individual is the beneficiary of a trust, but his access to the trust principal is restricted, that trust is not his resource.

In the mid-1980s, business and law journals and financial advisers began publishing articles recommending trusts as ways for parents to shelter assets for their disabled children and for elderly people to shelter their own assets and qualify for means-tested public assistance such as SSI and Medicaid.

Sheltering assets in this way raises fundamental questions and concerns. It has always been the generally accepted view that since SSI is a program of last resort, people should use resources in excess of the SSI resource limits to provide for their own support before the Federal Government begins providing support.

Mr. Chairman, we believe it is time to review how all trusts are treated in all income-maintenance programs, and we will be happy to work with your committee on this topic.

Finally, Mr. Chairman, let me say a word about the payment of benefits to drug abusers and alcoholics, and about the payment of benefits to aliens.

As you know, those who receive benefits based on a drug- or alcohol-related disability are required to undergo treatment when it is appropriate and available as a condition of receiving benefits. We ensure compliance with this requirement through agreements with

States and private contractors serving as our referral and monitoring agencies. In the past, we have been unsuccessful in securing agreements to cover all geographical locations in a uniform manner.

I am pleased to report considerable progress in this area. Working with the Substance Abuse and Mental Health Services Administration of the Public Health Service, we have developed a national model agreement to use in entering into referral and monitoring contracts with all 50 States and the District of Columbia, and we expect virtually all of these contracts will be in place by this December. We have increased the funding for this activity from $4 million in fiscal year 1993 to $20 million in this fiscal year.

We will also be starting demonstration projects to identify and test ways in which we can provide better treatment options to this population.

As to aliens, the law states that aged, blind or disabled residents of the United States who are not U.S. citizens may be eligible for SSI if they are either lawfully admitted for permanent residence or permanently residing in the United States under color of law.

For the most part, aliens in lawful residence status have sponsors who signed affidavits of support. In determining eligibility and benefit amount, a portion of his sponsor's, and sponsor's spouse's, income and resources are deemed to be available to the alien for 3 years after the alien's admission to the United States for permanent residence.

This has the effect of preventing SSI eligibility for most lawfully admitted aliens during their first 3 years in the country. Aliens permanently residing under color of law generally do not have sponsors and thus are not subject to the aforementioned deeming requirements. Therefore, they may become eligible for SSI after being in this country for 30 days without regard to anybody else's income or resources.

Mr. Chairman, I have had an opportunity to touch only briefly on the provisions that you asked us about, and I would be happy to answer any questions that you or the other members of the committee may have. And we, of course, would be happy to continue working with you to improve this program and deal with any of the issues that come up today.

Chairman FORD. Thank you very much, Dr. Thompson, for your testimony.

[The prepared statement follows:]

TESTIMONY BY LAWRENCE H. THOMPSON, PRINCIPAL DEPUTY COMMISSIONER SOCIAL SECURITY ADMINISTRATION

Mr. Chairman and Members of the Subcommittee:

I am very pleased to be here today to talk about the Supplemental Security Income (SSI) program. As you requested, I will specifically address the SSI Modernization Project, _Zebley_ matters, how trusts are treated under SSI, and SSI payments to aliens and substance abusers. Before I do so, however, let me begin with a brief overview of the SSI program in order to provide a frame of reference for the discussion of the subjects of today's hearing.

I want to say at the outset that I believe that the SSI program is a successful and effective program which has helped millions of people lead their lives with dignity. In fact, it has provided, and continues to provide, a very important element of the Nation's support system for aged, blind, and disabled people. SSI is a program of last resort. The fundamental goal is to provide a basic level of income support to the needy aged, blind, and disabled persons based on nationally uniform eligibility standards and payment levels, thus supplementing other income that an individual receives.

Let me now give you some numbers that show the scope of the SSI program. As of August 1993, the last month for which we have numbers, there were 5.9 million people receiving federally administered SSI and/or State supplementary payments. This figure represents an increase of almost 29 percent over the number of people receiving benefits 5 years ago and a 15.4 percent increase over December 1991 numbers. While the number of aged and blind recipients has not changed significantly since December 1991, the number of disabled persons has increased by almost 20 percent.

As the number of people receiving SSI climbs, so too do Federal outlays. Projected outlays for Federal benefits in fiscal year 1993 are almost $22 billion. This represents approximately a 90 percent increase over similar outlays in 1989.

SSI MODERNIZATION PROJECT

Mr. Chairman, let me now turn to the first of the specific issues you asked me to address today--the SSI Modernization Project.

Because the SSI program had been in operation for 18 years without a comprehensive outside review, in 1990 SSA enlisted the help of 21 experts in the SSI program and related public policy areas to undertake such a review. This project was chaired by the distinguished former Secretary of Health, Education, and Welfare, Dr. Arthur Flemming. The experts came from academia, State and local governments, and private, nonprofit organizations.

The first phase of the project created a dialogue that would provide a full examination of how well the SSI program serves people with very low or no income and who are over 65, blind, or disabled. The experts held 11 public meetings around the country which brought to light a number of issues and options for potential improvements in the SSI program. A full discussion of the major issues and options was published in the Federal Register in July 1991. Over 14,000 public comments were received.

After considering the public comments, the experts determined their individual points of view concerning what options they supported and which deserved priority consideration. Their conclusions are contained in their final report, which was published in the Federal Register on September 4, 1992. In response to a request for public comments, SSA heard from over 10,000 persons and organizations. We received comments from people in every State and the District of Columbia.

Options for Changes in the SSI Program

The final report identified over 50 options for changes supported by a majority of the experts. These addressed concerns about a wide range of areas--benefit levels, income and resources limits, the definition of "aged," the disability process and work incentives, how SSI is linked to the Medicaid and Food Stamp programs, and the adequacy of SSA staffing levels.

A majority of the experts identified four options that they thought deserved priority attention for Congressional action. Generally, they thought that these options would work toward the goals of improving the overall economic condition of SSI recipients, simplifying the program, enhancing recipients' dignity, and improving service to the public.

The four options are: increasing the SSI benefit amount incrementally over 5 years to 120 percent of the poverty level; increasing the resource limits to $7,000 for an individual and $10,500 for a couple (from $2,000 and $3,000, respectively), while reducing the number of resource exclusions; eliminating the consideration of food, clothing, and shelter as income; and initially increasing SSA staffing, including State Disability Determination Service agencies, by 6,000 employees. None of these options can be implemented without legislation authorizing the change or appropriating additional funds. However, the cost of all four options would be well over $80 billion over the first 5 years, which argues for caution.

We are evaluating the final report and the public comments. We will be using them in our ongoing efforts to identify changes that will improve the SSI program in the context of the Administration's current budget goals, and other initiatives.

CHILDHOOD DISABILITY

Mr. Chairman, I would now like to turn to the subject of childhood disability. You asked me to address the effect of the Supreme Court's 1990 decision in Sullivan v. Zebley. This important, wide-ranging decision required us to dramatically revise our rules for deciding whether children are disabled for establishing SSI eligibility.

Disability Rules Pre- and Post-Zebley

As you know, Mr. Chairman, title XVI of the Act provides only a brief definition of disability for children. In a parenthetical statement at the end of the general definition of disability for adults, the statute provides that a child under age 18 is disabled if he or she has any medically determinable impairment that is "of comparable severity" to one that would disable an adult. Since the general definition of disability is based on an inability to work, and since children do not generally work, our regulations for childhood disability prior to the Zebley decision were premised primarily on a medical standard. Specifically, our regulations required children to show that they had an impairment(s) that met the requirements of one of the impairments in our Listing of Impairments or that were equal in severity to a listed impairment.

For several reasons, the Supreme Court held that this listings-only rule did not implement the intent of Congress to provide a "comparable severity" standard for children. One of the main reasons was that our sequential evaluation process for adults contains a step at which adults whose impairments do not meet or equal one of our listings can show that they are disabled by alternative means, involving an evaluation of the functional effects of their impairments. Our prior regulations did not provide such an opportunity for children: A child whose impairments did not meet or equal the requirements of a listing was not disabled.

As a result of the Supreme Court decision, we began to provide an individualized functional analysis for children, as we do for adults who cannot be determined disabled at the listings step. The Court agreed that a vocational analysis was not applicable to children, but said that an evaluation of a child in terms of "age-appropriate activities" would be comparable.

SSA undertook a good-faith effort to implement both the letter and the spirit of the Supreme Court's decision and to strive to provide rules that would be state-of-the-art. To help us accomplish this task, SSA sought advice from leading advocates for children with disabilities, as well as numerous individual experts in fields related to childhood medicine and disability, including physicians and psychologists with both clinical and academic credentials, researchers, and experts in social work, nursing, education, genetics, physical therapy, and other related areas.

The new rules, which took all of this input into account, were, we believe, both state-of-the-art and based on standard pediatric practices for evaluating children. As required by the Supreme Court, they provided a means for establishing disability when a child's impairments do not meet or equal the criteria of a listing using an individualized assessment of a child's functioning. The new evaluation of childhood disability is based on a system of rating functional limitations in standard domains of functioning and behavior.

Experience to Date

After the new rules were published in early 1991, in accordance with the Zebley court order, SSA notified over 452,000 children who were denied SSI childhood benefits, or had their benefits terminated, since January 1, 1983. Over 70 percent of these (about 320,000) responded to the notice that SSA would readjudicate their claims under the new rules. About 126,000 of these class members have been found disabled.

In addition to the class member claims, another 500,000 children have been found disabled since the implementation of the new rules. Slightly over one-third of these children (187,000) were found disabled based on the new functional considerations that were put in place to comply with the Zebley Supreme Court decision.

The growth in new childhood entitlement is, in large part, a product of the increase in childhood SSI applications that the agency has processed over the last few years. For example, currently over 115,000 children are filing for benefits every calendar quarter, more claims than were received in all of calendar year 1989.

There are numerous factors contributing to the increase in childhood filings. For example, the overall childhood population has increased, as has the proportion of children in poverty. In addition, the Zebley court case, the new rules, and SSI outreach may have increased participation.

As a result of the new functional assessment rules, the large class relief, and the growth in new childhood applications, the total number of children receiving SSI has increased from almost 300,000 in December 1989 to over 729,000 in August 1993, an increase of 143 percent.

The Future

As you know, we published the new childhood disability regulations almost exactly a year after the Zebley decision, with a request for public comments. In September, we published revised final regulations which are in most respects substantively unchanged. Public comments on the rules we published in February 1991 were almost unanimously favorable, expressing concern only about areas in which the rules might still result in denials of deserving children. However, our 2 1/2 years' experience using the rules demonstrated that those fears were unfounded and did not show any major areas warranting revision.

Nevertheless, the rules are still relatively new. It would certainly not be unreasonable to expect that we will want to refine or even change the childhood rules as we gain experience and insight through hands-on adjudications, feedback from the public, and ongoing monitoring and studies. We provided a 4-year sunset date to the regulations when we published them in September and we will review program experience during that time.

In our stewardship role, we are gathering information about the program, looking at all kinds of changes that have occurred, and tracking cases to understand the effects of the new rules. Moreover, we have been carefully monitoring the quality of our adjudications since we first published the rules and we are providing training and written instructions as necessary. We are now also conducting a study targeting children with learning disabilities and behavioral disorders. Together with the Health and Human Services (HHS) Office of the Inspector General (OIG) audit and our ongoing reviews, we hope to be able to pinpoint any problem areas and to take appropriate action.

In addition, Mr. Chairman, the HHS OIG has initiated an audit to determine if the new eligibility rules for SSI mentally disabled children increase the vulnerability of the program to abuse and to evaluate whether there are sufficient controls to ensure that SSI payments are benefiting eligible disabled children. We understand that the preliminary results of OIG's audit are expected to be released early next year.

TREATMENT OF TRUSTS UNDER SSI RULES

Mr. Chairman, I would now like to turn to the third issue you asked me to discuss, which is the way trusts are treated under the SSI program.

There is no mention of trusts in SSI law. The way trusts are treated under the SSI program is determined by SSA's regulatory definition of a resource, and changes in the current treatment of trusts may require legislation.

We have defined resources as cash, other liquid assets, or any real or personal property that an individual owns and could convert to cash to be used for his support and maintenance. Regulations further provide that a person must have the right, authority, or power to liquidate property or his share of it in order for the property to be considered as his resource.

Based on these regulatory provisions, our policy is that, if an individual is the beneficiary of a trust but his access to the trust principal is restricted, the trust is not his resource. In the usual case, a trustee and not the beneficiary is the one who has the title to the trust principal and has access to and power over the trust. Consequently, the trust is not the beneficiary's resource.

Uses of Trusts

Often trusts are created using funds from inheritances or court judgments or from an individual's own funds. Also, parents of handicapped children set up trusts to assure that, after their deaths, their children will not be deprived of the level of care provided by the parents, any education or training, and other special needs, while also continuing to receive SSI and Medicaid benefits. The trust arrangements often direct trustees not to use any of the funds in ways that would cause the loss or reduction of public assistance.

In the mid-1980's, business and law journals and financial advisors began publishing articles recommending trusts as ways for parents to shelter assets for their disabled children and for elderly people to shelter their own assets and qualify for means-tested public assistance benefits such as SSI and Medicaid. There has been increasing activity among parents and advocates for the handicapped to create trust instruments specifically to provide funds only to supplement public benefits.

A provision of the Omnibus Budget Reconciliation Act of 1990 requires that we notify persons who were determined to be eligible for retroactive SSI benefits under the Zebley court ruling of the possibility of establishing trusts that would not be considered as resources and of the availability of outside legal assistance in establishing such trusts.

The sheltering of assets in trusts that prohibit their use in ways that might affect SSI eligibility raises a fundamental question concerning the appropriateness of this effect on public assistance programs. In that SSI is a program of last resort, it was the generally accepted view that it was reasonable to expect people to use resources that were in excess of the SSI resource limits for their support before the Federal Government should provide support. We believe it is time to review how trusts are treated in all income maintenance programs and we will be happy to work with you on this.

DRUG ADDICTS AND ALCOHOLICS

Now let me turn to the next issue you asked me to address--payment of SSI benefits to people who are substance abusers. As you know, those who receive SSI benefits based on a drug- or alcohol-related disability are required to undergo treatment when it is appropriate and available as a condition of receiving benefits. SSA ensures compliance with this requirement through agreements with States and private contractors serving as our referral and monitoring agencies. In the past, we have been unsuccessful in securing agreements to cover all geographical locations in a uniform manner.

I am pleased to report that we are now moving to improve our services to these beneficiaries. For example, we have been working with the Substance Abuse and Mental Health Services Administration (SAMHSA) in the Public Health Service for more than a year and have developed a national, model agreement to use in entering into contracts expanding the referral and monitoring activity to all 50 States and the District of Columbia. We expect to have virtually all 51 contracts in place by December 1993 and have increased the funding for referral and monitoring from $4 million in FY 1993 to $20 million in FY 1994.

In addition, SSA and SAMHSA have entered into joint demonstration projects with two States (Washington and Michigan) to identify and test ways in which we can provide better treatment options to this population.

SSI PAYMENTS TO ALIENS

Before closing, Mr. Chairman, let me also briefly discuss one other topic raised by your letter of invitation--SSI payments to aliens.

Aged, blind, or disabled residents of the United States who are not U.S. citizens may be eligible for SSI if they are either lawfully admitted for permanent residence or permanently residing in the United States under color of law. People residing in the United States under color of law (PRUCOL) represent many immigration statuses--16 specific statuses plus a general category. The latter consists of any aliens the Immigration and Naturalization Service (INS) knows of, permits their presence in the country, and does not contemplate enforcing their departure.

Most aliens lawfully admitted for permanent residence are immigrants--i.e., they are issued immigrant visas by the Department of State before they enter the United States. Others may be granted permanent resident status by INS after they have been in the United States. Some aliens granted permanent residence are required by INS to have sponsors sign affidavits of support.

For those aliens who have individual sponsors, SSI eligibility and benefit amount is determined by considering a portion of the sponsor's (and sponsor's spouse's) income and resources to be available to the alien for 3 years after his admission into the United States for permanent residence. This has the effect of preventing SSI eligibility for most lawfully admitted aliens during their first three years in the country. Aliens under color of law do not have sponsors and thus are not subject to the deeming requirements. Therefore, they may become eligible for SSI after being in the country for 30 days, without regard to anyone else's income or resources.

In December 1992, there were 601,430 people on the SSI rolls who were aliens; slightly over three-quarters were lawfully admitted residents, and the rest were PRUCOL.

CONCLUSION

In conclusion, Mr. Chairman, I would like to commend the Subcommittee for holding this hearing today, because the SSI program is of paramount importance in the lives of millions of poor, disabled, and elderly Americans. Certainly, the Administration is committed to making sure that SSI serves these Americans in the best way possible. Our fundamental goals are to improve the economic condition of recipients, enhance their dignity, simplify the program, and improve public service. I look forward to working with you and the other members of Congress to accomplish this task.

Chairman FORD. Dr. Flemming, we will hear from you now.

STATEMENT OF HON. ARTHUR S. FLEMMING, CHAIR, SSI MODERNIZATION PANEL, AND FORMER SECRETARY OF U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. FLEMMING. Thank you very much, Mr. Chairman and members of the committee. I appreciate the opportunity to discuss the Supplemental Security Income Modernization project with you.

This Nation believes in the dignity and worth of each individual. The national community, in accordance with this belief, has pooled some of its resources, beginning in the 1930s, both public and private, so that when individuals confront the hazards and vicissitudes of life, they can use these resources in order to help solve their problems and move forward.

It did so, almost 60 years ago, when it passed the overall Social Security program, during the deepest depression this Nation has ever experienced, and included in that program Aid to the Aged, Blind and Disabled, which has been a part of the social program from the beginning. It first started as a Federal-State program, and then in 1972, the Congress passed the Supplemental Security Income program.

As has been indicated, 20 persons from various walks of life were requested by Gwendolyn King, then Social Security Commissioner, to take a look at SSI and determine whether it was achieving the goals set by the Congress.

I was asked to serve as chairman. The group took about 2 years to conduct its work. We held public meetings and hearings, and I visited all 10 regional offices of the Social Security Administration, local offices in each region and met particularly with the persons that pass on SSI claims.

I would like to take—as a result of the opportunity that I had of meeting the persons that pass on SSI claims, I developed the conviction that we place too much reliance on rules and regulations and not sufficient reliance on the common sense of the person who function as a claims examiner.

For example, it was these claims examiners that called our attention to some of the very basic issues on which we have made recommendations. They called our attention to the fact that, in their judgment, the provision that says that if a person moves their household to the household of their family or household of a friend that their benefits should be reduced by one-third made no sense and we unanimously recommended that that provision be repealed.

Then, I am attaching to this testimony the names of the entire working group. We were ably assisted by Peter Spencer, who was then Director of our staff, and by Rhoda Davis, the Assistant Director of the Social Security Administration for the SSI program, and her entire staff.

Our report, as has been indicated by Larry Thompson, contains over 50 options, some obviously more important than others; and in view of the short time available this morning, I am going to—I have already mentioned one of them.

I would like to mention also your recommendation on resource requirements. It made no sense for a person who has slightly over $2,000 in resources—slightly over $3,000 as a couple are not—are still needy persons. We took cognizance of the fact that the government is urging the beneficiaries to develop sums of money that they can use in emergencies, and then proceeds to tell them to reduce that to 2,000 or 3,000.

We were impressed with the fact that this is a seriously understaffed program. The backlog of disability cases, for example, is indefensible. It means that persons who are qualified for SSI must wait 3 to 4 months and, on appeal, up to 1 year before they are told they are qualified.

While they are waiting for the help the national community has promised many of them, some are facing premature death or unnecessary suffering. Others are being denied the help that would enable them to use their abilities and to contribute to life. That is why we have recommended that SSA be authorized to employ 6,000 additional personnel.

I have noted that the pending bill appropriation bill for 1994 provides for about 2,400 additional—2,400 additional people which can be applied on the 6,000. I have also noted that the State groups that are working on additional requests for eligibility have been provided with about $200 million extra, so there is progress on both of the those fronts. I am glad to note that.

We urge you to consider the possibility of raising the SSI beneficiaries at least up to the poverty line. Is it right to insist that 5.4 million persons live below the poverty line? Is it right to insist that the poorest of the poor continue to juggle a very small income between paying the rent, paying for food, paying for clothing and paying for drugs that a doctor has said are essential to their well-being?

We also urge you to consider strengthening the work incentives that are built into this program. We feel it is imperative to provide incentives to the persons on the SSI roll to contribute to life by preparing for and going to work. Only by doing this can we persuade hundreds of thousands of persons that we believe in their dignity and worth. Only by doing this can we tap one of our most important resources for helping our Nation to move forward.

The persons on our SSI rolls do not want to be pitied; they want the opportunity to be involved in life in a meaningful manner. We can reduce our SSI rolls to some extent and strengthen our Nation by providing these work incentives.

I know that you recognize the seriousness of this situation. I will be glad to consider with you the facts we were called upon to face. In fact, I look forward to doing that in the future. I would be glad to discuss with you the pros and cons of the options that many of us decided to advocate.

The future of many of our fellow Americans calls for prompt action. Failure to correct glaring weaknesses in SSI and similar programs results in lack of confidence in our national community and sows the seeds that may sprout into riots. Correcting these weaknesses makes available to us unexpected resources and helps us to strengthen our national community.

The motto of the former Department of Health, Education and Welfare when I was Secretary was "Hope, the Anchor of Life." I hope that we can replace despair with hope in the lives of the approximately 8 million persons who are either on the SSI rolls or are qualified to be on those rolls.

Thank you very much.

Chairman FORD. Thank you very much, Dr. Flemming.

[The prepared statement follows:]

TESTIMONY OF ARTHUR S. FLEMMING
FORMER SECRETARY OF HEALTH, EDUCATION AND WELFARE

I. Introduction

A. I appreciate the opportunity of discussing the Supplemental Security Income Modernization Project with you.

B. This nation believes in the dignity and worth of each individual.

C. The national community, in accordance with this belief, has pooled some of its resources, beginning in the 1930s, both public and private, so that when individuals confront the hazards and vicissitudes of life they can use these resources in order to help solve their problems and move forward.

D. It did so, almost sixty years ago, when it passed the over-all Social Security program, during the deepest depression this nation has ever experienced, and included in that program Aid to the Aged, Blind, and Disabled when they confront economic conditions which they cannot surmount by themselves.

1. We felt that with this assistance these persons, in spite of the problems they faced could make a genuine contribution to life.
2. Today, this program is known as the Supplemental Security Income program and is about to celebrate its 20th anniversary.

E. Twenty persons, from various walks of life were requested by Gwendolyn King, then Social Security Commissioner, to take a look at SSI and determine whether it was achieving the goals set by the Congress.

1. I was asked to serve as Chairman.
2. The group took about two years to conduct its work.
3. We held public meetings and hearings, and I visited all ten regional offices of the Social Security Administration, local offices in each region and met particularly with the persons that pass on SSI claims.

    4. I am attaching to this testimony the names of the entire working group.
    5. We were ably assisted by Peter Spencer, who was the director of our staff and by Rhoda Davis, the Assistant Director of the Social Security Administration for the SSI program and her entire staff.

II. Body

- A. Our report contains over fifty options, some obviously more important than others.
    1. We look forward to discussing these options with members of this Committee.
    2. We recognize that you are the "conscience" of the House of Representatives on this program.
    3. Congresswoman Carrie Meek has introduced a bill containing some of our important options.
- B. In view of the short time available this morning I am going to make brief observations on three options.
- C. We were impressed with the fact that this is a seriously understaffed program.
    1. The backlog of disability cases, for example, is indefensible.
    2. It means that persons who are qualified for SSI must wait three to four months and, on appeal, up to a year before they are told they are qualified.
    3. While they are waiting for the help the national community has promised many of them, some are facing premature death or unnecessary suffering; others are being denied the help that would enable them to use their abilities and to contribute to life.

4. That is why we have recommended that SSA be authorized to employ 6,000 additional personnel.

D. We urge you to consider the possibility of raising the benefits of SSI beneficiaries at least up to the poverty line.

   1. Is it right to insist that 5.4 million persons live below the poverty line?
   2. Is it right to insist that the poorest of the poor continue to juggle a very small income between paying the rent, paying for food, paying for clothing and paying for drugs that a doctor has said are essential to their well-being?

E. We also urge you to consider strengthening the work incentives that are built into this program.

   1. We feel that it is imperative to provide incentives to persons on the SSI rolls to contribute to life by preparing for and going to work.
   2. Only by doing this can we persuade hundreds of thousands of persons that we believe in their dignity and worth.
   3. Only by doing this can we tap one of our most important resources for helping our nation to move forward.
   4. The persons on our SSI rolls do not want to be pitied; they want the opportunity to be involved in life in a meaningful manner.
   5. We can reduce our SSI rolls and strengthen our nation.

III. Conclusion

A. I know that you recognize the seriousness of this situation.

B. I will be glad to consider with you the facts we were called upon to face.

C. I will be glad to discuss with you the pros and cons of the options that many of us decided to advocate.

D. The future of many of our fellow Americans calls for prompt action.

E. Failure to correct glaring weaknesses in SSI and similar programs results in lack of confidence in our national community and sows the seeds that may sprout into riots; correcting these weaknesses makes available to us unexpected resources and help to strengthen our national community.

F. The motto of the former Department of Health, Education and Welfare was "Hope, the Anchor of Life". Let us--together--endeavor to replace despair with hope in the lives of the approximately eight million persons who are either on the SSI rolls or are qualified to be on those rolls.

SSI MODERNIZATION PROJECT EXPERTS

Elizabeth M. Boggs--the parent, guardian and representative payee (for Social Security) of an adult son with complex disabilities; she has been a volunteer advocate for people with developmental disabilities for more than forty years.

M. Kenneth Bowler--currently Vice President, Federal Government Relations with Pfizer Inc. He was formerly Staff Director of the House Ways and Means Committee, and is an Adjunct Professor at the University of Maryland, Baltimore. He is married and has four children.

A. Lorraine Brannen--District Manager, Social Security Administration (Retired)

John Costa--Former Commissioner, U.S. Assistance Payments Administration

Arthur S. Flemming--Former Secretary, Department of Health, Education and Welfare, has held many prominent posts including U. S. Commissioner on Aging and Chairman, U.S. Commission on Civil Rights. He currently chairs coalitions of national organizations serving as advocates in the areas of social security, health care, and civil rights.

Robert E. Fulton--an independent public policy analyst. He works part-time for the Oklahoma Alliance for Public Policy Research and the National Center for Children in Poverty (Columbia University). He formerly served for 35 years in executive-level positions in federal and State governments.

Lou Glasse--M.S.W., President of the Older Women's League, is a consultant on policies and services for older people. She serves on the Board of Advisors of the Mildred and Claude Pepper Foundation and of the National Academy on Aging.

Sharon Gold--President, National Federation of the Blind, California

Robert Gorski--Disability Advocate, City of Pasadena, California

Arthur E. Hess--Former Acting Commissioner of Social Security and first SSA director of Disability Insurance and of Medicare.

Chris Koyanagi--Vice President for Government Affairs, National Mental Health Association

Carmela G. Lacayo--National Association of Hispanic Elderly; President and CEO

Richard P. Nathan--Provost, State University of New York and Director of its Rockefeller Institute of Government, Albany, New York

Barbara L. Sackett--parent of an adult daughter with developmental disabilities, and a professional in the field of developmental disabilities; she has been a volunteer advocate for people with disabilities for more than thirty years.

Samuel Sadin--Deputy Director, Brookdale Center on Aging of Hunter College, Institute on Law and Rights of Older Adults, New York

Bert Seidman--was AFL-CIO Social Security Director from 1966 until his retirement in 1990. Since then he has been a consultant to the National Council of Senior Citizens. He has twice served on the Advisory Council on Social Security and more recently on the Prospective Payment Assessment Commission which deals with the hospitalization (Part A) phase of Medicare. One of his three daughters who is autistic and severely retarded has been in a State mental hospital for 30 years.

Timothy M. Smeeding--Professor of Economics and Public Administration, Maxwell School, Syracuse University

Michael Stern--R. Duffy Wall and Associates; formerly Minority Staff Director, U.S. Senate Finance Committee

Eileen P. Sweeney--Children's Defense Fund; formerly staff attorney, National Senior Citizens Law Center.

Fernando M. Torres-Gil--Professor, University of California, Los Angeles

Elaine T. White--retired management analyst, Office of Child Support Enforcement, Department of Health and Human Services, and a former SSA employee.

Chairman FORD. Dr. Flemming, the modernization panel that you served on and headed as chairman made several recommendations to improve the SSI program. It is unfortunate, some of us would want to say, because of the severe budget restraints that we are all working under in this particular Congress, that it would be difficult to implement many of the recommendations.

What areas do you believe should be given the most attention in light of the budget restraints we are working under in Congress?

Mr. FLEMMING. I appreciate that question.

First of all, I would urge this committee to recognize that we have an understaffed program, seriously understaffed program, and that is contributing very markedly to——

Chairman FORD. "Understaffed" meaning the SSA?

Mr. FLEMMING. Both SSA and SSI.

Chairman FORD. I mean, the administration——

Mr. FLEMMING. Personally, the SSI at this point—my emphasis should be on SSI, but my comment applies to all of SSA and applies to both title 2 and title 16 under the Disability Act; and we feel, particularly as a result of seeing situations in the field, that——

Chairman FORD. You didn't prioritize the areas that we should focus on. I have seen the list of recommendations that the modernization panel really have been able to come out of the——

Mr. FLEMMING. That is one of them. The fact of the matter is, I think most of us would put that first because without adequate staff, SSA cannot serve effectively the people of this Nation.

The second thing—the second recommendation that I would emphasize, and that we emphasized, was an increase over a period of—over a period of 5 years in the benefits. After all, when the Senate reported out this bill in 1972, they said they were providing for a program that would make it possible for the aged, the blind and disabled to live up at least to the poverty line. This country has never reached that goal.

I mean, for 20 years, the beneficiaries have been living right under the poverty line, and we think that at least the Congress should move rather quickly to bring this group up to the poverty line.

The third recommendation that we made, that I already emphasized, is the recommendation relative to a living arrangement. It made no sense to us that this government would say to beneficiaries, the poorest of the poor, who have a chance to move in with the household of a family or household of a friend, "We are going to penalize you by reducing your benefits by one-third."

We were unanimous on that, and some rather strong language was used in our report setting forth our convictions on that.

Then also we, as I have indicated here, do feel that a great deal of emphasis should be placed on the question of resources. We think that is outdated; 2,000 to 3,000 makes no sense. A number of programs in the Federal Government are moving up to 10,000 or 12,000.

We recommended 7,500 and 10,000 because it just doesn't make sense to take these beneficiaries on the one hand, say build up a sum of money that you can use if you confront a flood or a tornado or a hurricane or something of that kind, and then turn around and say, “Spend that down in order to qualify for SSI.” Because clearly people who are above resources of 2,000 or 3,000 are still needy persons. But we feel that a good deal of the emphasis should be placed on that.

Also, I would say that I think I share of the conviction of everybody when we place a great deal of emphasis on constantly improving the work incentives that we can provide people who are on our rolls with the opportunity of seeing—testing out their presence in the labor force without losing certain benefits that they have under SSI at the present time.

After all, every—a lot of these people are potentially members of the work force—full-time, part-time, volunteers and so on. And the government should certainly invest some money in making that possible. It seems to me that is all to the good, both for them and for the country as a whole. So we did place a great deal of emphasis on those recommendations.

I could pick out others. For example, Larry talked about drug addiction and alcohol addiction. The system that we have developed, the representative payee is very important on that. The Congress has passed a number of laws on it, and yet we found that Congress has never appropriated a red cent to carry out that provision. That doesn’t make sense.

I mean, it is—the claims people have got to make a decision on whether you are going to go out and get representative payees, whether they are going to deal with backlog or outreach and so on; and they are faced with impossible conflicts. If we are going to have a system of representative payees, let’s codify it. We recommend it and at the same time authorize appropriation for it, so we have got a real honest-to-goodness system so we can really tackle this drug and alcohol addiction problem.

Chairman FORD. Would you talk briefly about the continuing disability reviews that maybe are not being done by the SSA?

Mr. FLEMMING. Well, Larry is in a better position to talk about that, but we did go into that.

Chairman FORD. Your panel did go into that?

Mr. FLEMMING. Well, I would like to have the opportunity of working with the committee in some detail, because that is a complicated issue. We can err either way. We can err in making very strict reviews that are not consistent with the welfare of the people who are under SSI, and on the other hand, we can fail to make reviews at times.

Chairman FORD. The question is, should this be a priority? That is what I am trying——

Mr. FLEMMING. Yes, I definitely think so. It is a fundamental question, and I think this committee should go into it in some detail.

Chairman FORD. I have listed the SSA understaffed with SSI program, the living arrangements of SSI recipients, the resources, and the work incentives. I guess these are the four areas prioritized by you as chairman of the modernization panel?

Mr. FLEMMING. We would be delighted to work with you on those. They are very basic issues. They are controversial, the solutions and so on; the objectives, I think people tend to agree on.

We did assemble a good deal of evidence on that. I would be glad to share it with you, and I would glad to engage in a discussion of what is the best way to deal with it. And, incidentally, you—in effect, that is where the money comes from. And I would like to be able to discuss that also; we have got some ideas on that. As we know——

Chairman FORD. I certainly would appreciate it if you would submit information to the subcommittee addressing that particular issue.

Mr. FLEMMING. Of course, you have got the report. I would be very glad to supplement it and do anything you want, anything that would help you to come to grips. ,

I think it is a very basic issue. It is a basic and fundamental issue confronting the country. Our consideration of it is going to be altered considerably if we adopt a universal right of health care, which I am confident we will.

Chairman FORD. I have great confidence myself.

Mr. FLEMMING. But when that is adopted, that will have an effect on SSI. We ought to consider what the relationship between SSI and that is, because I think we are about to adopt that; and I think it is a great thing—the President has presented with us a great report and, of course, the First Lady has presented members of the committees on the Hill here with tremendous testimony, it seems to me. I think we are at an historic moment.

Chairman FORD. Thank you very much. My time has expired, but I do have one question for Dr. Thompson.

Dr. Thompson, I mentioned in my opening statement outlays growing at 8 percent per year. I think you somewhat responded to that in your statement. Is the administration considering ways maybe to control the rate of growth on the SSI outlays, and if so, could you?

Mr. THOMPSON. Mr. Chairman, we do not have any kind of a coordinated strategy, at least at this time, that we are developing to deal with this. I think that there are some areas that you mentioned also in your opening statement, such as the aliens issue, and there are some areas where we would be willing to work with you and look at some of the areas of growth. But we don't have any plan, or we don't have any coordinated program right now.

Chairman FORD. Do you see areas in the SSI program where savings can be reapproved and redistributed among the SSI program?

Mr. THOMPSON. I wouldn't want you to think that there aren't areas that are going to be just a little bit painful to deal with. We are dealing with people with very limited assets, and it is not comfortable taking benefits away from any of them. So the best I could say is that there are areas we could take a look at with you and see whether there is some money that could be saved, that we would feel better about spending it someplace else.

But I don't want you to think that we know of a pocket or a chunk of people who don't deserve benefits and that we would all feel happy about taking their benefits away. That is not the case.

Chairman FORD. Mr. Santorum.

Mr. SANTORUM. Thank you, Mr. Chairman.

Dr. Flemming, I noticed in reviewing your modernization project's findings that you are calling for an increase in spending over the next 5 years of $105 billion, and that you are talking about adding 3.5 million new recipients to the SSI program. Given what the chairman has just talked about and the growth of the SSI spending, given the problems we are having in dealing with a budget deficit, I would be interested in having you submit to the subcommittee and hear you talk about how we would finance this increase in spending.

Mr. FLEMMING. First of all, I sometimes say, however, that at the end of 5 years, the SSI budget would be about $38 billion, whereas today it is around $20 billion; in other words, close to double.

Now, the bulk of the cost of those recommendations is contained in the 5-year recommendation that we increase benefits to 120 percent, about $28 million.

Mr. SANTORUM. When you say "increase benefits to 120 percent," what you are talking about is a poverty calculation which does not include noncash benefits, so all of these people on SSI are receiving Medicaid, receiving food stamps and other noncash benefits that do not count toward poverty calculations, correct?

Mr. FLEMMING. I appreciate that Medicaid and food stamps and so on are very much involved in the SSI program. The only figure I was using was the——

Mr. SANTORUM. My question is, that truly reflect——

Mr. FLEMMING. There would be an increase there.

Mr. SANTORUM. Does that truly reflect what poverty is versus what the average American out there working for a living thinks it is?

Mr. FLEMMING. We could agree on figures, I am sure.

Let me take your fundamental issue. Yes, I had some very definite convictions along that line. The Congress has passed the economic plan proposed by the President which does provide a good deal of money for deficit reduction, but also provides some money for domestic programs, new programs or old programs. I am simply contending that SSI should receive its fair share of that additional money. What that would amount to I don't know. That is something we can discuss back and forth.

But there is a possible source of income there.

Mr. SANTORUM. I am not sure I understand where you are saying the possible source of income is.

Mr. FLEMMING. The possible source of income is, when you passed the economic plan of the President at the first of the year, you did provide some additional funding, additional revenue, a large part of which would be used for deficit reduction over a period of 5 years, but some of which can be used for proving existing programs or developing new—for example, you have just passed the National Service Corporation bill, which does provide for some additional funds; it doesn't provide as much as he had requested in the first place, but it does provide some.

Now, my contention is that when you consider supplemental funds of that kind, you should not pass over the SSI. This is a fundamental, basic program and——

Mr. SANTORUM. I guess my——

Mr. FLEMMING [continuing]. We should have a fair share of it apply to that.

We set some goals. You can use those goals for the purpose of appropriating additional money for SSI, only representing its fair share at this particular point.

Mr. SANTORUM. I hearken back to my question, which is, aside from where you say that there is an existing amount of money out there that we can draw from, what you are suggesting is that there are other programs that were given new funds under the Budget Reconciliation Act from which we would take money to fund SSI.

What programs would you suggest we take the money from?

Mr. FLEMMING. I am not suggesting—in 1994—well, first of all, in the 1994 budget, you appropriated funds for 2,400 additional personnel for SSA. That is part of our recommendation.

Mr. SANTORUM. And I——

Mr. FLEMMING. So you made that particular decision.

Mr. SANTORUM. I support that 100 percent.

Mr. FLEMMING. When it comes to the 1995 budget, you would have the opportunity for reviewing funds that have been appropriated for new programs or for old programs and so on; and I simply urge that—in the 1995 budget, that SSI receive its fair share of increase in funding.

Mr. SANTORUM. Again, try to answer my question which is, where would we get the money from? There is a deficit that we have, that we will have in 1995 as well as 1994. The new money for SSI is either going to come from some other program or increased revenues or an increased deficit. Those are the three options.

Mr. FLEMMING. I know. That is designed to put this program into competition with other programs.

Mr. SANTORUM. Sir, that is the reason we are here, because we have to set priorities for these programs.

Mr. FLEMMING. We would be very glad to sit down with you and discuss in detail the 1995 budget and where there is some money that can be used on SSI.

Mr. SANTORUM. If I can——

Mr. FLEMMING. I am not going—we should put additional money in AFDC, too.

Mr. SANTORUM. I appreciate that your panel's work recommends increasing the staffing limit. There are a lot of other recommendations as well, and I think they are well-founded and very helpful to the committee. My only suggestion would be, if the panel is going to come before us and ask us to increase spending on benefits $105 billion in an era where we are running $200-plus billion annual deficits, it should come with some suggestions as to where we are going to get this money and not just——

Mr. FLEMMING. I just told you one place where we can get the money. I faced that question very seriously as a member of the panel and chairman of the panel. And I have been convinced that under the present administration there is going to be additional money for domestic programs, new and old; and all I am saying is that SSI should receive its fair share of that money.

It got some share of it in 1994, and I think it should get a fair share in 1995.

Mr. SANTORUM. Mr. Thompson, just a couple of questions for you. It is my understanding that the subcommittee is going to be holding a couple of additional hearings on SSI. One of them is going to be on the drug problem, and I think it is going to be with the Social Security Subcommittee that we will hold that hearing.

Is there anyone in particular on your staff that we can work with in trying to come up with some solutions to this seemingly ever-increasing problem of growing numbers of addicts on SSI?

Mr. THOMPSON. Sure, we can identify somebody for you to contact.

Mr. SANTORUM. If you would get that to our subcommittee, I would very much appreciate it. And the same thing with money for noncitizens. That is another very rapidly increasing area of SSI, as the Chairman mentioned; and we would also like to have someone designated from your office to work with us on that.

Mr. THOMPSON. No problem.

Mr. SANTORUM. Thank you very much.

Chairman FORD. Thank you very much, Dr. Thompson and Dr. Flemming, for coming out this morning. We look forward to working with you over the next few months and looking into this area of supplemental security income.

I would like to call on some of the my colleagues, Gerald Kleczka from Wisconsin; Jim Slattery from Kansas; and Jim Ramstad of Minnesota.

I would like to welcome our first witness, a member of the full Committee on Ways and Means. We are delighted to have you here this morning.

Gerald, I am going to start with you as a member of the committee first. We are ready to proceed, Gerald, you may go ahead.

STATEMENT OF HON. GERALD D. KLECZKA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WISCONSIN

Mr. KLECZKA. Thank you, Mr. Chairman.

Mr. Chairman, I take this opportunity to speak to you regarding the supplemental security income program. I will summarize my testimony and ask that the full text be submitted for the record.

Chairman FORD. We have already stated earlier that you can summarize your text and all written testimonys will be made part of the record today, from all witnesses.

Mr. KLECZKA. Thank you.

Mr. Chairman, my State of Wisconsin has one of the largest SSI programs in the country, so it is with some experience and expertise and great interest that I come before you today. In general, I have some doubts on whether the SSI program for children is appropriate. And most of my testimony will focus on this area.

In most States, including Wisconsin, child SSI recipients also qualify for Medicaid. The question isn't, should we provide for these children; the question is, is there a better way. In addition, we must ensure that proper safeguards are in place so that no one is freeloading off the system.

I have four major concerns I would like to share with you about the current program. First, some families of recipients are abusing the program. There are records of children being "coached" on actions that will help them maintain benefits or gain acceptance into the program. A particularly startling example is a child whose father is on Social Security Disability and SSI. There are records of both sexual and physical abuse of the child. After the father learned of the *Zebley* decision, the child began showing up to school with gum in her hair, began acting up, and her grades dropped.

Once she was approved for SSI, the family received nearly $18,000 in retroactive benefits. They then purchased a car, new furniture and clothes and took a vacation to Florida. Since then, they have been evicted because they had not paid their rent in 6 months.

Additionally, counselors report that some parents are refusing to allow their children treatment, fearing that improvement will cost them their benefits. One blatant example involved parents of a child with an attention deficit disorder, and the parents said, "We don't want medication, that will screw up his SSI."

Thus, a cycle of dependency is perpetuated. It only hurts the child recipients in the long run. In too many cases, benefits are not being used to meet a child's medical needs, but are instead being spent on frivolous items by the parents. Under the current guidelines, the benefits that a child receives are not necessarily linked to improving the child's situation.

Clearly, we cannot permit these abuses to continue.

Second, there is no family limit for SSI. This means that some Wisconsin families with multiple members qualified for SSI can receive over $40,000 per year in tax-free benefits plus Medicaid coverage. Clearly, the program should have a family maximum, as there is for Social Security Disability.

Third, a major problem with the program which must be addressed is the enormous backlog of cases due, in many ways, to the increase in child applicants. Since the Supreme Court's *Zebley* decision in February 1990, SSA has spent $2 billion on retroactive payments to some 100,000 children. Under the new regulations which resulted from *Zebley,* the number of children on SSI has skyrocketed. Nationally, the number of children on SSI grew from 293,000 in December 1989, to 614,000 in December 1992, a 109 percent increase. Wisconsin experienced a 134 percent growth over the same period as the number of children on the program increased from 6,010 to 14,070.

SSI is doing the best it can with limited resources, but the saturation of the SSI system prevents SSA from fully reviewing financial accounts and actively overseeing the program. For example, in Wisconsin, most cases have not had reviews for determination of disability for some 5 years.

Fourth, although most recipients do not have experience handling large amounts of money they generally receive *Zebley* settlements in lump sum payments. This often leads to more questionable spending. The subcommittee might want to consider installments to help control this program. If it works for State lotteries, it can work for SSI. Other possibilities are vouchers or "packaged" trusts.

Mr. Chairman, the bottom line is that the basic premise of SSI is noble. But is SSI the right program for disabled children in need? Clearly, the current program needs to be modified or other programs substituted. We must continue to assist those who need benefits the most, but we must also curb the abuses and the freeloading.

Again thank you, Mr. Chairman, for this opportunity to address the committee. I look forward to working with you in the full committee to reform our Nation's SSI program.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

Statement of Gerald D. Kleczka
Member of Congress
Before the Subcommittee on Human Resources
Committee on Ways and Means
October 14, 1993

Good morning, Mr. Chairman, and thank you for this opportunity to appear before the Human Resources Subcommittee regarding the Supplemental Security Income (SSI) program.

With a maximum combined state and federal monthly benefit of $526.72 for an individual living independently, my state of Wisconsin has one of the largest SSI programs in the country.

In general, I have some doubts about whether the SSI program for children is necessary; and, most of my testimony will focus on this area.

I would like to clarify that I am not, for one moment, suggesting that the government's role is not to care for those children with disabilities who need our help. It is our role to assist them. However, we must place proper safeguards to ensure that these benefits are not abused.

Having said that, I question whether this program, despite its noble goals, is appropriate. SSI is designed as a welfare program to supplement income for those who are blind, disabled, or aged. Therefore, I question why children, who are dependents, need to receive it. In most states, including Wisconsin, child SSI recipients also qualify for Medicaid (Title 19). Besides medical and rehabilitation costs, which are covered under Title 19, and special program costs, which could be covered under an expanded Title 19, the cost of raising a child with a disability is not significantly different than the cost of raising a child without one. We need to provide them with medical, rehabilitative, and special education benefits, but not necessarily income. Some professionals in my district suggest that the benefits currently given directly to families could be more productive if they were channeled in some fashion directly to schools or special programs. This would ensure that the benefits are used to advance the child's situation and physical condition.

The current situation begs the question: is there a better way than SSI to provide the necessary services to low-income, disabled children?

Let me share four major concerns I have with the current program.

First, I am concerned that the SSI program for children is abused by the families of some recipients.

Reports of such abuses abound. Some have surfaced of children being "coached" on actions that will help them maintain benefits or gain acceptance into the program.

A particularly startling case is that of a child whose father was also on Social Security Disability and SSI. There were reports of both sexual and physical abuse of the child. According to local claims representatives, once the father learned of the *Zebley* decision, the child began showing up to school with gum in her hair, began acting up, and her grades dropped. She was then approved for SSI and received nearly $18,000 in retroactive benefits. The family purchased a car, new furniture, and clothes and took a vacation to Florida. They have since been evicted, because they had not paid their rent in six months. The child had a job but was instructed by the father "not to take too many hours, because it will make us lose your benefits."

Additionally, there are several examples of counselors reporting parents who refuse to allow their children treatment, fearing that improvements in their conditions would cost them benefits. One particularly blatant example is a counselor who quotes parents of a child with attention deficit disorder as saying, "We don't want medication, that will screw up his SSI."

Thus, a cycle of dependency is perpetuated that only hurts many of these young recipients in the long run. Some benefits are reportedly not used to help meet the disability needs of children, but are instead being spent frivolously by parents. Under the current guidelines, the benefits a child receives are not necessarily linked to improving the child's situation.

I cite the case of a woman who repeatedly called my Milwaukee office asking for updates on "her benefits." These were in fact her daughter's SSI benefits. After SSA received several calls from her that her checks were lost in the mail or her children were robbed while going to the store with her money, the case was investigated. The child was placed in a foster home when it was determined that the mother had been using the SSI money to purchase drugs for herself.

Clearly, we cannot permit these abuses to continue.

Second, there is no family limit for SSI. This means that some Wisconsin families, with multiple members qualified for SSI, can receive over $40,000 per year in tax-free benefits plus Medicaid coverage. Clearly, the program should have a family maximum as there is for Social Security Disability.

Third, a major problem with the entire SSI system is the enormous backlog of cases, which is due in part to the increase in child applicants. Since the Supreme Court's *Zebley* decision in February 1990, SSA has spent $2 billion on retroactive payments to 100,000 children. Nationally, the number of children on SSI grew 109.4% from December 1989 to December 1992, up from 293,320 to 614,190. In Wisconsin, the number was up 134.1% from 6,010 to 14,070.

SSA is doing the best it can with its limited resources. But, the saturation of the SSI system also prevents the agency from fully reviewing financial accounts and actively overseeing the program. For example, reviews of the determination of disability for most cases in Wisconsin have not been performed for five years, even in cases where the claims representative had marked the case as questionable.

Fourth, although recipients may not have experience in handling large amounts of money, they generally receive *Zebley* settlements as lump-sum retroactive payments. This often leads to more frivolous spending by the parents of some child recipients.

The subcommittee may wish to consider installments to help control this problem. If it works for state lotteries, it can work for SSI. Other possible alternatives are vouchers and "packaged" trusts, which could be put together at little expense.

Mr. Chairman, the bottom line is that the basic premise of SSI is noble. I'm just not certain whether this program is the best program for low-income, disabled children. The current program needs to be modified or other programs substituted. We should continue to assist those who are in severe need and cannot turn elsewhere. However, we must curb the abuses which constitute freeloading and ultimately only hurt the U.S. taxpayer and fail the recipients.

Again, thank you Mr. Chairman for this opportunity, and I look forward to working together to reform our nation's SSI program. I would be happy to answer any questions you or the other members of the subcommittee may have.

Chairman FORD. Mr. Slattery.

STATEMENT OF HON. JIM SLATTERY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF KANSAS

Mr. SLATTERY. Thank you, Mr. Chairman. First of all, let me thank you, Mr. Chairman, and the members of this committee for your assistance in passing legislation during the last Congress as part of the reconciliation package that addresses a very serious inequity, I think, in the SSI program as it affected the children of military families.

If you recall, prior to the change last year, if a person or a family in the military was transferred overseas they would lose their SSI eligibility for their children when they were transferred overseas. This committee, thank goodness, acted to change that law to enable SSI-eligible families in the military to continue to obtain SSI benefits when they are transferred overseas.

There is still a problem, however, and the legislation that I am here to talk to you about today H.R. 480 corrects that problem. The problem that remains is a situation where a family stationed with the military overseas may, for example, have a newborn child that would otherwise be eligible for SSI-type benefits, but by virtue of the fact that they were born overseas, would not be eligible for SSI benefits.

We are talking about a very small number of people. In fact, according to the Department of Defense projections, about 50 children per year will fall into this category. So we have these 50 children born overseas with military families that would otherwise be eligible for SSI benefits that are not eligible merely by virtue of the fact that they are overseas.

H.R. 480 is designed to correct that problem. And enable them to obtain the benefits that they would otherwise be entitled to. And the bottom line for me is, I don't think that these families by virtue of the fact that they are in the military should be denied SSI benefits that they would otherwise be eligible for.

The cost of this program to change is about $1.5 million over 5 years; we are talking about a small amount of money. It is projected to cost about $300,000 per year.

This legislation has been endorsed by the National Military Family Association, the Noncommissioned Officers Association. They played a very important role in the passage of the earlier legislation that I have already referred to, and they are very helpful in passing this legislation also.

I certainly hope, Mr. Chairman, and Mr. Santorum, that when you look at this area of the law, you recognize the need to make this correction. If you are interested in how we can pay for it, I will give you an opportunity to help us pay for it in the next few days by helping me defeat the supercollider. We will save $10 billion in the process, and all we need is just $1 million of the $10 billion to pay for what I am talking about here today.

So if you are looking for ways to pay for it, we can certainly find those ways.

Chairman FORD. Thank you, Mr. Slattery.

[The prepared statement follows:]

STATEMENT OF
THE HONORABLE JIM SLATTERY
BEFORE THE
SUBCOMMITTEE ON HUMAN RESOURCES
OF THE
COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES

OCTOBER 14, 1993

Thank you, Mr. Chairman, for the opportunity to participate in this important oversight hearing on the Supplemental Security Income (SSI) program. I am pleased to be here to discuss legislation, H.R. 480, I have reintroduced in the 103rd Congress to extend eligibility for SSI benefits to all eligible children of military personnel stationed overseas.

With the support of this Committee, I am pleased that it has been possible to correct the long-standing injustice against several hundred military families who previously were forced to forfeit their eligibility for SSI benefits when they were transferred overseas. These families now can continue to receive SSI benefits if they were eligible for benefits for the month before the parents were assigned to duty outside the United States, Puerto Rico, or the U.S. territories or possessions.

H.R. 480, however, targets the small number of military families with eligible children who continue to be denied SSI benefits. These patriotic families are <u>already stationed overseas</u> when they find that their newborn or newly diagnosed child may be eligible for a monthly SSI stipend. According to Department of Defense projections for total active duty military sponsors overseas in 1995, fewer than fifty (50) children per year will fall into this category. H.R. 480 would ensure eligibility for these families who face significantly increased financial burdens as they attempt to provide the specialized care their child needs -- while serving their nation abroad.

I have corresponded with U.S. Health and Human Services Secretary Donna Shalala regarding H.R. 480. Secretary Shalala has indicated to me that it would be possible to make determinations regarding SSI eligibility for military personnel stationed overseas if the Social Security Administration is given adequate time to prepare for implementation of this extension of SSI eligibility.

Further, an initial Congressional Budget Office (CBO) cost estimate for H.R. 480 indicates a total of $1.5 million over five years or an increase in direct spending of approximately $300,000 in each fiscal year from 1994 through 1998. I welcome the opportunity to work with the members and staff of the House Ways and Means Committee to find a source of revenue to offset this modest expenditure.

Finally, H.R. 480 has the endorsement and support of numerous military organizations including the National Military Family Association (NMFA) and the Non Commissioned Officers Association (NCOA). I am honored to have had the opportunity to work with these organizations to address the needs and interests of our NCO's, enlisted personnel, and their families.

Overseas assignment is considered an honor by many in the military. Service abroad also is an important component to a successful military career. The current system penalizes families suddenly faced with the tremendous challenge of caring for a disabled newborn or child while serving an overseas tour of duty. H.R. 480 ensures that all eligible active military personnel, regardless of their post assignment, will continue to receive the benefits to which they and their families are entitled.

Thank you, once again, for this opportunity to testify before this Committee. I applaud your efforts to improve and expand the SSI program and I look forward to working with you to include military families in this important effort. I am pleased to answer any questions you may have regarding H.R. 480.

Chairman FORD. Mr. Ramstad.

STATEMENT OF HON. JIM RAMSTAD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

Mr. RAMSTAD. Thank you, Mr. Chairman. I applaud you for calling this hearing to discuss the issues related to Supplemental Security Income. I am particularly concerned about the impact of SSI on individuals with disabilities.

When I first came to Congress with your distinguished ranking member in 1991, I was surprised to learn that of all the caucuses and task forces on the Hill, there was no group specifically focused on issues affecting people with disabilities. So I started the Republican Task Force on Disabilities. Last year, under the purview of that task force, I held a field hearing in Minnesota concerning disincentives created by those Federal programs, mainly SSI, which are supposed to assist people with disabilities. In fact, Allen Jensen, who is in the room today, a very distinguished social scientist from the George Washington University Center for Health Policy Research, was one of the panelists, along with the Associate Commissioner for Disability at the Social Security Administration here in Washington, and a number of local experts.

Most of the experts were people with disabilities. From them I heard countless stories of their frustrations. People who desperately want to work and contribute to society, are literally prohibited from doing so because of SSI simply because it is too expensive for them to work.

A good example is a very close friend of mine. His name is Tom Haben. He's chair of the Metropolitan Handicapped Coalition in the Twin Cities of Minneapolis and St. Paul. He is a brilliant guy; happens to be my same age, a person with quadriplegia.

Tom put it this way: It is a nightmare to try to unscramble the SSI cobweb. The most he can make and not risk losing his benefits, which enable him to live as independently as he can, is $500 a month. God knows he is worth as much or more in salary as anybody around here is making, but he is locked into a job paying no more than $500 a month.

Like everyone else, people with disabilities have to make decisions based on financial reality. The risk of losing vital Federal income benefits and medical assistance is too threatening to future financial stability, as well as physical well-being, so it discourages people with disabilities from maximizing not only their vocational potential but also their independence.

In addition, most parents, advocates, and social workers also perceive this as too big a risk, so they advise their clients and their children against even trying to work.

So Mr. Chairman, Mr. Santorum, discouraging people with disabilities from working and picking up that regular paycheck and eventually moving off public assistance results in a much smaller work force and reduced Federal revenues. It is counterproductive from an economic standpoint.

It is clear to me that creating work incentives for people with disabilities is not just humane public policy, it is sound fiscal policy. Eliminating the current barriers to work that so many individuals face is not only the smart thing to do, it is the right thing to do.

You might be aware of the legislation that our distinguished colleague, Pete Stark and I introduced. This legislation seeks to address the profound work disincentives that people with disabilities face because of the way Federal programs are structured and intertwined with State programs.

Several of our colleagues and several of my constituents have reviewed this legislation, H.R. 3264. The consensus seems to be that adoption of this bill would address many of the problems generated by the existing SSI program. In fact, one of the groups I asked to review the legislation, Tasks Unlimited, is an advocacy group in Minnesota for people with mental illness. They have extensive experience working with disabled adults and understand that, like most people in our society, people with disabilities are motivated to achieve, contribute, and be self-sufficient.

This group reported that if H.R. 3264 is implemented, at least 35 to 40 individuals in their group alone would take a chance at working themselves off the Social Security System. So, Mr. Chairman, in conclusion let me say that I believe strongly that reform of the SSI program is desperately needed. I urge you and your committee to carefully consider the changes recommended in H.R. 3264; and again, I am grateful and strongly applaud you for holding this hearing and look forward to working with you to address the problems with this system.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

STATEMENT BY CONGRESSMAN JIM RAMSTAD OF MINNESOTA
HUMAN RESOURCES SUBCOMMITTEE, WAYS AND MEANS COMMITTEE
October 14, 1993

HEARING ON SUPPLEMENTAL SECURITY INCOME

Mr. Chairman, I strongly applaud you for calling this hearing to discuss the issues related to Supplemental Security Income.

Thank you very much for allowing me to make a brief statement about the importance of this situation.

While the problems relating to SSI are numerous, I am particularly concerned about the impact of SSI on individuals with disabilities.

When I came to Congress in 1991, I was stunned to find that among all the caucuses, coalitions and task forces on the Hill, there was no group specifically focused on issues affecting people with disabilities. That's why I started the Republican Task Force on Disabilities.

Last year, under the purview of the task force, I held a field hearing in my district on the work disincentives created by those federal programs -- particularly SSI and SSDI -- which are supposed to assist people with disabilities.

I heard countless stories of frustrated individuals who desperately want to work and contribute to society but are literally prohibited from doing so because federal programs and rules make working too expensive for them.

Like everyone else, the people with disabilities have to make decisions based on financial reality. The risk of possibly losing vital federal income benefits and medical assistance is simply too threatening to future financial stability, discouraging people from maximizing their vocational potential. In addition, most parents, advocates and social workers also perceive this as too big a risk and often discourage people from even trying to work.

Discouraging people with disabilities from working, earning a regular paycheck and eventually moving off public assistance, results in a smaller work force and reduced federal revenues.

It is clear that creating work incentives for people with disabilities is not just humane public policy, it is sound fiscal policy. Eliminating the current barriers to work that so many individuals face is not just the smart thing to do, it's the right thing to do.

As you may know, I have joined your esteemed colleague on the Ways and Means Committee, Representative Pete Stark, in cosponsoring legislation to address the profound work disincentives people with disabilities face because of the way the federal programs are structured.

Several of my constituents have reviewed our legislation, H.R. 3264, and have indicated to me that adoption of the bill would address many of the problems generated by the existing SSI and SSDI programs.

Tasks Unlimited, an advocacy group in Minnesota for people with mental illness, has extensive experience working with disabled adults and understands that like most people in our society, people with disabilities are motivated to achieve, contribute and be as self sufficient as possible.

Tasks Unlimited estimates that if H.R. 3264 is implemented, at least 35-40 individuals in their group alone will take a chance at working themselves off the social security system.

Mr. Chairman, reform of the SSI and SSDI programs is desperately needed. I urge you and your committee to carefully consider the changes recommended in H.R. 3264.

Again, I strongly applaud you for holding this hearing and I look forward to working with you to address the problems with this system.

Chairman FORD. Mr. Faleomavaega, please.

STATEMENT OF HON. ENI F. H. FALEOMAVAEGA, A DELEGATE TO CONGRESS FROM THE TERRITORY OF AMERICAN SAMOA

Mr. FALEOMAVAEGA. Mr. Chairman and members of the subcommittee, I thank you for the opportunity to appear before your committee today. I certainly would like to commend——

Chairman FORD. Would you pass the mike over for me, please, Mr. Ramstad.

Mr. FALEOMAVAEGA [continuing]. The distinguished members of this committee for holding this oversight hearing to determine ways to improve the SSI and its services to the people with low or no incomes who are over 65 or blind or otherwise disabled.

In this regard, Mr. Chairman, I would also like to discuss the provisions of H.R. 188 and 189, which I introduced to provide equitable treatment for the elderly, blind and disabled individuals residing in my district.

As you know, Mr. Chairman, American Samoa is the only jurisdiction in the United States that is not served by either the SSI or the AABD program. The only significant difference between the two programs, as you well know, Mr. Chairman, is how it is currently being administered for the benefit of the five territories. The SSI benefits and the cost of administration are fully funded, whereas the AABD that is currently being used for the territories, the Federal Government pays 75 percent, with the territories absorbing 25 percent of the administrative costs.

Under the current law, in order to receive SSI benefits, a low-income, elderly, blind or disabled individual must reside in 1 of the 50 States, the District of Columbia, or the Commonwealth of the Northern Mariana Islands. As I stated earlier, our friends from Guam, Puerto Rico, and the Virgin Islands currently receive the benefits of the AABD program, but my territory does not get AABD or SSI.

I believe, Mr. Chairman, this is probably a simple oversight in the fact that in 1950 the Federal law provided the AABD program for the District of Columbia, Puerto Rico, Guam and the Virgin Islands, as well for the Northern Marianas, but not for my territory. I believe that this is in view also because the citizenship statutes were issues that were then considered by the Congress in the 1950s.

Mr. Chairman, we have a problem here, particularly in my district where the elderly population in the Territory have been caught between two systems. When Social Security went into effect in the Territory, this group of people were too old to contribute long enough to qualify for minimum benefits.

On the other hand, the territorial retirement system did not begin until 1971. By that time, many of these people had already left the work force or had so little time remaining that they were also excluded from benefits under this system.

Mr. Chairman, I am cognizant of the complications of extending the SSI program to my district, and I introduced legislation in 1991 and again earlier this year. The cost of approximately about $1 million of the AABD program is to be provided, or $3 million if the SSI was to be administered.

As you know, the three insular areas who currently have AABD are also asking for inclusion in the SSI program. I support this effort, but I also recognize the difficulties faced by this committee and others in including all Territories in the SSI program, mainly because of the anticipated increases in Federal outlays which would result from such a move.

Mr. Chairman, I simply urge the members of the committee to support H.R. 188, which I had introduced to include American Samoa in the AABD program, which is still in operation today, and this bill would correct this inequity which exists under current law.

Thank you, Mr. Chairman. I would be glad to answer any questions.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

Eni Faleomavaega
ENI F. H. FALEOMAVAEGA
Member of Congress

STATEMENT OF THE HONORABLE ENI F. H. FALEOMAVAEGA BEFORE THE HOUSE WAYS AND MEANS COMMITTEE SUBCOMMITTEE ON HUMAN RESOURCES

October 14, 1993

Mr. Chairman and Members of the Subcommittee: Thank you for the opportunity to appear before your Committee today. Before proceeding with my remarks, I would like to commend you, Mr. Chairman and the distinguished members of this committee, for holding this oversight hearing to determine ways for the SSI program to improve its services to people with very low or no income who are over 65 or blind or otherwise disabled. In this regard, I would also like to discuss H.R. 188 and H.R. 189 which I introduced to provide equitable treatment for the elderly, blind, and disabled individuals residing in American Samoa.

As you know, Mr. Chairman, American Samoa is the only jurisdiction of the United States that is not served by the SSI program, nor its predecessor program, the Aid to the Aged, Blind, or Disabled (AABD). SSI and AABD are basically the same in design. The only significant difference between the two programs is funding. With SSI, benefits and the cost of administering the program are fully financed by the Federal Treasury. On the other hand, the Federal Government pays 75 percent of AABD benefits up to a specified limit and the States absorb 25 percent. Administrative cost is shared by both the Federal Government and the States at 50 percent each.

Under current law, in order to receive SSI benefits, a low-income elderly, blind or disabled individual must reside in one of the 50 states, the District of Columbia, or the Commonwealth of the Northern Mariana Islands. For qualified individuals who reside in Guam, Puerto Rico, or the Virgin Islands, similar benefits are available to them through the AABD program. Unfortunately, the elderly, blind and disabled individuals in American Samoa who have low or no income are not covered by either program.

Mr. Chairman, this is yet another example of a vital program extended to all 50 States, the District of Columbia, Puerto Rico, Guam, Virgin Islands, and the Northern Mariana Islands, but not American Samoa. I believe this may have been an oversight when Puerto Rico and the Virgin Islands were included in the AABD program in 1950, and Guam after 1952.

According to a recent survey in American Samoa, there are now approximately 3,500 elderly, blind and disabled individuals with low or no income. These individuals are without resources which are available to other Americans who reside in other parts of the United States.

In addition, Mr. Chairman, the elderly population in American Samoa have been caught between two systems. When Social Security went into effect in Samoa, this group of people were too old to contribute long enough to qualify for minimum benefits. On the other hand, the territorial retirement system did not begin until 1971. By that time, many of these people had already left the work force or had so little time remaining that they were also excluded from benefits under this system.

In each Congress since 1990, I have introduced legislation to include Samoa's elderly, blind and disabled population in the SSI program to address their critical financial needs. In 1990, it was estimated that approximately 1,600 such individuals reside in the Territory. The Congressional Budget Office estimated that if SSI was in place in American Samoa in 1993, Federal outlays would be about $3 million higher than under current law.

During the 101st and 102nd Congresses, the Bush administration, through the Commissioner of Social Security, opposed extending SSI to Samoa due to cost considerations.

Mr. Chairman, because I am cognizant of the complications of extending the SSI program to American Samoa, I introduced legislation in 1991, and again earlier this year, to include Samoa in the AABD program which currently exists in the other three insular areas. A cost estimate prepared by the Congressional Budget Office indicates that Federal outlays would increase by $1 million if AABD were in place in American Samoa.

As you know, the three insular areas who currently have AABD are also asking for inclusion in the improved supplemental security income program. I support this effort but I also recognize the difficulties faced by this Committee and others in including all territories in the SSI program mainly because of an anticipated astronomical increase in Federal outlays which would result from such a move.

Should the Committee determine that it is not possible to include American Samoa in SSI at this juncture, I urge the members of the Committee to support H.R. 188 which proposes to include American Samoa in the AABD program which continues to operate in the other three insular areas. This bill will correct this inequity which exist under current law.

Thank you once again Mr. Chairman for allowing me to testify today on behalf those Americans who are denied vital services due to an unintentional oversight on the part of the U.S. Congress.

Chairman FORD. Let me thank all four of our colleagues for the testimony that you have given before the subcommittee today.

Mr. Kleczka, let me ask you this.

Let me first express concerns similar to those you have expressed in your testimony before the subcommittee today. In fact, my staff has met with officials in the Inspector General's Office of the Department of Health and Human Services about some of the alleged abuses that you have already discussed in your testimony before the subcommittee today.

I understand that the Inspector General's Office will be issuing a report later on her findings and recommendations, and I want to assure you and others that this subcommittee will make a careful review of those findings by the Inspector General's Office.

But you are suggesting, I guess, in your testimony that SSI benefits not be given to children with disabilities. Would it be better to give them some type of service to overcome their disability? Is that what I am hearing in your testimony?

Mr. KLECZKA. Yes, Mr. Chairman. As I indicated, these children are eligible for title 19. Clearly, if the child has a disorder, we want to help them out; so if in fact the current provisions of title 19 don't cover their disorder, I think we should probably amend title 19 to make sure that help is available versus just giving a stipend.

In the State of Wisconsin, maximum benefits are in excess of $500. There is no mandate that those dollars be used on medical treatment for the child.

Chairman FORD. Mr. Slattery, you also talked about the $1.5 million that we need for the military children.

I know you talked about the supercollider. I am going to vote with you on that from this subcommittee and in the Ways and Means Committee. We really need to fine tune the mechanism within the jurisdiction of the committee itself. I certainly appreciate your recommendations in providing the billions of dollars that will be needed.

Let me ask you this: I know we are going to have to find some way to fund it. I think this is an area that we are going to have to address. But I would really like to know from you, tell me, how would the Social Security Administration process such claims when there is no State disabilities determination in these other countries? Would we use the military for the basic determination of disabilities?

Mr. SLATTERY. Mr. Chairman, we have contacted and chatted with Secretary Shalala regarding this very question, and she advises us that it would be possible for the Social Security Administration to administer this change if they were given adequate time to prepare for it.

Chairman FORD. Madam Secretary, did she make recommendations as to how it would be physically done, contracted to the military?

Mr. SLATTERY. She didn't get into that level of detail, but she certainly indicated that it could be done; and I would personally think that perhaps the military could provide the information required, perhaps the military personnel or the military families, home State criteria would be used to administer this. That is a possibility.

Chairman FORD. My concern would be just that component, the determination, how will the determination be made? I mean, if we could get some clarification in that area, Jim, I think it is a bill that we could probably mark up and move on. It is an area that we must address, but the determination factor, if we can continue to make some recommendations to this subcommittee over the next couple of weeks, it is an area that we could probably move on.

Mr. SLATTERY. Let us follow up with Secretary Shalala and find out what she would recommend in terms of the best administrative approach for us to use. But I don't see any reason why this income information could not be handled through the military, and if not that, why, in some instances—and I would assume that most of these families would have a State of residence in this country—the normal process would be followed there to determine their eligibility.

So either/or. Again, I think we are only talking about 50 families, so it shouldn't be an insurmountable problem, I wouldn't think.

Chairman FORD. OK. Mr. Santorum.

Mr. SANTORUM. Thank you, Mr. Chairman. Mr. Kleczka, I must say that I was very impressed, and I consider this to be some courageous testimony. I don't normally hear this kind of testimony from members about welfare programs, because they are very politically sensitive; and I commend you greatly for coming to this committee and saying what you are suggesting. Frankly, it is not something I had looked at, and frankly, you may have really identified a very important issue for this subcommittee.

Have you put together a bill or do you have anything beyond the testimony that we might be able to look at and work from?

Mr. KLECZKA. OK. Mr. Santorum, I have not introduced legislation at this point. As the Chairman indicated, the IG is coming out with a report—I believe it is within the next 2 months—and based on what is contained in that report, I think—in concert with yourself and your committee, we should start looking at some alternatives to try to clean up the system.

You know, as a State legislator, I was always very supportive of SSI, and that is probably one reason why Wisconsin has one of the biggest supplements. Our per-person total is $526. However, when you see a program that, as I indicated, was noble and was working to help the disabled, blind, and aged, but is now being abused, I think it is time that this Congress take note of that and correct it.

I heard the previous speaker, as I was waiting to testify, say that we would like to increase the benefits for those currently on the system. You know—and in fact there is need there—I would like to do that, but once the public is presented with some of the abuses like I brought forward, there may not be a hue and cry to tamper with the program.

I might add that the information I have shared with you today comes from a series of Milwaukee Journal articles, one of the major newspapers in the State of Wisconsin. We are constantly receiving calls in our Milwaukee office, not only from SSI employees or SSA employees and former employees, but also receiving calls now from teachers who have to fill out these evaluation forms. And in some districts and in some schools, these teachers are deluged with these forms to provide an assessment of the children.

And you can just look at the increase in the number of children on the program—you know, over a period of 3 years, a 109 percent increase. We know something is wrong, and my fear is that some folks out there think they have found a program that is easy to get on, that is going to provide big Federal benefits; and sorry to say, I think it is being abused in some instances.

Mr. SANTORUM. Again, I appreciate your testimony very much. I look forward to working with you and the subcommittee and full committee on coming up with a solution.

Mr. Ramstad, as you know we were in Republican Conference yesterday, working on our welfare reform proposal; and many of the things that we had in the bill were addressing the problem of work disincentives for people on public assistance. We had some provisions in the bill with regard to housing disincentives and the laws and increasing of rents of people who decide to go off public assistance and go out to work. Your proposal falls under the same category.

The question I have is the question we always have here and that is, how much is this going to cost. Do you have any CBO estimates?

Mr. RAMSTAD. In fact, right now the CBO is working on those statements. We haven't received them yet.

Mr. SANTORUM. OK. I would again suggest to you that this kind of legislation is certainly in the area that I think everyone in America is crying for. Taxpayers want us to quit putting up barriers to people who want to go out and work and be productive in the mainstream of our society. I would support that as long as we can fashion a way to do it without breaking the piggy bank.

Mr. RAMSTAD. If I may respond briefly, make no mistake about it, there will be a cost to this transition. To enable these people, to empower these people to get out of SSI and to be gainfully, or more gainfully employed in some cases will allow them to enjoy the dignity of independent living and then become productive, contributing taxpayers. So in the long run, it is my hypothesis that this will actually be a cost-saving benefit to the Treasury.

Mr. SANTORUM. And I would agree with that, and the only problem is that CBO doesn't necessarily always agree with the way that I think common sense would work. But I would be anxious to work with you, and in fact, depending on when you get those cost estimates, even consider adopting your legislation as part of the program that we adopted in conference yesterday.

Thank you, Mr. Chairman.

Chairman FORD. Thank you very much.

I thank my colleagues.

Chairman FORD. The committee would like to call on the National Association for Hispanic Elderly, David A. Affeldt; Hardy and Associates, Dorcas R. Hardy, president, and the former Commissioner of the Social Security Administration; Samuel J. Simmons, the National Caucus and Center for Black Aged. He is president and chief executive officer. Also Ethel Zelenske, who is with the National Senior Citizens Law Center. She is a staff attorney.

I would like you to please be seated. The Chair is going to recognize you in the order you were called. Mr. Affeldt, I am going to recognize you first, and then the order that I called the names out: Mr. Simmons, Ms. Hardy, and Ms. Zelenske.

Mr. Affeldt, the Chair recognizes you at this time.

STATEMENT OF CARMELA G. LACAYO, PRESIDENT AND CHIEF EXECUTIVE OFFICER, NATIONAL ASSOCIATION FOR HISPANIC ELDERLY, AS PRESENTED BY DAVID A. AFFELDT, CONSULTANT

Mr. AFFELDT. Thank you very much, Congressman Ford and members of the subcommittee.

Because of time constraints, I shall just focus on two key issues for older Hispanics, first, the need to raise SSI benefits, and second, outreach. The Association has other recommendations which are included in our longer written statement.

Aged Hispanics are confronted with a whole host of problems and challenges during the 1990s. However, none is more important or formidable than inadequate income. Virtually every major problem affecting older Hispanic-origin persons has some linkage with insufficient income. Older Hispanics have one of the higher poverty rates among older Americans. Hispanics 65 years of age or older were more than twice as likely to be poor as elderly white nonHispanics during 1992, 22 percent versus 10.4 percent. This historic ratio has prevailed for several years.

Poverty for older Hispanics is likely to be long term in that it tends to be persistent and, unfortunately, inescapable. In many respects, Hispanic older persons represent an underclass in our society that has often been beyond the reach of conventional strategies.

SSI offers the most direct and cost-effective means to improve the economic well-being of aged Hispanics and other low-income older Americans because it focuses on the most needy elderly people in our society. These facts underscore the need to strengthen and improve SSI.

As a practical matter, the poverty rate for elderly Hispanics and other low-income older Americans is not likely to be reduced appreciably in the years ahead unless SSI is strengthened.

Two major sources of income for elderly Hispanics, Social Security and SSI, have typically played, at best, a catch up game with inflation. Cost-of-living adjustments for Social Security and SSI are certainly necessary and crucial to aged Hispanics and other older Americans. However, it is important to recognize that COLAs alone will not permit older poor persons to escape from poverty's clutches.

Unfortunately, our Nation does not have an income strategy for Social Security or SSI other than annual COLAs. Social Security beneficiaries have essentially received only COLAs since the automatic adjustment mechanism first became effective in 1975. SSI recipients have had only one benefit hike exceeding the inflation rate since the program began to pay benefits in 1974. However, it was linked to a 6-month delay in the Social Security COLA under the 1983 Social Security amendments.

For these reasons, the Association urges that the Federal SSI standard be raised as soon as possible above the poverty line.

Congress clearly intended that SSI should eventually provide an income floor which would enable the aged, blind and disabled to live above the poverty line. The SSI modernization panel has recommended that the SSI benefits standard be raised.

Congresswoman Carrie Meek has introduced legislation, H.R. 2676, the 1993 SSI Reform Act, which would carry out these recommendations. We fully recognize, though, that budgetary considerations may require that the goal of raising the Federal SSI benefits along the lines recommended by the SSI Modernization Panel will probably require implementation on an incremental basis. However, this should not deter our Nation from working expeditiously to implement this objective.

It is crucial, in the judgment of the Association, that our Nation begin now to work toward this goal, even if budgetary constraints necessitate a modest increase above annual SSI COLAs. A few extra dollars a month can enable an SSI recipient to avoid the dilemma of deciding between food necessary for nourishment or medicines to maintain one's health.

We must also remember that time is not on the side of the elderly. Therefore, we believe that it is essential to act soon to raise SSI benefits.

Many elderly Hispanics, as well as other low-income Americans, are eligible for both means-tested and entitlement programs that they did not receive. In 1992, only 29.2 percent of Hispanic aged Americans lived in households that received means-tested cash assistance.

Unfortunately, a large proportion of potentially eligible persons do not receive SSI because they do not know about the program or have insufficient knowledge. Older Hispanic-origin persons have an added dilemma and that is language.

I see the caution light is on. So, let me just summarize my statement very briefly then. We have a three-pronged approach to improve outreach. First, we believe there should be a dedicated percentage of SSI administrative funds earmarked for SSI outreach in order to have a permanent, ongoing outreach program at the Social Security Administration.

Second, bilingual outreach workers should be in areas where large concentrations of limited English-speaking or nonEnglish-speaking populations reside.

Third, a senior-to-senior approach should be employed as one crucial component in the overall outreach strategy.

Now, in conclusion, the Association strongly endorses the key recommendations of the SSI Modernization Panel. We favor Congresswoman Meek's bill, H.R. 2676. We fully recognize that it may be necessary to implement these recommendations on a phase in basis because of cost considerations.

However, the key feature from the standpoint of the Association and elderly Hispanics is that future SSI legislation should have some type of benefit increase to launch an income strategy to come to grips with the growing poverty problem affecting older Americans, and aged minorities in particular. This is essential. And we believe there should be no compromise on this fundamental principle.

Thank you.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

TESTIMONY OF CARMELA G. LACAYO
NATIONAL ASSOCIATION FOR HISPANIC ELDERLY

The Asociacion Nacional Pro Personas Mayores (National Association for Hispanic Elderly) is pleased to testify at this oversight hearing on Supplemental Security Income.

Aged Hispanics are confronted with a whole host of problems and challenges during the 1990's. However, none is more important, nor more formidable, than inadequate income. Virtually every major problem affecting older Hispanic-origin persons has some linkage with insufficient income.

Older Hispanics have one of the higher poverty rates among older Americans. Hispanics 65 years of age or older were more than twice as likely to be poor as elderly White, non-Hispanics during 1992: 22.0 percent vs. 10.4 percent. This historical ratio has prevailed for several years.

Poverty for older Hispanics is likely to be long-term in that it tends to be persistent and, unfortunately, inescapable. As a consequence, numerous aged Hispanics find themselves mired in poverty's vice-like grip. This has caused great despair for the Hispanic elderly population. In many respects, Hispanic older persons represent an underclass in our society that has often been beyond the reach of conventional strategies.

SSI, though, offers the most direct and cost-effective means to improve the economic well-being of aged Hispanics and other low-income older Americans because it focuses on the most needy elderly persons in our society.

Abolition of Poverty: The Top Priority Goal

These facts underscore the need to strengthen and improve SSI. As a practical matter, the poverty rate for elderly Hispanics and other low-income older Americans is not likely to be reduced appreciably in the years ahead unless SSI is significantly strengthened.

The major sources of income for elderly Hispanics -- Social Security and SSI -- have typically played, at best, a "catch-up game" with inflation. Cost-of-living adjustments (COLAs) for Social Security and SSI are certainly necessary and crucial for aged Hispanics and other older Americans. However, it is important to recognize that COLAs alone will not permit older poor persons to escape from poverty's clutches.

Unfortunately, our nation does not have an income strategy for Social Security or SSI -- other than annual COLAs. Social Security beneficiaries have essentially received only COLAs since the automatic adjustment mechanism first become operational in 1975.

SSI recipients have had only one benefit hike exceeding the inflation rate since the program began to pay benefits in 1974. However, this was linked to a six-month delay in the social Security COLA under the 1983 Social Security Amendments.

For these reasons, the Asociacion urges that the federal SSI benefit standard be raised, as soon as possible, above the poverty line. Congress clearly intended that SSI should eventually provide an income floor which would enable the aged, blind, and disabled to live above the poverty line.

The SSI Modernization Panel has recommended that the federal SSI benefit standard be raised eventually to 120 percent of the poverty threshold. Congresswoman Carrie Meek has introduced the 1993 SSI Reform Act (H.R. 2676), which would carry out this recommendation and others developed by the SSI Modernization Panel. The Asociacion strongly supports H.R. 2676.

We fully recognize, though, that budgetary considerations may require that the goal of raising the federal SSI benefit to 120 percent of the poverty threshold may require implementation on an incremental basis. However, this should not deter our nation from working expeditiously to implement this objective. It is crucial, in the judgment of the Asociacion, that our nation must begin now to work toward this goal, even if budgetary constraints necessitate a modest increase above annual SSI COLAs. A few extra dollars a month, though, can enable an SSI recipient to avoid the dilemma of deciding between food for necessary nourishment or medicines to maintain one's health. We must also remember that time is not on the side of the elderly. Therefore, it is essential for the Human Resource Subcommittee to act now to raise SSI benefits.

Outreach and Bilingual Services

Many elderly Hispanics, as well as other low-income older Americans, are eligible for both means-tested and entitlement programs that they do not receive. In 1992, only 29.2 percent of Hispanic aged poor persons lived in households that received means-tested cash assistance.

Unfortunately, a large proportion of potentially eligible persons do not receive SSI because they do not know about the program or they have insufficient knowledge. Many older Americans also have major misconceptions or erroneous beliefs. Aged Hispanic-origin persons often have an added burden: language. This can be a formidable barrier for them to qualify for SSI or other means-tested programs.

The Asociacion strongly believes that effective outreach is essential to assure greater Hispanic participation in SSI, as well as for other low-income elderly persons. Basically, we support a three-prong approach:

1. There should be a dedicated percentage of SSI administrative funds earmarked for SSI outreach in order to have permanent, ongoing outreach activities at the Social Security Administration.

2. Bilingual outreach workers should be in areas where large concentrations of limited English-speaking or non-English-Speaking populations reside.

3. A senior-to senior approach should be employed as one crucial component of an overall outreach strategy. The Asociacion has found this approach to be an effective technique because many potentially eligible SSI recipients are more comfortable being helped by older persons, especially if they are friends or acquaintances or if they are bilingual in the case of Hispanic applicants.

We also support outreach for Social Security, since older Hispanics have a lower participation rate than for other groups.

Eliminate More Restrictive Criteria for Medicaid

All states now provide Medicaid coverage for some SSI recipients. Current law requires states to provide Medicaid for the mandatory categorically needy. States, though, can use a more restrictive standard or set of standards than the SSI definition for the mandatory categorically needy aged, blind, and disabled. Some, in fact, do.

These major restrictive criteria for Medicaid can be a major problem for SSI recipients with infirmities. Quite often, Medicaid coverage can be more valuable than SSI, especially for those recipients with major medical bills.

Therefore, the Asociacion urges that states should not be able to use eligibility criteria that age more restrictive for the mandatory categorically needy than those governing SSI.

Repeal One-Third Reduction

SSI recipients now have their basic benefit reduced by one-third if they reside in the household of another and receive in-kind maintenance and support.

In some respects, this provision is anti-family because it discourages family members from helping less fortunate relatives.

It clearly works against the interests of SSI recipients who are members of minority groups because the extended family concept is more prevalent for minority families than for Anglo families.

As a practical matter, this measure is misunderstood by numerous SSI recipients. Moreover, Social Security personnel probably misconstrue this provision frequently when they administer the one-third reduction measure.

We, therefore, support repeal of the existing one-third recommendation. We back Congressman Meek's approach in H.R. 2676, and urge the subcommittee to approve it.

Update the Resource Limits

The Asociacion favors updating the countable resource ceiling to make appropriate adjustments for rising prices since the program began in 1974. Currently, the countable asset limitation is $2,000 for a qualifying individual and $3,000 for an eligible couple.

The rules governing countable resources must also be simplified. We urge the Social Security Administration to work with organizations representing the aged, blind, and disabled to simplify the applicable rules for determining and counting resources.

We also support the SSI Modernization Panel recommendation to update the SSI resource limitation. We believe that H.R. 2676, which would increase the countable asset ceiling from $2,000 to $7,000 for qualifying individuals and from $3,000 to $10,500 for eligible couples, would be an effective approach to implement this recommendation. If the Human Resources Subcommittee wishes to limit the cost of this recommendation, the proposal could be phased-in on an incremental basis.

Conclusion

In conclusion, the Asociacion strongly supports key recommendations of the SSI Modernization Panel. We also strongly endorse the 1993 SSI Reform Act to implement those proposals. We fully recognize that it may be necessary to implement those recommendations on a phased-in basis because of cost considerations.

However, the key feature from the standpoint of the Asociacion and elderly Hispanics is that future SSI legislation should have some type of benefit increase to launch an income strategy to come to grips with the growing poverty problem affecting older Americans, and aged minorities in particular. This is essential. We further believe that there should be no compromise on this fundamental principle.

Chairman FORD. Mr. Simmons.

STATEMENT OF SAMUEL J. SIMMONS, PRESIDENT, NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

Mr. SIMMONS. Congressman Ford and Congressman Santorum, the National Caucus and Center on Black Aged welcomes the opportunity to testify at this hearing. At the outset, we want to commend you for calling this timely hearing.

We have a longer statement, which I would like to be included in the record, and I will just go ahead and summarize.

The recent Census Bureau report on poverty in the United States provides a grave reminder that United States has a serious and growing economic problem, for today the United States has a huge and growing underclass. Poverty is concentrated to a large degree among the young and aged in our society. The most recent Census Bureau statistics provide clear and convincing evidence that poverty is still a problem for older Americans despite important gains made during the 1970s and late 1960s.

About 4 million Americans, 65 years of age or older, were poor in 1992. Poverty for older Americans has increased by more than 600,000 during the past 3 years from 3.36 million in 1989 to 3.983 million in 1992. This disturbing trend continued during the past year as the number of poor older Americans grew by 202,000.

Poverty is especially widespread and deep rooted for aged minorities, particularly African-Americans. Nearly 900,000—887,000 aged blacks, 1 out of 3 African-American, 65 years of age or older, were poor in 1992.

Older blacks were more than three times as likely to live in poverty as aged white nonHispanics during 1992. In other words, 33.3 percent versus 10.4 percent. These figures dramatically underscored the need to improving SSI benefits for elderly persons in the United States.

SSI reform without some type of benefit increase would be a tragic disappointment for the aged poor and especially older African-Americans who are disproportionately poor. That is why NCBA's number one legislative objective is to raise the SSI Federal benefit level to above the poverty line. We, however, are realistic in recognizing that budgetary considerations and cost constraints may necessitate incremental increases and perhaps modest increases initially. NCBA believes, though, that it is absolutely indispensable to start the process now by enacting benefit increases and in a soundly conceived and fiscally responsible matter.

SSI recipients have waited long for an adjustment in their benefits. SSI has been operational since 1974; however, there has been only one adjustment above the poverty level, but this was coupled with a 6-month delay in 1983 and 1984 and the Social Security cost-of-living adjustment. This postponement in the COLA denied elderly and other Social Security beneficiaries, as a group, $4.3 million in fiscal year 1986 alone. Their future Social Security benefits are lower than they would otherwise be because of the compounding effect of the delay.

Congress did not provide an income standard equal to the poverty when it created SSI. However, the legislative history is clear that Congress established the SSI to eliminate the ugly cancer of poverty for the aged and disabled.

The Senate Finance Committee made a point emphatically when it said, “SSI would create a new Federal program administered by Social Security to provide a positive assurance that the Nation’s aged, blind and disabled people would no longer have to subsist on below-poverty incomes.”

However, the SSI standards are still below the poverty threshold. The maximum benefit is 75 percent of the census poverty threshold for an individual and about 90 percent for an aged couple. The maximum Federal benefit in 1993 is $434 for an individual—a month for an individual, and $652 for an eligible couple.

A unique opportunity exists now for action to make the urgently needed changes. You have heard earlier today about the recommendations of the Modernization Panel, and we concur with that. We are also strongly in favor of the SSI Reform Act, H.R. 2676, that has been introduced by Congresswoman Meek; and also we—SSI—H.R. 2676 would raise the Federal SSI level to 100 percent of poverty by 1996, thereafter taking it to 120 percent by 1998.

We also concur with what has been said earlier in terms of repealing the one-third reduction rule and other administrative changes for SSI.

I would just like to say that we have a challenge and an opportunity to move ahead to begin doing something to ensure that the elderly in this country do not have to live in poverty. We know that it cannot be done overnight, but we think that, at a minimum, the process ought to be started so that we can do it on an incremental basis. Otherwise, if we don’t get it started, it will never be done.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

STATEMENT OF SAMUEL J. SIMMONS
NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC.

Congressman Ford and Members of the Human Resources Subcommittee, the National Caucus and Center on Black Aged (NCBA) welcomes the opportunity to testify at this hearing. At the outset we wish to commend you for holding this timely and important hearing.

The recent Census Bureau report on poverty in the U.S. provides a grim reminder that the U.S. has a serious and growing economic problem. Poverty in the U.S. continued its ominous and upward spiral during the past year, as 1.172 million Americans were added to the poverty rolls. Overall, 36.880 million were poor in the U.S. This figure is roughly equivalent to the entire population of Poland. The number of persons living in poverty in the U.S. is at the highest level since 1962, when 38.625 million Americans were poor.

The poverty rate for the total U.S. population grew from 14.2 percent in 1991 to 14.5 percent in 1992. The 1992 poverty rate was higher than at any time during the 1970's and exceeded the level for much of the 1960's In 1966, the U.S. poverty rate was 14.7 percent, which is essentially the same level as in 1992 (slightly more than a quarter of a century later).

Today the U.S. has a huge and growing underclass. Poverty is concentrated, to a large degree, among the young and aged in our society. Persons under the age of 18 had the highest poverty rate (21.9 percent) in 1992, followed by people 18 to 24 years old (18.0 percent). Individuals 75 or older had the third highest poverty rate in 1992: 16.2 percent.

The most recent Census Bureau statistics provide clear and convincing evidence that poverty is still a major problem for older Americans, despite important gains made during the 1970's and late 1960's. Almost 4 million Americans 65 years of age or older were poor in 1992. Poverty is a bare bones existence. Under the Census Bureau definition, an elderly person was poor in 1992 if his or her annual income fell below $6,729 -- basically $129 a week to pay for food, housing, medical care, transportation, clothes, and other everyday necessities. A couple with an aged head was poor if their annual income was less than $8,487 ($163 a week).

The extent of poverty for older Americans would be even greater if the same poverty thresholds were used for people 65 or older as for persons under age 65. In 1992, the poverty threshold for an individual 65 or older was 92 percent of that for a single person under age 65 ($6,729 vs. $7,299). It was 90 percent of the poverty threshold for a two-person household with a head under age 65 ($8,487 vs. $9,443).

Poverty for older Americans has increased by more than 600,000 during the past three years, from 3.363 million in 1989 to 3.983 million in 1992. This disturbing trend continued during the past year, as the number of poor older Americans grew by 202,000.

Poverty is especially widespread and deep-rooted for aged minorities, particularly elderly African-Americans. Nearly 900,000 (887,000) aged Blacks -- one out of every three African-Americans 65 years of age or older -- were poor in 1992. Older Blacks were more than three times as likely to live in poverty as aged White, non-Hispanics during 1992: 33.3 percent vs. 10.4 percent.

Elderly African-American women are an especially vulnerable group. Three out of every eight (37.7 percent) Black females aged 65 or older were poor in 1992. Quite clearly, one of the most economically deprived groups in our entire society today is elderly African-American women living alone. Nearly three out of five (57.9 percent) were poor in 1992, and nine out of ten (89.3 percent) were economically vulnerable. They had annual income below twice the poverty line.

Poverty is exceptionally high for African-Americans 75 years of age or older. Their poverty rate in 1992 was very close to the level for Black youngsters and teenagers (persons under 18 years of age): 40.0 percent vs. 46.6 percent.

A. Raise SSI Benefits Above the Poverty Line

These figures dramatically underscore the need for improving SSI benefits for elderly persons in the U.S. SSI reform without some type of benefit increase would be a tragic disappointment for the aged poor, and especially older African-Americans who are disproportionately poor.

This is why NCBA's number one legislative objective is to raise the SSI federal benefit standard to above the poverty line. We are realistic in recognizing that budgetary considerations and cost constraints may necessitate incremental increases, and perhaps modest increases initially. NCBA believes, though, that it is absolutely indispensable to start the process now by enacting benefit increases in a soundly conceived and fiscally responsible manner.

SSI recipients have waited far too long for an adjustment in their benefits. SSI has been operational since 1974. However, there has been only one adjustment above the cost-of-living, but this was coupled with a six-month delay (from July 1983 to January 1984) in the Social Security cost-of-living adjustment (COLA). This postponement in the Social Security COLA denied elderly and other Social Security beneficiaries, as a group, $4.3 billion in fiscal year 1986 alone. Their future Social Security benefits are lower than they would otherwise be because of the compounding effect of this delay.

Congress did not provide an income standard equal to the poverty line when it created SSI. However, the legislative history is clear that Congress established SSI to eliminate the ugly cancer of poverty for the aged and disabled. The Senate Finance Committee report made this point emphatically when it said SSI would "create a new federal program administered by the Social Security Administration (SSA) to provide a positive assurance that the nation's aged, blind and disabled people would no longer have to subsist on below-poverty incomes."

However, the SSI income standards are still below the poverty thresholds. The maximum federal SSI benefit in 1992 represented only 75 percent of the Census Bureau poverty threshold for an elderly individual and about 90 percent of the poverty threshold for an aged couple.

Comparison of 1992 SSI Standards and the Census Bureau's Poverty Thresholds for Aged Individuals and Couples

Recipient	Annual SSI Standard	Poverty Thresholds	Percent of Poverty Thresholds
Individual	$5,064	$6,729	75.3%
Couple	$7,596	$8,487	89.5%

Sources: Supplemental Security Income Modernization Project: Final Report Of The Experts, August 1992, p. 24.

Poverty in the United States: 1992, Current Population Reports, Consumer Income, Series P60-185, U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, September 1993, p. vii.

The maximum monthly federal SSI benefit payable in 1993 is $434 for a qualifying individual ($5,208 per year) and $652 for an eligible couple ($7,824 per year).

A unique window of opportunity exists now for action to make urgently-needed SSI changes. An SSI Modernization Panel, a prestigious advisory unit chaired by Dr. Arthur S. Flemming, has provided a blueprint for reform. This report represents the first time in the history of SSI that a detailed analysis of its activities and impact on beneficiaries has been undertaken.

All panel members believe that the current SSI benefit standard is inadequate and favor, at a minimum, increasing it to 100 percent of the poverty guideline. A majority support raising the SSI benefit standard to 120 percent of the poverty guideline because they believe needy people "could not attain a minimally decent standard of living at 100 percent of the guideline."

Representative Carrie Meek has introduced the 1993 SSI Reform Act (H.R. 2676), which would implement key recommendations of the SSI Modernization Panel. S. 2676 would raise the federal SSI benefit standard to 100 percent of the poverty threshold by 1996. Thereafter, the federal benefit standard would increase incrementally until it reaches 120 percent of the poverty threshold by 1998.

NCBA strongly supports the Meek bill and urges Congress to enact this measure into law as soon as possible. We fully realize that budgetary constraints and cost considerations may prevent immediate enactment of the 1993 SSI Reform Act. Consequently, NCBA urges that the Human Resources Subcommittee approve, at the very minimum, an incremental benefit increase as part of an SSI reform package. This is absolutely essential for any meaningful SSI reform legislation.

B. <u>Repeal One-Third Reduction Provision</u>

The SSI benefit standard should not be reduced by one-third when low-income aged, blind or disabled recipients live in the household of another for a full calendar month and receive in-kind maintenance and support. This provision discourages families from helping other needy relatives. In addition, it may cause some low-income elderly persons to be unnecessarily or prematurely institutionalized. Experts estimate that relatives represent 84 percent of all caregivers. The one-third reduction provision intensifies the financial hardship for an SSI family member. By discouraging family support, it has the effect of encouraging institutionalization, which, of course, is a more expensive alternative to family support.

Furthermore, SSA personnel claim that enforcement of this provision is a complex and time-consuming task because it requires collecting information and making decisions which can be very subjective.

Therefore, NCBA supports the SSI Modernization Panel's recommendation to eliminate consideration of in-kind maintenance and support as income. H.R. 2676 includes a provision to implement this recommendation. NCBA urges adoption of this measure.

C. <u>Expanded Outreach</u>

NCBA further supports greater outreach efforts to assure that low-income aged African-Americans and other older Americans receive the benefits to which they are legally entitled. A substantial proportion of potentially eligible persons do not participate in SSI because of inadequate knowledge.

One of the great myths in our society today is that low-income older Americans are protected, to a large degree, by safety net programs, such as SSI, Medicaid, food stamps, and other programs. The harsh reality is that the safety net is full of holes. Many poor older persons simply do not receive benefits from safety net programs which they are entitled to receive.

The Census Bureau's poverty report made this point very dramatically. Only about one out of every four (26.4 percent) poor persons 65 years of age or older were in households that received means-tested cash assistance in 1992. In other safety net programs for similarly situated poor older Americans, their participation rates were as follows: Medicaid, 33.8 percent; food stamps, 23.4 percent; and federally-assisted housing, 15.3 percent.

NCBA favors statutory earmarked funding authority to increase SSI outreach.

D. Increase Countable Resource Limitations

NCBA supports the recommendation of the SSI Modernization Project to (1) increase the countable resource limitations from $2,000 to $7,000 for qualifying individuals and from $3,000 to $10,500 for eligible couples; (2) simplify the resource test; and (3) simplify the exclusions.

Congress established the original countable resource limitations at $1,500 for qualifying individuals and $2,250 for an eligible couple. Beginning in January 1985, these ceilings were increased by $100 a year for an individual and by $150 annually for a couple until the resource limitations reached $2,000 for an individual and $3,000 for a couple by January 1989. Congress has made no adjustment in the countable asset amounts since 1989.

The current resource limitation is outdated and needs to be adjusted. SSI recipients and applicants should be able to have increased assets in order to meet emergencies (such as unexpected medical expenses, home repairs, and others). H.R. 2676 would implement this provision. NCBA urges its adoption.

E. Periodic Review Panel

Former Social Security Commissioner Gwendolyn S. King took an historic first step when she named a panel -- the SSI Modernization Project -- to conduct a comprehensive review of SSI and to make appropriate recommendations to improve the program.

Our nation has benefitted greatly from the thoughtful review of this important safety net program by the distinguished panel. NCBA believes that this detailed analysis should be an ongoing activity in order to assess whether SSI is performing its mission and to determine whether improvements are needed. A blue ribbon advisory panel reviews Social Security periodically and makes recommendations to improve and strengthen this vital program which touches the lives of almost every American family in one form or another. The ongoing review has been instrumental for Social Security's sound development and adaptation to changes in our society.

NCBA believes a similar process is essential for SSI. Therefore, NCBA urges the Human Resources Subcommittee to mandate statutorily the periodic review of SSI at least every four years by a distinguished panel of private citizens.

F. Conclusion

In conclusion, NCBA commends the Human Resources Subcommittee for holding this hearing on SSI. We look forward to working with the Subcommittee to improve and perfect SSI. We wish to reaffirm again as strongly as possible that a benefit increase is an absolute must for any type of SSI reform or improvements.

Chairman FORD. Ms. Hardy.

STATEMENT OF DORCAS R. HARDY, PRESIDENT, HARDY & ASSOCIATES, AND FORMER COMMISSIONER, SOCIAL SECURITY ADMINISTRATION

Ms. HARDY. Thank you, Mr. Chairman, and Mr. Santorum for the opportunity to be here today.

First, I would like to commend the thorough work of the SSI Review Panel and its chairman, Dr. Flemming.

I heartily concur that much needs to be done to improve the SSI program, especially its administration. It seems to me that the complexity of SSI has been a nightmare for every Commissioner of Social Security since the program was Federalized in the early 1970s. However, the recommendations of the panel do not totally address all the aspects or complexity, nor do they really, quote, "fix the problem"; and they just perpetuate the "cobweb," as one of your colleagues called it.

Additionally, in this day of a very large Federal deficit, when there is a need to restrain our government's growth, it is difficult to agree totally with the proposed recommendations in light of their potential tremendous costs.

As you well know, entitlement programs currently are about 49 percent of the Federal budget. They are projected to rise to about 65 percent by the mid-1990s. Federal spending on major means-tested programs has increased nearly fivefold since 1968, and the cost of the SSI program will also continue to increase.

You have before you a recommendation for $105 million in new spending for the next 5 years for SSI. That would bring the program to about $72 billion in 1997 and would make it about the third or fourth largest Federal program depending on what happens with health care.

But there are still a lot of unanswered questions. Where would the revenues come from for program expansion? How would the program increases make the program less complex or better address the impoverishment of many of its clients?

I would like to take a moment here to look at Supplemental Security Income reform. When H.R. 1 was passed, I was serving as Assistant Secretary of Health in the State of California. Any Californian, and especially a State employee, believes that they know better than Washington. But when Congress said they would do all our work for us in administering a welfare program to the aged and blind, we thought that was a terrific idea, and we were very happy to see the program become a Federal problem.

But, in retrospect—and this became very clear to me as Commissioner—the SSI program, I think, should be State administered. I appreciate that this belief probably is heresy and it is possibly—definitely, in many quarters without political support, and therefore perhaps unlikely to occur. It certainly endangered lot of the discussion when it was discussed at SSA. But I honestly believe it would be for the best and in the best interests of the American public, especially the poor whom the program is supposed to serve.

Over the years, the SSI program, as Secretary Flemming's report has pointed out, has been enhanced and now serves nearly 6 million recipients, 25 percent of whom are aged, 63 percent disabled adults, and 12 percent children. When SSI was a State program, there were no children were included.

The SSI report is very thorough. It has lots of details, and I am sure you will continue to debate many of the recommendations for a long time. But the current facts are that it pays nearly $30 billion annually to the poor, aged, blind and disabled. The percentage of aged who are served continues to decline dramatically while the number of disabled and children increases. By 1994, the number of dollars paid to disabled children will exceed the dollars paid to aged beneficiaries. The fastest growing portion of aged are aliens and the fastest growing portion of the nonaged are addicts and alcoholics. So clearly the population served by SSI has changed dramatically since its inception. I think it is appropriate to review its success as well as its failures and the changes that are needed as well.

I would like you to look at these particular areas:

One is aged aliens. It was never anticipated that the number of aged aliens would be so great. The original intent of the SSI program was to support American citizens, a program of last resort for those in poverty. Now, about 25 percent of the aged recipients are aliens and 85 percent of those aliens are just in seven States. That continues to grow.

In the second area, disabled addicts and alcoholics, the SSI program has always required treatment referral for this group of beneficiaries. But it has historically been very difficult to work with State services to ensure that recipients receive what they need in terms of treatment. Without rehabilitation, just like without work incentives, these people will always be SSI clients. If the intent of the program, at least for working-age adults, is to provide a temporary safety net, then we have defeated the purpose and we just have a permanent, very complex, cash benefit program.

You have begun to address the issue of SSI children, and I would just like to say that many parents do apply for SSI for their disabled children. It is a gateway to Medicaid programs. We should be looking at some other way to have those children eligible for Medicaid, as opposed to through the SSI program, and an SSI benefit.

Finally, you should promote service integration. SSI is just one of very many means-tested programs in the government. They are all trying to assist people who are impoverished, but they are doing it piecemeal. I suggest, as you develop proposals for welfare reform, that you insist that SSI be included so that, for once, we will have a policy about the relative roles and responsibilities of governments and individuals for alleviating poverty.

SSI is the most complex of any Federal program. SSA employees are the best in the Federal service, but they are not trained nor do I believe they should be trained to be social workers; and the comments in this report and from many SSA employees is that they are supposed to be all things to all people. I don't think that is appropriate.

We need an overhaul of these programs so they are rational, so they are fair and comprehensible. We are supposed to be reinventing government, providing, quote, "service to customers" and I think that means more than just eliminating layers of bureaucracy. There is not enough money to go around for everybody, as we well know. But there has got to be a way to make this a program that does replace despair with hope, a program that we can meet that challenge. There is an opportunity here for the Congress to relook at the entire SSI program—it has drastically changed in the last two decades—and to integrate who is responsible for what. Consider: Who should pay? Should we reconsider an annual guaranteed cash benefit? Without all the rules and regulations, would it be less expensive in the long run? And why is SSA, a payment, banking and adjudication agency, trying to be all things to all people?

Thank you Mr. Chairman.

Chairman FORD. Thank you, Ms. Hardy.

[The prepared statement follows:]

Testimony of Dorcas Hardy
Subcommittee on Human Resources
Hearing on Supplemental Security Income Program
October 13, 1993

Thank you for the opportunity to testify before the Subcommittee today regarding the SSI program. First, I want to commend the thorough work of the SSI Review Panel and its chairman, Dr. Fleming.

I heartily concur that much needs to be done to improve the SSI program, especially its administration. The complexity of SSI has been a nightmare for every Commissioner of Social Security since the program was federalized in the early 70s. However, the recommendations of the panel do not totally address all the aspects of complexity. Additionally, in this day of bulging federal deficits and a desperate need for restraint of government's growth, it is difficult to agree with the proposed recommendations in light of their tremendous costs.

As you know, entitlement programs already represent 49% of the federal budget and are projected to rise to 65% by the mid-90s. Federal spending on major means-tested programs in constant dollars has increased nearly 5-fold since 1968, from $43 billion to $208 billion.

The costs of the SSI program also continue to increase. We have before us a report that recommends $105 billion over the next 5 years in new spending on the SSI program. This is an astounding figure. In a program that is already scheduled to grow from $23 billion to $33 billion without Congressional action, the SSI Modernization report recommends increasing SSI outlays by $39 billion in 1997. If followed, this recommendation would bring SSI outlays to $72 billion in 1997, making SSI the fourth biggest social program in the federal budget after Social Security, Medicare, and Medicaid.

Yet there are still many unanswered questions: where would revenues come from for program expansion? How would these program increases make the program less complex or better address the impoverishment of many of its clients.

When HR 1 was passed and implemented in the early 70s I was serving as Assistant Secretary of Health for the State of California. Any Californian, and especially a state employee, believes that they know better than Washington. But when the Congress said they would do all our work for us in administering a welfare program to the aged and blind, we thought that was a great idea...and were happy to see the program become a federal problem. But, in retrospect, and this became very clear to me as Commissioner, the SSI program should be state administered. I appreciate that is probably heresy, without political support from this body and therefore very unlikely to occur but I honestly believe it would be in the best interest of the American public, especially the poor whom the program is intended to serve.

Over the years the SSI program, as Secretary Fleming's report has pointed out, has been enhanced and now serves nearly 6 million recipients, 25% of whom are aged, 63% disabled adults, and 12% children. When SSI was a state program, no children were included.

The SSI report is very thorough with regard to the myriad of details of the program. I am confident that you will debate for many hours the recommendations, particularly the costs to the taxpayers of implementing those recommendations.

But as you examine the program and probably learn more about its details than you ever intended or needed to know, I would like to try to put some of your deliberations into a different perspective, not just dollars because it is certainly unclear how any of these recommendations would be funded, but more in light of the purpose of the program and the role of the federal government with regard to delivery of cash grants to those in our society who generally, through no fault of their own, are eligible and need public assistance.

The current facts are:

SSI pays nearly $30 billion annually to the poor, aged, blind and disabled. The percentage of aged who are served continues to decline dramatically while the number of disabled and children increases. By 1994, the dollars paid to disabled children will exceed the dollars paid to aged beneficiaries. Additionally, the fastest growing portion of aged are aliens; the fastest growing portion of non-aged are drug addicts and alcoholics. Clearly the population served by SSI has changed dramatically since its inception. And it is appropriate to review its success and failures as well as its future.

I suggest you begin by looking at several diverse SSI populations:

Beneficiaries:

Aged Aliens

It was never anticipated that the number of aged aliens would be so great. Original intent of the SSI program was to support American citizens -- the program of last resort for those in poverty. But since 1982, the application rate from aliens has tripled. About 25% of aged recipients are aliens. 85% of the aliens on the rolls are in 7 states. I only can guess how many aged aliens have recently come to the U.S.

Disabled addicts and alcoholics:

The SSI program has always required treatment referral for this group of beneficiaries but it has historically been difficult to work with state services to ensure that recipients secure and successfully complete treatment. Expenditures will only continue to increase. Without rehabilitation, these people will always be SSI clients. If the intent of the program, at least for working-age adults, is to provide a temporary safety net. We have defeated the purpose and indeed have just perpetuated a permanent complex cash benefit program.

Service Integration:

These are means tested/welfare beneficiaries that everyone is trying to assist, but the job is being done piecemeal. I suggest that as the Administration develops its welfare proposal that you insist that they include the SSI programs so perhaps, for once, we will have one policy about the relative roles and responsibilities of governments and individuals for alleviating poverty, or at least providing cash benefits and social services.

The SSI program, with the exception of the Social Security program, is the most complex of any federal program. That makes it nearly impossible to administer, as the SSI panel pointed out. I recall that nearly 50% of SSA's resources are used to address 15% of the beneficiaries, Title XVI, SSI. Though the panel certainly looked at some of the complex issues, most of their recommendations are expansion of what is currently in place, such as increasing income tests or raising benefit payments. But the outcome of these recommendations will just be more operating instructions for the claims representatives.

Social Security employees are the best in the federal service but they are not trained nor do I believe they should be trained to be social workers. The comments in this report and from many others is that SSA employees should be all things to all claimants. That is not appropriate. There are numerous state support and state social services that should be the primary vehicles for assistance.

What needs to occur is an overhaul of all these programs so they are rationale, fair, and comprehensible. If "service to customers" is the new watchword in town, SSI has a lot of difficult customers to whom we have a responsibility to figure out how to serve them well, and fairly and simply and cost effectively. In turn, through these myriad of government programs and cash grants, beneficiaries should be empowered, through incentives, to move themselves, as much as possible, off the government rolls. (Example: 1619 a and b; work incentives for disabled SSI beneficiaries).

This Administration has set about to reinvent government. I submit that means more than just eliminating layers of bureaucracy. It means your providing the leadership to put these myriad of programs together, to charge the career service to redesign programs, to work with their counterparts in the States and figure out who does what. There is not enough money to go around to do everything. I think it is far more important to get a cash grant to a needy person, hopefully for an interim period of time, than to have numerous monthly checking/oversight as to whom a beneficiary is sharing housing with or who paid for dinner last week. I appreciate that many SSDI recipients are not able to cope...in the world or with government...maybe that makes them no different from us...but there must be a way to simplify this tremendously labor intensive and complex program that needs tremendous improvement. There are numerous examples beyond computation of income support and maintenance or the inadequate representative payee program.

There is an opportunity here for the Congress relook at SSI, a program which has drastically changed in the last two decades, and integrate your thinking about other poverty programs. Ask yourselves: Who is responsible for what? Who should pay? Should we reconsider an annual guaranteed cash benefit without all these rules and regulations? Would it/could it be less expensive in the long run? Why is SSA, a payment/banking/adjudication agency being asked to be all things to all people? (Last week they were to run the new health care plan, too!) Within a realm/environment of compassion for those who need your attention, there are much larger issues here which I ask you to address.

Chairman **Ford**. Ms. Zelenske.

STATEMENT OF ETHEL ZELENSKE, STAFF ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER

Ms. **Zelenske**. Thank you for the opportunity to testify this morning before the subcommittee. My testimony will focus on those who remain unserved by the SSI program and the need for increased outreach in the program.

You have heard testimony on this panel about the increasing numbers of young and elderly persons living at or below the poverty rate. The data is particularly distressing for certain segments of the elderly population; depending on your gender, race or age, you are even more likely to be living in poverty.

Clearly for many people, there are gaping holes in the safety net. SSI plays a vital role in providing benefits to vulnerable members of our society living at subsistence levels; however, the statistics show that those who are intended to be beneficiaries of the program are not receiving it.

According to the GAO, only 28 percent of poor elderly persons lived in households receiving Federal means-tested cash assistance, which is primarily SSI. Other studies have consistently shown that only about 50 percent of eligible elderly persons receive SSI. This figure is even lower, depending again on age, gender, race, type of eligibility and living arrangement.

Why is participation so low? Many barriers have been identified which prevent eligible persons from obtaining SSI. These include difficulty with the English language, including illiteracy, the perceived welfare stigma of SSI, distrust or fear of government bureaucracy, and physical or mental disabilities which limit the ability to access Social Security, to understand the process, or to access organizations that assist with the process.

For the elderly population, it appears that lack of information about SSI is a main factor. Many elderly individuals are simply unfamiliar with the complicated but beneficial rules available to them. Surprisingly, there are many people who don't even know that SSI exists.

What can be done to address the problem? Congress has been aware of the need to increase participation and has appropriated $27 million over the last 5 years for outreach. With these funds, SSA has funded over 80 projects throughout the country, focusing on underserved target populations. Most of these projects are localized, involving community organizations, coalitions or local government agencies who are trying to address the needs of the populations they serve.

When you review a list of the projects, you can see the creative and innovative thinking that is beginning to address the problem. But I want to stress that this is only a beginning to address the problem.

There are some States that have had no demonstration projects. In other States there may have been a project at a single site, which is either rural or urban, but addresses only one small portion of the population. In other States, there has been no grant to a local organization.

My point here is that there are many areas of the country that remain untouched and many target populations remain unserved. Obviously, given the Census Bureau report, the need for SSI has not lessened as the number of poor elderly, disabled and blind persons increase.

We recommend that the outreach program be made permanent. The SSI Modernization report recommended that a specific funding mechanism be established for outreach.

Last month, Senator Riegle introduced legislation in the Senate which would accomplish this goal. S. 1451 makes permanent what has become an annual congressional appropriation for SSI outreach by providing that a very small percentage of SSA's administrative budget be made available on a yearly basis to fund grants to the local agencies and organizations. This bill has broad support among organizations representing persons with disabilities and persons who are elderly, blind and/or homeless.

We support any efforts to introduce similar legislation in the House and urge its passage.

Thank you.

Chairman FORD. Thank you very much.

[The prepared statement follows:]

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STATEMENT OF ETHEL ZELENSKE, STAFF ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER, BEFORE THE SUBCOMMITTEE ON HUMAN RESOURCES, COMMITTEE ON WAYS AND MEANS UNITED STATES HOUSE OF REPRESENTATIVES

OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

OCTOBER 14, 1993

Thank you for the opportunity to testify before the Subcommittee today. My testimony will focus on the need for increased outreach in the Supplemental Security Income (SSI) program.

The National Senior Citizens Law Center (NSCLC) provides national advocacy on behalf of poor persons with specific emphasis on representing the interest of the lowest income elderly people, particularly women and racial and ethnic minorities. NSCLC also provides support to legal services, pro bono, and seniors' advocates who represent elderly poor people. One of NSCLC's priority areas is increasing income security for low-income elderly persons, which includes the SSI program.

The overall percentage of elderly persons, age 65 or older, living in poverty has declined over the past 30 years due, in great part, to federal initiatives such as Social Security. However, the *number* of elderly persons who are poor or near poor continues to grow, especially among certain groups who are economically vulnerable.

Despite the increasing need for SSI, the participation rate by eligible persons in the SSI program remains low. A number of barriers have been identified and outreach is needed to increase participation. In every fiscal year since 1990, Congress has earmarked funds for SSI outreach demonstration projects through the appropriations process. This program should be made permanent through legislation guaranteeing that funds are available every year for outreach activities.

I. THE PROBLEM: THE NUMBER OF POOR ELDERLY PERSONS CONTINUES TO INCREASE

After many years of a dramatic decline in the poverty rate among elderly persons in this country, thanks in large part to federal programs like Social Security, the problem appears to be on the increase. Recent Census Bureau reports indicate that the number of elderly persons who are poor or near poor continues to grow: over 5.7 million elderly persons or 19% of the elderly population.[1]

According to the GAO, this figure may in fact "underestimate the magnitude" of poverty among elderly persons. A 1992 report by the GAO, *Elderly Americans: Health, Housing, and Nutrition Gaps Between the Poor and Nonpoor*,[2] studies the size and characteristics of the poor and near poor elderly population and the extent to which poor elderly persons receive services from principal federal programs, including SSI. This report starkly portrays that certain groups of elderly Americans have not benefitted from the general economic improvements experienced by the elderly population as a whole:

- Elderly women were nearly twice as likely as elderly men to be poor or near poor.

- Elderly Hispanics were twice and elderly blacks three times as likely as elderly whites to be poor or near poor.

- Persons over the age of 75 were almost twice as likely as persons between 65 and 74 to be poor or near poor.

- The additive effect of sex, race, and age was dramatic: More than half of all black women over the age of 75 were poor or near poor in 1990.[3]

The statistics in the GAO report, unfortunately, remain valid in 1993. Just last week, the U.S. Census Bureau issued its report, *Poverty in the United States: 1992*,[4] which shows that the number of poor persons age 65 or older rose by 202,000 between 1991 and 1992. The 1992 data also indicates that the poverty rates for older women of color living alone or with nonrelatives remains shockingly high: nearly 58 percent for elderly African-American women and nearly 50 percent for Hispanic elderly women.

II. PARTICIPATION IN SSI BY ELIGIBLE ELDERLY PERSONS REMAINS LOW.

Given the increasing number of poor elderly persons, especially among women and persons of color, the need for programs like SSI is increasing. Nevertheless, studies have consistently shown that the participation rate in SSI by eligible elderly persons remains low.

In contrast to the 89 percent of poor households in which all members were 65 or over and received Social Security benefits, only 28 percent of poor elderly persons lived in households receiving means-tested cash assistance, primarily SSI.[5]

Other studies indicate that only about 50 percent of elderly eligible persons receive SSI.[6] Even among the group receiving benefits, participation rates vary greatly depending on the type of eligibility and living arrangement:

- About 66 percent of eligible, unmarried individuals participate. However, only 30 percent of eligible couples and only 14 percent of eligible married individuals with an ineligible spouse participate.[7]

- Participation is twice as great for elderly persons living independently as for persons living in the home of another (58% vs. 25%).[8]

- Only 48% of eligible, elderly persons receiving Social Security benefits participate. The lowest levels of participation were for persons with some earned income: only 8% of those eligible participate.[9]

Participation rates also vary by age, gender and race:

- Participation among eligible women is lower than among eligible men (53% vs. 57%).[10]

- The participation rate is lower among elderly Hispanics than among all elderly persons (44% vs. 50%).[11]

- Participation among eligible persons age 65 through 69 remains lower (48%) than for persons 70 to 79 (57%), but declines again for persons age 80 years or more (55%).

III. THE BARRIERS TO PARTICIPATION: WHY THE RATES ARE SO LOW.

The GAO identified the lack of effective outreach efforts to enroll the eligible population as one of the reasons why participation rates are so low.[12] SSA has compiled a long list of "barriers to filing for benefits"[13] including:

- Lack of correct information about the SSI program within the target population and organizations serving these persons.
- Difficulty with reading and/or spelling the English language.
- Limited exposure to traditional communications media.
- Perceived welfare stigma of receiving SSI benefits.
- Distrust or fear of government bureaucracy.
- Lack of transportation and/or access to a telephone.
- Homebound status due to age or infirmity.[14]

Lack of information about the SSI program appears to be the main factor contributing to low participation. In contrast to the Social Security program, many individuals do not even know that SSI exists. Others are unaware or unfamiliar with the complicated, but beneficial rules regarding, for example, deeming of income from an ineligible spouse or how earned income is counted. As a result, they do not consider themselves as eligible.

One study on elderly Hispanic Americans surveyed those with incomes near the poverty line, asking for their reasons why they did not enroll in SSI. According to the report, the responses given were similar to those given by all elderly poor persons, primarily lack of information about SSI: 26 percent had *never* heard about the program.[15] The study recommends that targeting SSI outreach efforts toward Hispanic communities could help to increase rates of participation and reduce rates of poverty.[16]

IV. BEGINNING TO ADDRESS THE PROBLEM: THE SSI OUTREACH DEMONSTRATION PROGRAM

Congress has been aware of the need to increase participation in the SSI program and has appropriated funds in each fiscal year since 1990 for outreach demonstration projects. In 1990, $3 million was appropriated for this purpose, and in each year since, including 1994, $6 million has been provided, for a total of $27 million.

Since the inception of the program, SSA has funded over 80 projects in nearly 100 sites, following solicitation of proposals in two announcements.[17] The grantees represent a wide range of backgrounds, including local government agencies, nonprofit organizations, and universities and colleges, engaging in innovative projects to reach hard to access populations. These projects have concentrated on underserved target populations such as urban and rural elderly persons; people with AIDS; persons who are homeless; minority/ethnic groups including African-Americans, Native Americans, Hispanics and Asians; disabled children; and severely mentally ill adults.

In June 1993, SSA announced its third request for proposals, under which it expects to fund up to 40 projects, totalling more than $5 million.[18] SSA has built on its experience from the first two rounds of grants and its own outreach efforts and has focussed on specific methodologies to be tested and priority outreach areas to reach targeted populations. The announcement also includes detailed project standards and evaluation requirements.

This initiative is a good beginning but has only scratched the surface. There are still some states where no demonstration project site has been located. In many more states, a single site in only one discrete part of the state has been chosen. Many states have not yet had a project awarded to a local organization. In sum, many geographic areas of the country and many diverse low-income populations remain unassisted.

V. SOLVING THE PROBLEM: ESTABLISH PERMANENT AND SPECIFIC FUNDING FOR SSI OUTREACH

There is no evidence that the need for SSI outreach has lessened. As discussed above, the number of elderly poor persons continues to grow while their participation rate in the SSI program remains low. The demonstration project program has shown that outreach can be successful. A permanent program is now needed to assure continuity and thoroughness in the outreach effort.

The SSI Modernization Report recognized that many potentially eligible disabled and elderly individuals are not participating in the program and that many groups, including the frail elderly, have been underserved by outreach.[19] The experts recommended that specific funding for outreach should be established by increasing the administrative budget by at least 5 percent.[20]

Last month, Senator Donald Riegle (D., MI) introduced S. 1451, the "SSI Outreach Act of 1993." This bill will strengthen outreach services in the SSI program. The purpose of the legislation was simply stated by Senator Riegle upon introduction of the bill:

> This legislation does not extend new benefits to anyone. It simply gives the Social Security Administration the tools it needs to effectively reach out to people who are unable to apply for assistance.[21]

Highlights of S. 1451 include:

- Makes permanent the annual Congressional appropriation for SSI outreach by providing that no less than .37% of SSA's administrative expenses (about $17.8 million at current levels) shall be available on a yearly basis to fund grants.
- Provides for a permanent grant program to local governments and nonprofit organizations to conduct outreach activities and services to targeted populations, as determined by the Secretary of HHS.
- Establishes criteria for applicants to ensure that entities applying for grants demonstrate ability to provide outreach assistance.
- Creates an Office of Outreach Coordination in SSA to coordinate outreach efforts in SSA field offices and to administer the outreach grant program.
- Requires an annual evaluation of outreach activities conducted under the Act.
- Provides special procedures relating to homeless individualsincluding expedited consideration of applications, assistance in filing documents for appeal, and steps to contact the individual before denying or suspending benefits.

This legislation is endorsed by a broad range of organizations representing adults and children with disabilities, and persons who are elderly, blind, and/or homeless. We strongly support efforts in the House to introduce similar legislation and urge its passage.

1. *Elderly Americans: Health, Housing, and Nutrition Gaps Between the Poor and Nonpoor* (GAO/PEMD-92-29, June 1992), p.2 (hereafter GAO Report).

2. *Id.*

3. GAO Report at 2.

4. Current Population Reports, Consumer Income Series P-60-185, U.S. Dept. of Commerce, Economics and Statistics Adm., Bureau of the Census, Sept. 1992.

5. GAO Report at 7, 40.

6. *RATES OF PARTICIPATION OF THE ELDERLY IN THE SUPPLEMENTAL SECURITY INCOME PROGRAM* (Commonwealth Fund Commission on Elderly People Living Alone); Zedelewski & Meyer, *TOWARD ENDING POVERTY AMONG THE ELDERLY AND DISABLED THROUGH SSI REFORM* (Urban Institute Rep. 89-1, 1989); Sheils, Barnow, Chaurette, Constantine, *ELDERLY PERSONS ELIGIBLE FOR AND PARTICIPATING IN THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM* (U.S. Dept. of Health and Human Services, Contract No. HHS-100-86-0051, Final Report, Jan. 1990)("HHS Report").

7. HHS Report at IV-8.

8. HHS Report at IV-9 to IV-10.

9. HHS Report at IV-10 to IV-11.

10. HHS Report at IV-11.

11. Andrews, *Poverty and Poor Health Among Elderly Hispanic Americans* (Commonwealth Fund Commission on Elderly People Living Alone, Sept. 1989), at 32-33 ("Cmwlth. Fund Comm. Report").

12. GAO Report at 42.

13. 58 Fed. Reg. 34154, 34156 (June 23, 1993).

14. For a more in-depth discussion of many of these barriers, see Gottlich and Clark, *Fifteen Reasons Why Low-Income Elderly Clients Don't Get Public Benefits*, 25 *Clearinghouse Review* 1012 (Dec. 1991).

15. Cmwlth Fund Comm. Report at 32-33.

16. *Id.* at 57.

17. 55 Fed. Reg. 13748 (April 11, 1990) and 56 Fed. Reg. 47874 (Sept. 20, 1991).

18. 58 Fed. Reg. 34154 (June 23, 1993).

19. SSI Modernization Project Final Report at 131.

20. *Id.* at 132.

21. 139 Cong. Rec. S11577 (daily ed. Sept. 13, 1993) (statement of Sen. Riegle).

Chairman Ford. Mr. Simmons, what is your recommendation for a modest initial increase in the Supplemental Security Income benefits? We talked about budget restraints earlier, but what incremental increase might you suggest, and what do you suggest that we look to, to get the money from?

Mr. Simmons. I knew someone was going to ask me that question, and the major thing I ask people to tell me is, for every dollar of increase in SSI benefit level, what is the cost? So for every dollar of increase in the benefit level, that is $65 million. So the big question is, how many $65 millions can we come up with on a reasonable basis?

I am not on an appropriations committee or anything of that sort, and I would not be presumptuous enough to say that is the exact amount; but there isn't any question——

Chairman Ford. Over what period of time, and what incremental increases—I mean, what should we look at?

Mr. Simmons. I would say that probably we should establish a target to say, 5 years from now—that we should be at 125 percent of poverty 5 years from now; and I would think that it could be staggered. And I am the first one to recognize that in this period of a budget deficit now, we may have to do it on a small basis the first couple of years and then hope, as we come up with different efficiencies, forms of revenues, that we could increase that as we move along.

But at a minimum, I think that we have to get started on this in a meaningful kind of way.

Chairman Ford. Thank you.

Ms. Hardy, do you have any suggestions for controlling the growth of SSI? You talked about the alcoholics, addicts, and aliens.

Are there recommendations of the modernization panel that you support? I think Dr. Flemming, when he testified earlier, gave us a list of about—he prioritized the first four areas that this subcommittee should be looking into as it related to the recommendations of his modernization panel.

Do you have any recommendations that you would support—not any recommendations, but are there areas that you could support, any of the recommendations that the panel has submitted?

Ms. Hardy. I think we concur on the work incentive discussion. I worked on the 1619 (a) and (b) pieces of the SSI to get disabled adults the opportunity to get back to work. I think that is a real important part of the program.

I also believe the whole problem with regard to children that your——

Chairman Ford. I am sorry.

Ms. Hardy [continuing]. Children that your colleagues pointed out is something that—I assume the administration will be coming forward to you with some suggestions.

I am really looking at this, as I said, in a much bigger picture, and I am not—I am not convinced that just nibbling at the edges of the SSI program in terms of an increase of cash grant or decreasing here or letting people have $7,000 in the bank instead of $2,000, are the only ways to improve the program. I don't think that is the way to go. I think it is time to look at all these poverty programs together to figure out where we are going; they have got to be fully integrated. We can't afford to have all these little rabbit holes where everybody fits. I pointed to three populations, just three of the problems I think that are coming down the line even faster.

Chairman FORD. When you said that we ought to take all of these—I don't know your words—all of these different programs and consider them together, obviously there is a welfare reform package that will be coming from the administration—hopefully in the next 2, 3, 4, whatever amount of months—and I think this subcommittee will look at the SSI program, as we reform or replace the welfare system in this country.

But the SSI program was established in 1972, and I guess it took effect in 1974 for the purposes of the aged, blind and disabled of this country; and I am not sure that the review process—and you certainly served in the administration over at the Social Security Administration—even under your leadership, I don't know of any time that the review process had any significance about it or any substance about it.

I certainly hear and appreciate your recommendations today, but when you served there, I certainly didn't see any goals for the Social Security Administration to move to review these disability claims in these very areas that you have testified on today before this subcommittee.

Ms. HARDY. Well, that is not quite true.

Chairman FORD. Maybe you will correct me. I am not pointing you.

Ms. HARDY. The idea of returning SSI to the States was part of the strategic plan, in the 1980s, that we wrote, and was greatly discussed and debated. The concept of disability—and that is a whole other discussion of how all these reviews—take place, and frankly, things have changed substantially since I left, and I think you need to discuss that with the previous administration.

I think we have an SSI program which is very, very complex. And I think there is no reason for all this complexity. For example, why does a recipient have to go to the SSA every month and declare who they had dinner with and whether or not they are living in the same room with somebody? This is not our business.

And that is where I come down, that maybe we should relook at some kind of cash grant program that is not nearly as complex as SSI. Though the advocates and the interest groups probably would want to spend more money than I do, I believe we could agree that the program is still too detailed. The concept of trying to simplify this program is just not in this report. We aren't there yet at all.

These complexities are beyond many people's comprehension, and those are the people we are trying to serve. We are making it very difficult for people.

The States and local agencies and many of the organizations that are here are also trying to serve those people, and yet the integration is very difficult at the national level.

Chairman FORD. Thank you very much.

Mr. Santorum.

Mr. SANTORUM. Thank you, Mr. Chairman. Ms. Zelenske, you mentioned that one of the things we need to do is outreach. We have had all these demonstration programs. Can you provide some information as to how these programs have worked on a demonstration basis?

Ms. ZELENSKE. I think you would have to ask the administration how they have been administering. I sit on the board of one of the community mental health rehabilitation programs in Baltimore that got one of the grants, so I know about it in incidental ways.

I know the administration is undertaking an evaluation process, but I think you have to get that information from them.

Mr. SANTORUM. I think it is important before we commit a permanent resource to outreach that it be shown to be cost effective and it makes sense to do it.

Ms. ZELENSKE. I understand, and I agree. One thing that is included in the legislation are evaluation criteria and standards for grant applicants, to make sure that they can provide the assistance that is recommended in the legislation.

Mr. SANTORUM. Thank you.

Ms. Hardy, I very much would like to work with you in coming up with some ideas on your point of simplification, and I think I would agree with you that we don't necessarily want to spend a whole lot more on this program. But if what we can do is better serve the folks who are in this program, and do it in a more cost-effective and humanitarian way, then I would be very anxious to work with you on putting that together.

Ms. HARDY. I certainly would be pleased to participate, Mr. Santorum. I also hope that any proposals that are before the committee, welfare reform proposals, do indeed include SSI.

Mr. SANTORUM. We have been working, as I mentioned earlier, with a welfare reform proposal. We have a couple of provisions dealing with SSI, but just in checking with SSI, it was not my recollection that we had any simplification in there; and that is something you have brought to my attention, and that we would like to work with you on.

Thank you very much, Mr. Chairman. We have to go vote.

Chairman FORD. Mr. Camp.

Mr. CAMP. No questions.

Chairman FORD. Let me thank each of the panelists for appearing before the subcommittee today. I want to go ahead and call the next panel, but we have to go vote.

They can be seated. Ms. Stephanie Blackwell, the president of Citizens Advisory Committee, the Center for Community Development of Prince George's County; Richard Weishaupt, the HHS project head of Community Legal Services, Incorporated. I would like for you all to come to the witness table and be seated.

There appear to be two votes on the House floor; that is why there were so many bells just a few minutes ago. I would say that we are going—we would like for you to be seated because another member of the panel could come in and chair while I go over to vote. That is why I am trying to wait, but if not, we are going to recess.

It might be 10 minutes, because there is a second vote immediately after this particular vote, 5-minute vote, so by the time I walk over it would probably be 10 minutes before we get back.

The committee is going to stand in recess for 10 minutes.

[Recess.]

Chairman FORD. The committee will come to order. You may proceed at this time. Let me apologize for the time; it was out of my control really. The House of Representatives delayed that second vote; we just completed the vote.

But we want to resume the hearing at this time. Pronounce your name correctly for me, so I won't make a mistake, Mr. Weishaupt.

Mr. WEISHAUPT. Weishaupt.

Chairman FORD. OK, you may proceed at this time.

STATEMENT OF RICHARD P. WEISHAUPT, HHS PROJECT HEAD, COMMUNITY LEGAL SERVICES, INC., PHILADELPHIA, PA.

Mr. WEISHAUPT. Thank you Mr. Chairman. My name is Richard Weishaupt. I am an attorney with Community Legal Services in Philadelphia. Community Legal Services was the law firm responsible for bringing the *Zebley* case through the Federal court system and litigated it up through the Supreme Court of the United States; and in fact, I argued the case before the Supreme Court.

The Supreme Court, as you know, in February 1990, by a seven-to-two vote, with only Justices Rehnquist and White dissenting, found that Social Security had been managing the SSI program for children incorrectly since the very beginning of the program.

I am happy to say, contrary to some of the negative testimony that you already heard here today, that the SSI program for children is back on track, that it is basically functioning well and that most of the criticisms of the program are based on misapprehension of how the program works and the kind of rumor-mongering that is just not very helpful in terms of discussing social programs.

First of all, I would like to start by addressing the issue of the number of children who are on SSI. That number has increased greatly within the last year, but that is not an increase that is expected to persist. It its largely due to the fact that there was this one-time bubble of children who had to have their cases looked at again, because they had been misjudged under the old system.

There are 452 thousand children who were denied SSI benefits from the period 1980 to 1990; roughly a half a million kids, and all of those were misjudged using the old, overly strict standard that was in place before the Supreme Court acted. All of those children were sent a letter at their last known address, and through some extraordinary efforts by Social Security, by our office, and by colleagues in the Children's SSI campaign, we succeeded, so far, in finding about 70 percent of those children.

Of that 70 percent of a half million kids—approximately 350,000—who asked for review, 47.7 percent have been awarded benefits, many of them with cases that you wonder how in the world they could have been initially denied in the first place—children with AIDS, children with cerebral palsy, children with repeated episodes of sickle cell anemia and repeated crises, all denied under the old system.

The old system, as you probably know, used 57 conditions and you had to meet 1 of those 57 conditions. If your child had a rare disorder, if a child had a disorder that caused debilitating pain, if the child had a combination of impairments or had other subjective complaints that weren't adequately captured by the former pigeonhole approach, they were denied.

And it was in response to—to that mismanagement that a rather conservative Supreme Court said this is not the way to run the SSI program, this is not the way that Congress intended. Congress intended that we take a look at each child as an individual and that we give those kids disability benefits if they have an impairment of comparable severity; that is, that which would disable a adult. A child still must meet the rather strict test for disability that adults are required to meet.

As I said before, about 120,000 to 150,000 children from the Zebley class have been put on. There are probably some more children left to be adjudicated. Once that is over, however, we are going to return to a situation where you see relatively normal growth.

There have also been some other factors that have contributed to the SSI children's program growth that are all commendable. One is that Congress mandated outreach specifically aimed at children. A second is that the publicity generated by the Supreme Court decision also increased awareness of the program.

Another positive factor was the efforts of private foundations to do SSI outreach, and they have done a very effective job.

And last, the Social Security Administration took away a glitch that penalized working parents. (See 57 Fed. Reg. 48,559 (October 27, 1992) amending the deeming formula.) Children of these working parents are now receiving SSI, albeit a small amount of cash benefit, and of course, at least in the majority of States—Medicaid.

While Medicaid is helpful, there are also nonmedical expenses that any parent of a disabled child can tell you about—and I am sure Ms. Blackwell will be talking about them in a minute. It does cost more to raise a disabled child. Depending upon the disability, there are trips to the doctor; there are trips to therapists; there is special equipment that is needed. If a child is incontinent, they may need special products for that. The child may need special diet.

Many Medicaid programs have artificial limits on physical therapy or occupational therapy or psychotherapy or on medication, all of which needs to be paid for. And people living below the poverty line simply don't have the kind of income necessary to defray those kinds of expenses.

We get calls daily from parents of disabled children. We run an 800 number to assist parents. We get calls daily from people who tell us what they have done with their SSI. Things like build an indoor bathroom so they don't have to carry a child in a wheelchair out to the outhouse or move into a first floor apartment so a child in wheelchair can have direct access to the street.

It is those kinds of things that the people are using the SSI program for, that are totally worth their while and totally appropriate.

We hear rumors that children are being coached. I would like to say just a few things about that because I know my time is almost up. The allegation is that children are being coached to misbehave, but I personally have never seen such a case.

Somewhere in the United States, I suppose it is conceivably possible, but the people who are raising these rumors don't fully understand the SSI program. In order to qualify for SSI, you need a physical or mental impairment that is documented by a physician, a psychologist or other health care professional. It is not enough for the parent to come in and say, "There is something wrong with Johnny, why don't you give him SSI?" It requires a great deal of medical evidence in order to establish disability.

Once Social Security has collected that data, they then apply a decisionmaking tool called the sequential evaluation process, where they first say, does this child have a severe impairment or is it just some mild impairment that really doesn't merit further attention? That weeds out 10 percent of the cases.

Then they fully develop what the child can do and not do. They talk to his teachers. They talk to counselors in the school, they talk to physical therapists, they talk to any hospital or doctor that that child may have been to and they get a full and complete picture of that child.

I would dare say if any health care professional or teacher flat out said, this child is not disabled, the likelihood that that child would get benefits would be almost zero.

Admittedly there is some strain on teachers having to fill out these reports and perhaps Social Security could figure out a way to make it easier for teachers to respond to the additional paperwork that comes up, but it is simply not the case that children are waltzing into SSI offices, saying they are disabled, putting some gum in their hair and qualifying for huge amounts of SSI. That simply is not the way cases are evaluated and that is not the way that the program is being run.

Social Security is monitoring this program very carefully. If anything, we have been prodding them to be more flexible in the way they adjudicate these cases. SSA internal quality control statistics show that the error rate on proposed allowances is very low.

I would conclude by saying that the—three-quarters of a million children who are on this program desperately need this program. They need the health care. They need the cash benefits. They are a very small part of the population and it is probably easy and politically expedient to beat up on them, but they need friends and they need advocates. I thank you for your attention.

Chairman FORD. Thank you very much.

[The prepared statement and subsequent submission follows:]

TESTIMONY OF RICHARD P. WEISHAUPT
COMMUNITY LEGAL SERVICES

Thank you Mr. Chairman and members of this subcommittee. My name is Richard Weishaupt and I'm a lawyer with Community Legal Services in Philadelphia. Our office brought the Zebley case that put the children's SSI program back on the right track; in fact, I personally argued the case in the Supreme Court on behalf of Brian Zebley, Joseph Love and Evelyn Raushi and the 452,000 children who were turned down for SSI in the 10 years before the Supreme Court decision argument in February 1990. I am here today to tell you that implementation of the Supreme Court's decision is well under way and that the revamped children's disability program is a great success. We are proud of the role we have played in remaking this worthy program.

Since the Supreme Court's 7-2 decision our office has been deeply immersed in the operation of the SSI childhood disability program. We maintain and staff a toll free "800" number to answer questions from parents and others who have questions about the childhood SSI program or their cases in particular. We monitor all SSA policy and interpretations relating to the Zebley case. We also participate in the Children's SSI Campaign, along with the Bazelon Center for Mental Health Law, the San Francisco Youth Law Center and Rural Legal Services of Tennessee. The purpose of the privately funded campaign[1] is to publicize the changed in the program and encourage families to apply. We are proud that our joint efforts have played a part in increasing new childhood SSI applications to unprecedented levels. Currently, there are 720,458 children receiving SSI benefits. We estimate that the program is still not reaching 50% of the eligible children, although considerable progress has been made.

I would estimate that through our hotline and outreach activities we have been in contact with over 10,000 children and families alleging disabilities. Many of these children were unjustly turned down for SSI benefits (and the accompanying Medicaid) and are only now having their cases properly decided. Tragically, several thousand have died before they have had the opportunity to have their cases readjudicated. Ironically the impairments that led to their death were deemed not sufficiently severe to justify an award of SSI.

The Supreme Court in Zebley found that the Social Security Administration (SSA) had failed to adopt an appropriate test for evaluating disability for children. As the Supreme Court explained, that statute says that SSI benefits should be provided to children with

> "any impairment of 'comparable severity' to an impairment that would make an adult 'unable to engage in any substantial gainful activity.'"

110 S. Ct. 885 897 (1990), quoting 42 U.S.C. §1382c(a)(3)(4). Instead of evaluating children the same way as adults, that is, by looking at each applicant as an individual and assessing the effect of that person's impairment on their overall ability to function, children were evaluated by comparing their conditions to a list of 57 disabling conditions. For many children with serious and even life threatening conditions, this pigeon hole approach was grossly inadequate. Children with rare disorders or newly diagnosed disorders such as AIDS; children with debilitating pain and other "subjective complaints" as is frequently the case with sickle cell patients, and children with atypical symptoms or combinations of impairments were frequently denied benefit as the Supreme Court noted. Even such relatively straightforward conditions such as spina bifida, Tourette syndrome, Down syndrome, muscular dystrophy and cystic fibrosis were difficult to properly analyze.

Children with mental disorder were particularly disadvantaged under the old approach. Not only were they harmed by the lack of an individualized functional assessment but they were also harmed by listings that omitted generally accepted conditions like attention deficit disorder (ADD)/hyperactivity and did not even reflect standard psychiatric nomenclature for the diagnosis and assessment of mental impairments in children. Even before the Supreme Court decision, SSA conceded as much, publishing long delayed Mental Impairment listings and releasing a study that showed that SSA was misadjudicating mental health cases more

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[1] The Campaign is funded by the Robert Wood Johnson Foundation, The Nathan Cummings Foundation, The Annie E. Casey Foundation and the Pew Charitable Trusts.

often than any other kind of case. Indeed it is little wonder that former Commissioner Gwendolyn King spoke publicly of the Zebley case as one that she was pleased to have lost.

When the Court's decision was read in February of 1990, the Social Security Administration was already embarked on proposing new listings for the evaluation of mental disorders. 54 Fed. Reg. 33240 (August 14, 1989). These listings came out five years after the Congressional deadline for the rewriting of the listings for adult mental disorders. The delay was largely due to the controversy surrounding including recognized conditions such as ADD and other behavior disorders as part of the listings. Eventually the Administration adopted new standards with almost universal approval. Already, however, the seeds of controversy had been planted by those who would like to label disturbed children as "bad."

Reform of the children's program began in earnest in 1991 with the publication of the new Zebley regulations that were specifically drafted to meet the requirements of the Supreme Court's decision and to afford children and "individualized functional assessment" (IFA) for the first time. 56 Fed. Reg. 5333 (February 11, 1991). Prior to this time, the children's program was seen as an afterthought to the SSI program. Only 5% of all SSI recipients were children and virtually no attention had been paid to the criteria for evaluating disability for children since the program's inception in 1974. Many of the listings of impairments dated back to the beginning of the program and SSA didn't even have a separate bureau for children's disability policy.

The combination of the attention brought to bear on the program by the Supreme Court decision, the activities undertaken to find 452,000 class members the efforts of the Children's SSI Campaign and Congressionally mandated SSI outreach have all played a part in expanding the program. Thus far, over 320,000 class members have been located and had their cases reviewed. Of that group, over 127,000 (47%) children have been awarded SSI as a result of this Zebley review. The total number of children receiving SSI increased from 438,853 in 1991 to over 720,000. The increase includes all sorts of children including children suffering from mental illness and retardation (the most prevalent disabilities), cystic fibrosis, sickle cell anemia, AIDS, and cerebral palsy. Many of these children were so disabled that it is difficult to imagine how they could have been denied under any rational system. Here are just two examples.

A.W. is a fourteen year old resident of Dyersburg, Tennessee. Adam was sixteen months old when he spiked a 106 degree fever and had to be transported to Lebonheur Hospital in Memphis by helicopter. His parent applied for SSI in February 1980, but were denied. A.W. took seizure medication until age five. He experience frequent periods of inattention in school, and IQ testing revealed serious problems with cognitive functioning, which a psychologist attributed to post-ictal dementia. In September 1993 A.W. was finally granted SSI.

A.F. is a twenty-four year old resident of Philadelphia who has suffered from cerebral palsy since birth. An SSI application was filed for him in September 1979 by his parents (now deceased), but was denied. Following his father's death, he reapplied for SSI and Social Security disabled child's insurance benefits in 1988. Although he was denied by the Pennsylvania state agency initially and on reconsideration, A.F. persisted with an appeal to an Administrative Law Judge who issued a favorable decision in August 1989, finding that he had major motor dysfunction involving both legs as well as mental retardation. A.F. requested Zebley review of his 1979 denial, and his claim was denied again. Only after A.F. requested reconsideration did he receive a favorable decision which will result in his receiving retroactive benefits for the period 1979-88.

Our experience with Zebley families is that they are enormously grateful and relieved; many had given up any hope of getting any help for their children. They, in turn, have shared their enthusiasm with other parents with similarly situated children and with supportive social workers, who in turn have referred other people to the program. As a result, there has been a considerable growth in the program in the last year or two, as many clearly disabled children have become eligible for benefits. (This growth was not anticipated. In the initial Zebley rulemaking in February 1991, the Administration estimated that applying the correct rules would result in an additional 214,000 children being found eligible over a five year period (1991-96), 56 Fed. Reg. 5550.

Needless to say, we have been carefully monitoring SSA's implementation of our victory in the Supreme Court. We have pressured SSA to put out final rules, which they have just done. 58 Fed. Reg. 47,531 (September 9, 1993). We have also carefully studied implementation of the new rules. If anything, SSA has been conservative in its implementation, tilting toward denials in many borderline cases. Erroneous denials have, at times, been as high as 20% in some states, leading SSA to take corrective measures at our urging. Some states have continued to be remarkably strict in awarding benefits. While SSA officials have taken steps to correct overly restrictive state interpretations, it is by no means easy to qualify for children's SSI. The national allowance is barely better than 50%, even given the backlog of clearly deserving children. We continue to get calls from all over the country from distraught parents who cannot believe that their children have been denied aid. Many of these children should be getting benefits.

Despite this we do hear occasional complaints from a few members of the public. Much of it has to do with the mental health issues that I already alluded to that pre-date Zebley. A few educators call us, outraged that parents have even applied for benefits and that they have been asked to fill out a two page questionnaire. A few of these cases are borderline -- but almost all these are cases that will be denied. Many more are cases where the educator does not have the whole picture. SSA regulations attach great weight to the opinion of school personnel, especially psychologists with direct knowledge of the child applicant. An opinion of a school psychologist that a child is not disabled is almost always controlling, unless countered by a psychiatrist, psychologist or pediatrician who persuasively argues for a finding of disability.

Many advocates find that educators are unduly conservative in evaluating children, especially since school district are required to provide costly individualized educational placements for such children. That financial incentive, plus the normal inclination to see children as capable of learning and overcoming substantial impairments makes for an understandable, if misguided, bias. Our experience has shown that SSI often makes a tremendous difference in a family, allowing the disabled child to obtain services, or purchase equipment he or she needs, or even get to needed medical care.

Here are two more examples:

Jane Doe is an eleven year old girl with sickle cell anemia. She had her first crisis at six months, and experienced more than twenty episodes in the next three years, with several hospitalizations and numerous outpatient visits. Jane was a very bright child who attended pre-school in South Memphis, and often hid her symptoms from her mother and teachers so that she could attend; on several occasion she had to be carried out of her classroom. Her mother lost several laborer jobs when she had to stay home with her daughter or take her for emergency treatment, initially and on reconsideration by the Tennessee state agency. Eventually she was awarded benefits in 1986. The SSI benefits have provided the resources which allow Jane's mother to work part-time.

J.P. is a sixteen year old resident of Southern Oklahoma who has been diagnosed with a psychotic disorder, an affective disorder, a personality disorder, and a learning disability. His parents applied for SSI in November 1987, but were denied. As a result of Zebley review, J.P. was found disabled by the Oklahoma state agency, but only as of February 1992. J.P. suffers from auditory hallucinations, has seriously injured at least one other child, and was recently hospitalizated after attacking his father. Despite this evidence, an Administrative Law Judge has not only refused to find disability as of 1987, but has reversed the state agency decision that J.P. is currently disabled. In an attempt to stop the Social Security Administration from termination J.P.'s SSI benefits, his attorney has filed an emergency appeal which is pending with the Appeals Council.

If anything, our experience shows that the vast majority of American parents want what is best for their children, and only turn to SSI as a last resort, often waiting too long to make application. Indeed, we estimate that less than one half of all eligible children are receiving SSI.

We have several suggestions for improving the children's SSI program, based on our experience:

1. Improve Quality of Decision Making: encourage states to have pediatric specialists available to disability adjudicators and encourage states to have specialization among adjudicators. Children's claims still represent a very small proportion of disability claims. Many adjudicators are unfamiliar with children's cases and the special issues they present.
2. Increase Staffing: Both the Zebley class and the ongoing increase in applications from children has put a tremendous burden on an already backlogged system. We are greatly concerned that decisional quality will decline as pressures for quick decisions mount.
3. Modernize the Listings of Impairments: SSA needs to revamp all its children's listings. Although the listings are no longer the endpoint of children's cases, most awards are still made on the listings. Using up-to-date standards will help make the program more efficient by quickly identifying the easiest cases. Most of the children's listings are scheduled to expire in 1993. Despite their impending expiration on December 6, there seems to be little activity to make timely revisions. Historically Congressional pressure has been key in getting revisions made.
4. Revise rules for children who die while their claims are pending: Currently only parents of children who die before turning 18 can get any benefits. SSA is contemplating changing this rule slightly, to allow for benefits to be paid for children who die after 18, but only for their time before they turned 18. This has worked a grave injustice in the Zebley case.
5. Encourage recipient savings: Current policy encourages people to spend money quickly, which is a particular problem in the Zebley case, involving children who need to save for the future and relatively large sums of money. We suggest expanding the "grace period" for larger sums of money and allowing families to set up special accounts, without the need to trusts, which are cumbersome and often difficult to establish. One way to do this would be to lift the 4 year limit of Plans for Achieving Self Support (PASS) and better publicizing their availability. Children shouldn't need a lawyer to qualify for SSI.
6. Build on the already sound work incentives that "make work pay" for SSI recipients and their families: The SSI program already has generous work incentive programs that reward recipients for working, by allowing them to keep part of their check, by allowing recipient to requalify if they lose their job and by protecting Medicaid status. This could be further strengthened for teens and young adults just entering the work force by allowing deduction for special expenses.

Similarly, parents of SSI kids should be afforded deductions for special work expenses they incur including special child care. Even without these improvements, parents of SSI children can earn their way out of poverty, a feature that is underappreciated in the SSI program by the general public and should be better publicized by SSA. Working parent should also be afforded Medicaid continuation.

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October 20, 1993

Ms. Harriet Lawlor
Committee on Ways and Means
Subcommittee on Human Resources
B-317 Rayburn H.O.B.
Washington, DC 20515

RE: SSI Hearing of October 14, 1993

Dear Harriet:

Enclosed please find an addendum to the testimony of Richard Weishaupt, Esquire, Zebley co-counsel of our office, to make part of the official hearing record. Chuck Jones, Director of the Michigan DDS, sent us the document entitled, "The National Council of Disability Determination Director's Positive Anectdotes About Childrens' SSI." These show the success and value of SSI benefits for disabled children.

Thank you for your cooperation.

Sincerely,

Jonathan

JONATHAN M. STEIN
General Counsel

JMS/cjt
Enclosures

cc: Richard Hobbie (w/encl.)

The National Council of Disability Determination Director's

Positive Anecdotes About Childrens' SSI

The following is a brief collection of some of the positive anecdotal examples provided to us from agencies across the United States. These examples represent the strong impact this program has had on the lives of many individuals, and their families, across the country.

A thirteen year old boy was diagnosed as having chloracne, a severe skin condition, as well as the bone disease spina bifida. The chloracne had caused the boy great pain and embarrassment due to his entire body and face being covered with severe acne and lesions. Fortunately, after going through a lengthy appeals process, the boy was awarded the SSI benefits and his family, of meager income, was able to provide the specialists that their son so desperately needed. Another case is of a three year old girl who suffers from asthma and multiple allergies. The girl is frequently hospitalized for her illnesses including asthma attacks, pneumonia, chronic colds and infections. She takes high doses of medication, eats a restricted diet and uses a breathing machine daily. Her mother states that a huge financial burden was lifted when her daughter was awarded SSI benefits.

"I am writing to you to express the relief my family feels due to our handicapped childrens recent approval for Supplemental Security Income.. Two of our three children have a rare genetic disorder.. The SSI has allowed us to buy a booster chair (specially designed) for our 20 month old son.. and a new car seat". "..family outings were near impossible before we purchased a backpack carrier and jog stroller that allows us to take trips". "Our older child.. is easily frustrated and fears losing control, resulting in severe emotional problems. Two major purchases we have made are adapted clothing and the foods she needs for her low-fat diet.. She cannot do any fasteners with the exception of velcro.. her new clothes will make her more independent". "We have also purchased learning toys and games that teach cooperation, following rules and instructions, and fine and gross motor skills that she currently lacks. We also are experimenting with video and computer technology to help her with letter recognition, spelling and eventually reading. Before we applied for SSI, we filed for bankruptcy due to the costs of caring for our children. Now we can provide them with the basic specialized care and adapted devices they need".

An 80 year old grandmother is raising six children, most on disability benefits for severe emotional and mental disabilities. "(The children) know because of SSI, their 80 year old grandmother was able to take them shopping this week for new school clothes for the first time". "Before the SSI checks, she, a widow, supported the six children on her monthly Social Security check, plus welfare benefits and food stamps. She's been taking care of them since her two daughters died in the 1980s. With SSI, the family's welfare grant and food stamps have been cut, but they still come out ahead by about $240 a month - enough for a few luxuries".

Occasionally, a state agency or hospital using Medicaid funds will comment that a child has received health care or services as a result of a favorable disability decision.

A treating physician called our office to thank us for follow-through on our disability investigation of a child's seizure activity. Through our contacts the physician became aware of a change in the child's seizures. Thus the treatment was modified to bring them to control.

A beneficiary indicated on the reporting forms that through the use of SSI funds awarded when he was a child, he was able to stay in school. He felt without those funds he would have still been "on the streets" and unable to work.

A mother wrote our office to say due to the disability investigation, she was able to identify that her child had a developmental delay and then got him involved in an Early Childhood program.

A Rehabilitation Counselor reported that a beneficiary had used SSI funds to find an apartment. Without the apartment the rehabilitation facility would not have accepted the beneficiary into the appropriate treatment program. When he had been allowed, he was living on the streets, had not been in school for over a year, and had never worked; a child claim at time of allowance.

A parent reported they could not afford the child's medication. While reviewing an issue of prescribed medical treatment, we did a presumptive disability decision, which allowed the parent to get the appropriate medication.

We've had calls from hospital social workers, in which they will be holding for surgery scheduling based on our disability determination.

We have had multiple reports of children for which we did special testing for a disability application, when the parent and/or treating source would not have done it due to cost. The treating source was subsequently able to use the special testing to better refer the child for appropriate treatment/testing.

Our pediatric medical consultant has frequently commented that parents are frequently overwhelmed by the medical bills for traumatic birth impairments. The neo-natal outreach program and multiple-body system disability decisions have been a (quality of) life saver for these families.

Social Workers tell story after story about how parents have to change job status when the child comes home from the hospital. Most expect to continue working, but with an ill newborn, they have to change plans and stay home. The loss of income in many cases is partially replaced by SSI. This is a stressful time for new families. The financial and medical help from SSI is part of the reason some families stay together despite the stress.

An eight year old child in Milwaukee received SSI after Zebley review found her medically eligible back to initial application at 12 months. The extra money allowed for a purchase of a van to assist in her transport to programs that will help her maintain/regain improved self care functioning.

A young teen with spina bifida was found eligible after Zebley review, and the family was able to remodel their home to make him more independent.

SSIDC eligibility was obtained for a girl after a head injury and seizures, allowing her to access pediatric specialty care that they previously were unable to afford.

A LaCrosse family could not afford to make several changes to the bathroom, etc. for their son with cerebral palsy, but were able to with Zebley settlement.

A four year old with facial deformity became suicidal. Expertise was not available locally. SSIDC/MA allowed family to take her to a child psychiatrist and she is doing very well now, four years later.

A family was able to purchase an air conditioner for a neurologically impaired child with SSI monthly payment. (No other program reliably pays for items such as air conditioners.)

An eight year old Native American girl with cerebral palsy was able to receive a power wheelchair enabling her to increase her independence. SSIDC also provided funds for expert rehabilitation services.

A family with a son with achondroplasia and hearing impairment obtained specialized care for his special needs.

A premature infant with multiple congenital anomalies had the lengthy hospitalization funded, as well as care at home for a gastric tube, oxygen administration, and special medical services.

A child with a severe seizure disorder became depressed and displayed many behavioral problems. The family had incurred thousands of dollars of outstanding bills for outpatient counseling which was paid for when the child became eligible for SSI.

A family with three children affected by a genetic bone-joint disease have been helped by their SSI/DC to travel from far northern Wisconsin to Milwaukee. With the assistance they can pay for travel expenses and the specialty care.

CAJ: pjs   Compiled (9/93)

Chairman FORD. Ms. Blackwell.

STATEMENT OF STEPHANIE BLACKWELL, PRESIDENT, CITIZENS ADVISORY COMMITTEE—SSI APPEAL TO CONSCIENCE, ON BEHALF OF CENTER FOR COMMUNITY DEVELOPMENT OF PRINCE GEORGE'S COUNTY, INC.

Ms. BLACKWELL. Yes, Congressman Ford and members of the committee, thank you for inviting me here today on your congressional oversight hearing for SSI.

My name is Stephanie Blackwell and I live in Langley Park, Md., and I am also the president of the Citizens Advisory Committee—SSI Appeal to Conscience in Maryland. I am a mother of three, one of whom receives SSI. His disability is ADHD, attention deficit hyperactive disorder and autistic-like behavior which is associated with autism. This means that my son, 6-year-old Terrence, is way below average in writing, social skills, motor and speech development. On the other hand, he is very high functioning in other academic skills. These are his strengths and his weakness with which we are working to improve his development.

I also have two daughters: Angelia, age 6, and Constance, age 4. I applied for SSI for my daughter Angelia who has speech and language disabilities over 2 years ago and have been turned down twice because she didn't "meet eligibility requirements." But last week under reconsideration because of the *Zebley* case, she is to be evaluated again. I have also applied for SSI for Constance who has chronic asthma and speech delay. I am still waiting for an answer.

I am in favor of the recommendations for increasing SSI to 120 percent above the poverty level. As a single parent of three, I live on $800 a month and $296 in food stamps. My rent is $660. After I pay my rent, I only have $140 to buy clothing, school supplies, transportation, additional food, cleaning materials, phone, utilities and tutoring service for my son.

The tutoring for Terrence provides additional activities for him which are very important for autistic child development and gives him learning to socialize in a more normal way.

I am also in favor for the reform which automatically gives a medical card with SSI benefits. When Terry was to receive SSI, his medical benefits from AFDC were canceled. However, his medical benefits under SSI was delayed 15 months. It was very painful and unfair to require a sick child to wait over a year for help which he was already qualified to receive. While waiting to receive a medical card for Terry, I made many phone calls, and visits to a social service and several calls to the SSI to get some action. Finally, through the Department of Human Resources, I received his medical card 15 months after they were prematurely canceled.

On behalf of my children, and many other needy children, I am in favor of limiting the waiting period to 90 days for determining SSI benefits. If determination cannot be made, SSI benefits should begin. If later the claim is denied, there should be no repayment of penalties from the applicant. The stress of survival over long periods is very damaging, not only to the SSI person, but to the family in which the person lives. You can't imagine the stress and depression.

I am also in favor of a permanent outreach to the public. The outreach should start with Social Services, extended through the special public school educational centers. At these center schools, there are so many families who receive AFDC and have children with disabilities who are never made aware that they can apply for SSI.

Thank you very much for allowing me to testify before you today because many children and adults with life threatening disabilities will not survive without the reforms that are proposed. These reforms also provide the foundation so that many of them will become self-supporting members of society and not adult burdens.

I have one more thing to say. I mentioned the tutoring services for my son. Right now my son has been suspended from school because of behavior—because of his disability. He is home with no services. It is distressing for disabled children and parents to go through withdrawal of services when they are most critically needed.

I cannot begin to say how much these changes need to be made to help parents like me who have disabled children.

Chairman FORD. Thank you, Ms. Blackwell.

Mr. Weishaupt, you have heard one of my colleagues testify earlier today in the area of SSI benefits and some of the horror stories that have been said. Much concern has been expressed by educators, as well as others, that the SSI program may actually be hindering children because of them becoming eligible or just not to be determined ineligible once they are accepted into the SSI program.

Let me ask you, is there a better way? We have discussed this earlier with a couple other witnesses, but is there a better way to respond to this need other than cash assistance for the children on SSI to address the illness or whatever deficiencies that they might be suffering with?

Is there a better way other than just the cash assistance?

Mr. WEISHAUPT. Well, ideally you would take each family and you would look at what they need. The problem is that frequently what you would find would not be cheaper than what we now have.

I mean, many of these children have even more needs than the SSI check can possibly pay for.

Chairman FORD. Given——

Mr. WEISHAUPT. They are living in abject poverty. We do have some thoughts about how we could make it work better, and I would like to get into that in a second.

Chairman FORD. The question is whether cash assistance versus addressing the disabilities that they might suffer with——

Mr. WEISHAUPT. I think the cash assistance is an essential part of the entire package, and I would also point out that in at least 12 States that are so-called 209(b) States, those children don't automatically qualify for Medicaid, and in those States, all they get is that cash.

And in the State of Wisconsin, I would also point out that SSI was cashed out. Wisconsin cashed out food stamps, so that an SSI child is not eligible for food stamps.

There are some things that could certainly be improved upon—the program, like any program, could be improved, and certainly if there are isolated cases where parents are not getting appropriate treatment for their child, I think that anybody who knows about that has an obligation to report that to the Social Security Administration. They take those kinds of allegations very seriously.

What SSA tells us, though, is that nobody makes those allegations, and we hear story after story about people who don't want their kids to get better or that are abusing their children, but then when we ask, well, if a child is being sexually and physically abused, why isn't that parent being reported to the child welfare agency, or if they are not being taken for medical treatment, why aren't they being reported to Social Security so that Social Security can step in and either threaten to cut off benefits, which they can do if treatment is refused, or to name someone else to manage the funds if the question is one of fund mismanagement.

Both those mechanisms exist. Perhaps they need to be better communicated to the entire community that services disabled children, but those mechanisms are there, and I have seen cases where they have been used to deal with isolated instances of inappropriate behavior by parents.

In addition, things could be done to encourage parents, as we said, to work. One of the things that SSI does help poor families do is pay for extra daycare so that a parent can go to work.

I have an autistic nephew. He can't be left with the girl down the street. He has to be cared for by a trained professional. Fortunately his parents are upper middle class and they can afford the huge amounts of money it costs to watch him while they go to work. He has programs. He had school. He is in a day program, but there are other times, as you know, work isn't always 9 to 5 and employers expect you to be there and they expect someone—they expect you not to bring your personal problems to work.

There are ways that we could make it easier for parents of disabled children to work by giving them deductions in the deeming formula for special child care. Those kinds of things are certainly reasonable and we would applaud any efforts to modernize the SSI program in that respect.

We also agree with one of your colleagues who suggested the notion of prepackaged trusts to allow parents to put aside money for a child's education and special needs, without running afoul of the resource limit. A lot of parents of *Zebley* class members have received large amounts of money for benefits they were entitled to. They run up against the fact that the SSI program has a statutorily enacted rule that says that a family cannot have more than $2,000 in cash resources. They can't put the money away for the child for higher education or schooling beyond 18. There should be a simple way, without getting lawyers involved and without having to draft up fancy trusts, to put the money in an earmarked account, I think that that is something that we could achieve consensus on fairly quickly.

These children, many of whom are severely disabled, if they are going to make it in life, need to have some future planning done for them, and one way to plan for the future is to do something about the resource problem that many of them encounter.

Chairman FORD. Mr. McDermott.

Mr. MCDERMOTT. No questions, Mr. Chairman.

Chairman FORD. Let me thank the panel very much for their testimony today.

Mr. WEISHAUPT. Thank you, Mr. Chairman and we are available for further consultation.

Chairman FORD. Thank you.

Mr. McDermott, I am going to have to handle the emergency unemployment compensation bill on the floor. The rule is going to come up. Would you chair? It is going to come up about quarter of 1. They are trying to bring the rule up.

Mr. MCDERMOTT [presiding]. We will call the next panel of witnesses. Mr. Peysakhovich—if I did reasonably well.

Mr. PEYSAKHOVICH. Pretty good.

Mr. MCDERMOTT. Julia Roher, Paul Schroeder, and Stephanie Shelton. And we will have you testify the order in which I introduced you.

Mr. Peysakhovich.

Mr. PEYSAKHOVICH. Peysakhovich, yes, sir.

Mr. MCDERMOTT. Last syllable.

STATEMENT OF MARK E. PEYSAKHOVICH, PROJECT COORDINATOR, CHICAGOLAND SSI COALITION, CHICAGO, ILL.

Mr. PEYSAKHOVICH. Mr. Chairman, before beginning, I would like to thank you for the opportunity to testify today.

My name is Mark Peysakhovich and I am the project coordinator for the Chicagoland SSI Coalition, and I am here today on behalf of people like Ms. Dorothy Williams from Chicago who I just had a recent opportunity to meet.

She is a 71-year-old SSI recipient who suffers from a whole slew of tremendous physical problems. Ms. Williams is dependent on an oxygen machine to assist her breathing, and her SSI check is not sufficient to cover even some of her most basic needs, including utilities.

Recently she had to choose between paying her gas bill and her electric bill, and her solution was a simple one. Because of the oxygen machine that she uses and that requires electricity, she let her gas be cut off.

I would also like to talk about the staffing problems at SSA. As you know, between 1984 and 1990, SSA underwent a significant and I would say a crippling downsizing in staffing, 21 percent to be exact.

One issue that is raised by this problem is lack of outreach capacity within the SSA. In Chicago, this translates to more than 40,000 homeless, at least as many former general assistance recipients who have been cut from the rolls, and huge numbers, even larger numbers of senior citizens and the mentally ill who could and should be getting SSI, but only if they knew about it.

By far, the most serious problem we see in SSA offices is the delay in processing cases, and if an applicant has—if an applicant's initial application is turned down, the appeal process can take years.

Another problem that insufficient staffing causes is the client's files have become lost for months and years and often professional intervention is needed to deal with that. Long waits at SSA offices are another problem.

Often when clients have to go to a Social Security office, we tell them to get there by 8:30 a.m. and to bring lunch. Many clients, particularly the severely disabled and the mentally ill, simply cannot manage the long waits. Some just give up and go home.

Staffing problems at SSA have not been resolved by SSA's 1–800 teleservice. While some basic services are available over the phone, the teleservice representative does not have actual access to a client's file. She can only punch up whatever information is available on the computer.

I would also like to talk about the level of benefits for SSI recipients. The SSI program serves a population requiring assistance in meeting their basic human needs of food, clothing, and shelter. They often have medical transportation and other living costs which are higher than those of the nonelderly and nondisabled population.

If you take $434 a month and assume that a person is working a 40-hour week and figure out that monthly income, the hourly wage so to speak would come out to $2.71 an hour, and surely that is not enough to live on.

I could really attempt to shock you with stories of little old ladies having to share their pet food with their pet the last week of the month, but let me just point out instead that in Chicago, as well as any other city, it is impossible to rent even an inexpensive apartment and still have significant money for anything else.

A study published in March 1993 in the Journal of Hospital and Community Psychiatry cites that nowhere in urban America were rents for efficiencies or one bedroom apartments affordable to SSI recipients, and this is according to the HUD definition of affordability.

In Illinois, there is also a second application for a State supplement and a separate application for Medicaid. The triple SSI, SSP, Medicaid application is grossly inefficient. While SSI is the only lifeline available to many recipients and its intentions should be commended, these become a leash to poverty and hopelessness rather than a step up to hope and opportunity.

In particular, we strongly support your colleague, Carrie Meek's bill, H.R. 2676, because it would resolve a lot of those problems, and thank you once again for listening.

Mr. McDERMOTT. Thank you.

[The prepared statement follows:]

MARK E. PEYSAKHOVICH
CHICAGOLAND SSI COALITION

Mr. Chairman, before beginning, I would like to thank you and the members of this subcommittee for holding this important hearing and also for the opportunity to present this testimony.

My name is Mark Peysakhovich. I am the Project Coordinator for the Chicagoland SSI Coalition (Coalition). The Coalition was established one year ago in response to growing concern with the shortcomings in the Supplemental Security Income (SSI) program and their devastating effects on the Chicago area. Currently, the Coalition is comprised of more than eighty social service and advocacy organizations representing the SSI constituency in the area. In the last year, we have had the opportunity to work with hundreds of SSI clients and advocates and to document their problems and concerns.

I am here today on behalf of Dorothy Williams, a seventy-one year old SSI recipient who suffers from a whole menu of tremendous physical problems. Ms. Williams is dependent on an oxygen machine to assist her breathing. Her SSI check is not sufficient to cover even some of her most basic needs including utilities. Recently, she had to choose between paying her gas bill and her electric bill. Her solution was a simple one: because the of the oxygen machine, Ms. Williams let her gas be cut off.

I am also here on behalf of Mr. Joel Scheffel who had a history of several severe epileptic seizures each day. Mr. Scheffel's disability determination process took over two years while he was forced to depend on an inadequate patchwork of local and state assistance. As a result, Mr. Scheffel could not pay rent for an apartment and became homeless. In complete despair, he attempted suicide. Today, with a little money in his pocket, and even more importantly, with health care eligibility through the Medicaid program, Mr. Scheffel has been able to effectively control his seizures. He is attending a community college and remains an outspoken advocate for SSI reform.

I am here for all the other people who view SSI as a life or death issue and many of whom remain in limbo today. The issues I raise here today are the issues we have encountered hundreds of times throughout the last year.

I would like to stress that we support the suggestions contained in the SSI Modernization Project Final Report of the Experts published in 1992 and the SSI reform legislation (H.R. 2676) sponsored by your colleague, Congresswoman Carrie Meek.

First, I would like to discuss the staffing problems within the Social Security Administration (SSA). As you know, between 1984 and 1990 SSA underwent a significant, I might say crippling, "downsizing" in staffing. As the Modernization Report points out, current staffing levels remain approximately 21 percent below the pre-1984 levels. While SSA personnel are committed to providing high quality services to the public, given the reduced staff and the explosion of SSI applications and appeals, SSA district offices are unable to provide service in a timely, efficient, or orderly manner. Despite the best of intentions, SSA simply does not have adequate staffing to handle the workload.

One issue that is raised by this problem is the lack of outreach capacity within SSA. Although it is very difficult to get recent and accurate data from SSA (for some of the same reasons outlined here), it is commonly believed that only one half of SSI eligibles are on the rolls. In Chicago, more than 40,000 homeless, at least as many former state General Assistance (GA) recipients cut from the GA rolls, and huge numbers of senior citizens and the mentally ill could and should be receiving SSI - if they only knew about it. This problem was recently exemplified when a field officer from a local SSA office, previously assigned to work with the Coalition, was reassigned to take SSI applications because that office is "overwhelmed".

By far, the most serious problem we see in SSA offices is the delay in processing cases. Four years ago, in 1989, the average time needed to process an initial disability determination was 64 days. SSA's own projections reflect that average will have grown to an average of 213 days in fiscal year 1993.

If applicants' initial applications for SSI are denied, and nationwide about 57 percent of initial applications are denied, they face even more serious and frustrating delays. Currently, in the Chicago Office of Hearings and Appeals, it is not unusual for SSI applicants to wait five to seven months for their hearings to be scheduled, and several months for written decisions to be issued by the Administrative Law Judges. If there are no other complications, such as lost paperwork, and they are approved, they face several months of delays while their claims are processed for payment. From personal experience, I can tell you that hearing stories of three, four, and five year waits, including the appeal process, no longer astound me.

The insufficient staffing causes other problems. Clients' files have become lost for months and even years at a time. Often professional intervention is needed before the SSA locates or recreates a client file. Without such intervention, it is certain that many files simply stay lost and the applicants give up.

Long waits at SSA offices are another problem. Visits to SSA are known to take many hours. Often when clients have to go to an SSA office, we tell them to get there by 8:30 a.m. and to bring lunch! Many clients, particularly the severely disabled and mentally ill, simply cannot manage the long waits. Some just give up and come home.

Staffing problems at SSA have not been resolved by SSA's 1-800 teleservice. While some basic services are available over the phone, the teleservice representative does not have access to an individual client's file. For example, if a new application has been lost, but had been recorded on the computer, the applicant will be told that the application is pending, when in reality it is in administrative "limbo". The teleservice representative may not be able to tell that the file has not reached its destination and that no one is working up the claim. I can attest to waiting 20 minutes at a time on hold at SSA's 1-800 number. At times like that, I feel fortunate that I can generally use some contact at SSA and avoid the wait.

One particular example of a problem caused by understaffing and long waits that I want to raise is in the case of substance abuse related disability. As you know, SSI benefits are retroactive. This means that a substance abuser, having gotten SSI at some stage of appeal, may get a bulk payment of ten or twenty thousand dollars for the past years. While the promise of having some money to count on is an important part of recovery, many specialists and clients agree that retroactive bulk payments leave substance abusers with choices they are not equipped to make. We suggest that by eliminating long waits many other problems may also be eased or solved.

I would now like to turn my remarks to the benefit levels for individuals who receive SSI. The SSI program serves a population requiring assistance in meeting their basic human needs of food, clothing, and shelter. They often have medical, transportation, and other costs which are higher than those of the non-elderly and non-disabled population. SSI benefits should make it possible for those individuals to meet these needs and to live with a measure of dignity. As you know, SSI beneficiaries currently live in poverty.

I could attempt to shock you with stories of little old ladies having to share pet food with their pet the last week of the month. Let me point out that in Chicago, as well as any other city, it is impossible to rent an apartment, even an inexpensive one, and still have significant money for anything else. A study published in March of 1993 in a journal of Hospital and Community Psychiatry sites that nowhere in urban America were rents for efficiencies or one-bedroom apartments affordable to SSI recipients, according to the HUD definition of housing affordability.

In Illinois, there are also other issues involved. A separate state supplemental payment (SSP) is available for the few who find out about it, but its formula has not been changed since 1969. Thus, percentage of eligible SSI recipients for the SSP as well as the amount of the grant itself is very low. In addition, eligibility for Medicaid in Illinois is not automatic. Many of the SSI recipients are placed on an additional "spendown" by the Illinois Department of Public Aid. Basically, our state says that you may be poor, but not poor enough for us, and you are going to have to spend some of your SSI check to prove to us that you need Medicaid. In such cases, as much as one-half or more of an SSI check can go to getting health care. In addition to the severity of this problem in terms of medical and human cost, the triple SSI/SSP/Medicaid application is grossly inefficient.

The Coalition membership is grateful to the many fine people at SSA who make our lives a little bit easier. However, lack of allocated resources can only make survival more difficult for many SSI recipients and applicants who are very vulnerable to begin with. It has been our experience that inefficiency and confusion only breed more of the same. The information presented above only scratches the surface of all the issues that should be addressed in terms of the federal SSI program and its state components. While SSI is the only lifeline available to many recipients, and its intentions should be commended, it has become a leash to poverty and hopelessness rather than the a step up to hope and opportunity.

Several member organizations of the Chicagoland SSI Coalition will be supplying written testimony for the record under separate cover.

Thank you, once again, for the opportunity to present testimony today. I am happy to answer any questions you may have now or at a later date.

Respectfully Submitted,

M. Pey

Mark E. Peysakhovich
Project Coordinator
Chicagoland SSI Coalition

Mr. McDermott. You are going to testify for Ms. Roher.

Mr. Maseroni. Yes, sir, if that is all right.

Mr. McDermott. Surely. Please give your name.

STATEMENT OF JULIA ROHER, CASE MANAGER, EMPLOYMENT OF SSI RECIPIENTS, CASE MANAGED SUPPORTED EMPLOYMENT, AS PRESENTED BY ROBERT MASERONI, COMMUNITY LIAISON, CITIZENS ADVISORY COMMITTEE—SSI APPEAL TO CONSCIENCE IN MARYLAND

Mr. Maseroni. My name is Dr. Robert S. Maseroni. I am staff to the Citizens Advisory Committee—SSI Appeal to Conscience in Maryland.

On behalf of Julia Roher, I thank you for inviting me to testify today regarding the SSI reform. I work for an agency that helps with people who have developed mental disabilities in Bowie, Md., where I also reside.

The past 5 years I have worked with this disabled population helping them try to receive all the benefits they are entitled to. I have also become a member of the Citizens Advisory Committee—SSI Appeal to Conscience organization.

I am in favor of the final report of the experts, Supplemental Security Income Modernization Project and I support several of the recommendations.

For instance, one of my clients, Tony, receives $434 of SSI monthly to live on and receives $53 in food stamps. He currently has a utility gas bill that is over $500, which he is unable to pay off. He had his gas turned off until he pays his bill in full.

Social services told him that he would not receive energy assistance because he does not have any children. He lives alone and winter is approaching quickly. This is why I am in favor of raising the SSI benefits 120 percent above poverty level.

Speaking to another recommendation, if Tony were allowed to have roommates, he would be able to afford these bills because they would be shared. That is why I am in favor of eliminating the one-third reduction in benefits for people who live with someone else and receive SSI.

Tony and another disabled individual could house themselves in an accessible housing apartment, share expenses, and be able to live and socialize more normally.

I am also in favor of automatic Medicare with SSI benefits. If Tony had not been linked with professional services, he would not have known how to receive Medicaid. He has a very severe disability. Through my connections as a professional in the social services field, I am able to get Medicaid for people like Tony. I can do it quickly through SSI by writing one letter.

But many others do not have the advantage of an individual case manager who can advocate for them, thus the need to have automatic Medicaid with SSI approval.

I am also in favor of the 6,000 permanent outreach personnel to help people learn more about SSI. Through my experience in working with transitionally disabled high school students to adult services, I find a large majority of the families unaware that SSI is an option for them.

Permanent outreach could overcome much of the ignorance of these already available rights. There is a need for SSI outreach work for not only teens, but for all people transitioning into SSI services.

Most of the families I work with were unaware that such a door of opportunity exists. This means that people without professional caseworkers lose out on services. In actuality, we estimate that 30,000 people may be eligible for SSI in Prince George's County, but there are little over 6,000 on the rolls.

I am in favor of the work incentive, not work disincentive program. I currently am assisting disabled individuals to enter into the work force, however, I am unable to convince many participants to sign up for my program because they tell me they cannot afford to lose what little benefits they are receiving if they should fail at work or not earn enough, and that is certainly true with the mentally ill people with whom I deal with.

SSI recipients are afraid and sometimes incapable of doing the PASS/IRWE program because they do not want to lose their benefits.

I am concerned with the recommendations which would establish a long enough period of time of work while receiving benefits so that stability may be established and termination of benefits be gradually withdrawn so the person may stand on their own efforts.

I am in favor of raising the income exclusion from $65 to $200 and reducing the SSI benefits by $1 for every $3 earned instead of the current $1 for every $2.

I am also in favor of the recommendations from the final report of the experts, which would allow disabled single people to keep $7,000 in assets and couples retain $10,500 rather than current levels of $2,000 and $3,000 respectively.

A new roof on the house, repairs on a furnace or a hospital stay can easily dissipate even these meager resources. This recommendation doesn't cost government any new funding.

Finally, I support the increase in Social Security Administration staff to reduce the waiting period for applicants who are disabled. For example, a member of our Citizens Advisory Committee SSI reform waited 7 years for his SSI. The agency carried him for the entire time until he became eligible and he repaid the agency for the services received.

Now, because of budget cuts at his agency, if this crisis arises for other clients awaiting SSI for longer than 90 days, as it does, there is no way this agency could carry them for years. The result for them is often homelessness and loss of services.

In closing, I thank you again for inviting me to testify. I know that I only am able to reach a small percentage of the disabled population through my work, but it is gratifying to see people like Tony transcend their disability with a little help, and Tony is only one of many, many crisis cases. I hope you will support the changes that have been proposed in my testimony.

Thank you, sir.

Mr. McDermott. Thank you.

Mr. Schroeder.

STATEMENT OF PAUL W. SCHROEDER, DIRECTOR, GOVERNMENTAL AFFAIRS, AMERICAN COUNCIL OF THE BLIND

Mr. SCHROEDER. Good afternoon, my name is Paul Schroeder and I am director of governmental affairs for the American Council of the Blind.

I have also been a recipient of SSI for approximately 1 year. I have lived in States with good, little, and no subsidy. I have experienced the work incentives. I have experienced the appeals and some of the degrading treatment that people with disabilities go through. I have also experienced the pride of independence from the rolls.

I hear the stories similar to mine in the job that I now hold at the American Council of the Blind. Overall what I wish to suggest to the subcommittee and to Congress in general is that the SSI program needs more resources and less complexity.

The American Council of the Blind has long urged the SSI program to receive sufficient resources that monthly benefits can be brought to proximity—at least proximity with the Federal poverty line. We support the 120 percent recommendation of the SSI modernization project.

We also wish to note that people who are blind, who have other disabilities, usually face even higher proportional costs of living and additional expenses than nondisabled individuals. For example, because of inadequate public transportation and difficulties getting around independently, blind people often use taxicabs to travel to work, conduct business, and perform personal errands, while other individuals can, of course, drive a personal automobile, if they own one, take public transportation, or even walk.

In most communities, taxicabs, even for a short distance, taxi fares are fairly steep. Individuals with disabilities often pay for personal assistant services in order to live independently. In addition, individuals with disabilities, particularly blind people, often need special technology simply to help them carry out the basic tasks, such as communication.

These devices often cost thousands of dollars and few dependable means of financial or technical assistance are available.

Therefore, for all of the reasons which have been cited this morning, and for the reasons which I have just included, we believe that a first and top priority of this subcommittee ought to be to move the SSI program in a direction which provides for at least a poverty level of benefit.

Second, we believe that the staffing issues can be addressed and should be addressed with deliberate speed.

In particular, we would like to offer that for people who are blind, under SSI, we believe that some of the staff backlog could be diminished.

Because the definition of blindness is functionally based, it is unnecessary for the condition of blindness to be reviewed at the DDS level. Eligibility determinations and backlog would be improved by adopting one of the following changes: You could either empower field staff to determine whether or not the available medical evidence supports an applicant's claim of blindness.

Second, and I think less desirable, a centralized Federal program could be developed simply to review the medical evidence of blindness. It is indeed the simplest definition within the SSI program to determine.

We concur with the recommendation regarding resources that has been put forth by the SSI modernization project. We believe that increasing the resources available would help make the program more responsive in terms of eligibility and would assist ultimately in allowing someone to move to independence.

A $2,000 limit on resources requires someone obviously to spend into poverty and to emerge from SSI, if they are able to, with virtually nothing to stand upon.

In-kind support, we believe, within the SSI program is one of the most bureaucratically burdensome and mean-spirited parts of the program. To penalize a recipient for trying to be responsive, for trying to improve his or her situation is, in fact, a horrible and tragic burden.

In addition, the paperwork, staff time, and other problems put upon the SSA staff who are trying to determine the level of in-kind support are absolutely incredible and wasteful.

I experienced this myself, both the indignity of having one's life probed into, house mates, others with whom the person is associated, queried about their association with a SSI applicant. It is something which should be dropped forthwith.

I want to touch for a moment on work incentives and simply to note that the passage of the Americans with Disabilities Act, the accompanying publicity about that act and as well the reemphasis of employment in the rehabilitation act amendments of 1992 should dramatically improve employment opportunities for people with disabilities.

SSI must respond to these improved opportunities. Issues around Medicaid, particularly the section 209(b) allowance for States to establish a separate Medicaid eligibility needs to be eliminated.

In addition, countable income, which is a second area of extreme complexity within the SSI program, countable income and the work expense reductions which are available to SSI applicants both need to be addressed as part of a work incentive program.

ACB recommends that the current impairment-related work expenses and the blind work expenses should be explored to determine if, in fact, these incentives are too confusing, both to recipients and to program staff. It is likely that the elimination of the extensive recordkeeping and paperwork may well make this—the recommendation put forward by the SSA modernization project to increase income and to improve the reduction of benefits to a $1 for $3 may well make these work incentives no longer necessary, or at least no longer necessary for most people.

We urge, of course, that individuals continue to have the choice of documenting their work expenses. ACB also believes that it must stress to this subcommittee that we are supportive of changing the impairment-related work expenses to reflect the same levels associated with the blind work expenses and the same means of calculation.

There is no reason for these two work expenses to be different, and as a blindness organization, we wish to put our support forthwith for the improvement of IRWEs, if they are kept in the program.

Last, I simply want to note that I would hope that this subcommittee would ask Social Security Administration officials to submit evidence that shows that outreach and case materials are produced promptly in accessible alternative formats to regular print. By these, I mean Braille, large print, cassette tape, and electronic file.

Many people who are eligible and who are currently on the SSI program are unable to read print, obviously because of blindness, but also for many other disabilities and the Social Security Administration needs to dramatically improve its ability to communicate and outreach to these individuals.

Thank you very much for the opportunity to testify.

[The prepared statement follows:]

STATEMENT OF PAUL W. SCHROEDER
AMERICAN COUNCIL OF THE BLIND

Mr. Chairman and members of the Subcommittee, my name is Paul Schroeder. I am Director of Governmental Affairs for the American Council of the Blind, the nation's largest and most diverse organization of blind and visually impaired persons. ACB is pleased to provide comments with respect to the Supplemental Security Income program and, specifically regarding the Social Security Administration's "Supplemental Security Income Modernization Project." We compliment the efforts of the SSI Modernization Project to thoroughly examine the Supplemental Security Income program and suggest comprehensive reforms in this very important income maintenance program. The Project's report has framed in clear and articulate language the current status of the SSI program and its many limitations. Of even greater value is the inclusion within this Paper of much of the best current thinking regarding recommendations for improvement in the SSI program. I wish to comment on some of the recommendations included in the SSI Modernization Project report, and to address some specific concerns of the American Council of the Blind.

INTRODUCTION

The Supplemental Security Income program has saved millions of recipients from utter impoverishment, however, bureaucratic obstacles, insufficient federal benefit levels, unchanged resource and income limitations, and inadequate work incentives keep SSI out of reach of many needy people, while shackling the drive and determination of recipients who wish to achieve self sufficiency. For nearly 20 years, SSI has proven to be of critical importance, but many provisions of the program no longer reflect current economic or social realities. Significant changes in the SSI program are necessary so that it reflects changed circumstances, including the passage of the Americans with Disabilities Act.

The SSI program faces two critical realities. Many recipients (because of age or other factors) will not find reliable, ongoing employment and these individuals should be assured of an income at least at parity with the federally-determined poverty level. Improved opportunities resulting from the Americans with Disabilities Act, improved vocational rehabilitation services and improvements in other programs and services will enable other individuals to seek gainful employment and SSI should be designed to afford maximum assistance to these individuals. Work incentives now in place are not sufficient to meet this challenge and current income and resource limitations serve as an obstacle to independence and gainful employment.

I. DISCUSSION OF PRIORITIES FOR CHANGE

Each SSI recipient, or potential recipient, possesses a special set of needs and circumstances which profoundly shape his or her needs under the SSI program. For some, ongoing income is most critical. Others need a "safety net" to allow them to become self sufficient. Still others are most in need of medical benefits. Balancing these needs and setting priorities among them is virtually impossible. However, the findings of the SSI Modernization Project, as well as 20 years of "living" with this program clearly show that certain categories of changes must be made. Without dramatic and comprehensive improvement, the SSI program will not succeed either as a income maintenance program or as a means to help SSI recipients move out of poverty. The most critical changes require statutory amendment and/or additional appropriations. However, some important improvements can be made administratively and we hope that this Subcommittee will urge the Department of Health and Human Services and the Social Security Administration to take action on those improvements in the SSI program over which they have administrative control.

The American Council of the Blind supports the basic intent of the four priorities listed in the SSI Modernization Project report:

--increase SSA staffing;

--increase the Federal benefit standard;

--stop counting, as income, in-kind support and maintenance; and

--increase the resources limits, while streamlining the resources exclusions.

Among these priorities, ACB urges Congress to put immediate emphasis on increasing the federal benefit level and on increased staffing and related changes to improve the time lines for program decisions.

Federal Benefit

The American Council of the Blind has long called for an increase in the cash payment to SSI recipients as a high priority in bringing rational improvement in the SSI program. However, accomplishing this needed change will require a great deal of effort.

We completely support the SSI Modernization Project Panel's recommendation to raise the SSI Federal benefit standards to 120 percent of the poverty guideline for individuals and couples. Our society must assure subsistence at least equivalent to the federal poverty level for individuals dependent on SSI.

The higher proportional costs for essential items such as food, clothing, housing and transportation borne by the poorest individuals and families in our society is now well established. These individuals do not have access to the variety of choices which are typically available to the majority of Americans who live in or near suburban housing/shopping developments. **People who are blind or who have other disabilities usually face even higher proportional costs of living or additional expenses not generally faced by nondisabled individuals.** For example, because of inadequate public transportation and difficulties in getting around independently, blind people often must use taxicabs to travel to work, conduct business and perform personal errands, while other individuals can drive a personal automobile, take public transportation or even walk. In most communities, taxi fares, even for relatively short distances are quite steep. Individuals with disabilities often pay for personal assistance services in order to live independently. In addition, individuals with disabilities, particularly blind people, often need special technology to help them carry out basic tasks such as communication, including reading and writing. These devices often cost thousands of dollars and few dependable means of financial or technical assistance are available. Therefore, we strongly urge the Congress to move forward on implementing this minimal level of federal benefit which the SSI program was supposed to guarantee.

Staffing/Backlog Issues

The backlog in eligibility determination, especially for a program providing assistance to the very poor, is particularly harmful. SSI-eligible individuals obviously have little or no resources or income on which to rely during delays in eligibility determination. While altering the definition of disability under the SSI program could alleviate some of the backlog at the Disability Determination Services (DDS), ACB believes that some of the backlog could also be eliminated with a change in the determination of blindness. Because the definition of blindness is functionally-based, it is unnecessary for the condition of blindness to be reviewed at the DDS level. Eligibility determinations and backlog could be improved by adopting one of the following changes:

1. empowering field staff to determine whether or not the available medical evidence supports an applicants claim of blindness; or,

2. establish a central federal determination system to review the medical evidence submitted by an applicant alleging blindness.

In either case, an individual denied for SSI because of insufficient evidence to support blindness could then submit an application alleging some other disability (conditions which cause partial vision loss often also cause other disabilities). Alternatively, the individual could appeal the denial.

Resources and Eligibility

When establishing and administering need-based public assistance programs, those who frame public policy should carefully consider the time and effort which must be expended in gathering information needed to document an applicant's claim. The difficulty involved in obtaining such information and the often demeaning circumstances under which it is sought also must be considered. While not unique in its extensive bureaucratic requirements, the SSI program contains several examples of eligibility and related requirements which are exceedingly difficult to satisfy both for individual applicants/recipients and SSI staff.

Assets/Resources

SSI is a need-based program which justifiably includes eligibility criteria to assess an individual applicant's need. An assessment of an individual's available resources and assets is one necessary criterion. **However, the current resource test used to establish eligibility for the SSI program is unnecessarily restrictive and deleterious to the important goal of enabling a recipient to gain independence and self sufficiency.** Indeed, the current approach is especially damaging to the recipient, or applicant, whose long-term goal is independence from SSI.

The American Council of the Blind urges Congress to amend the SSI program to enact these changes to the current approach to "countable resources" as part of a package to improve the prospects for independence for SSI recipients:

1. Increase resource limits to at least $7,000 and $10,500 as recommended in the SSI Modernization Project Report

While a $7,000 limit (individual) and $10,500 limit (couples) is a very modest amount of assets, this level allows the recipient to establish a minimal amount of security in order to address emergency needs such as home repair or, a modest step toward self-sufficiency if he or she elects to leave the SSI program.

2. Maintain current exclusions

ACB believes that even with an increase in the resource limit, maintaining current exclusions such as a home, life insurance and burial funds is a sensible and humane approach. The current exclusions should be maintained even if resource limits are raised to the levels recommended above.

In-kind Support and Maintenance

Few aspects of the Supplemental Security Income program are as bureaucratically burdensome and mean spirited as the counting of in-kind support against a recipient's cash payment. The amount of staff effort expended in determining the value of support, pursuing the contributions provided by a recipient's housemates and establishing the amount of overpayment, let alone processing the paperwork generated by these inquiries, is a tragic waste of time, resources and staff morale. The damage caused to SSI recipients' self esteem, independence and initiative is tragic as well. ACB believes that the resources expended in this effort, and the harm done to individuals warrants the elimination of the counting and assessment of penalties for in-kind support. SSI field staff should be spending their time in more rewarding and useful ways than pursuing documentation of the meager in-kind and other supports which recipients are able to achieve. Indeed, recipients should be encouraged to seek this kind of assistance as part of an overall strategy to lessen dependence and enhance individual self sufficiency.

Deeming of Parents' Resources

The American Council of the Blind supports the SSI Modernization Project Panel recommendation regarding the deeming of parental resources where one or more SSI-ineligible children are in the child's family. The Report calls for the exclusion or deeming of $2,000 (index) to each ineligible child in the family. In addition, the special disability-related costs which parents must bear should also be excluded from the child's resources since these dollars are obviously not available to meet the child's other needs.

II. WORK INCENTIVES

Taken together, implementing the above recommendations will lead to substantial improvements in the SSI program. However, ACB strongly supports the need for amendments to and changes in the administration of the SSI program in order to improve the work incentives available to SSI recipients who strive for independence and self-sufficiency.

The American Council of the Blind believes that most people with disabilities want to work. Presumably, SSI recipients are not an exception. Passage of the Americans with Disabilities Act and the accompanying publicity of its provisions, as well as the enhanced emphasis on employment in the 1992 amendments to the Rehabilitation Act should dramatically improve employment opportunities for people with disabilities. The documented desire of people with disabilities to work, combined with the protection against discrimination and enhanced opportunities provided by the ADA and the Rehabilitation Act make the work incentive provisions of SSI doubly important. Issues around Medicaid eligibility must also be addressed in any improvements in work incentives under the SSI program, e.g., the provision under Sec. 209 (b) which allows states to establish separate Medicaid eligibility should be eliminated.

Countable Income

As one of the more archaic provisions of the SSI program, the income exclusions and countable income rules and levels should be given attention. Toward this end, ACB urges Congress to seriously examine the SSI Modernization Project Panel's recommendations regarding changes in the exclusion of unearned income, as well as the counting of earned income and the benefit reduction formula.

The Report calls upon Congress to Raise the income exclusion from $65 to $200 and reduce the SSI benefit by $1 for every $3 (instead of the current $1 for every $2) of earned income over $200. This "one for three reduction" is the approach now taken for working retirees age 65-69 under Title II of the Social Security Act. The Report further recommends that "the increased exclusion amount would be intended to compensate the recipient for his/her work expenses." ACB recommends that the current Impairment Related Work Expenses (IRWE) and Blind Work Expenses (BWE) be explored to determine if these incentives are too confusing to both recipients and program staff alike. It is likely that the elimination of extensive record-keeping and paperwork may well make this recommendation worth exploring. However, as the Report recommends, "individuals whose actual work expenses are more than the amount of earnings excluded (i.e., more than $200 plus two-thirds of the remaining income) should continue to have an individual exclusion computed which would consider the person's actual work expenses."

ACB wishes to stress that whether or not a change such as that recommended above is adopted, IRWE should be changed to be equivalent with BWE. The members of this organization believe that parity should be established in the SSI programs by bringing individuals with other disabilities up to the work expense level and calculation method now available to blind individuals. In addition, field staff should receive better training to help them better understand the nature of BWE which are any expenses related to work.

ACB also urges a modification in the counting of income which fluctuates. If income is likely to fluctuate, (this can occur for many reasons--intermittent work, irregular pay periods, etc.), the counting of income should be annualized so that an individual is not needlessly considered ineligible for an SSI payment, or more important, for continued receipt of Medicaid.

PASS

The American Council of the Blind supports many of the recommendations made by the SSI Modernization Project regarding the SSI provision for a Plan to Achieve Self Support (PASS). For example, it is reasonable for field staff to make a determination on a PASS within 30 days. As the Report recommends, if this 30 day time limit is not met, the PASS should be considered approved, and if it is later disapproved, resulting benefit changes should be prospective not retrospective, i.e., resultant payments, which should begin at once based on application of the plan exclusions, would not become overpayments if the plan were subsequently disapproved.

In addition, ACB supports the recommendation that SSA alter the current administrative time limit on the duration of a PASS. Any time limit should consider the nature of the Plan. For example, the expected outcome of a Plan, e.g., education may indicate a useful guideline for the time needed to complete the PASS. Or, other factors may be important guides in establishing a reasonable time period, e.g., the vocational goal of establishing a small business may require a few years to show a profit. Disability considerations should also be accounted for in imposing any time limits on a PASS. For example, an individual who is blind may take longer to complete postsecondary education or vocational training because of program access obstacles faced by blind people.

Independence Account

Although the SSI Modernization Project Panel rejected the recommendation for an "Independence Account," such an incentive should be explored, particularly if resource levels are not substantially increased. The Independence Account would operate similar to the Program to Achieve Self Support (PASS) so that individuals or couples could set aside resources in order to prepare for independence. Approved items for such an account should include such things as the purchase of a home, assistive technology/device or vehicle, relocation for employment or other valid reason, personal assistance services, child care and other expenses necessary to achieve independence. Recipients, working or not working, should be able to establish such an account.

III. APPEALS

The appeal process in both the SSI and SSDI programs is unnecessarily bureaucratic and impersonal. The American Council of the Blind supports the two primary recommendations of the SSI Modernization Project with respect to improvements in the appeal process. The Report calls for the elimination of the reconsideration level of appeal, and for providing claimants with an opportunity for a face-to-face interview with the decision-maker prior to issuing a denial based on lack of disability or insufficient evidence to support blindness.

ACB also supports a change in the statute to establish time limits for the determination of blindness or disability as well as for the adjudication of appeals. We note that the 1992 amendments to the Rehabilitation Act include a requirement for eligibility determinations within 60 days.

IV. OTHER NECESSARY IMPROVEMENTS

Training and Sensitivity

Individuals applying for SSI have the right to be treated with dignity and respect. Currently, however, complaints about poor, degrading, and humiliating treatment of SSI applicants and recipients by SSA staff are quite common. Disability-awareness and sensitivity training will require resources which will affect allocation of those resources to other needs. However, building disability-awareness and sensitivity into staff recruitment and screening processes will lessen the need for future training. In addition, several agencies will provide disability-awareness training at little or no direct cost. For example: many advocacy organizations provide training regarding the concerns and needs of those they represent; most state affiliates of the President's Committee on Employment of Persons with Disabilities, as well as most vocational rehabilitation agencies also have staff who can provide this training. Making use of such existing resources would greatly minimize the cost to the Social Security Administration.

One additional step would be needed: commitment on the part of Social Security

Administration management, at all levels, to stress to staff the importance of treating people who are receiving or seeking benefits with the utmost respect and dignity. Attitudes can change, but bringing about this change requires dedicated management leadership. Incidentally, part of this leadership should be a commitment to recruit and hire workers with disabilities and older workers.

Clearly, these modest steps are only a beginning. However, ACB believes these actions could be taken with minimal costs and burden to SSA, and the long-term effect on improved interactions between recipients and program staff would be very positive.

Information and Referral

A second, relatively immediate, improvement which SSA could implement is improved information and referral capacity among SSI field staff. Providing SSI field office staff with resource lists and a modest amount of time to establish a working relationship with staff in the many existing assistance programs and resources in the local community would be well worth the effort. The "one stop" approach to human services has long been advocated by many in the field. While we are not yet close to that reality, SSI staff, as an important link in the system of services and supports--often a point of first contact--should possess the knowledge and ability to steer individuals toward services such as nutrition and health counseling, food stamps, employment/vocational training, housing, transportation, etc.

While the direct cost to the Social Security Administration in implementing this approach to information and referral would be relatively modest, the demand for staff will increase and the work of those employees will be altered. ACB believes that relieving SSI staff of other current burdens would enable staff to begin to undertake an enhanced information and referral role. Because this primarily requires administrative initiative and flexibility, rather than statutory change, it should be more easily implemented.

V. A NOTE ABOUT ACCESS TO THE PROGRAM

ACB continues to call upon the Social Security Administration to improve its provision of program and case-related documents in formats which individual recipients can read and use independently. Specifically, SSA must improve the availability of documents in Braille, large print, cassette tape and electronic file. Any one of these formats alone is not sufficient to meet the needs of the large number of SSA consumers who do not read standard print. The accessible formats mentioned above are no longer difficult to produce and the expense can be minimized through technology and judicious production. Indeed SSA has an obligation, as a federal agency, to make its programs accessible to people with disabilities.

ACB urges Congress to direct the Social Security Administration to submit evidence which shows that outreach and case materials are produced promptly in alternate formats to regular print, e.g. braille, large print, cassette tape and electronic file and that the availability of materials in alternative formats is publicized. In addition, SSA should be asked to show that publicity/outreach information is distributed to agencies/organizations of and for the blind, radio reading services, parent groups, optometrists and ophthalmologists. And, evidence that public service announcements for television have been thoughtfully scripted and/or audio described in order to provide the same information in audio which is communicated visually. We do wish to compliment SSA on its efforts to provide specific information through the radio reading service network. These services provide over-the-air information to eligible individuals who are unable to read or use standard printed material.

VI. CONCLUSION

The American Council of the Blind is committed to working with the Congress and the Social Security Administration in order to find ways to improve the SSI program. The work of the SSI Modernization Project establishes an excellent starting place for Congressional and Administration efforts to enable the SSI program to meet its early promise to help lift the poorest of the poor out of poverty.

Mr. McDermott. Thank you all three.

Let me ask you a question, Mr. Schroeder. You suggest face-to-face interviews in your testimony, and I wonder if that wouldn't slow down the process. One of the things we worry about—at least looking at the backlog—is how can you speed the process. I wonder if you have a face-to-face interview with everyone, if you would in fact slow down the process.

Mr. Schroeder. That recommendation actually—and thank you for the question—is in reference to a discussion of appeals in my testimony. It is in that context that I recommend a face-to-face interview being available, which I think would short circuit some of the paperwork and documentation flowing back and forth between individuals and SSA before that individual has ever been able to sit down with somebody in the field office to talk about the medical condition, particularly people who are blind.

Mr. McDermott. So you are basically talking about the second step, after somebody has been rejected and they appeal it?

Mr. Schroeder. That is correct, sir.

Mr. McDermott. OK. I sit here listening to this, I have so many questions, but on the other hand, I think if anybody who objects to this program had to go out and spend a day sitting and examining cases, they would very quickly stop making assertions about this program. In my professional role in my other life, I frequently had to examine people and testify on their behalf on SSI rejections. So I sit with a certain amount of disbelief at people who, if they looked carefully at who the population is in the SSI program, would come away saying that there are people who should lose their SSI.

The myth of the welfare queen is applied to this program too, that there are somehow people out there who are ripping it off. I think the biggest problem for the program is figuring a way to quickly make decisions and get people on it who need benefits.

One of my questions to the three of you is about the issue of giving people benefits and then asking for repayment if they are judged not to be eligible for the program. What kind of problems do you think that would create?

Mr. Maseroni. Well, that has been done to some of our people who are mentally ill after they got better. It creates horrendous things in all cases, when the pulling back of funds was unjustified. People had to go through a horrendous process; plus deal with the terror of losing everything that they had finally gotten.

Mr. McDermott. Are you saying that they were on the program?

Mr. Maseroni. Yes.

Mr. McDermott. Having been judged to be eligible?

Mr. Maseroni. Yes.

Mr. McDermott. Then how did they get taken off the program?

Mr. Maseroni. There was a miscalculation made in the SSA office or they were credited with benefits they didn't get, and the benefits were pulled or terminated.

Mr. McDermott. So it was not a matter that they were started on benefits before an adjudication was made?

Mr. Maseroni. No, I am not talking about a work incentive. I am just talking about that kind of mix up.

Mr. PEYSAKHOVICH. If I could just point out that I think, and indeed everyone I work with thinks that one of the greatest expenses to the SSI program is this back and forth policing.

I think, in fact, if Congress and the Social Security Administration attempted to do that to try to get repayment in such an instance, they would probably find themselves spending more money than they would be saving.

Mr. MCDERMOTT. Because of the nature of the people who are on SSI and the economic circumstances of the people who have received the money?

Mr. PEYSAKHOVICH. Not necessarily. The process itself takes a—I mean, it takes a lot of staff time and it takes a lot of work, coupled with the—some inefficiencies in the computer system and the staff system. You probably know this.

I mean, if somebody gets an overpayment now and gets notice of an overpayment, they can initiate a process of appeals. I mean, you can appeal any decision. And you can also do some horse trading. You can go in there and say, well, I can't pay you $100. I will pay you $10 back. The guy at the other end of the line says, OK, if you pay us $10 back, it will take you 2,000 years to pay back. You have to pay $75.

So I think that a lot of staff time and a lot of recordkeeping and a lot of administrative costs would probably cost more money than they would be saving or recouping.

Mr. SCHROEDER. I think the amounts of money are relatively small in this program, and I can tell you that one of the greatest fears I have ever had in my life was to receive a notice that I received from SSA that I owed them $1,500 in an overpayment.

First of all, the notice was unaccessible and we ran into several problems around that. But after that was straightened around, I appealed through the administrative law judge level, costing SSA Lord knows how much money and it resulted in a $2.22 finding against me. I remember that figure and always will, and I can only imagine how much time and money was wasted by SSA in that effort.

I think the problem with overpayment comes from several sources, both mistakes made by claimants and their applicants, beneficiaries in this case—these were my mistakes in large part, but also mistakes made by the field office staff, and we have heard about some of those. Both contribute to the problem.

I sense there is probably little worth in the effort now in most instances to go after those who have been overpaid benefits.

Mr. MCDERMOTT. Thank you very much, all of you, for coming. We appreciate your testimony.

The next panel is Larry McElwain, Elizabeth Boggs, and Fred Rockwood. I would remind all of you—I didn't say it to the last panel, but I will say it to this panel—as you know, your entire statement will go into the record without objection. So if there are things you want to say beyond that, rather than read into the record what you have already written, that might be most useful for the staff and the committee.

You each have 5 minutes. Why don't we start with Mr. McElwain.

STATEMENT OF LARRY K. McELWAIN, CHAIRMAN, GOVERNMENT AFFAIRS COMMITTEE, NATIONAL FUNERAL DIRECTORS ASSOCIATION, ACCOMPANIED BY SCOTT GILLIGAN, GENERAL COUNSEL

Mr. McElwain. Thank you, Congressman McDermott. I really appreciate the opportunity to be here this afternoon and to talk to you about the SSI modernization issue.

My name is Larry McElwain. I am a funeral director and I am chairman of the National Funeral Directors Association, Governmental Affairs Committee. Scott Gilligan is our general counsel and he is here with me this afternoon.

The National Funeral Directors Association is a federation of associations representing all 50 States and the District of Columbia. We are the largest organization of funeral service professionals in the country.

Approximately 98 percent of our 15,000 member firms provide consumers the opportunity to prearrange or to prepay their expenses for a funeral.

We are concerned about the general recommendation of the SSI modernization panel to eliminate many current resource exclusions, including those for funds set aside for the funeral and burial. Our position is that these exclusions should be retained.

Prepaid funeral arrangements are funded in various ways, including trusts, insurance policies and annuities. Some arrangements are irrevocable, meaning that they cannot be changed or canceled by the consumer, and the State laws across this country vary regarding the use of revocable and irrevocable instruments.

The SSI program currently provides that irrevocable funds available to meet the funeral and related expenses are not considered to be resources. In addition, the program allows a $1,500 burial fund and a burial space exclusion for revocable arrangements.

Interest and accruals on those trusts or insurance on burial space and burial funds are also excluded.

Current exclusions work well in all States because they offer the consumers in those States a variety of funding instruments and facilitate variations in State laws.

First and foremost today, we believe that current SSI exclusions for funeral and burial funds constitute sound public policy. Funeral expenses are inevitable. The cost of a funeral for individuals without resources at the time of death is generally borne by State and local government programs, unless prepaid arrangements have been made in advance by those persons or their families.

The panel reports it was told repeatedly during hearings that SSI benefits are not adequate to provide a dignified quality of life. In 1982, Congress recognized that SSI benefits were not adequate to provide dignity in death either.

In recognition of this inadequacy, Congress took action to ensure that SSI recipients could provide for this necessary final expense via prepaid funeral contracts without forfeiting their right to receive SSI benefits.

Current SSI funeral resource exclusions constitute articulated public policy on care for the elderly and disabled that recognizes as a part of that obligation the provision for a dignified funeral and burial.

An overall increase in allowable resources alone, as one of the proposals put forth would be, would not be sufficient to ensure the availability of funds for a funeral and burial. If resource exclusions for a funeral and burial funds are not maintained, we believe that increased allowable resources will be likely used by recipients for day-to-day sustenance purposes without consideration of the need for monetary resources at the time of death.

The continued formal designation of these funds is necessary, we believe, to insure that the funds remain intact for the designated purposes during the recipient's lifetime.

In summary, we wish to leave you with two clear messages today. First, we oppose any changes that would eliminate current resource exclusions for funds set aside for a funeral and burial. Second, we are the leading national expert on funeral services with direct lines of communication to our constituent associations in every State and the District of Columbia.

We ask you to call upon us as a committee and staff for assistance as you continue to study the complex ramifications of the board recommendations of the SSI modernization panel.

We are an unbiased resource in that we do not favor one funding instrument over the other. We believe it is in the best interest of funeral directors and their consumers to offer the widest variety of products and services possible. Current law and regulation strikes a delicate balance between all funding instruments, and changes could easily tip this market balance in favor of one instrument or another.

If we do not have information you require, we pledge we will get it. If Members of Congress or the administration determine that changes impacting resource exclusions for funeral and burial funds are required for some specific reason, we will develop viable proposals with you and for you.

On behalf of our 15,000 members, we thank you for your consideration of our concerns and we will be most happy to entertain any questions that you may have regarding our concerns.

Thank you, very much.

Mr. McDERMOTT. Thank you.

[The prepared statement follows:]

STATEMENT OF LARRY K. McELWAIN
NATIONAL FUNERAL DIRECTORS ASSOCIATION

Thank you Chairman Ford, and distinguished members of this subcommittee for the opportunity to speak to you today.

My name is Larry McElwain, and I am the Chairman of the NFDA Government Affairs Committee. Scott Gilligan, our General Counsel, is with me this morning.

The National Funeral Directors Association is a federation of associations representing all 50 states and the District of Columbia. We are the largest organization of funeral service professionals in the country. Approximately 98 percent of our 15,000 member firms provide consumers the opportunity to prearrange and/or prepay expenses for a funeral.

We are concerned about the general recommendation of the SSI Modernization Panel to eliminate many current resource exclusions, including those for funds set aside for a funeral and burial. Our position is that these exclusions should be retained.

Prepaid funeral arrangements are funded in various ways, including trusts, insurance and annuities. Some arrangements are irrevocable, meaning they cannot be changed or cancelled by the consumer. State laws vary regarding the use of revocable and irrevocable instruments.

The SSI Program currently provides that irrevocable funds available to meet funeral and related expenses are not considered to be resources. In addition, the Program allows a $1,500 burial fund and a burial space exclusion for revocable arrangements. Interest and accruals on burial space and burial fund are also excluded.

Current exclusions work well in all states because they offer consumers a variety of funding instruments and facilitate variations in state laws.

First and foremost, we believe that current SSI exclusions for funeral and burial funds constitute sound public policy.

Funeral expenses are inevitable. The cost of a funeral for individuals without resources at the time of death is generally borne by state and local government programs, unless prepaid arrangements have been made.

The Panel reports it was told repeatedly during hearings that SSI benefits are not adequate to provide a dignified quality of life. In 1982, Congress recognized that SSI benefits were not adequate to provide dignity in death. In recognition of this inadequacy, Congress took action to ensure that SSI recipients could provide for this necessary final expense via prepaid funeral contracts without forfeiting their right to receive benefits.

Current SSI funeral resource exclusions constitute articulated public policy on care for the elderly and disabled that recognizes as part of that obligation the provision for a dignified funeral and burial.

An overall increase in allowable resources alone would NOT be sufficient to ensure the availability of funds for a funeral and burial.

If resource exclusions for funeral and burial funds are not maintained, we believe that increased allowable resources will likely be used by recipients for day-to-day sustenance purposes, without consideration of the need for monetary resources at the time of death.

The continued, formal designation of these funds is necessary to ensure that the funds remain intact for the designated purpose during the recipient's lifetime.

In summary, we wish to leave you with two clear messages today:

First, we oppose any changes that would eliminate current resource exclusions for funds set aside for a funeral and burial.

Second, we are the leading national experts on funeral service with direct lines of communication to our constituent associations in every state and the District of Columbia. We ask you to call upon us for assistance as you continue to study the complex ramifications of the broad recommendations of the SSI Modernization Panel.

We are an unbiased resource in that we do not favor one funding instrument over the other. We believe it is in the best interest of funeral directors and consumers to offer the widest variety of products and services possible. Current law and regulation strikes a delicate balance between all funding instruments, and changes could easily tip this market balance in favor of one instrument or another.

If we do not have information you require, we will get it. If members of Congress or the Administration determine that changes impacting resource exclusions for funeral and burial funds are required for some specific reason, we will develop viable proposals with you or for you.

On behalf of our 15,000 members, thank you for your consideration of our concerns.

We would be happy to address any questions you may have at this time.

Mr. McDermott. Mrs. Boggs.

STATEMENT OF ELIZABETH M. BOGGS, PH.D., MEMBER, GOVERNMENTAL AFFAIRS COMMITTEE, THE ARC

Ms. Boggs. Thank you. I am here representing The Arc and I want to thank the committee for this opportunity. I came down from New Jersey today from where I live, and this is now approximately my 45th year addressing issues related to the administration of the Social Security Act as they affect people with mental retardation.

I am a parent of a 48-year-old son who receives adult disabled child Social Security benefits in an amount which precludes his receiving SSI, but I am very familiar with the problems of determining disability and dealing with the Social Security Administration.

I must say that I find the staff of the Social Security Administration exceptionally qualified and considerate, but that I affirm—reaffirm what has been said by other witnesses here, that they are under great stress at the present time and the understaffing really continues to be an acute problem.

I was appointed to the panel of experts that Dr. Flemming chaired and that too gave me considerable insight into the operations of the Social Security Administration which I much appreciate and I was certainly an active participant in the development of that report.

I would like to speak briefly first about people with mental retardation in the context of SSI because they are a subgroup which has some distinctive characteristics.

First of all, there have been several comments on the change in the demographics of the SSI population, and I want to emphasize that also. People with mental retardation constitute between 40 and 50 percent of the children on SSI and 28 percent of all those under 65.

It is often more difficult for the public to visualize the nature of the disability that is mental retardation, but like others who have other disabilities originating in childhood, people with mental retardation arrive at the age when they would normally go to work with a preexisting condition and they do not arrive at the state of becoming disabled with any of the entitlements that go with having been in the work force and they have not had the entitlement, if you will, of having had a normal education.

They usually are not married, and in point of fact, the majority, although they come in all ages, the majority of the adults with mental retardation are between 20 and 40 years of age. They are young and many of them are attempting to do some work. The indications are that people with mental retardation constitute about 50 percent of the SSI recipients who are—who are of working age and are earning some money, usually under the $500 a month limit.

I might also add, in terms of the increased number of adults with disabilities on SSI, I think it is extremely important to look at the reasons for that. Some of the reasons are just plain demographic. The group that has grown fastest are the members of the baby boom generation, but in addition to that, it has become very clear that in the postwar World War II baby boom, we had a higher survival rate of children with disabilities.

In addition to that, we must not forget that the Vietnam veterans who suffered some disability are also in that adult group and many are dependent on either Social Security or SSI.

I want to speak first to the issue of the resource limits and to recommend to you the panel's recommendations for increasing the resource limitations from $2,000 to $7,000 for an adult. I would have more to say about that, but I want to use what time is left to address the issue of trusts.

This is a complex issue, but it has been addressed just recently by the Congress in relation to Medicaid, and we find that the resolution which was included in OBRA 1993 (and which was not referred to by Mr. Thompson this morning) with respect to the assets, limitations and the various permissible trust arrangements available for people who might need Medicaid can be applied to SSI.

Though we find those OBRA provisions very suitable for the SSI picture, it would represent a slight limitation over the existing Social Security Administration trust policy. That policy has never been codified and therefore it is rather hard to grasp hold of it.

I see that the red light is on and I will discontinue any further elaboration of that topic, but the details are given in our written statement.

Mr. McDERMOTT. Thank you.

[The prepared statement and attachment follow:]

TESTIMONY OF ELIZABETH M. BOGGS, Ph.D. FOR THE ARC
COMMITTEE ON WAYS AND MEANS, SUBCOMMITTEE ON HUMAN RESOURCES
OCTOBER 14, 1993

INTRODUCTION

On behalf of The Arc, I want to thank the Ways and Means Subcommittee on Human Resources for this opportunity to testify regarding the Supplemental Security Income program. I am a member of the national Governmental Affairs Committee of The Arc, as well as a Past President of The Arc and one of its founding members. In addition, I had the honor of being appointed by then-Commissioner Gwen King to serve on the Panel of Experts advising the SSI Modernization Project.

The Arc is the largest voluntary organization in the United States devoted solely to the welfare of the more than seven million people who are mentally retarded and their families. Its national membership numbers over 120,000 people, more than half of whom are parents of children and adults with mental retardation, and includes people who are mentally retarded themselves. The Arc has approximately 1,200 state and local chapters throughout the country. Since its founding in 1950, The Arc has participated actively in the formulation of public policy with respect to the rights of, and services for, citizens with mental retardation, including public policy concerning the SSI and Social Security disability programs.

SSI AND PEOPLE WITH MENTAL RETARDATION

People with mental retardation who are SSI beneficiaries are dependent upon SSI and Medicaid for many of their basic needs such as food, shelter, clothing, medical care and long term supports and services. Nearly one million children and adults with mental retardation receive SSI benefits. In order to remain eligible for the program, they must keep their resources within the established limits. With the erosion of the value of the resource limits ($2000 for and individual, $3000 for a couple) over time, this requirement has become harsher. While the concept of a resource limit may be necessary to ensure that scarce governmental resources are available to serve people in need, the reduced value of the resource limitation increasingly places people on the brink of financial collapse. By its very nature, the SSI program provides only a very minimal income subsidy which does not even bring people to the federal poverty line. For any type of emergency or unexpected expense, SSI beneficiaries must look somewhere other than their SSI benefit check. Allowing beneficiaries to maintain a reasonable amount of assets to rely upon when necessary seems not only prudent in the long run but also respectful of the dignity of SSI beneficiaries in their attempts to meet their own needs.

The Arc's written testimony will focus on three issues which are the subject of this hearing: the recommendations of the SSI Modernization Project's Panel of Experts; treatment of trusts; and the effects of the Supreme Court's decision in *Sullivan v. Zebley*.

I. SSI MODERNIZATION PANEL RECOMMENDATIONS

We are pleased to have this opportunity to comment on the Supplemental Security Income Modernization Project Final Report, as published in the Federal Register on September 4, 1992. The Modernization Project's recommendations to improve the SSI program, through both regulatory and legislative changes, have the potential to substantially benefit people with mental retardation who rely upon the SSI and Medicaid programs.

The Arc supports the Project's recommendations as a whole and believes the report could result in substantial and far reaching improvements for people who rely on the SSI program due to disability and low income and resources. We particularly note the following recommendations as critical to people with mental retardation and their families. (Page references are to the Federal Register page (September 4, 1992) on which the recommendation is summarized with its estimated cost and to the corresponding page in the Final Report, dated August 1992, respectively.):

1) Need for an Increase in the Federal Benefit Amount (p. 40753/ p. 43) -- A majority of the experts recommended an increase over five years in the federal benefit amount to at least 120 percent of the federal poverty guideline for an individual. The Arc supports this recommendation. In addition, the panel recommended that the benefit rate for couples continue to equal 150 percent of the rate for individuals (as opposed to 135 percent of the individual rate). The Arc supports this recommendation; however, we have some additional recommendations regarding couples who are disabled, as set out further below.

2) Elimination of the "1/3 Reduction" Rule and other Counting of In-kind Income (p. 40763/ p. 78) -- Most of the experts recommended the elimination of the in-kind income rules, including the 1/3 reduction rule, because they are "harsh, demeaning, inequitable, an invasion of privacy, subject to manipulation, and contrary to principles" of support for the family unit and encouragement of voluntary assistance. The Arc supports this recommendation.

3) Need to Increase the Resource Limits (p. 40763/ p. 78) -- The Panel of Experts made several recommendations regarding resource limits and exclusions.

A majority of the experts recommended an increase in the allowable resource limits from the current $2,000 per individual to $7,000 and from the current $3,000 per couple to $10,500. Included in this recommendation is elimination of some current exclusions, such as a burial fund, since the higher resource limits would provide ample room to absorb those funds. Certain resources would still be excluded (not counted) within the resource limits: the home, an essential car, business property essential for self-support, and household goods and personal effects. The Arc supports this recommendation and urges the Subcommittee to consider and report legislation to accomplish this goal. In addition, The Arc believes that the resource limits must be indexed for inflation to avoid the enormous erosion in value seen in the limits in the past.

As discussed further below in Section II, "Treatment of Trusts", there have been recent and significant developments in the treatment of trusts for purposes of Medicaid. We believe that any changes in the treatment of trusts for SSI purposes should be in line with the recent Medicaid changes in the Omnibus Budget Reconciliation Act of 1993. Therefore, we do not support the Modernization Panel's specific recommendations regarding treatment of trusts where the source of the funds is the individual or a judgement payment or settlement of a suit.

The Arc also supports the following recommendations regarding resources of the SSI Modernization Project:

- In determining the amount of resources to be deemed from a parent(s) to a child, exclude $2000 for each ineligible child in the household.
- Change the method for calculating overpayments that result from excess resources. The amount of an overpayment resulting from excess resources would not be greater than the maximum amount that the person's resources exceeded the resources limit.
- Change the current periods for the time-limited exclusions to 12 months.

4) Need to Increase Social Security Administration Staffing (p. 40781/ p. 145) -- All of the experts who took a position on the lack of adequate staffing for the Social Security Administration agreed that an increase in the administrative budget to increase the number of staff and related support is a top priority. An immediate increase of 6,000 positions is recommended as a reasonable first step toward alleviating the shortages. The Arc supports this recommendation.

5) Need to Re-examine the Definition of Disability and SGA (p. 40770/ p. 104) -- In addressing the issue of work incentives, a majority of the Panel recognized the possible need to look more globally at what constitutes disability rather than to limit the concept of disability solely to the realm of work and substantial earnings. Therefore, a majority of the Panel recommended a change in the definition of substantial gainful activity (SGA) to recognize that people who are working with substantial supports are not performing SGA and are therefore still disabled. The Panel further recommended a study of the feasibility of eliminating the use of SGA in the Social Security disability programs, including SSI, and developing criteria in terms of being disadvantaged in major areas of life activity, including, but not limited to, work. The Arc supports these recommendations.

6) Improvement of Work Incentives (p. 40771/ p. 106) -- A number of work incentive issues were examined by the Panel and recommendations were made to do the following: increase the earned income disregard to $200 (from $65) plus two-thirds of the remaining (currently one-half of the remaining) and eliminate the regulatory time limit for completing a plan for achieving self-support (PASS). The Arc supports these recommendations.

7) Improvements in Provisions Affecting Children (p. 40762, 40763, and 40771/ p. 76-80, 105) -- While many of the majority's recommendations will positively affect children, there are several which will have a particularly beneficial impact. They include recommendations: to allow parents to deduct the special expenses of a child with disabilities from their income before determining "countable" income; to recognize parental obligations to support other children in the family by providing a resource allocation of $2,000 per "ineligible" child when calculating the amount of parental resources remaining for the support of the child with disabilities; and to have the Social Security Administration develop criteria for a presumption of disability for children up to age four who are difficult to test or diagnose. The Arc supports these recommendations.

8) Automatic Medicaid Eligibility (p. 40784/ p. 157) -- The majority of experts recommended that "anyone who is eligible for SSI should have Medicaid coverage as part of a total benefit package" and that the coverage should be automatic. The Arc supports these recommendations.

9) Time Limits on Claims and Appeals (p. 40771/ p. 105-106) -- A majority of the experts recommended establishing a 90-day time limit on initial decisions on disability claims and on administrative appeals. If the agency did not issue a decision within the time limit, benefits would automatically begin. If it was later determined that the individual did not meet disability criteria, the benefits paid would not be treated as "overpayments" subject to reimbursement by the recipient. The Arc supports this recommendation.

While The Arc is supportive of the recommendations of the SSI Modernization Project as a whole, we believe the following areas need further exploration and work:

o Substantial Gainful Activity (SGA) -- While The Arc supports the Project's recommendations regarding SGA (see number 5 above) as a step in the right direction, the recommendation does not go as far The Arc believes it should. The Arc believes that legislation should be enacted to remove the current concept of SGA from the definition of disability and replace it with an assessment of functional limitations in all areas of life activities. Interim steps to achieving that goal would include (a) an immediate increase in the SGA level to the same level as that for persons who are blind, indexing that level to average wage growth in future years, and (b) immediate elimination of the use SGA for initial eligibility in the SSI program, thus achieving consistency with treatment of people who are blind. The Arc supports the concepts submitted by Elizabeth M. Boggs (Chapter IV, Appendix ii, "Definition of Disability") and appreciates the majority's recommendation for a study along those lines.

o Representative Payment Issues(p. 40782/ p. 149) -- While The Arc generally supports the recommendations of the Project regarding representative payee issues, we have several concerns which we believe must be addressed before these recommendations are acted upon.

Regarding the Project's recommendation to strengthen the recruitment, monitoring, and training of payees, we believe care must be taken to balance legitimate concerns regarding accountability with concern for preservation of the viability of family members serving as payees. Monitoring tasks for family members should not become so burdensome as to discourage their participation as representative payees.

Second, while we believe it is important to authorize qualified non-profit organizations to be reimbursed for costs for service as payees and for such fees to be paid out of administrative funds (rather than recipients' benefits), we believe that the payee should be responsible to the beneficiary and not function as a contractor or employee of the Social Security Administration. The discussion and recommendation on this point is unclear in the final report and The Arc has strong reservations about establishing any SSA contractor/employee relationship in these representative payment situations.

In addition to the above noted concerns regarding the Modernization Panel's recommendations, The Arc is also concerned about the current temporary authority for non-profit organizations to receive a fee for performing representative payee duties.

About 80 percent of people with disabilities originating in childhood who are receiving SSI or "adult disabled child's" (DAC) benefits under Titles II or XVI have representative payees. The people in need are diverse, ranging from those who just don't know how to keep track of their bills so that their utilities are not turned off, to those who could squander their money wildly or are quite unaware of what money is used for. We consider representative payee services as a form of personal assistance for people with cognitive impairments, and would like to see this form of service eventually incorporated in a long term services agenda.

As with other forms of personal assistance, much can and is provided informally and without payment by friends and family members of individuals with impairments. In choosing payees, SSA properly gives priority to family members and, for the most part, finds that such appointees combine the desired functions of being accountable for the recipient's benefits while using common sense about what is personally pleasing and beneficial to the particular person whose money it is. As mentioned in our oral testimony, people with mental retardation and other disabilities originating in childhood are living longer and now more frequently survive their parents. At the same time, SSA is finding it increasingly difficult to find suitable payees for individuals who do not have family members able to perform this function.

Various initiatives are underway, including an attractive program sponsored by AARP which is recruiting some of its own members as volunteers to serve on a senior-to-senior basis. Such a program is promising but not without costs and not all recipients can be appropriately served by volunteers. Like SSA, The Arc is concerned with people who have diverse needs. For this reason state chapters of The Arc have become increasingly active in trying to assure that someone will be "there" for the adult son or daughter when parents are no longer able. A community based organization with expertise in protective services can offer an additional alternative.

Section 205(j) of the Act was amended effectively July 1, 1991 to provide SSA with another option that can address some problem cases -- the option of choosing as payee a suitable non-profit social service organization which is not otherwise being paid to deliver services to the SSI recipient who needs a payee. It permits the organization to collect a small fee to cover the costs of its administration. This amendment sunsets next July. The original sponsors of this amendment are, we understand, proposing to extend this provision for another 3 years, with modifications. We support this extension.

Some people have criticized the concept because the fee is taken out of the recipient's benefit, which is already meager. The SSI Modernization experts recommended that the costs (which may not exceed $25 a month) be paid out of SSA's administrative budget. SSA has been adamantly opposed to this suggestion. While we share the view that any reduction in the benefit on an individual is to be deplored, we find that it is better to have the slightly reduced sum efficiently expended in a personalized way than to have the full benefit check less wisely spent. The 205(j)(4)(A) arrangement may not be ideal, but should remain as an option.

o Treatment of Married Couples -- In SSA parlance a "couple" is a "unit" in which the spouses are each categorically eligible on the basis of age, disability or blindness, and have combined countable income and assets that do not exceed 150% of the amounts allowed to an individual; in computing the countable income and assets the law allows exclusions to the "unit" which do not exceed those allowed to a single person (e.g., one set of earned income disregards, one $20 unearned income disregard (exclusion), one automobile, one burial fund etc.).

If a categorically eligible individual is married to an ineligible spouse, the individual may be eligible as an individual; if the spouse has countable income in excess of 50% of the Federal benefit rate for a single person (FBR-S), the excess income is "deemed" to the categorically eligible individual. This deemed income excludes income earned by the ineligible spouse to the same extent that income earned by a person with a disability can be excluded or disregarded (i.e. the first $65 plus half the excess over $65). The recipient who is disabled can also take similar exclusions on any income he or she may earn. When income deemed from the ineligible spouse, combined with any countable income that the individual may have, exceeds 150% of FBR-S, SSI payments will cease. If the partner with a disability has no earnings or other income, the ineligible spouse may earn up to $1,380 a month (in 1993) before causing the partner's SSI eligibility to be terminated.

The standard rationale for paying an eligible couple based on 150% of the "single" rate is that it reflects the well established paradigm of the Social Security retirement benefit where a non-working spouse receives a benefit based on 50% of the retired worker's PIA (primary insurance amount). This model does not take into account the changes that have taken place in the last thirty years during which an increasing number of married women have acquired entitlements to Social Security benefits based on their own earnings. These benefits are unaffected by marital status. Even where a widow's or adult child's benefit is payable, marriage to another Social Security beneficiary does not diminish the benefit. This includes the marriage of two adults who receive benefits as adults disabled during childhood (DAC); benefits are not reduced for either party. This pattern is not followed by SSI, however, with results that are particularly bizarre where one or both members of a "couple" wish to attempt to work despite severe disability.

The following excerpts are taken from an Office of Supplemental Security Income summary document on "couples" dated November, 1991. It was provided to the experts following the series of public hearings conducted by the experts in major cities.

> Many commenters agreed that the SSA rules relating to couples are often punitive and archaic. They are based on outdated concepts which SSA and IRS have been trying to move away from. They said that low income people should not be penalized financially for wanting to enter into a living arrangement with another person as that person's spouse or otherwise. Each person should be allowed to maintain his or her own exclusions, as well as an individual benefit standard. They emphasized that it is simply not true that two people can live as cheaply as one.

While these claims may overstate the case, I can affirm that these concerns are real, because they were powerfully expressed at the hearing in Atlanta which I attended. In addition, we hear these complaints directly from young adults who have been disabled since childhood, and who constitute the major portion of SSI adult recipients who are under 45. These are also the SSI recipients who are most likely to try to work, using the work incentives that this Committee has, to its credit, authorized in recent years.

A major concern to these young adults is what happens if they marry another person with a disability who is also eligible for SSI. Under present conditions they will clearly be disadvantaged, both relative to persons who have non-disabled spouses, and relative to single recipients with disabilities who also share housing (e.g., with other disabled family members or friends). These young adults are also well aware that, as mentioned above, when two adults each receive SSDI or DAC benefits based on their own disabilities, their benefits are personal to each and are unaffected by their marital status.

Although deeming rules can be altered at the discretion of the Secretary, the treatment of a "couple" as a single eligibility unit with only one set of disregards is mandated by the language used in Section 1612(b).

As mentioned earlier, we favor a general increase in the assets limits for both individuals and couples; if this recommendation of the experts is effected we see no need for special exceptions. If, however, the Committee chooses to keep the burial fund exclusion, we urge you to allow for an exclusion for each eligible member of a couple.

The Experts recommended that the law be changed to allow appropriate income and asset exclusions, including earned income disregards, for each eligible individual who is part of a "couple". We urge this Committee to implement this recommendation without delay.

In addition to recommending a fairer approach to exclusions from income, many of the experts were eager to provide an augmented benefit for married couples where both have disabilities; such couples clearly have living expenses which exceed those normally experienced by their age peers. The suggestion most often discussed was that each member of a couple retain his or her individual entitlement. The Arc would support that approach. However, it was pointed out that this construct might disadvantage some couples, usually those in the age range 55-64 who are making a transition to retirement. In the end, the majority of experts were dissuaded by economic arguments and cost estimates based on the assumption that all couples should be treated in the same way regardless of age. At the time this subject came up for reconsideration, it was too late to search out a more detailed analysis which recognizes a number of realities that were not taken into account in the debate.

When one considers the particular case of people who become disabled before a first marriage and where a couple may be formed in which both members are disabled, one can focus on a small but especially disadvantaged constituency, which, if separated out, can also be treated more fairly at relatively little cost. The following table shows how the estimated 717,000 people who were married SSI recipients in 1990 were distributed by age and status:

MARRIED ADULTS RECEIVING SSI BY AGE, IN 1990 (in thousands)

Age	as couples	with ineligible spouse
18-55	19	225
55-64	66	92
65 +	213	102
Totals	298 (149 couples)	419

(Source: Social Security Bulletin Annual Statistical Supplement 1993, Table 7.A7.)

When considering the situation of the 9,500 young couples (19,000 individuals) under 55 listed above, there are several factors that should be taken into account, beginning with the issue of cost of living for non aged adults with disabilities.

The Committee is undoubtedly aware that the formula for computing the poverty level is distinctly out of date, in that the relative importance of food and shelter as respective cost factors for individuals and families have changed substantially since the poverty formula was first devised in the early sixties. In any case the poverty level ordinarily used in discussing SSI (without regard to age) -- and used in the Project by the expert economists -- is the one applicable to "elderly households". Under the formula the FBR for individuals has hovered around 75 percent of poverty while that for couples has come close to 90 percent. (See Green Book, pp. 836-7); however, when (higher) poverty thresholds as computed for householders under age 65 are used, the ratio of the FBR to poverty thresholds are distinctly lower, e.g., 69 percent for an individual and 80 percent for a couple under age 65 (Social Security Bulletin, Annual Statistical Supplement, 1993, Table 3.E1; see also Table 2, in Relative Benefit Levels and Benefit Adequacy in the Supplemental Security Income Program prepared for the SSI Modernization Project by Steve Bartolomei-Hill and Daniel R. Meyer of the Office of Human Services Policy of the U.S. Department of Health and Human Services).

It is clear, of course, that for most persons with disabilities, there are further costs of maintaining even a minimally adequate life style as compared to those incurred by an "average" individual or married couple of working age, even if one looks only at food, clothing, shelter and transportation. In recent years, SSI recipients who work have been permitted to deduct impairment related work expenses from their countable earned income but these computations do not extend to similarly essential expenses that are not considered "work related."

Many indexes point to a significant distinction between those current recipients who are under 50 and those over 55. The vast majority who are taking advantage of the Section 1619 work incentives are in the younger age groups; on the other hand, most of the "couples" are over 55. Of some 4 million adults now receiving Federal SSI payments, only about 21,000 -- half of 1 percent (but up 14 percent since 1990) -- are under 55 and married to other recipients. We do not know how many of these became disabled after being married. We do know that some of those in the same age group, who already receive benefits as individuals who are disabled, would like to marry but are deterred by the prospective loss of income. Recognizing that there are some economies associated with a marriage even where both spouses are disabled, but also recognizing the problems associated with early disability, we propose providing couples with double the individual rate, or, if that approach is not feasible at this time, we propose the following conservative initiative as a way of probing the problem further.

Specifically, we recommend , as an initial step, that for marriages between two individuals who are under 55 at time of marriage and who both have been disabled since before the marriage, the FBR for a couple be raised to 175% of the FBR for a single individual.

This still keeps the couple with disabilities below the poverty level for other couples of the same age; maintaining this rate as the couple ages recognizes the disadvantages they will continue to experience as a result of the relatively early age of onset of their disabilities. This recommendation could be implemented for a cost of about $14 million annually if eligibility is not made retroactive for those now over 55. If eligible individuals who are now single are motivated to marry, corresponding savings may be achieved.

Again, The Arc appreciates this opportunity to comment on the excellent work of the SSI Modernization Project. The Arc believes that, as a whole, the work and recommendations of the SSI Modernization Project were excellent and timely and that the recommendations should be implemented as soon as possible. We urge the Subcommittee to give serious consideration to the entire report. The Arc is committed to working with the Social Security Administration and the Congress to achieve the long overdue improvements in SSI as outlined by the SSI Modernization Panel.

II. TREATMENT OF TRUSTS

In general, current policy for treatment of trusts in the SSI program has worked well, and has been widely relied on by families and attorneys, although at present it exists only as Social Security Administration interpretation of SSA regulations. There have been some criticisms of the ways in which "windfall" assets that belong to the SSI recipient may be handled in trusts; these concerns as they arise in relation to Medicaid were addressed earlier this year in OBRA '93. The Arc believes that, with comparable revisions as indicated, SSA's present policies on trusts should be codified to make them more visible, citable, durable, and reliable.

The issue of treatment of trust assets and income as standby and auxiliary resources for individuals disabled by mental retardation is a very important one for The Arc, many of whose members are parents of people with mental retardation or related disabilities. Like other parents, they are not legally liable for the support of their adult sons and daughters; yet they recognize that SSI barely covers the cost of food, shelter, and clothing, and that Medicaid may also fall short of meeting all health care and long term service needs. During the life of the parent, the parent may supplement these basic entitlements by paying for such things as telephone service, transportation, personal assistance, recreation, and other social or educational services that are not covered by state or charitable agencies. In order to maintain these options for an adult with mental retardation after the death of the parent, parents seek to create durable trusts that do not jeopardize the basic benefits of Title XVI and XIX.

For these reasons we seek codification of the SSA policy on trusts, modified to track the action taken by Congress in the Omnibus Budget Reconciliation Act of 1993 regarding treatment of trusts under Medicaid.

Under current SSI policy, assets in trust are treated according to the basic rules regarding the definition of resources and which resources will be counted for purposes of determining eligibility. If the individual owns the funds in the trust and can legally access the trust to use the money for self-support, then the trust assets are considered as available resources. If, on the other hand, the person cannot legally access the funds, then the trust assets are not counted as resources. This policy for applying the rules allows third parties, such as parents and other family members, to set aside funds in trust for the benefit of an SSI eligible individual without negatively affecting the individual's eligibility for SSI. In addition, income and assets paid out from the trust are treated in the same way as payments from any third party. If cash is given directly to the individual, then SSI benefit amounts, and possibly even eligibility, are affected. If, on the other hand, payments are made to someone else for goods or services to benefit the individual (other than food, clothing, or shelter), then SSI benefits and eligibility are not affected. Such goods and services may include, for example, social services, rehabilitation services, educational supplies and services, ongoing monitoring or advocacy services, or other items not covered by SSI or Medicaid.

RECENT CHANGES IN MEDICAID

OBRA '93 included some major changes in the Medicaid treatment of assets, transfers of assets, and recovery of Medicaid expenditures from estates of deceased Medicaid beneficiaries. While the overall package of amendments establish stricter requirements for transfers of assets and establishment of trusts and harsher penalties for the average person applying for Medicaid coverage of nursing home costs, these changes are important improvements to Medicaid treatment of trusts from the perspective of families of people with mental retardation. The amendments affect only the Medicaid eligibility of the person who owned the assets before transferring them (below market value) or placing them into trust. Special exemptions were included for:

- transfers by a parent to a child who is disabled (regardless of age) or transfers by a parent to a trust for the benefit of a child who is disabled (regardless of age); and

- transfers to a trust (including a pooled trust) established for the benefit of a person who is disabled and under the age of 65. This provision is new and will allow other family members (and others, generally) to contribute to a trust for a person who is disabled while protecting the potential Medicaid eligibility of the person who transferred the funds.

These Medicaid provisions were silent on the question of the Medicaid eligibility of the individual who is disabled. The presumption is that the trusts will be treated as under current SSI policy (only cash payments from the trust directly to the individual will affect SSI benefits or eligibility).

In addition, OBRA '93 added protections for the individual with a disability who places his/her own assets in trust. This approach will be especially useful in situations where the individual receives an SSI back payment award (including *Zebley* class members) or receives payment in judgement or settlement of a personal injury suit. The individual's own Medicaid eligibility is protected when funds are transferred to a trust:

- o when the trust is established for the individual's benefit where the individual is under 65 and the trust is set up by a parent, grandparent, legal guardian, or a court; or
- o when an individual account is created within a pooled trust established and managed by a non-profit organization and where the funds are placed in trust by the individual, parent, grandparent, legal guardian, or a court.

In both cases, the amounts remaining in the trust upon the individual's death must be paid to the state up to the amount expended on Medicaid services. In the case of the pooled trust, the amount paid to the state for Medicaid will be subject to any agreed upon amount or percentage of remaining funds which must be paid to the general pooled trust funds, as determined by the trust agreement. (There is a third provision, with similar remainder requirements, which allows placement of pension and Social Security income into trusts for nursing home residents in certain states.)

These are important improvements in the law regarding trust assets for purposes of Medicaid eligibility for people with mental retardation. We believe that, rather than adopting the Modernization Project Panel's recommendation to count trust assets which belong to the individual or result from a settlement or a judgement, SSI law should be made parallel to the Medicaid amendments so that people are not penalized for actions in one program which are legitimate in the other program. In addition, the provisions for remaining amounts going to the state would seem to address any issues about people with their own resources being allowed to remain in the SSI program: funds could be used to supplement SSI and Medicaid during life while state Medicaid programs are reimbursed for services to the extent possible from such funds remaining at death. We recognize that this will result in some tightening of the current SSI approach.

Given the statutory clarification and improvements in Medicaid treatment of trusts, The Arc believes that it is time to codify the SSI policies regarding treatment of trusts. Codification should allow parents, family members, and others to more securely rely on the rules for making arrangements, which will last long after the parent (or other) is no longer living, to benefit an individual with disabilities who needs on-going assistance.

III. THE EFFECT OF THE SUPREME COURT'S DECISION IN *SULLIVAN V. ZEBLEY*

The Arc believes that it is important to view the developments stemming from the *Zebley* case, the subsequent revised childhood disability criteria, and the revised childhood mental impairment regulations in historical context with an understanding of the problems which existed prior to these major developments. Essentially, it must be remembered that the U.S. Supreme Court issued a landmark opinion in the case of *Sullivan v. Zebley* on the basis of the finding that the Social Security Administration's (SSA) regulations regarding childhood disability criteria were inconsistent with the law.

Title XVI of the Social Security Act authorizes payment of Supplemental Security Income (SSI) benefits to children who have an impairments of "comparable severity" to one that would be considered disabling for an adult. Under the Social Security Act, an adult is considered disabled, and therefore eligible for SSI benefits if, in addition to meeting income and resource criteria, he or she has an impairment that prevents him or her from engaging in any substantial gainful activity (SGA). SSA has a five-part test for determining disability for adults. The third step allows a person to be considered disabled if medical evidence of the impairments matches or is equal to ("meets or equals") one of the listings of impairments [20 CFR 404, Subpart P, Appendix 1], which are presumed to be severe enough to preclude any gainful activity. If the adult does not qualify for SSI benefits at that step, steps four and five are designed to allow a vocational analysis to determine whether the adult could engage in his or her past work or any other work given his or here education and work experience.

Prior to the *Zebley* decision, the determination of disability for children ended at the listings of impairments step. To be determined disabled, a child had to show that his or her impairment matched or was equal to one of the listed adult or childhood impairments. If the child could not make such a showing, there was no step in the childhood disability determination process comparable to the vocational assessment for adults. The child was simply found to be not disabled for purposes of the SSI program.

The *Sullivan v. Zebley* case was a class action suit on behalf of Brian Zebley, two other named plaintiffs, and all individuals "who are now, or who in the future will be entitled to an administrative determination . . . as to whether supplemental security income benefits are payable on account of a child who is disabled, or as to whether such benefits have been improperly denied, or improperly terminated, or should be resumed". In a 7-2 decision written by Justice Blackmun, the Supreme Court ruled that the childhood disability regulations were inconsistent with the statutory standard of "comparable severity." The Court found that failure to provide for an individualized functional analysis for children nullified Congressional intent to link the childhood disabilities criteria to the adult criteria. The Court went on to state:

> The fact that vocational analysis is inapplicable to children does not mean that a functional analysis cannot be applied to them. An inquiry into the impact of an impairment on the normal daily activities of a child of the claimant's age--speaking, walking, washing, dressing and feeding oneself, going to school, playing, etc.--is, in our view, no more amorphous or unmanageable than an inquiry into the impact of an adult's impairment on his ability to perform any other kind of substantial gainful work which exists in the national economy".

The Court also noted that childhood disability listings were not exhaustive and included only the more common impairments: "There are, as yet, no specific listings for many well-known childhood impairments, including spina bifida, Down's syndrome, muscular dystrophy, autism, AIDS, infant drug dependency and fetal alcohol syndrome.

The judicial resolution of this issue came after years of effort by many advocacy organizations in the courts, in Congress, and through SSA to correct the failure of the regulations to correctly deal with childhood disability.

In 1990, SSA appointed a panel of experts in child development and childhood disability to help the agency develop criteria for determining disability based on an individualized functional assessment. The experts represented a wide range of areas: general pediatrics, developmental genetics, developmental pediatrics, infant development, behavioral pediatrics, pediatric psychology, pediatric neurology, child psychology, pediatric special education, home and community care, family and support systems, physical and occupational deficits, early childhood education, pediatric rehabilitation, learning disorders, chronic illness and somatics, and communication disorders.

New regulations for determining childhood disability on the basis of functional limitations were published by SSA and were immediately effective on February 11, 1991 as interim final regulations. Final regulations were published on September 9, 1993.

Under the regulations, provision is made to conduct an individualized functional assessment, which incorporates all relevant past and present medical and nonmedical evidence in a child's case records. Evidence from people who know the child and his or her functional limitations, in addition to the evidence provided by doctors and other health professionals, is strongly encouraged. Information about the child from parents, other family members, caregivers, educators, and practitioners in other disciplines should be collected. Where discrepancies exist between formal test results and the child's usual behavior and daily activities, SSA encourages the documentation and resolution of discrepancies. The evaluation of a child's development or functioning from infancy through childhood to maturation into adulthood may include his or her cognitive communicative, motor, social and personal/behavioral spheres of activity. The evaluation may further address responsiveness to stimuli (in children from birth to age one); personal/behavioral patterns (in children from one to 18); and concentration, persistence, and pace in completion of tasks (in children from three to 18). The evaluation also seeks to determine the extent to which the child can engage in sustained activities appropriate to his or her age.

In reviewing the current status of childhood disability determination, it should also be noted that SSA took one other critical action in the early "90s. On December 12, 1990, new regulations or "listings" for determining disability for children based on mental disorders (or impairments) and a new listing for disabilities based on Down syndrome or other serious hereditary, congenital, or acquired disorders. This was a result of work initiated by SSA years before the *Zebley* decision, but is integral to the effectiveness of SSA in its response to the *Zebley* decision. These regulations were effective immediately.

The childhood mental impairments listings were substantially revised and took into account the child's age. The listings improved the criteria for determining who is disabled based on mental impairments before the need for a full individualized functional assessment, while, in fact, including some new functional assessment criteria at the listings level. The listings cover the following: mental retardation; psychoactive substance dependence disorders; autistic and other pervasive developmental disorders; attention deficit hyperactivity disorders; developmental and emotional disorders of newborn and younger infants (birth to age one); organic mental disorders; schizophrenic delusional, and other psychotic disorders; mood disorders; anxiety disorders; somatoform, eating, and tic disorders; and personality disorders.

In the preamble to the new Down syndrome rules, SSA indicated that experience showed that virtually all children with Down syndrome (except Mosaic Down syndrome) would be found disabled when the effects of their impairments could be properly documented and evaluated. Therefore, the new rules allow children whose Down syndrome has been established by clinical and laboratory findings to be considered disabled from birth without waiting until such time as functional limitations could be proven.

Finally, the new listings for multiple body dysfunction due to hereditary, congenital, or acquired conditions should also be of benefit to many children who would have more difficulty establishing disability under the old rules. This listing may be used to determine disability resulting from phenylketonuria (PKU); fetal alcohol syndrome; mental retardation with known causes associated with impairments of other body systems; and other impairments.

The ultimate impact of the *Zebley* decision will depend on the commitment and dedication of many family members, advocates, and professionals, including teachers and other school system personnel. SSA's new efforts to collect information from such sources will mean that such people will play pivotal roles in just how many potentially eligible children and class members eventually will receive benefits.

In a nutshell, the final rules for childhood disability determination in response to the *Zebley* decision, the childhood mental impairment regulations, and the regulations for Down syndrome and other serious hereditary, congenital, or acquired disorders were the result of much careful deliberation over the course of several years and involving numerous experts on child development and disability. While there may be problems here and there, overall the new regulations are a tremendous improvement for children and long overdue. As we approach the 20-year mark for the SSI program, children are just now beginning to receive the consideration of their disabilities which should have occurred from the beginning of the program. With such a long delay in implementation of the original intent of the program, it is no wonder that the numbers of children becoming eligible for the program are increasing rapidly. The dramatic increase in the numbers of eligible children must be seen in historical context and must not be allowed to serve as the basis for inappropriate cutbacks.

Further, where there are problems, resolutions must be carefully and surgically crafted to ensure that they are not overreaching in effect. Frankly, we believe that many of the "problems" which have been reported are the result of misunderstandings of the SSI program, generally, and of the process for determining childhood disability, specifically. Where instances of abuse or exploitation are reported, proper avenues for redress exist in the state child protective services systems and within the SSA representative payee system. In addition, we understand that SSA is engaged in a thorough internal study of the application of the regulations and, as particular problems are noted, is taking immediate steps to resolve the issues. We believe that most legitimate issues can be handled in this manner. We would, of course, be willing to work with the Subcommittee to deal with those few areas where statutory solutions are necessary.

The Arc endorses the main points made in the oral and written testimony of Richard Weishaupt of Community Legal Services and the testimony for the record of Rhoda Schulzinger and Joseph Manes of the Bazelon Center for Mental Health Law. Both organizations have extensive experience in working directly with SSI beneficiaries and their families. In addition, for further information on the history of the *Zebley* decision, the childhood disability regulations, and the childhood mental and other related disability regulations, see "Expanding Eligibility for Supplemental Security Income Based on Childhood Disability: The *Zebley* Decision", Ford and Schwamm, Child Welfare, July-August, 1992 (copy enclosed for Committee files).

Again, The Arc appreciates the opportunity to comment on the above issues and looks forward to working with the Subcommittee to enact improvements to the SSI program. If you have any questions on the above, please contact Marty Ford at The Arc Governmental Affairs Office, (202) 785-3388.

Expanding Eligibility for Supplemental Security Income Based on Childhood Disability: The *Zebley* Decision

MARTHA E. FORD
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Thousands of low-income children have been denied disability benefits due to an invalid childhood disability determination process. This changed when the United States Supreme Court issued its decision in the case of Sullivan v. Zebley. *The authors review the* Zebley *decision and the response by the Social Security Administration, present the new regulations for determining childhood disability, and discuss implications for child advocates, service providers, and social work educators to implement successfully the new federal regulations.*

On February 20, 1990, the U.S. Supreme Court issued a landmark finding in the case of *Sullivan v. Zebley* that the Social Security Administration's (SSA) regulations regarding childhood disability criteria were inconsistent with the law. A major victory for low-income children with disabilities, the

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Court's decision will make it possible for over 400,000 children to have their cases reviewed and, if eligibility is found to have been improperly denied since 1980, to receive retroactive benefits [''Children to Get . . .'' 1991]. In addition, based on new regulations published in response to the *Zebley* decision, 38,000 more applicants in each of fiscal years '91 and '92 are expected to receive Supplemental Security Income (SSI) benefits that they otherwise would have been denied. The five-year projection is at least 159,000 [Federal Register 1991].

This article describes the *Zebley* decision, its history, and the Social Security Administration's response. It focuses particularly on the new regulations for determining childhood disability and the U.S. District Court's final order to resolve all outstanding issues related to the *Zebley* decision, and concludes with implications for child advocates, service providers, and social work educators, all of whom are vital to a successful outcome.

Background

Title XVI of the Social Security Act authorizes payment of Supplemental Security Income (SSI) benefits to children who have an impairment of ''comparable severity'' to one that would be considered disabling for an adult. Under the Social Security Act, an adult is considered disabled, and therefore eligible for SSI benefits, if, in addition to meeting income and resource criteria, he or she has an impairment that prevents him or her from engaging in any substantial gainful activity (SGA).* SSA has a five-part test for determining disability for adults. The third step allows a person to be considered disabled if medical evidence of the impairment meets or is equal to one of the listings of impairments [20 CFR 404, Subpart P, Appendix 1], which are presumed to be severe enough to preclude any gainful activity. If the adult does not qualify for SSI benefits at that step, steps four and five are designed to allow a vocational analysis to determine whether the adult could engage in his or her past work or any other work given his or her education and work experience [Supreme Court of the United States 1990].

Prior to the *Zebley* decision, the determination of disability for children ended at the listings of impairments. To be determined disabled, a child had to show that his or her impairment matched or was equal to one of the listed adult or childhood impairments. If the child could not make such a showing,

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*The SGA level is generally defined by a monthly earnings limit, currently $500 per month, although other factors are also taken into account in determining whether work is considered substantial and gainful.

there was no step in the childhood disability determination process comparable to the vocational assessment for adults. The child was simply found to be not disabled for purposes of the SSI program [Supreme Court of the United States 1988].

The *Sullivan v. Zebley* case, which began in Pennsylvania, was a class action suit on behalf of Brian Zebley, two other named plaintiffs, and all individuals "who are now, or who in the future will be entitled to an administrative determination . . . as to whether supplemental security income benefits are payable on account of a child who is disabled, or as to whether such benefits have been improperly denied, or improperly terminated, or should be resumed" [*Sullivan v. Zebley* 1990]. The district court found in favor of the Secretary of Health and Human Services, noting that the regulations were not invalid or incomplete as written. The Court of Appeals for the Third Circuit, however, found in favor of the *Zebley* class, ruling the regulatory scheme for childhood disability determinations invalid because the listings-only approach failed to take into account all impairments of "comparable severity" and denied children the individualized functional assessment that the statute required for adults [*Sullivan v. Zebley* 1988].

In a 7–2 decision written by Justice Blackmun, the U.S. Supreme Court ruled that the childhood disability regulations were inconsistent with the statutory standard of "comparable severity." The Court found that failure to provide for an individualized functional analysis for children nullified congressional intent to link the childhood disabilities criteria to the adult criteria [*Sullivan v. Zebley* 1990]. The Court went on to state:

> The fact that vocational analysis is inapplicable to children does not mean that a functional analysis cannot be applied to them. An inquiry into the impact of an impairment on the normal daily activities of a child of the claimant's age—speaking, walking, washing, dressing and feeding oneself, going to school, playing, etc.—is, in our view, no more amorphous or unmanageable than an inquiry into the impact of an adult's impairment on his ability to perform any other kind of substantial gainful work which exists in the national economy" [*Sullivan v. Zebley* 1990].

The Court also noted that childhood disability listings were not exhaustive and included only the more common impairments: "There are, as yet, no specific listings for many well-known childhood impairments, including spina bifida, Down's syndrome, muscular dystrophy, autism, AIDS, infant drug dependency and fetal alcohol syndrome."* The Court also commented on evidence of cases where children, unsuccessful in obtaining childhood dis-

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*Some of the listings of impairments for childhood disabilities were modified in 1990.

ability benefits, were found eligible on the basis of the same impairment upon reaching adulthood at age 18 [*Sullivan v. Zebley* 1990].

The judicial resolution of this issue came after years of effort by many advocacy organizations in the courts, in Congress, and through SSA to correct the failure of the regulations to deal adequately with childhood disability. The invalidation of SSA's childhood disability determination process should prove beneficial to thousands of children with disabilities from low-income families. First, there are the children who were previously denied benefits. The *Zebley* attorneys indicated that "100,000 children applied for SSI every year and only half were approved. The national class includes more than 400,000 children previously denied from January 1, 1980 on" [Weishaupt and Stein 1991: 1]. Second, there are the children who will be eligible under the new standards who in the past would have been found ineligible or who would never have applied due to the common perception that the rules for qualifying children for SSI were too stringent.

The Response to the Court Decision

Key Actors

In 1990, the SSA appointed a panel of experts in child development and childhood disability to help the SSA develop criteria for determining disability based on an individualized functional assessment. The experts represented a wide range of areas: general pediatrics, developmental genetics, developmental pediatrics, infant development, behavioral pediatrics, pediatric psychiatry, pediatric neurology, child psychology, pediatric special education, home and community care, family and support systems, physical and occupational deficits, early childhood education, pediatric rehabilitation, learning disorders, chronic illness and somatics, and communication disorders. The SSA met with the experts during the months of April, May, and June [Federal Register 1991]. The panel made recommendations, such as the areas to address for functional assessments, the use of interdisciplinary evaluations, the need for flexibility to cover children whose conditions do not easily fit the established criteria, the need for certain categories of presumptive eligibility, and the need for erring on the side of inclusion for very young children.

The SSA also developed a cadre of corresponding experts who had been unable to attend the public meetings to respond to the SSA's draft regulations. In addition, in March 1990, the SSA met with over two dozen advocacy groups concerned with children and/or SSI. Finally, representatives from four advocacy groups were invited at one stage to assist in the drafting of the SSA's new policies: Philadelphia's Community Legal Services (the attorneys representing the *Zebley* plaintiff class), the Association for Retarded Citizens of the United States, the Mental Health Law Project, and the National Senior Citizens Law Center [Federal Register 1991].

Interim Standard

For children who continued to apply for SSI benefits after the *Zebley* decision and before a final rule was published, the U.S. District Court for the Eastern District of Pennsylvania issued a stipulated order that put into effect in May 1990 the Interim Standard: Claimants for SSI Disabled Children's Payments. The interim standard required an adjudicator to consider fully a child's functional ability to perform a full range of age-appropriate daily living activities and to behave in an age-appropriate manner [U.S. District Court for the Eastern District of Pennsylvania 1990].

Even with a liberalized interim standard, several state disability-determination agencies continued to do an inadequate job of evaluating and adjudicating children's claims. In the period June 1990 to January 1991, according to the *Zebley* attorneys, "Of 117,608 claims nationally, 54% were allowed," with some state agencies allowing at rates of 76% to 98%. In the nine states with the lowest rate, however, the "allowance rates were below the pre-*Zebley* national rate of 50%" [Weishaupt and Stein 1991: 8]. An additional nine states had allowances in the 50% range. According to the district court's order, children who were denied benefits under the interim standard would have their cases reviewed again when the final regulations were published [Weishaupt and Stein 1991: 8].

Mental Impairment Listings Revision

In one other major action before publication of the new criteria for assessing childhood functional limitations, SSA published on December 12, 1990 new regulations or "listings" for determining disability for children based on mental disorders (or impairments) and a new listing for disabilities based on Down's syndrome or other serious hereditary, congenital, or acquired disorders [Federal Register 1990]. This was a result of work initiated by SSA before the *Zebley* decision, but is integral to the effectiveness of SSA in its response to the U.S. Supreme Court's *Zebley* decision. These regulations were effective immediately.

The childhood mental impairment listings were substantially revised and took into account the child's age. The listings improved the criteria for determining who is disabled based on mental impairments before the need for a full individualized functional assessment, while, in fact, including some new functional assessment criteria at the listings level. The listings covered the following: mental retardation; psychoactive substance dependence disorders; autistic and other pervasive developmental disorders; attention deficit hyperactivity disorders; developmental and emotional disorders of newborn and younger infants (birth to age one); organic mental disorders; schizophrenic delusional, and other psychotic disorders; mood disorders; anxiety disorders; somatoform, eating, and tic disorders; and personality disorders [Federal Register 1990].

SSA also published the new Down's syndrome rule, which is also expected to substantially improve disability determinations for children. In the preamble to the new rules, SSA indicated that experience showed that virtually all children with Down's syndrome (except mosaic Down's syndrome) would be found disabled when the effects of their impairments could be properly documented and evaluated. Therefore, the new rules allowed children whose Down's syndrome had been established by clinical and laboratory findings to be considered disabled from birth without waiting until such time as functional limitations could be proven [Federal Register 1990].

The new listing for multiple body dysfunction due to hereditary, congenital, or acquired conditions would also be of benefit to many children who would have had more difficulty establishing disability under the old rules. This listing would be used to determine disability resulting from phenylketonuria (PKU); fetal alcohol syndrome; mental retardation with known causes associated with impairments of other body systems; and other impairments [Federal Register 1990].

Interim Final Zebley *Regulations*

The December 12, 1990 final regulations pertaining to the mental impairment and other listings did not include the long-awaited regulations regarding disability based on functional limitations for all children in response to the *Zebley* decision. New regulations for determining childhood disability on the basis of functional limitations were published by SSA and were immediately effective on February 11, 1991 as interim final regulations. Despite SSA's not having adopted some of the recommendations from the panel of experts and the advocacy community, the regulations, often referred to as the *Zebley* regulations, were considered to be a significant advance for children and to reflect current understanding of childhood disability in a way never before seen in SSA. These regulations became effective immediately, although SSA accepted public comments until July 8, 1991 after an extension of the original April 12, 1991 deadline.

As a direct result of the *Zebley* decision and the publication of the final regulations, SSA expects to process 237,000 retroactive *Zebley* class claims, 74,700 reconsiderations, 33,100 hearings, and 6,800 Appeals Council reviews through September 30, 1993. Furthermore, SSA anticipates the reevaluation of an additional 60,000 claims for childhood disability benefits that were denied since the court decision on the basis of the May, 1990 interim standard [U.S. Department of Health and Human Services 1991].

Childhood Disability Determination under Interim Final Regulations

Under the interim final regulations, the determination of disability involves a sequence of steps. SSA may stop at any step in the process in which an affirmative decision or determination of disability can be made; otherwise, except for findings of work at the "substantial gainful activity" (SGA) level in Step 1 or "nonsevere" in Step 2, the adjudicators proceed to the next step. A determination or decision must be made by the final step. The following questions guide each of the steps:

Step 1: Is the child engaging in substantial gainful activity?

Step 2: Does the child have a severe impairment or combination of impairments that causes more than a minimal limitation in his or her ability to function?

Step 3: Does the child have a medically determinable impairment that meets or equals a listed impairment at a level of severity precluding any gainful activity? If not, does the child have an impairment or combination of impairments that is equivalent in severity to any impairment in the listings of impairments, including those functionally equivalent to any listing?

Step 4: Does the child have an impairment or combination of impairments that so limits his or her physical or mental abilities to function independently, appropriately, and effectively in an age-appropriate manner that the limitations are comparable in severity to those that would disable an adult? [Federal Register 1991: 5537–5538].

Step 2 for determining severity is new to the childhood disability determination process. It calls for dismissing the child's claim without going through all the steps. This severity step was not required by the *Zebley* decision but was added by SSA to make the sequence more comparable to the sequence used for adults [Federal Register 1991].

The equivalency test for children in Step 3 embodies a new approach. In fact, it allows for listings-level determinations of disability based on the child's functional limitations before the individualized functional assessment (IFA) in Step 4.

Under Step 4, provision is made to conduct an individualized functional assessment, which incorporates all relevant past and present medical and nonmedical evidence in a child's case records. Evidence from people who know the child and his or her functional limitations, in addition to the evidence provided by doctors and other health professionals, is strongly encouraged. Information about the child from parents, other family members, caregivers, educators, and practitioners in other disciplines should be collected. Where discrepancies exist between formal test results and the child's usual behavior and daily activities, SSA encourages the documentation and resolution of discrepancies. The evaluation of a child's development or functioning from infancy through childhood to maturation into adulthood may include his or her cognitive, communicative, motor, social, and personal/behavioral spheres of activity. The evaluation may further address responsiveness to stimuli (in children from birth to one); personal/behavioral patterns (in children from one to 18); and concentration, persistence, and pace in completion of tasks (in children from three to 18). The evaluation also seeks to determine the extent to which the child can engage in sustained activities appropriate to his or her age [Federal Register 1991].

Other factors considered in the IFA include but are not intended to be limited to repeated hospitalizations or frequent outpatient care with supportive therapy for chronic impairments, the effects of medication, the effects of structured or highly supportive settings, the nature and extent of any other adaptations, frequent and ongoing multidisciplinary therapy, school attendance, and the effects of treatment and intervention [Federal Register 1991].

The Final Court Order

The publication of interim final regulations did not resolve all outstanding issues related to the U.S. Supreme Court's decision in *Sullivan v. Zebley*. On March 14, 1991, the U.S. District Court for the Eastern District of Pennsylvania issued the final "Stipulation and Order." Pursuant to the order, the scope of the class is nationwide and includes all individuals whose applications for childhood disability payments were denied in whole or in part or whose payments were terminated on the basis of medical (disability-related) grounds on or after January 1, 1980, until the date of publication of the new childhood disability regulations. This includes cases filed before January 1, 1980 that were still pending at some level of review on that date, and includes cases that were denied by the federal courts within those same time periods [U.S. District Court for the Eastern District of Pennsylvania 1991].

SSA must readjudicate the claims of any class member who requests review of his or her case within the given time frames. SSA must pay benefits to people for all months for which the person was eligible on both disability and income and resource requirements. This order will result in substantial back payments to many people, including adults who were denied benefits as children. SSA, however, will not reopen any claims for the period of time after the individual turned 18 [U.S. District Court for the Eastern District of Pennsylvania 1991].

For purposes of determining disability factors for eligibility, SSA will assume, in the absence of contrary evidence or contrary medical judgment, that an individual was disabled from the date of first application (within the class period) if he or she had subsequently been found disabled under any disability program of the Social Security Act's Titles II or XVI, either as a child or as an adult. If the person had not been determined to be disabled under those circumstances and if evidence of the past condition is not readily available, SSA will decide whether it was reasonable to presume, based on the nature of the impairment, that his or her past condition and impairments were as severe as they are currently [U.S. District Court for the Eastern District of Pennsylvania 1991].

For purposes of determining the nondisability factors of eligibility (i.e., income and resource limitations), SSA will assume, for months prior to January 1990, that the person met income and resource requirements unless ineligibility is established by records available to SSA or by information provided by the claimant. Payments will be calculated to equal the applicable monthly national average federal SSI childhood disability payment, plus the applicable federally administered state supplement for that month. Class members may submit evidence that they qualified for more than the average payment. The average benefit assumption will not apply for months after a person turned 18. For January 1990 to the present, SSA will use existing procedures for determining income and resource eligibility [U.S. District Court for the Eastern District of Pennsylvania 1991].

The Secretary of Health and Human Services will notify all state Medicaid agencies about the effect of the new childhood disability standard and encourage them to extend retroactive benefits to any class member (a) whose Medicaid coverage was terminated or denied after January 1, 1980 on the grounds that he or she did not meet the former SSI childhood disability criteria, and (b) who could provide documentation regarding certain paid or unpaid bills for services that would be Medicaid-reimbursable in that state. SSA must also notify class members that if they seek Medicaid benefits, they should contact the appropriate state Medicaid agency [U.S. District Court for the Eastern District of Pennsylvania 1991].

Other major agreements reached by the parties and ordered by the court under the Stipulation and Order pertained to nationwide outreach, notice to potential class members, priority for review, quality assurance and other reviews, and a toll-free telephone number [U.S. District Court for the Eastern District of Pennsylvania 1991]. This order, along with the Final Interim Rule, provides the foundation for ensuring children with disabilities their rights under the U.S. Supreme Court's *Zebley* decision.

Implications

The ultimate impact of the *Zebley* decision will depend on the commitment and dedication of many professionals, advocates, and family members. In particular, child welfare workers, other social work practitioners who work directly with children with disabilities and their families, and social work educators will play pivotal roles in just how many potentially eligible children and class members eventually will receive benefits.

The child welfare community should be aware that, in determining childhood disability, the inclusion of Step 2 dismisses a claim without going through all the steps, including the IFA. The potential for misapplication of this test could result in negative decisions for children who, under the law, should be considered disabled. Short of the complete elimination of this childhood severity step, advocates are urging SSA to make a commitment to monitor carefully its implementation and reexamine the value or appropriateness of such a step. It then becomes incumbent upon child advocates and service providers, in particular, to help ensure that a child is given every opportunity to prove that a combination of "mild" impairments in fact limits his or her ability to function in an age-appropriate manner. In many cases, this will require that service providers make special efforts to collect or develop the information necessary to prove the child's eligibility. More broadly, diagnostic assessment centers could facilitate all relevant steps in childhood disability determinations by accomodating their recordkeeping to the type of information needed for making these determinations.

Child advocates and service providers must also be cognizant of the problem of determining disability for children who are too young for test results to reflect functional limitations accurately. The current language of SSA's regulations provides some leeway for infants but fails to accomodate those children over age one who may be too young for certain kinds of tests, such as certain vision and hearing tests. Yet this information may be especially critical to the child during the IFA stage when it is important to take into account all limitations, since the child's overall functional abilities are at issue. To accomodate children over age one who are also too young to test, child advocates and service providers should seek inclusion within SSA's regulations concerning consideration of a child's age and how it affects his or her ability to be tested. Provision should be made for equivalence determinations of present disability based on available evidence, medical knowledge of the course and early signs of impairments, and informed clinical judgments.

Unquestionably the most important response to the *Zebley* decision from the professional community will be comprehensive outreach to inform potential class members of their right to request readjudication of their claims and to encourage the families of children with disabilities who would not be part of the class to make formal application for SSI childhood disability benefits. Because virtually all children who receive or are eligible for these benefits are likely to come into contact with health care facilities, social service agencies, and local education agencies, a successful outreach program will be best delivered when these three systems communicate their individual efforts and coordinate their collaborative efforts. Once a potential recipient is identified, the child and the family should be directed to the appropriate Social Security office for filing an application. For potential *Zebley* class members, additional assistance may be obtained through the plaintiff's counsel, *Zebley* Implementation Project, Community Legal Services in Philadelphia. Informed decisions by families of children with disabilities will best be made when professionals provide accurate and up-to-date information on all entitlement and assistance programs available to them (such as Aid to Families with Dependent Children) and the implications of each and interactions among them.

The major changes brought about by the *Zebley* decision in determining SSI childhood disabilities also require the dissemination of information to social workers and others involved with children who are disabled. Social work educators should incorporate this information into social welfare policy courses both at the B.S.W. and M.S.W. levels. Field supervisors and other practitioners should be encouraged to attend inservice training programs on this topic and share this information with others. Students undertaking their field internships at agencies serving children with disabilities should be encouraged by their supervisors as part of their educational experience to present workshops to parents of children with disabilities. Practitioners will have to expand their knowledge and understanding of the new regulations so that they may appropriately counsel parents of children with disabilities, whose claims might have been considered in the past to be too much of a long shot, to apply for benefits on their behalf. Furthermore, practitioners should be aware of broader social welfare policy implications; for instance, the availability of SSI benefits to assist families may release other funds, such as foster care funds, for use in other important areas including family support and reunification and out-of-home placement prevention.

Lastly, implementation of any new policy initiative is influenced by a multitude of factors. Child welfare researchers should begin to conduct research profiling children with disabilities benefiting from the *Zebley* decision in their communities and states and documenting the obstacles to serving potential recipients successfully. Armed with such information, the child welfare community will be better positioned to recommend appropriate changes in the regulations and their implementation.

Although the *Zebley* decision probably will encounter many impediments as the government proceeds to meet its responsibilities, this decision will dramatically improve the quality of life for thousands of children with disabilities in low-income families. The child welfare community will have a significant role to play in bringing this about. ◆

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Mr. McDERMOTT. Mr. Rockwood.

STATEMENT OF FREDERICK W. ROCKWOOD, PRESIDENT, THE FORETHOUGHT GROUP, BATESVILLE, IND.

Mr. ROCKWOOD. Thank you, Congressman McDermott, Congressman Camp. It is indeed a privilege and opportunity to be here today and I thank the committee for this chance to express our views.

My name is Fred Rockwood, and I am president of the Forethought Group, which is headquartered in Batesville, Ind. Forethought markets preneed funeral planning through funeral directors throughout the United States, and provides life insurance products to fund those funerals.

I am testifying today on behalf of a coalition of companies which strongly oppose the burial exclusion recommendations in the final report. These companies are listed in my testimony.

While simplification of the current SSI resource exclusions may appear appealing on its face, the recommendation to eliminate the burial exclusions fails to take into account numerous undesirable consequences which would result if this proposal were adopted. In particular, elimination of the burial exclusions would, first, impose serious emotional and financial burdens on SSI claimants; second, undermine the policy considerations on which the exclusions are based; and third, increase the likelihood that SSI recipients will have to be buried at government expense.

Nor will "streamlining" the resource exclusions bring desirable consequences, such as administrative simplification and elimination of systemic inequities, as proponents may promise. Congress should undertake real, not illusory, simplification of the SSI resource exclusions by enacting a new burial exclusion which treats burial assets in the same manner as other essential resources.

Life insurance-funded plans came into existence after the statutorily provided exclusion and therefore presented several unique policy and regulatory questions to the Social Security Administration. The industry has attempted to work in good faith with SSA to ensure development of reasonable, fair regulatory policies so that life insurance-funded plans enjoy equal competitive footing in the marketplace.

Clearly, some "modernization" of the SSI resource exclusions is needed to clarify the burial exclusions and to ensure that the most accessible means of prefunding funerals is available to SSI recipients. The industry supports this modernization. However, we disagree strongly with SSA's approach—the solution to these problems is not simply to eradicate the burial exclusions.

Many elderly individuals are plagued by fears about how they or their spouse will be buried, and who will bear the expenses of the burial. Congress recognized that the peace of mind engendered by preneed funeral planning was important enough to warrant both the exclusion of the value of burial space items and burial funds as countable resources for SSI benefit determination purposes. To do away with either exclusion in the name of simplification, without any assertion (much less evidence) that the administration of these particular exclusions is especially burdensome, flies in the face of the policy objectives underlying the exclusions without any attempt at justification.

We agree that the current resource limits are woefully inadequate and should be increased to a level which would allow recipients to save money for certain basic needs, such as medical emergencies. However, these limits should be raised, period—not raised to "offset" the elimination of certain exclusions. This approach does nothing to increase the effective resources available to SSI recipients. It is, in effect, a "robbing Peter to pay Paul" approach.

Eleven years ago, Congress enacted the burial space and burial funds exclusions to relieve beneficiaries from having to make a cruel and insensitive choice between necessary SSI benefits and their funeral plans. The authors of the modernization project's final report reinvent this macabre choice for SSI recipients.

Despite assertions to the contrary, the proposed increase in resource limits will not spare current SSI beneficiaries from redetermination if they elect to prefund their burials. The final report itself notes that several experts voiced concern that the elimination of these exclusions would require some recipients to dispose of assets in order to maintain benefit eligibility. This criticism is glossed over in the report, which adopts the opinion of others who are confident that the proposed increase in general resource limits should allow recipients with currently excluded resources to keep them.

This confidence is misplaced. The proposed increases in resource limits, in fact, will not be sufficient to allow recipients to keep currently excluded burial arrangements. Many SSI recipients use life insurance policies and burial trusts to fund their funerals, and would be forced to surrender those policies or cancel the trusts which have grown in value over time to keep pace with inflation.

In addition, the cost of burial will certainly shift directly to the Federal, State, or local government if the burial space and burial funds exclusions are eradicated. Other than very restricted veterans' benefits, there are no viable government resources directed at covering indigent burial expenses.

In changing the SSI rules, the Federal Government should be alerted to unintended consequences of substantial potential cost-shifting. By eliminating the incentive to prefund and prearrange one's funeral, government may ultimately bear the burden of providing funerals in many instances.

The only statutory exclusions to be eliminated by the proposed "streamlining" are those relating to burial spaces and burial funds, life insurance, and Federal housing assistance.

This raises several issues. First, the report claims that the elimination of these four exclusions will spare the Social Security Administration significant administrative costs. SSA fails to offer any data or substantiation on time or paperwork spent in administering these exclusions. Second, the proposal leaves in place provisions which arguably are more difficult for SSA to administer, such as the exclusion for business property essential for self-support. Third, the proposal fails to take into account that its implementation will add a new administrative burden: That of valuing those assets which were previously excluded.

In sum, it is unrealistic to assume that the proposed streamlining will fulfill its proffered objective of reducing administrative expenses.

An additional justification offered on behalf of the proposed streamlining is that it will remove present inequities in the SSI program. We believe this assertion is incorrect. The inequities are not caused by permitting individuals to prearrange their funerals. Prearranging meets a need which, over time, becomes more important to SSI recipients. It is a necessity for all people.

Clearly, the solution to the administrative and interpretive problems which have accompanied the burial space and burial funds exclusions is not to "streamline" them out of existence. Instead, Congress should effect real simplification of the existing exclusions by enacting a new burial exclusion which first, replaces the bifurcated scheme which separates burial assets into arbitrary categories, and two, clearly specifies its applicability to the prefunding arrangements which have developed since the exclusion first went into effect. Our coalition is prepared to submit a legislative proposal for the enactment of a new burial exclusion which meets both of these above-listed objectives, and we would be happy to work with the subcommittee.

In conclusion, our companies urge the members of this subcommittee to reject the recommendation to eliminate the burial space and burial funds exclusions under the auspices of "streamlining." Congress should undertake real, not illusory, simplification of the SSI resource exclusions.

Congress has always recognized the dignity of the individual unto death. The certainty of death and the resources required for a humane funeral are essential to all individuals, perhaps more so for those who find themselves in need of SSI benefits. They should not be eliminated from the resources which SSI claimants are allowed to retain. We look forward to working with Congress and the Social Security Administration to ensure genuine simplification of the burial exclusions.

Thank you, very much.

[The prepared statement follows:]

TESTIMONY OF FREDERICK W. ROCKWOOD
COALITION OF COMPANIES

Good morning, Mr. Chairman. My name is Fred Rockwood, and I am President of the Forethought Group, headquartered in Batesville, Indiana. Forethought markets pre-need funeral planning through funeral directors throughout the United States, and provides life insurance products to fund those funerals.

I am testifying today on behalf of a coalition of companies which strongly oppose the burial exclusion recommendations in the Final Report. These companies include:

American Funeral Assurance Company, Amory, MS;
First Capital Life Insurance Company, New Orleans, LA;
Forethought Life Insurance Company, Batesville, IN;
Funeral Security Plans, Inc., Kansas City, MO;
Hartland Management Company, Topeka, KS;
Homesteaders Life Insurance Company, Des Moines, IA;
Investors Heritage Life Insurance Company, Frankfort, KY;
Loewen Group, Covington, KY;
Pan Western Life Insurance Company, Columbus, OH;
Pierce National, Greenville, SC;
Prairie States Life Insurance Company, Rapid City, SD;
Service Corporation International, Houston, TX;
Settlers Life Insurance Company, Briston, VA;
United American Insurance Company, Dallas, TX; and
United Family Life, Atlanta, GA.

We appreciate the opportunity to appear here today both to express our concerns and our desire to work with Congress as you move forward with SSI reforms.

While simplification of the exclusions permitted under the current statute may appear appealing on its face, the recommendation to eliminate the burial exclusions fails to take into account numerous undesirable consequences which would result if this proposal were adopted. In particular, the elimination of the burial space and burial funds exclusions would: (1) impose serious emotional and financial burdens on SSI claimants; (2) undermine the policy considerations on which the exclusions are based; and (3) substantially raise government expenditures by both enlarging the pool of eligible SSI recipients and increasing the likelihood that these recipients will have to be buried at government expense.

Nor will "streamlining" the resource exclusions bring desirable consequences, such as administrative simplification and elimination of systemic inequities, as proponents may promise. The burial space and burial funds exclusions perhaps have presented technical and sometimes complicated implementation issues. However, the solution to perceived administrative problems is not to eliminate the exclusions. Instead, Congress should undertake <u>real</u>, not illusory, simplification of the SSI resource exclusions by enacting a new burial exclusion which treats burial assets in the same manner as other essential resources.

PREARRANGEMENT AND PRE-FUNDING OF FUNERALS THROUGH LIFE INSURANCE AND THE CURRENT REGULATORY SCHEME

Before discussing our concerns with respect to the proposed "streamlining," I would like to briefly address the pre-funding of funerals through life insurance. Insurance-based programs are designed to allow consumers to fund their funerals by purchasing life insurance or annuities equal to the value of the funeral arrangements they select. The consumer can choose to pay the premium all at once, or pay monthly for up to ten years. The consumer also executes a contingent assignment of proceeds to a funeral firm in return for the firm's promise to provide funeral goods and services. All assignments are fully contingent on the performance of the promised services. If the services are not provided, proceeds are paid to the beneficiary of the policy. Any excess proceeds over the retail cost of the funeral are likewise payable to the designated beneficiary.

Life insurance plans offer several advantages to the consumer. First, insurance-funded plans require a smaller initial cash outlay, and second, they benefit the consumer through their guarantee to pay, regardless of whether all of the premiums have been paid. Almost all of the policies offered to consumers are guaranteed issue and have little or no underwriting. Even if a customer is ill at the time of purchase, he or she can still be fully covered after two years of payments. In contrast, individual plans and regulated trusts must both be fully funded in order to pay for services. Thus, life insurance plans provide several economic benefits to elderly and/or disabled SSI recipients who wish to secure a guaranteed funeral.

Life insurance-funded plans came into existence after the statutorily-provided exclusion and therefore presented several unique policy and regulatory questions to the Social Security Administration (SSA). The industry has attempted to work in good faith, closely and cooperatively with SSA to ensure development of reasonable, fair regulatory policies so that life insurance-funded plans enjoy equal competitive footing in the marketplace. Differing interpretations as to what constitutes a burial space "held for" an individual have led to a regulatory scheme which could, at best, be described as murky. These changing interpretations have presented difficulties to the industry and have left many SSI recipients uncertain as to whether life insurance-funded plans remain a viable option under the statute.

Clearly, some "modernization" of the SSI resource exclusions is needed to clarify the burial exclusions and to ensure that the most accessible means of pre-funding funerals is available to SSI recipients. The industry supports this modernization. However, we disagree strongly with SSA's approach -- the solution to these problems is not simply to eradicate the burial exclusions.

NUMEROUS UNDESIRABLE CONSEQUENCES WILL RESULT IF THE BURIAL EXCLUSIONS ARE ERADICATED

1. "Streamlining" the Burial Exclusions Undermines the Policy Objectives Underlying the Resource Exclusions

The fundamental right of an individual to maintain his or her dignity while qualifying for assistance has always been an underlying principle of the SSI program. As noted in the Final Report, the rationale behind the resource exclusions is that "certain property is so essential to one's well-being . . . that its owner should not be expected to sell it and use the cash to meet day-to-day living expenses." See 57 Fed. Reg. 40759-60 (1992).

Many elderly individuals are plagued by fears about how they or their spouse will be buried, and who will bear the expenses of that burial. Of all of the exclusions currently permitted, it may be argued that the burial exclusions are the only ones which every person ultimately needs. Congress recognized that the peace of mind engendered by pre-need funeral planning was important enough to warrant both the exclusion of the value of burial space items and burial funds as countable resources for SSI benefit determination purposes. To do away with either exclusion in the name of simplification, without any assertion (much less evidence) that the administration of these particular exclusions is especially burdensome, flies in the face of the policy objectives underlying the exclusions without any attempt at justification.

Note that raising the resource limits to counterbalance eliminating the exclusions thwarts the SSI program's goal of identifying the truly needy and ensuring more equitable treatment among recipients. The scheme for the determination of eligibility established by Congress -- low resource limits with specified exclusions -- was designed to target the neediest segment of the population without excluding persons who own certain assets deemed essential to their well-being.

Certainly, we agree that the current resource limits are woefully inadequate and should be increased to a level which would allow recipients to save money for certain basic needs, such as medical emergencies. However, these limits should be raised, period -- not raised to "offset" the elimination of certain exclusions. Redefining someone who has a $5,000 pre-paid funeral plus $2,000 in other resources to an individual who has not made arrangements regarding his or her burial but has $7,000 in the bank is a "robbing Peter to pay Paul approach" and does nothing to identify and assist the truly needy or promote equity.

2. Elimination of the Burial Exclusions Will Impose Serious Emotional and Financial Burdens on SSI Claimants

Eleven years ago, Congress enacted the burial space and burial funds exclusions to relieve beneficiaries from a cruel and insensitive choice. As then-Senator Howard Cannon (R-Nev.) noted, prior to enactment of the burial exclusions, "many elderly Americans . . . [were] being faced with the macabre choice between lifesaving welfare assistance and giving up their plans for disposition of their bodily remains." 128 Cong. Rec. S8943 (daily ed. July 22, 1982). To correct what was, in the words of Senator Cannon, "an insensitive and appalling test of eligibility," Congress enacted the burial space and burial funds exclusions, which allow SSI recipients to exclude from countable resources up to $1,500 in burial funds, in addition to the value of burial spaces held for the recipient and his or her spouse. See 42 U.S.C. § 1382b(a)(2)(B), 1382b(d) (1991).

The authors of the Modernization Project's Final Report reinvent this macabre choice for SSI recipients. Despite assertions to the contrary, the proposed increase in resource limits will not spare current SSI beneficiaries from redetermination if they elect to pre-fund their burials. The Final Report itself notes that several experts voiced concern that the elimination of these exclusions would require some recipients to dispose of assets in order to maintain benefit eligibility. See 57 Fed. Reg. 40761 (1992). This criticism is glossed over in the Report, which adopts the opinion of others who are confident that the proposed increase in general resource limits should allow recipients with currently excluded resources to keep them.

This confidence is misplaced. The proposed increases in resource limits, in fact, will not be sufficient to allow recipients to keep currently excluded burial arrangements. The National Funeral Directors Association reported that in 1992, the average cost of a traditional funeral including a vault was $4,493, with an in-ground burial adding up to $1,000 to total funeral costs. The July 1993 issue of Consumer Reports advised its readers to estimate about $7,000-$8,000 for total funeral costs. Thus, funeral costs for an SSI recipient and/or spouse could exceed the proposed $7,000 and $10,500 individual and couple resource limits.

Many SSI recipients use life insurance policies and burial trusts to fund their funerals, and would be forced to surrender those policies or cancel the trusts which have grown in value over time to keep pace with inflation. The cash surrender values of these policies and, in many cases, the cancellation value of burial trusts are substantially less than the amount set aside by the recipient for funeral and burial expenses. If forced to cancel such an arrangement, the SSI recipient would be left with no funeral -- and without sufficient funds to pay his or her funeral expenses. New claimants would likewise be forced to "spend down" these assets in order to qualify for benefits.

Aside from these obvious financial burdens, eliminating the burial exclusions would put claimants through unfathomable emotional pain. Forcing elderly individuals who want to take steps to plan for their death into uncertainty as to the disposition of their bodily remains is unfair and horribly insensitive, and entirely at odds with the policies underlying the resource exclusions.

3. Eradication of the Burial Exclusions Will Increase Government Expenditures

In addition, the cost of burial will certainly shift directly to the federal, state, or local government if the burial space and burial funds exclusions are eradicated. Although some widows and widowers still receive a small Social Security lump sum benefit following the death of their spouse, as of 1981, these payments may no longer be funeral-related.[1]

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[1] See Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35, sec. 2202, § 202(i), 95 Stat. 357, 834 (codified as amended at 42 U.S.C. § 402(i) (1991)).

Other than very restricted Veterans' benefits, there are no viable government resources directed at covering indigent burial expenses.[2] In changing the SSI rules, the federal government should be alerted to unintended consequences of substantial potential cost-shifting. By eliminating the incentive to pre-fund and prearrange one's funeral, the federal government may ultimately bear the burial burden in many instances.

THE PROPOSED "STREAMLINING" WILL NOT FULFILL ITS PROFFERED OBJECTIVES

1. The Proposed "Streamlining" Will Not Simplify Program Administration

The authors of the Final Report propose streamlining the resource exclusions by eliminating exclusions other than those for the home, an essential car, business property essential for self-support, household goods and personal effects, and those which are time-limited. Simply put, the only statutory exclusions to be eliminated are those relating to burial spaces and burial funds, life insurance, and federal housing assistance.

This raises several issues. First, the Report claims that the elimination of these four exclusions will spare the Social Security Administration significant administrative costs. SSA fails to offer any data or substantiation on time or paperwork spent in administering these exclusions. Second, the proposal leaves in place provisions which arguably are more difficult for SSA to administer, such as the timing-based exclusions for various government payments and the exclusion for business property essential for self-support. Third, the proposal fails to take into account that its implementation will add a new administrative burden: that of valuing those assets which were previously excluded. In sum, it is naive and unrealistic to assume that the proposed streamlining will fulfill its proffered objective of reducing administrative expenses.

2. Elimination of the Burial Exclusions Will Not Reduce Systemic Inequities

An additional justification offered on behalf of the proposed streamlining is that it will "remove present inequities (i.e., differences in how much people can retain, depending on the manner of retention). . . ." See 57 Fed. Reg. 40761 (1992). This assertion is patently absurd. The primary source of inequity within the SSI system is left firmly entrenched: the limitless exclusions for the home[3] and an "essential" automobile.[4] Theoretically, one could live in a million-dollar house (with unlimited equity) and drive an essential Mercedes Benz and still receive SSI benefits if he or she otherwise met the specified income and resource limits. Although this scenario might seem extraordinarily unlikely, it cannot be disputed that there is substantial inequity in a system in which a homeless person and a person who has home equity of $300,000 are under equal consideration for benefits.

CONGRESS SHOULD SEEK REAL, NOT ILLUSORY, SIMPLIFICATION THROUGH THE ENACTMENT OF A BURIAL-RELATED RESOURCE EXCLUSION

Clearly, the solution to the administrative and interpretive problems which have accompanied the burial space and burial funds exclusions is not to "streamline" them out of existence. Instead, Congress should effect real simplification of the existing exclusions by enacting a new burial exclusion which (1) replaces the current bifurcated scheme which separates burial assets into arbitrary categories, and (2) clearly specifies its applicability to the pre-funding arrangements which have developed since the exclusion first went into effect. Our coalition is prepared to

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[2] The current SSA and VA burial benefit levels of $255 and $300-$1500 respectively are woefully inadequate to fund a traditional funeral. See 42 U.S.C. § 402(i) (1991) (SSA burial benefit); 38 U.S.C. §§ 2302, 2303, 2307 (1991) (Veterans' burial benefits).

[3] See 20 CFR § 416.1212 (1992) ("We do not count a home regardless of its value.").

[4] See 20 CFR § 416.1218 (1992) ("One automobile is totally excluded regardless of its value if . . .[i]t is necessary . . . .").

submit a legislative proposal for the enactment of a new burial exclusion which meets both of the above-listed objectives.

1. Replacement of Burial Funds and Burial Space Categories With One Broad Provision Applying to All Burial Assets

The current burial space and burial funds exclusions should be replaced with one broad exclusion which applies to all types of burial assets and necessary items and services. Although when first enacted, the current burial exclusions were intended to separate two distinct types of burial-related resources --"spaces" (e.g., burial plots) and "funds" (cash set aside to pay for one's funeral) -- these distinctions today present artificial and sometimes inconsistent delineations.

As consumers have increasingly pre-funded a variety of burial-related items and services, the "space" and "funds" distinctions have become less clearcut. For example, under the SSA's current Program Operations Manual System ("POMS"), a pre-paid contract for a headstone is considered a burial space (subject to no limitations as to value) while a contract for embalming is considered as "burial funds" subject to a $1,500 limitation on excludability. See POMS § SI 01130.420(E)(2)(a) (1990). These kinds of arbitrary distinctions should be eliminated by grouping burial-related items and services necessary for the use of such items into one broad category of excluded "burial assets."

The Federal Trade Commission's Funeral Industry Practices Rule (16 CFR § 453) was initially promulgated in 1982 and was reviewed and amended in 1992. It defines and regulates funeral service practices and provides an excellent basis upon which to define the broad range of services and merchandise which are selected by SSI claimants who prearrange their funeral. These definitions provide clear guidance as to the scope of funeral merchandise services and funeral related items which when blended with current SSI definitions, could be defined as "burial assets." These definitions also provide uniformity and a legislative history which would promote a streamlining of the program through common definition and a recognition of the common elements of today's funerals which may run from cremation to a traditional burial.

2. Applicability of Exclusion Only to Pre-Funding Arrangements Which are Irrevocable

Under a streamlined definition which would meet any budget neutrality test, SSI would recognize that the value of the funding vehicle (life insurance, bank trust, or other similar arrangement) designated to purchase burial assets currently or upon the death of the SSI claimant would be excludable as a countable resource. The present arbitrary distinction, made relative to whether there is a current purchase of merchandise and services versus a future purchase at time of death, would be eliminated. Thus, the proposed exclusion would specify its applicability to all forms of pre-need funding, provided that such funding is clearly tied to purchase of burial assets for the individual, his spouse, and/or members of his immediate family. This represents not an addition to, but rather a clarification of, current SSA policy with respect to such arrangements.

No public interest is served by restricting the manner in which burial assets are secured. As long as a contract exists which ties the funding directly to the assets, the integrity of federal funds should be protected. The use of alternative methods of funding burial assets does not create a new class of individuals who will fund their funerals; it simply provides an option as to how their funerals will be funded.

In conclusion, our companies urge the Members of this Subcommittee to reject the recommendation to eliminate the burial space and burial funds exclusions under the auspices of "streamlining." The proposed change undermines the considerations underlying the SSI resource exclusions. Moreover, if implemented, numerous SSI beneficiaries will be subject to re-determination, loss of SSI benefits, and probable loss of their funded funeral.

Aside from the increased administrative burden and inequity to existing recipients, Congress should undertake real, not illusory, simplification of the SSI resource exclusions. Congress has always recognized the dignity of the individual unto death. The certainty of death and the resources required for a humane funeral are essential to all individuals, perhaps more so for those who find themselves in need of SSI benefits. They should not be eliminated from the resources which SSI claimants are allowed to retain. We look forward to working with Congress and the Social Security Administration to ensure genuine simplification of the burial exclusions.

Mr. McDermott. Thank you.

Mr. Camp, do you have questions?

Mr. Camp. Thank you, Mr. Chairman.

Mr. McElwain, I am sorry I wasn't here for your testimony. I did read your written statement, however, and I just have a couple of questions.

What is the average cost of burial services?

Mr. McElwain. Well, it will vary from State to State, but I think nationally probably somewhere between $4,000 and $5,000 would include merchandise, services, and cemetery expenses, but I would say somewhere between $4,000 and $5,000 would be an average.

Mr. Camp. And as a practical matter, if there is no way to pay for the burial, how is that accomplished, because obviously everyone gets buried, so how are indigent burials dealt with?

Mr. McElwain. Well, there are a couple of ways. Some States have funds available. For example, I am from Kansas. We have a maximum of $1,150 that is available. The family cannot add funds to that in any way. It is a take-it-or-leave-it proposition. They have to be eligible for that through a budgeting process that SRS does.

There are States, such as Missouri, next to us, that has no provision for that. That is mainly borne on the back of the funeral industry to take care of those people, or if someone in the community comes forward and adds some funds to it, that can be done.

The third way would be if there is a family member from somewhere that would want to come forward and take that responsibility. But primarily government—the governmental agencies in most States will provide some sort of basic indigent funeral expense.

Mr. Camp. What—I don't know if you know this or not, but you mentioned that States often have prepaid funeral statutes, and many of them are irrevocable. Do you know how many States allow revocable prepaid funeral plans?

Mr. McElwain. I am going to pass that question to Scott Gilligan. I think he has a better picture of it.

Mr. Gilligan. Nearly all States would allow revocable, approximately anywhere from 35 will allow irrevocable, and some have caps on dollar amounts, how much can be put in an irrevocable trust.

Mr. Camp. But if they are receiving public assistance, don't many more States require that that prepaid funeral plan be irrevocable?

Mr. Gilligan. Yes.

Mr. Camp. What is that percentage, I guess, of those?

Mr. Gilligan. We would have to get you the numbers. I hesitate to guess. It would probably be less than half have some kind of dollar cap on that, but it would be over 10—some number in between there would have a cap on that.

Mr. Camp. OK.

I do want to work with you on this issue. I do think that the resource exclusion for funeral and burial expenses has merit, and I would certainly like to work with you on seeing that maintained.

I have no further questions, Mr. Chairman.

Mr. McDERMOTT. Thank you. We want to thank all of you for coming. Obviously the issue of the trust is a complicated one and is probably a subject for another hearing at another point, but I think we will hold off on that one for today.

Chairman FORD. So we thank you very much, all of you, for coming today. Thank you.

[Whereupon, at 1:28 p.m., the hearing was adjourned.]

[Submissions for the record follow:]

AMI-NYS

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TESTIMONY for the OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME held by the Honorable Harold E. Ford, Chairman, Subcommittee on Human Resources, Committee on Ways and Means, under date of September 1993.

BY: ALLIANCE FOR THE MENTALLY ILL of NEW YORK STATE, represented by Mrs. Julie Renda

Thank you, Mr. Chairman, for this Oversight Hearing on the SSI program, and for the opportunity to testify here today. I am speaking to you as the mother of a mentally disabled daughter who has been an SSI recipient since 1980. Her mentally disabling condition today is mild schizophrenia, and she is able to live in the community with another sharing person thanks to modern day assistance from a local community mental health center, anti-psychotic medications provided through the Medicaid program and her own medication compliance. I am fiercely proud of her for her courage and character in continuing to battle this debilitating illness.

I am also here to speak in behalf of other parents of the mentally ill who belong to the New York State Alliance for the Mentally Ill (AMI-NYS), a non-profit organization of advocacy and support. We have been studying the SSI Modernization Panel Report, and we have even submitted our views to this panel. I am here to lend our support to their recommendations on behalf of our statewide organization. Indeed, the Alliance is nationwide, with a national office nearby in Arlington, Virginia. National AMI will also be presenting testimony today.

Nationwide there is also an SSI Advocacy group which has and will continue to support the recommendations of the SSI Modernization panel of experts. In brief summary, we join them in supporting an increase in the monthly benefit rate for the disabled and elderly on SSI, and we support their recommendation for an improvement in outreach efforts by the Social Security Administration. Also we support their recommendation that the 1/3rd In Kind Support and Maintenance rule be eliminated. However, there is some concern in our minds whether or not Congress will be willing to eliminate this rule across the board. What we would like to see is a more equitable rule. To discuss this complicated rule in this short period of public testimony might add to the confusion. We have included in our written testimony more detailed suggestions on how it might be modified to be fairer to families and recipients who share expenses together.

I would like to say this, however. In the Second Circuit Court of Appeals, which covers New York State, Vermont and Connecticut, a ruling came down in a case entitled Ruppert v. Bowen that has already improved the way this 1/3rd rule can be administered. A short article about this case is enclosed, and also a longer brief of it is attached separately which was taken from the Federal Reporter. In the three states I mentioned we already have a better interpretation of the law regarding rent subsidies by sharing people. Our minimum hope is that this ruling will be applied throughout the nation.

Our testimony also includes our thoughts on the other items on your agenda today, namely, (3) Eligibility requirements for (immigrants and) substance abusers, as well as (4) Certain criteria for establishing trusts. It is our considered opinion that the SSI Modernization Panel did not come out with the right recommendations regarding the matter of trusts. This, too, is a very complicated and legal matter which we are vitally concerned about but which cannot be attempted in the short time we are allotted. We have, therefore, written our views and submitted them in the additional pages to this testimony.

We wish to publicly commend the Social Security Administration for assembling the SSI MODERNIZATION PANEL, and to thank the Panel for the thorough job they have done in seeking input from all segments of our society and all geographic locations, and for delving into all the hard-to-understand rules and regulations. And for their courage in recommending a raise in the benefit level to 120% of the poverty level within five years. That would go a long way in helping the deinstitutionalized mentally ill and disabled to stay afloat. In our written testimony we give you some examples of the formidable problems these people face every day trying to make it in a world that is tough even for those of us who have fared a lot better health wise.

We would, if permitted, like to outline some of the specific problems that we have come across as parents of disabled young adults who are on the SSI entitlement program. In my own case, I have a daughter currently living in California, who has had to move four times in the past year. And those moves were not due to her illness, but were due to the inadequecy of the SSI benefits, which force her to take inappropriate living situations. The benefit rate in California is indeed the highest in the nation, but it only allows the rental of a room in a private home with cooking privileges. If the renting family and the SSI recipient get along, then it may happen that they also share the living room and watch TV together. But it often happens that the SSI recipient is restricted to the lone room, cooking on a single burner on the community stove (or eating out), and sharing a bath that has restrictions on its use.

And that is the bright side. The truly handicapped might find themselves in a gloomy SRO or the streets or park benches. The rental subsidies, like Section 8 of the Federal Housing Act, are badly funded and the wait is 10 months to three years. For someone coming out of treatment in a hospital for serious mental problems, this is not a solution. This is an invitation to relapse.

Many deinstitutionalized persons are living back at home with their families. Today it is estimated that 50 to 65% of the deinstitutionalized are living with aging parents. The bad news is that we are truly aging out and our help and support will not be around ten or twenty years from now. It is time to think into the future a little and plan for that day when hundreds of thousands of disabled persons will be on their own who are now cared for by loving families.

One option for that future is for the disabled to live together and share homes, meals, transportation, etc. It is being done today in what is called group homes that are run by non-profit organizations. But it is our hope that it can be done by private individuals who have learned how to live with their illness in the community. But there is a serious impediment to doing this under the current rules of the Social Security Administration. Please let me explain.

Two or three or four people can rent an apartment together, split the expenses evenly, and each of them receive a total SSI check to cover their monthly expenses, PROVIDED that each of them is on the lease as rentors and have equal liability for the rent. This is the "pro rata" rule.

BUT, if one of the above owns the house they are sharing and becomes ill and is reduced to an SSI check for his support, the income he charges the others is considered "unearned" income and will be subtracted from his SSI check! This must be corrected somehow. So that persons who own a home or are left a home someday in the future by parents in their will can rent rooms and share expenses and thus maintain themselves independently in the community in their own home. Everyone should not be reduced to an SSI check and an SRO in some dingy neighborhood. Please help us to see that this doesn't happen to the children we leave behind.

And this brings us to the subject of trusts for the disabled, allowed under current SSI regulations provided the trust is a "discretionary" trust and the beneficiary does not have "control" of the assets. Families of disabled children or young or middle aged adults want to leave their homes and other assets to benefit their independent children. In doing so they will assure their safety and well being. A trust created now or in a Will is the principal means for accomplishing this. We see NO NEED TO CHANGE the way that the SSA now deals with discretionary trusts. We think that back payments of retroactive SSI payments can and should be put into a similar trust, so that the recipient is not forced to spend the money within a six month period or have it considered a countable "resource." The only problem with this solution is finding a suitable trustee. In the case of children that receive payments as a result of the Zebley case, their parents would be the obvious trustees. But in other cases, where the lump sum might come from a lawsuit won as a result of injury, it might be harder to find a trustee. It also might not be equitable to allow an SSI recipient to have a LARGE trust, of say over $300,000, AND an SSI entitlement benefit and Medicaid. This matter merits further study. And a fair resolution. Disabled persons must not have to choose between spending money foolishly or having no SSI benefit at all. The wise investment of family legacies and/or tort settlements can enable at least some of our disabled citizens to live in community settings in dignity, at little expense to the taxpayers.

Before these hearings are completed I expect you will hear more about these matters from others. We are willing to work with you further to find suitable solutions to very complex problems. There are further comments and suggestions in the following pages.

Thank you again for this opportunity to speak to our own personal grievous concerns.

Additional testimony

Regarding the monthly benefit level, it is obvious to all of us that the federal benefit of $434.00 per month is grossly inadequate for living in today's world. For this reason individual states often add a supplement, and the government(s) have programs to subsidize the rent of such low-income persons. When all these items are put together, a person can squeeze by and live in a modest but adequate environment. If the disabled or elderly person lives with a family or caring and sharing other individual, he or she can squeek by. Then why are there so many homeless, mentally ill persons on our streets?

The answer does not lie totally in the inadequacy of the government programs. Sometimes, in the case of the mentally ill, the answer is in their illness and the inadequacy of the treatment that they get or they refuse to avail themselves of. There is some serious fixing of the mental health system that needs to be done also. The homeless mentally ill will not disappear from our city streets until adequate community mental health services exist for them. And they avail themselves of these services.

Many of the so-called homeless that wander our city streets are simply people who have no jobs and therefore no way of paying for a roof over their heads. They qualify for no program except a city shelter and a soup kitchen. They can't be helped via the SSI program. They should be helped to regain a productive living style. To neglect them is to invite more burden on the taxpayers of the country, because the stress of their current lifestyle can precipitate a serious breakdown and all its consequent costs.

ASSET LEVELS

Regarding the current $2,000.00 asset level that SSI recipients are allowed to have there are several points that need to be made. Those representing the elderly can address the problems inherent in "spending down" assets to qualify for SSI. Our young, chronic mentally ill family members seldom have any assets to spend down. Their problem with assets will come in the form of how much money they might be allowed to keep from a family inheritance in a will. Or how much money they might be allowed to save for a rainy day from a rehabilitation job that they perform at present. The deinstitutionalized mentally ill of today are our children, and their ages range from teens to the forties or fifties, if they are still in our care. They are surviving on government benefits and our help. We are very fearful that when our help is no longer part of the equation, they will join the legions in shelters and soup kitchens. We want to avoid that eventuality and are willing to do all in our power to prevent it. The laws regarding asset levels don't leave us much room to provide for that rainy day.

At the May 30th, 1989, hearing before a Subcommittee of Human Resources - this same committee - Louis D. Enoff, Deputy Commissionery for Programs, SSA, said that "an individual can own resources of considerable value and still be eligible for SSI. For example, a person's total net worth could be $110,000; this could include a home and a car." At today's prices that arbitrary amount could double. But how does one pay the mortgage on such a home and the car payments on a monthly check of $434.00 per month (or in New York State on $520.00 a month)?

Even if a disabled or elderly person were GIVEN a house and a car, the taxes and upkeep would be impossible on an SSI check. The SSI recipient would be obliged to sell the house and move into a rental. Immediately upon the sale of the house the SSI recipient would no longer be qualified to receive a penny from SSI because he would now have that asset converted to cash and the amount would be way over the $2,000.00 asset level. Now the "spending down" process would start. And no SSI checks would be available until that cash was spent down to the $2,000.00 level.

As we touched upon before, the only way that a person on SSI could continue to maintain himself in his own private home would be if others shared the home and shared the expenses. We desperately want Congress to pass a law to make that possible. A multitude of laws have already been passed, and after this hearing some new ones will be added. Please include in this package the ability of disabled and elderly persons on SSI to be allowed to "share" their homes by renting out a room or two. Any "profit" made on such an arrangement could be legitimately deducted from the owner's SSI check, but first the mortgage, taxes, heat, electric and phone bills must be pro-rated and shared equally.

All we want is for our disabled adult children to be able to survive in dignity. Not on the streets. To be forced to sell a family home because of glitches in the regulations regarding "unearned" income is a travesty. It will cause more homelessness eventually, if you don't change the regulations/laws now.

SSI and Substance Abusers - by Jean Little, AMI-NYS Member

This is not a simple subject to tackle, but I have some definite ideas on the subject, born of experience with a family member. If a person is simply an alcoholic or substance abuser, he or she is not handicapped. That person is addicted. And addictions can be cured through therapy and abstenance, after which the person can resume his/her place in society as a working member. To achieve sobriety may take special help, and while receiving that help, government subsidy for living may be in order. But checks should not be mailed out to persons simply because they are "alcoholics."

There is another category of person, however, who is both handicapped and a substance abuser. This person may legitimately receive a check for the handicapping condition, and then use it foolishly for alcohol. This can happen most easily when the supporting family pays the bills for food, and rent, and the handicapped person gets a reduced check under the 1/3rd rule. The check is too small to support the individual, but large enough for a couple of good benders that can result in rehospitalization - in the case of mentally disabled persons especially.

It is too late for my family to find a solution to this problem. This behavior led to my middle son's death in 1989. So I am well attuned to the dangers of allowing such individuals to have control of any funds at all. However, even the mentally ill must learn how to cope with both their illness and their addiction(s) in this day and age of deinstitutionalization. It is a sink or swim affair. Many sink. Perhaps a better way can be found to help them learn to manage money. There is certainly a glitch in the system that just sends out a check and does not expect an accounting, especially for persons who are mentally ill and addicted. I suspect that Congress does not want to face the fact that the checks are too small to provide adequate help.

Today we are here to face facts. The simple truth is that you cannot live on an SSI benefit, but you can get drunk on one - and maybe lose your life. Such irresponsible people often have a representative payee. But the check is made out to both the recipient and the representative payee, and the banks don't seem to pay any attention to who opens the savings account or who withdraws the money. I was manipulated by my son into allowing him to have control over his SSI money. Since he was saving most of it toward the day he would have his own place, I thought I was doing the right thing. But now and then he misused some of it. And I am sure plenty of others do too. How to prevent this is the question. Tighten up the rules for the representative payee. And inform banks that an account can only be opened by the representative payee, not the actual recipient.

TRUSTS and the RUPPERT v. Bowen case

The regulations for SSI say that money in an irrevocable discretionary trust cannot be counted as an asset since the SSI recipient does not have control of the money, only the trustee has control. And the "income" from such a trust cannot be counted until it passes to the individual, and if paid by the trustee to third parties, i.e. landlords, mortgage holders, the electric company, then it cannot be counted as "unearned" income but falls under the "In kind support and maintenance rules." The Ruppert v. Bowen ruling in the Second Circuit Court of Appeals says that if an SSI recipient pays 1/3rd of their federal benefit for rent, then they need not suffer any SSI deductions if they receive a rent supplement from family or trust. This means that a relatively small trust could help with the support of a recipient by paying 2/3rds of the rent or some part thereof. Before this ruling, small trusts were restricted to paying only for "supplemental needs," which meant anything but rent, food and clothing. This is why we are looking forward to the Ruppert ruling being applied to everyone on SSI.

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ATTENTION

SSI RECIPIENTS

YOU MIGHT BE ENTITLED TO MORE SSI

THE NEW RULE IN N.Y.

If you rent from a parent or child, and your SSI has been less than the full rate because Social Security charged you with a "rental subsidy" due to your low rent, you may be entitled to receive more SSI retroactive to July 1990.

As a result of a court decision called Ruppert v. Bowen, if you rent from a parent or child, and pay at least $165 per month (for 1993) ($160/month for 1992; $156/month for 1991; and $149/month for 1990), Social Security cannot charge you with receiving a rental subsidy. If you now buy and prepare your food alone, you could receive $520 SSI per month in 1993 (the living alone rate).

Ruppert applies retroactively to decisions made by Social Security on or after July 16, 1990. If you think you might qualify for more SSI, go to your local Social Security office, and request re-evaluation under the Ruppert Acquiescence Ruling #90-2(2).

The only way that a trust can be used to protect large awards for damages would be in the same way as above, by setting up a discretionary trust with somebody else as trustee, a parent or a sibling. Provided the award was under a certain amount, like $200,000, I can see that putting it in a trust would be a good way to assure that a supplement to the SSI benefit would always be available to the recipient. If the award were much higher, and the income alone from the trust was more than the SSI benefit amount, it would seem to be wrong for such a beneficiary to be eligible for the full SSI benefit. Awards are set high for the purpose of taking care of the injured person. No government benefits would seem to be in order in such a case. Special rules will have to be written for such cases.

Thank you for your consideration of SSI matters at this time. Our disabled citizens and the elderly on low pension or no pension certainly need the program. And it needs to be improved. I hope the benefits can be brought to the poverty level. And if two people in a family are both handicapped, they should each receive the same benefit. Just because they are married they should not have to live on 1 and ½ benefits.

Enclosures include Ruppert v. Bowen decision, TAKE ME TO YOUR LAWYER, a handbook on SSI and Trusts for the Disabled, and ALL IN MY FAMILY, a story of a MICA patient.

TESTIMONY OF EVELYN MORTON
AMERICAN ASSOCIATION OF RETIRED PERSONS

The American Association of Retired Persons (AARP) submits the following statement for the record on the Supplemental Security Income (SSI) program. Improvement and expansion of SSI is an important priority for the Association.

BACKGROUND

Implemented in 1974 to reduce poverty among the poor, aged, blind and disabled, SSI provides a monthly cash benefit to eligible low-income persons. In 27 states, the federal benefit is augmented for some beneficiaries by a state supplement. Even with this supplementation, the combined benefits generally fall below the poverty line.

Since 1974, Congress has made a number of improvements in the SSI program. As a result, some unduly restrictive eligibility requirements were removed and modest benefit improvements implemented. However, additional reforms are needed to significantly reduce poverty among the aged, blind, and disabled.

In 1990, then Social Security Commissioner Gwendolyn King appointed a panel of experts headed by Dr. Arthur Fleming to study the SSI program and recommend changes. Called the SSI Modernization Project, the group's review of the program was the first since SSI began, more than 15 years earlier.

The SSI Modernization Project's preliminary suggestions were published in the Federal Register for comment in 1991. Based on the 14,000 responses received, the panel issued a final report in September 1992. It contained over 50 recommendations covering 20 categories. Some suggestions were broad in scope and others affected specific aspects of the program. To date, Congress has not acted on these proposals. We are pleased that the Committee is examining them today.

AARP believes the most sorely-needed changes in SSI are:

- increasing the federal benefit level to at least the poverty line;
- raising the assets limit to reflect growth in the economy;
- continuing an aggressive outreach effort so that all SSI-eligible persons know about and can participate in this important program;
- eliminating the rule that reduces benefits for those who live in a household with another; and
- ensuring that SSA is adequately staffed so that SSI applications are processed in a timely manner.

Many of these recommendations are part of H.R. 2676, introduced by Representative Carrie Meek.

POVERTY AND BENEFITS LEVELS

SSI recipients are among the poorest of the poor. Since the federal cash assistance provided is less than the federal poverty level, SSI recipients -- especially those in states that do not adequately supplement the federal benefit level -- live on less than a subsistence level of income.

While the overall poverty rate for older Americans has declined, the incidence of poverty among many subgroups is shocking. For example, according to Census Bureau data for 1992, about 35 percent of all Black persons 65 and over lived in poverty, and older Black women experienced a slightly higher poverty rate.

The Modernization Panel recommended a phased-in increase in the federal benefit to 120 percent of poverty. The Association recognizes that this recommendation would be difficult to achieve in this period of fiscal austerity. However, we believe that the present benefit level is too low and needs to be raised.

THE ASSET & INCOME TEST

The Overall Limit

Unfortunately, many whose monthly income is sufficiently low to qualify for an SSI benefit are excluded from the program because their "countable" assets exceed the allowable limit of $2,000 for an individual or $3,000 for married couples. Although certain assets such as a home and a wedding ring are excluded, it is very difficult for poor persons to meet asset criteria that were developed in 1972 and revised only once. Another problem is that excluded assets under SSI are more narrowly defined than in other means-tested programs such as Food Stamps.

In 1988, Brandeis University conducted a study for AARP of individuals found to be ineligible for SSI. They found that 34 percent of older persons who meet the income requirements are disqualified by their asset holdings. Moreover, a substantial number of these income-ineligible older persons have countable assets relatively close to the asset test limit.

Satya Kochhar's study of all those denied SSI in 1989 because of excess resources ("Denial of SSI Applications Because of Excess Resources", Social Security Bulletin, Summer 1992, pp. 52-56) shows that 37 percent were applying for aged benefits. Their total assets (liquid and non-liquid) had a mean value of $10,500. Most often, the 65 and over ineligibles had excess bank accounts, but 64 percent had accounts that were less than $4,000 over the limit. Cash was the next most common factor leading to disqualification. Most of those with excess cash had less than $1,000 over the limit. An automobile was the third most common asset causing ineligibility. About 58 percent of these ineligibles owned a vehicle that was less than $2,000 over the $4,500 exclusion for automobiles.

The SSI panel recommended raising the resource limit to $7,000 for an individual and $10,500 for a couple -- slightly above the thresholds that would be in affect now if the thresholds had been adjusted annually for inflation. Being able to keep a larger amount of resources would be particularly helpful to older recipients who are likely to face an unforeseen medical emergency or need to replace a broken appliance or a leaky roof.

Since the SSI Modernization proposal eliminates existing resource exclusions, the proposed increase is not as large as it might appear at first glance. AARP believes the new level would not alter the fundamental nature of the SSI program.

Specific Assets

In addition to adjusting the asset limit for inflation, the Association recommends changes in the treatment of specific assets. The face value life insurance limit should be increased from $1,500 to $2,500. Currently, a person can exclude a life insurance policy with a face value only up to $1,500 as an asset for SSI eligibility purposes. Raising the limit to $2,500 would give older recipients some peace of mind knowing that their loved ones would be better protected after their death. The Association also recommends that the burial fund limit be raised in tandem with the increase in the face value of life insurance.

AARP also supports increasing the current exclusion for dividend and interest income to $200. This change would be particularly important to older Americans, who greatly value "saving," even if these savings are small. With this increase, recipients still cannot earn more than $17 per month of dividend and interest income.

IN-KIND SUPPORT AND MAINTENANCE

In-kind assistance, unless provided by a nonprofit organization or specifically excluded by statute, is counted as income in determining SSI eligibility. An SSI recipient who resides in the home of another, usually a family member, and does not contribute his fair share, is usually subject to one-third reduction in benefits. This reduction occurs regardless of whether the recipient is contributing his entire SSI benefit. The reduction puts an individual's benefit level at about half the poverty line.

AARP supports the Modernization Panel's recommendation to eliminate the one-third reduction. Although the proportion of SSI recipients whose benefit level standards are reduced because they live in the household of another is low, those affected are hurt because they do not receive a full benefit.

In addition, the in-kind support and maintenance rule is a barrier to caregiving. It penalizes the well-meaning family that wants to help a relative who is frail or has a disability. It is inconsistent with the American view of the importance of family.

Further, the rule does not make economic sense. It is highly unlikely an individual with a reduced SSI benefit will accumulate the resources to begin paying his pro-rata share. Moreover, some individuals will end up in a care facility, which costs Medicaid even more than the full SSI benefit.

The in-kind maintenance and support rule is an administrative nightmare for SSA. Collecting the information and enforcing the rule is time-consuming and diverts agency resources from other tasks, such as helping SSI beneficiaries in other ways. Currently, SSA's instructions regarding the rule take up 100 pages of the instruction manual. Also, verification of a recipient's living arrangement can occupy up to one-third of some SSA employees' time.

AGENCY STAFFING

In order to properly serve the SSI population, the Social Security Administration (SSA), which administers the SSI program, must be properly staffed. No program can achieve its goals if those who administer it lack the resources they need. Inadequate resources cannot be overcome even by the most well-intentioned employees. Even a dedicated staff can get worn down by pressure and frustration.

SSI recipients and applicants are among the first to notice the effects of chronic understaffing. The mounting disability backlog is the most visible and distressing symptom of this understaffing. For those awaiting SSI disability benefits, the wait is particularly cruel. Not only is their income limited, but they lack the resources to sustain themselves until a determination is made. If the initial determination is negative, they must wait even further until their appeal is heard. This delay exacerbates an already difficult financial situation.

The increase in the disability backlog comes at the worst possible time as states, seeking to balance their budgets, either terminate or severely reduce their general public assistance programs. For more Americans than ever before, SSI has become the only safety net.

AARP believes SSA must receive adequate resources to reduce the disability backlog and must give SSI applicants the assistance they need in completing the complex application form.

FUNDING FOR OUTREACH ACTIVITIES

Since 1989, AARP has sponsored SSI outreach projects throughout the United States. It is estimated that only about half of those 65 and over who are eligible for SSI actually participate in the program. The success of AARP's outreach activities indicates that program enrollment will rise as knowledge increases. However, in a time of tight resources, funds will not be used for outreach unless money is specifically earmarked.

AARP believes that the Modernization Project's recommendation to earmark a portion of the administrative budget for outreach is the only way to ensure meaningful outreach.

LINKAGE OF SSI AND THE MEDICAID PROGRAM

AARP agrees with the Modernization Project's recommendation to strengthen the linkage between SSI and Medicaid. We think that everyone should have access to basic health care, which is best achieved through comprehensive health care reform, including reform of the way health care is financed, rather than through minor adjustments to our present fragmented system. However, because of the extreme need of the SSI population, improvements in access for this group should not be delayed pending broader reform.

AARP recommends that the "209(b)" exception be eliminated. This would make Medicaid newly available to over 400,000 low income individuals living in the twelve states that require the blind, the aged and those with a disability to meet criteria for Medicaid eligibility which are more restrictive than the criteria for SSI eligibility (the other 38 states automatically grant Medicaid to persons eligible for SSI.) Medicaid coverage is essential for this population, despite the fact that many individuals are technically eligible for Medicare. Many of them cannot use their Medicare benefits because they cannot afford the coinsurance and deductibles, and the Qualified Medicare Beneficiary program which is supposed to pay those expenses for them (plus the Medicare premiums which otherwise come out of their already meager Social Security checks) has not been reaching all who are theoretically eligible due to inadequate outreach efforts. In addition, Medicaid may cover costly services that are not covered by Medicare such as long-term care, extended home care, outpatient prescription drugs and dental care.

However, such a change must be accompanied by a requirement that the 209(b) states which now permit spend-down for the aged, blind, and disabled continue to do so, at least for the population that is currently receiving benefits. In the context of reforming Medicaid, AARP also supports requiring all states to implement medically needy programs for persons of all ages.

DISABILITY & WORK INCENTIVES

The focus of SSI has always been to provide benefits to people with very low income and assets. Undoubtedly, disability and poverty go together. Since the inception of the SSI program in 1974, the population of beneficiaries receiving benefits based on disability has grown from 1.2 to over 3.4 million. (According to a Harris study completed in 1980, one-half of all Americans with disabilities had incomes of $15,000 or less.) AARP agrees that there must be adjustments in the SSI system for people with disabilities. In particular, there should be more flexibility in the system for those receiving SSI who wish to try to return to work.

AARP agrees with the Modernization Project's recommendation to change the definition of Substantial Gainful Activity (SGA) in the SSI program for people with disabilities who require significant support services to work. The definition should include the statement: "To establish initial eligibility to SSI an individual would be considered to be earning at the SGA level only if he is earning above the SGA level without significant support services."

This change would help to eliminate the contradiction in disability policy that first requires an individual to prove he is totally unable to work and then, once he is found eligible for SSI disability benefits, encourages him to re-enter the workforce. The proposed statement recognizes that many people with disabilities want to work but find it impossible to do so because they would not receive the necessary financial and medical assistance. Changing the definition for those who require significant support services to work would encourage those individuals to try to do so. Additionally, for the population already working and scraping by without health insurance and with very low income, this change would provide encouragement to remain in the workforce.

In addition, the Association supports the following work incentive recommendations proposed by the Modernization Project:

- Work incentive demonstration programs should be undertaken. AARP recommends specific two-year limits on these demonstrations.

- Increase the monthly earned income exclusion from $65 to $200. This increase acknowledges that a person with a disability has work expenses that are a significant portion of his income and may prevent him from attempting to enter the labor force. This would also eliminate the disparity between the blind, who can exclude all work related expenses, and people with other disabilities.

- Eliminate Continuing Disability Review (CDRs) triggered by work activity and defer scheduled medical reviews for working recipients for three years after beginning work. A person who participates in the SSI Section 1619 program is subject to CDRs when: 1) his earnings make him ineligible for SSI cash benefits or Medicaid, or conversely, when he becomes eligible for benefits or Medicaid again; and 2) when he is within 12 months of initial eligibility for 1619. It is thus possible for an individual, because of income changes, to be subject to numerous CDRs over the course of one year. This change would protect SSI recipients who try to work from an unreasonable number of evaluations of their status. It also eliminates some of the paperwork burden for the administrators.

- Treat unemployment compensation, workers' compensation, sick and other similar benefits received because of recent work activity as earned income. Each of the benefits replaces earnings and therefore should be considered earned income instead of unearned income. This would enable SSI recipients to keep more of these benefits since earned income receives more favorable treatment under SSI than unearned income.

- Eliminate the regulatory time limit for completing the plan for achieving self-support (PASS). An individual who is in a training program that lasts longer than the regulatory limit of 48 months or an individual with a disability that prevents him from attending a program full time would be unable to complete a PASS. Eliminating the time limit would allow more people with disabilities to take advantage of this opportunity.

- Make all individuals who receive benefits based on age eligible for all work incentives. Some older individuals find it financially necessary or socially desirable to return to the workforce after a period of non-work. Older individuals should be allowed the same opportunities to work as other individuals in the program.

REPRESENTATIVE PAYMENT

Of the panel's recommendations regarding representative payees, AARP supports mandating training and monitoring of representative payees, authorizing sufficient funding to implement the program, requiring periodic documentation to support annual accountings, recovering misused funds from the monthly check of representative payees receiving benefits in their own right, and prosecuting representative payees who misuse funds. AARP also urges that there be a presumption when an overpayment has occurred that the beneficiary is "without fault."

Unfortunately, some representative payees mishandle the recipients' funds and others simply do not understand the SSI program. A beneficiary with a representative payee is, by SSA's definition, incapable of handling his funds. These beneficiaries cannot be expected to know when representative payees are using their funds inappropriately, nor should these beneficiaries be expected to figure out an appropriate remedy. SSA must monitor representative payees to ensure that vulnerable beneficiaries are protected. Representative payees should be required to provide documentation to support their annual accountings.

When a disabled recipient with a representative payee is charged with an overpayment, SSA applies a presumption that the recipient and the payee are jointly liable for repayment. Holding the recipient jointly liable with the representative payee is unjust. A representative payee is appointed because SSA has determined the recipient cannot manage his affairs -- often because he is too young or mentally unable to do so.

Unless a waiver is requested, when an overpayment occurs, SSA can recoup the overpayment from the recipient's future benefits. It is up to the recipient with the disability or the representative payee to request this waiver. However, the representative payee is not likely to request a waiver because, if recovery from the recipient is waived, Social Security may recover the overpayment from the representative payee. This situation needs to be corrected.

SSI ADVISORY COUNCIL

The Modernization Project called for a separate advisory council on SSI. The Social Security Advisory Council could evaluate the program when it meets on a quadrennial basis, but the Advisory Council has responsibility over a range of programs and understandably has limited time to give each one. A separate council would be in a position to call for additional SSI changes as well as be able to determine the progress which has been made on the recommendations of this current panel.

CONCLUSION

The SSI rules and benefit levels are similar to the ones adopted almost 20 years ago when the program began. The SSI Modernization Project undertook a comprehensive examination of the program and made specific recommendations for its improvement. It is up to Congress to implement some of those recommendations.

AMERICAN CEMETERY ASSOCIATION
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Stephen L. Morgan, CCE
Executive Vice President

October 22, 1993

The Honorable Harold E. Ford
Chairman
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Representatives
Rayburn House Office Building
Washington, D.C. 20515-6351

Re: SSI Modernization Project

Dear Chairman Ford:

The American Cemetery Association (ACA) respectfully submits its views regarding the Supplemental Security Income Modernization Project and the oversight hearings your Subcommittee is presently conducting. We appreciate this opportunity and request that our testimony be made part of the permanent hearing record.

The ACA represents over 2,000 members including private, religious, and municipal cemeteries throughout the United States and in twenty foreign countries. Our concern with the SSI Modernization Project is limited to a proposal in the Final Report, as published in the Federal Register at 57 FR 40732 et seq., to "streamline" certain resource exclusions.

Specifically, the Final Report proposes the elimination of the current burial space and burial fund exclusions in determining SSI recipient eligibility. The current dollar resource exclusion of $2,000 per individual and $3,000 per couple would then be increased to $7,000 and $10,500 respectively as an ambiguous offset to the loss of the burial exclusions (57 FR 40760-61, 40763). While ACA agrees that the current dollar levels are unrealistically low and should be increased, we oppose the elimination of the burial space/fund exclusions.

When Congress enacted the SSI burial exclusions into law through P.L. 97-248, the Tax Equity and Fiscal Responsibility Act of 1982, it acknowledged that "many elderly Americans...(were) being faced with the macabre choice between lifesaving welfare assistance and giving up their plans for disposition of their bodily remains." Section 185 of this Act created the burial exclusions to relieve "an insensitive and appalling test of eligibility." (Statement of Sen. Howard Cannon, 128 Cong. Rec. S8943, July 22, 1982).

The highly personal choices involved in making funeral and burial arrangements are based on a variety of factors including religious considerations and should never be subjected to government intrusion. These factors were implicitly recognized by the SSI Modernization Project Final Report when it stated that the reasoning "behind the resource exclusions is that certain property is so essential to one's well being...that its owner should not be expected to sell it and use the cash to meet day-to-day living expenses." (57 FR 40759-60).

However, the Final Report then proceeds to blur the fundamental distinctions between "living expenses" and funds set aside for the "final expenses" of a funeral and burial by recommending that an increase of excludable resources to $7,000 and $10,500 will provide an offset for the elimination of the burial space/fund exclusions. These kinds of resources serve two entirely different purposes: the one for living and the other, quite literally, for death.

The Report also noted that some of its panelists expressed concern over eliminating the exclusions because some SSI recipients would be required to dispose of these assets to maintain their eligibility (57 FR 40761). Yet in advocating the termination of the burial exclusions, the Report provides no data or evidence as justification, but only a conclusory observation that administrative time and expense would be saved. In fact, a new layer of bureaucracy would be created by the need to evaluate the worth of the assets which were previously excluded.

The ACA suggests an alternate approach to streamlining the resource exclusions. We recommend amending Section 1613 of the Social Security Act by combining the burial space and burial fund exclusions into a single resource exclusion called "burial assets." This exclusion would include but not be limited to cemetery property, merchandise and services, cemetery purchase agreements, trusts, life insurance policies, annuities, or any other similar arrangement. Items currently recognized under "burial spaces" would continue to have no dollar limitation. Likewise, accumulated interest or earnings on the assets would also continue to be excluded as resources.

In addition, the ACA recommends that the current $1500 limit on burial funds should be eliminated (in a manner similar to the existing SSI treatment for a home, personal effects and other items) provided that these funds are related to an irrevocable burial or funeral contract. We believe that any potential abuse of this exclusion by "sheltering" funds for purposes of obtaining SSI benefits will be removed through a requirement for irrevocable agreements.

Finally, the ACA believes that the elimination of the burial exclusions will ultimately shift the cost of burials to the government when present and future SSI recipients are given "incentives" not to assume responsibility for their own funeral, interment and memorialization arrangements.

For these reasons, the American Cemetery Association respectfully urges the Subcommittee to oppose any proposal to eliminate the SSI burial space and burial fund exclusions. Thank you.

Sincerely,

Stephen L. Morgan, CCE
Executive Vice President

SLM:mws

TESTIMONY OF GLENN M. PLUNKETT
AMERICAN FOUNDATION FOR THE BLIND

This statement is submitted for the record on behalf of the American Foundation for the Blind relative to the Subcommittee's October 14, 1993 oversight hearing on the Supplemental Security Income (SSI) Program and recommendations made by the SSI Modernization Panel, as well as other subject matters concerning the program.

The mission of the American Foundation for the Blind is to enable persons who are blind or visually impaired to achieve equality of access and opportunity that will ensure freedom of choice in their lives. AFB accomplishes this mission by taking a national leadership role in the development and implementation of public policy and legislation, informational and educational programs, diversified products, and quality services.

SSI has benefited millions of recipients over the years and has gone a long way in providing a safety net to keep them from absolute impoverishment. However, the program should be updated to take into consideration the needs of people who have little in the way of income and resources in the current economic and social realities. Implementation of the recommendations by the SSI Modernization Panel would bring the program generally in line with the current economic conditions. However, any program changes concerning income and resources and other measures of need should be indexed to provide for future changes.

One of the more important program needs is sufficient staffing in the Social Security Administration to handle the program in an efficient and timely manner so that people who are in need will receive benefits to which they are entitled without further hardship. This is one of the major recommendations of the SSI Modernization Panel and one with which we heartily agree.

We have excerpted the more significant options reported by the Panel and have given our recommendations and comments on each of them; indicating whether legislation would be needed or whether the suggestion could be accomplished through the regulatory process. We have noted that numerous recommendations made by the Panel could be accomplished in whole or in part through the regulatory process. In those cases we cannot see why the Department of Health and Human Resources has not proposed regulations to improve the program as quickly as possible. For example, the situation concerning "deeming" of all resources, after a set aside for a parent(s), to the disabled/blind child(ren) when there are other children in the family who are not disabled/blind is one that is inequitable and should have been corrected at the program's inception.

Summary of the More Significant Options Reported by the SSI Modernization Project and Recommendations for Improvement by the American Foundation for the Blind for Congressional Consideration

Panel Recommendations\AFB Comments

1. Increase the Federal benefit standard for an individual, in 5 equal annual increments, to 120 percent of poverty guideline. Keep the couple's benefit standard at 150 percent of that for individuals.

   Comment: Requires legislation. Should go to poverty level in one step and next to 120% of poverty. Should give couples twice individual rate or at least 175% because of extra needs of blind/disabled/aged.

2. Eliminate the concept of "holding out" in defining a spouse.

   Comment: Requires legislative change . Agree that it should be done. However, both members of a married SSI couple should be treated as an individual. See preceding option.

3. Give each member of a couple a full set of earned income exclusions.

   Comment: Agree. If each member treated as an individual, should receive exclusion as suggested.

4. Adopt the current "earned and unearned" income formula for use in all parent-to-child deeming situations. Deduct itemized special expenses of a disabled child before deeming parental income. In deeming parental resources, exclude $2,000 (indexed) for each ineligible child.

> **Comment:** Should be done. The Act permits the Secretary to do such by regulations. Deeming of parental income and resources are mandated in the Act "... except to the extent determined by the Secretary to be inequitable under the circumstances." May require legislative change for deducting special expenses of disabled/blind child.

5. In parent-to-child deeming, treat as earned income benefits intended to replace a parent's earnings (e.g., unemployment, worker's compensation, and disability and survivorship social insurance benefits).

> **Comment:** Should be done. Would require some legislative change as to what is "earned income".

6. In-Kind Support and Maintenance: Eliminate consideration of in-kind support and maintenance as income.

> **Comment:** Should be done. Requires legislative action. Would encourage people to live with others and help keep people out of institutional care situations.

7. Resources: Increase resource limits to $7,000 and $10,500 with fewer resource exclusions.

> **Comment:** The amounts are too low. They should be increased and indexed. Would need some legislation but much could be done by regulation.

8. Change all periods for time-limited resources exclusions to 12 months.

> **Comment:** Should be done. Can be done by regulations. Secretary can prescribe period or periods of time for disposal of resources.

9. Change the calculation of overpayment resulting from excess resources.

> **Comment:** Desirable to do. Would require legislative change. This would permit the Secretary to recover overpayment, because of excess resources, only to the extent of value of excess resources.

10. Disability Issues: Redefine "substantial gainful activity" in the SSI program to recognize that persons who need substantial support services in order to work are not performing substantial gainful activity, and study the feasibility of:

(a) eliminating use of substantial gainful activity in both the SSI and the disability insurance programs; and

(b) formulating disability criteria in terms of being disadvantaged in participating in major life activities.

> **Comment:** This is not an issue for people who are blind and in receipt of SSI program payments since there is no "substantial gainful activity" in SSI for people who are blind. Also, people who are blind have a definition of blindness in the Act.
>
> However, SSI payments should be made on the basis of income and resources tests and SGA should not be a part of SSI criteria for "disabled" individuals. Requires legislation.

11. Work Incentive Options

(a) Raise the earned income exclusion to $200 plus two-thirds of any remaining earned income.

> **Comment:** Should be done but should be indexed to keep pace with cost of living/inflation. Needs legislation.

(b) Eliminate continuing disability reviews triggered by work; defer scheduled medical reviews for 3 years after work begins.

> **Comment:** Also, should eliminate any disability reviews where disability or blindness could never be expected to improve. Could do some by regulation.

(c) Treat as earned income: unemployment compensation, workers' compensation, sick pay, and similar benefits related to recent work activity.

> **Comment:** Should be done. Requires legislation.

(d) Allow aged individuals to be eligible for all work incentives.

> **Comment:** Needs legislation. There should be no age discrimination in the SSI program. An aged person should be given all the work incentives given to people under age 65 without special requirements concerning work prior to age 65.
>
> Discriminates against aged people as now written.

(e) Disregard deemed income of an ineligible spouse when determining continued Medicaid eligibility under section 1619(b).

> **Comment:** Should be done . Requires legislation but if each person in a "couples" situation was treated as an individual this could be done anyway.

(f) Eliminate the time limit for completing a plan for achieving self-support.

> **Comment:** Desirable and can be done by regulations.

(g) Require SSA to make a decision on a plan for achieving self-support within 30 days. If there is no decision within that time, assume the plan is acceptable.

> **Comment:** Could be done by regulation. Should be done immediately.

(h) Require States which supplement regular SSI payments to supplement payments under 1619(a).

> **Comment:** Requires legislation. Desirable to provide health care service and encourage working.

(i) Provide Medicaid under section 1619 to all working individuals.

> **Comment:** Requires legislation but medical care should be provided.

12a. In both SSI and the SSDI programs, eliminate the reconsideration level of appeal; and provide opportunity for a face-to-face interview with the decision-maker prior to issuing a disability denial.

> **Comment:** Desirable and should be done as quickly as possible for both SSI and SSDI since backlogs in processing appeals are building at ever increasing rates. Need legislation

12b. Establish 90 day time limits which, if exceeded, would result in benefits payments not to be considered overpayment. Apply such limits to: initial SSI disability determinations; completing cases at the administrative law judge level; and completing cases at the Appeal Council level. Study the effects after 4 years of experience.

> **Comment:** Needed quickly in both SSI and SSDI programs since processing times are delaying initial payments, and appealed cases, excessively and creating hardships for those in need. Need legislation.

13. Representative Payment: Some recipients need representative payees to protect them. There should be specific recruitment, training and monitoring of representative payees, and provision of reasonable compensation to non-relative non-custodial payees out of administrative funds.

> **Comment:** Needs legislation to accomplish this as stated, especially in the training and compensation out of administrative funds.

14. PROGRAM LINKAGE ISSUES: Medicaid . Require all States to use SSI eligibility criteria and mandate Federal determinations of Medicaid eligibility.

> **Comment:** This is needed. Requires legislation. In some States the criteria for medicaid is more restrictive than SSI criteria and people on SSI may not be eligible for Medicaid.

15. Continue Medicaid coverage when SSI eligibility is lost solely due to a calendar-related income fluctuation.

Comment: Agree. Could be partially effectuated by regulations but would need some legislative change.

The American Foundation for the Blind appreciates this opportunity to present our views concerning the Supplemental Security Income program, and to make recommendations that if implemented will improve the lives of those who are dependent upon SSI.

Respectively Submitted,

Glenn M. Plunkett
Governmental Relations Specialist
American Foundation for the Blind

TESTIMONY OF ANDREW KOSKI
BROOKDALE CENTER ON AGING OF HUNTER COLLEGE

Good morning, Chairman Ford and other distinguished members of the House Ways and Means Subcommittee on Human Resources. My name is Andrew Koski. I am the Public Policy Coordinator of the Institute on Law and Rights of Older Adults, part of the Brookdale Center on Aging of Hunter College. The Law Institute researches the laws and regulations pertaining to SSI and other entitlement programs; provides publications that explain these programs for agencies serving the elderly; conducts seminars on public benefits; and represents individuals who wish to appeal denials, terminations or reductions in benefits. Our testimony is based upon fifteen years of experience with the SSI program.

First, we want to commend the Committee for holding today's hearing. SSI is a program integral to the survival of over five million people in the United States which supports the health and well being of disabled children and adults and impoverished older adults by providing vital income support. Although SSI has been a successful program, improvements to the program are long overdue.

My testimony will address the recommendations of the SSI Modernization Project. This Project conducted an exhaustive study of the SSI program, held numerous hearings across the country and developed sound recommendations for improvement of the program. These recommendations must be acted upon so that this country's poor elderly, visually impaired and disabled individuals can live a better life.

The Law Institute recommends that the following improvements be made in the SSI program.

I. BENEFIT LEVELS

A. Federal Benefit Amount. **Increase the federal benefit levels to 120% of the poverty guideline over 5 years.** Although the Law Institute would prefer to have the benefit levels raised to 125% of the poverty guideline over a 3 year period, we believe that the Modernization Project's recommendation of raising the level to 120% over 5 years is a sensible and worthy goal in this time of high federal budget deficits and decreased funding for social programs. Our experience has been that New York SSI recipients cannot survive on their monthly benefits--which equal 90% of the poverty level for individuals--and that a substantial increase is needed.

B. State Supplement. **Mandate states to provide a supplement to bring recipients up to at least 125% of the poverty line until the federal benefit levels are raised to 125% of the poverty line.**

II. RESOURCES

A. **Increase resource limits to $7,000 for individuals and $10,500 for couples and simplify the resources test by streamlining** the exclusions. This recommendation will encourage recipients to save some funds for necessities or emergencies which cannot be met from their monthly benefits. Eliminating specific exclusions (i.e. burial funds) while increasing the resource limits would simplify the SSI program and provide greater flexibility to recipients for conservation and use of their funds. This change would particularly help homeowners on SSI who accumulate funds to pay their property taxes and then find that they have exceeded the resource limit resulting in their ineligibility and being charged with an SSI overpayment.

B. **Change the period for time-limited exclusions to 12 months.** This proposal will provide additional time for SSI recipients to spend funds (i.e. retroactive SSI and Social Security payments). Some older recipients who, by necessity, are accustomed to purchasing only basic necessities have difficulty spending down even moderate sums of money.

C. **Change the method for calculating overpayments that result from excess resources.** The method for calculating overpayments resulting from excess resources should be changed to limit the amount of the overpayment to the person's excess resources. The present rule, whereby individuals whose resources exceed the allowable limits by even one dollar can be charged with an overpayment for several thousand dollars, is excessively punitive and causes many problems for SSI recipients.

III. INCOME

A. **Eliminate the consideration of in-kind support and maintenance as income.** For too long, SSI recipients have been unfairly penalized for receiving in-kind assistance from family members and friends. Present rules allow in-kind assistance from non-profit organizations to be excluded from income calculations; now we must allow families and friends to provide similar assistance.

B. **Exclude all interest and dividends from income.** All interest and dividends should be excluded from income calculations; otherwise, individuals who have resources up to the increased levels recommended above will continue to be charged with overpayments (due to unreported income) when their cases are recertified. Allowing recipients a certain amount of resources and then counting the interest or dividends earned on these resources as income results in much anger and confusion among the recipients affected and causes excessive administrative costs for the Social Security Administration (SSA).

IV. DISABILITY

A. In both the SSI and Social Security Disability programs: (a) eliminate the reconsideration level of appeal; and (b) provide claimants the opportunity for a face-to-face interview with the decisionmaker prior to issuing a denial based on a disability issue. In addition, we urge that the decisionmaker be bound by Social Security regulations (as administrative law judges are) and not by the Program Operations Manual System.

B. Establish a 90-day time limit to make initial determinations for new SSI claims on the basis of disability and begin paying benefits which would not be considered overpayments even if the individual is later found ineligible to receive SSI if the 90 day limit is exceeded. Close monitoring and scrutiny of claim denials are also necessary to prevent SSA's issuance of denials in order to meet the 90-day time limit.

V. AGE REQUIREMENT

A. Lower the age requirement to age 62, phased in over 3 years. This recommendation is a first step in providing benefits to individuals who have health problems which prevent them from working but are unable to meet strict disability criteria, recognizing that other benefits are available under the Social Security program for individuals between the ages of 60 to 65.

VI. SSA'S SERVICES

A. Increase SSA's administrative budget to provide for at least 6,000 additional positions as a first step toward adequate staffing. This modest increase in SSA's administrative budget is desperately needed to help an understaffed SSA meet the increased and growing workload.

B. Establish specific funding for outreach by increasing the SSI administrative budget by at least 5%. Outreach funds should be made available to non-profit organizations on an annual basis to support ongoing activity to reach a population which is difficult to identify and to enroll.

C. Mandate that SSA offices complete short-form food stamp applications for all interested SSI claimants. Any short-form should elicit enough information to make determinations on eligibility for food stamps without applicants' having to go to the food stamps office.

VII. ACCOUNTING ISSUES

A. Change from retrospective monthly accounting to prospective monthly accounting. Benefits should be computed based on a prospective monthly accounting basis. Too often, individuals who are no longer in receipt of income (cash or in-kind) have such assistance counted for an additional two months. Congress recognized the hardships resulting from retrospective monthly accounting and excluded certain types of income from this rule.

Now is the time to abolish this accounting rule entirely.

We hope these comments are helpful. We will continue to make ourselves available to work with the Subcommittee on Human Resources to improve the SSI program so that needy aged, disabled and visually impaired persons receive sufficient assistance from this vital program.

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July 14, 1993

Honorable Harold E. Ford, Chairman
Subcommittee on Human Resources
U.S. House of Representatives
1102 Longworth HOB
Washington DC 20515

Re: SSI Hearings
Attn: Harriett Lawler

Dear Congressman:

1. The SSI Modernization Panel recommendations, although well intentioned, would break the bank without any promise of success for the stated goals.

2. Zebley has created a standard (unable to do "age appropriate activities") that is maleable and uneven in application. The "educators and others" should suggest an alternative standard since the present one has proven unworkable for SSA.

3. In Chicago, the problem with substance abusers obtaining SSI benefits and not meeting treatment requirements is acute. Essentially, federal funds are financing drugs on the street. Since I handle about 20 to 30 of these types of cases (alcohol and drug - §12.09) each year over the last 20 years, I have seen a decline in the will and ability of SSA to follow the law mandating program participation. What exists is on paper only. "Good" drug rehab programs have extensive waiting lists and priorities, (ie alternative sentencing).

What exists, isn't working - except to the benefit of some addicts in terms of funding a bad habit. Either admit defeat or fund rehab programs.

4. In very limited circumstances, SSI Trusts are appropriate. However, this area has ripened with abuses and unnavigable pits for well meaning relatives. Ask Sen. Braun from Illinois. Is SSI meant for "poor" people who are disabled?

Since you have not scheduled a Hearing date yet, I wish my general written comments to be made a part of the printed record. I will be in Europe for much of August to review the merger of the East and West German Social Security systems. Hopefully, I will be able to expand in some detail on the four areas you intend to cover.

Very truly yours,

David R. Bryant

DRB:maa
cc: Janice Mays
cc: Nancy Katz

CALIFORNIA STATE DEPARTMENT OF SOCIAL SERVICES TESTIMONY FOR OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

My name is Eloise Anderson and I am the Director of the California State Department of Social Services (CDSS). The CDSS wishes to express its appreciation to the Panel of Experts for their extensive review of the Supplemental Security Income (SSI) Program. We agree with their findings regarding several issues, in particular, the need for simplification of the State Supplementary Payment (SSP) Program. Additionally, we have comments regarding the SSI/SSP rules for drug and alcohol addicted recipient populations and the issue of fraud in the SSI/SSP Refugee/Immigrant population. Finally, we wish to call attention to an oversight by the panel regarding the issue of federal pass along rules. The following provides California's comments regarding the Modernization Project and other SSI/SSP related issues.

SIMPLIFICATION OF THE SSP PROGRAM

The Panel's review of the SSI Program revealed that, in an attempt to protect recipients who were receiving benefits pursuant to States' pre 1974 programs for the needy, SSP laws were enacted to require States to maintain those programs' payment and living arrangement categories. States cannot eliminate a payment category without risking the loss of Title XIX Medicaid funds.

While a category could be absorbed into another existing category, the persons in the absorbed category must be paid at their prior rate if it is higher. This means that a State would actually add a category to designate the former members of the absorbed category for payment purposes. This does not result in fewer payment categories and in fact adds to the administrative complexity and costs of the program.

In order to restrict States from reducing their costs by reducing their SSP payment levels when SSI benefits are adjusted for the cost of living, the SSI statute was amended in 1976 to require States to maintain their SSP benefit levels at the levels in effect in 1976. In 1983, another amendment was enacted which required that SSP payment levels be maintained at the levels in effect in July, 1983. These amendments, coupled with the payment and living arrangement category restrictions prevent States from simplifying their SSP programs.

In consideration of the Omnibus Budget Reconciliation Act (OBRA) of 1993's requirement that States pay for the administration of the SSP based upon the complexity of the States' SSP Programs, California proposes that federal statutes be amended. Specifically, we propose that amendments be enacted to allow States to reduce the number of payment and living arrangement categories without penalty. Additionally, amendments to the federal pass along requirements should be enacted. This issue will be discussed in detail in the following comments regarding the report's section on the federal pass along rule.

FEDERAL PASS ALONG STATUTE

The Report of the Experts on the SSI Modernization Project did not accurately explain either the federal pass along statute or its effect upon the States. Specifically, the report states that in 1976, the SSI statute was amended to require states to pass along any SSI increases. Actually, that law required that States maintain their SSP payment levels at the levels in effect in 1976. The report failed to note that this requirement was amended again in 1983 to require States to maintain their SSP payment levels at the levels in effect in March, 1983.

While the report accurately reflects the intent of the 1976 amendment, i.e., to prevent States from reducing their SSP payments when federal increases are granted, it does not speak to those States which granted SSP cost-of-living increases (COLAS) between 1974 and 1983. Between 1974 and 1983 and especially between 1976 and 1983, California granted generous COLAS for SSP recipients. These increases were granted in good faith and in acknowledgement of the intent of the SSI/SSP Program, which was to lift the aged, blind, and disabled above the poverty level in order to give them the chance to become self-supporting. For States which did not increase their levels, the imposition of the pass along requirement and the current mandate regarding the States' responsibility for administrative fees do not have the severe fiscal effect that is being experienced by California.

Because California granted substantial COLAS between the years 1976 and 1983, our SSP payment levels are among the highest in the nation. Due to a severe state fiscal crisis, we have reduced some of our levels during the past two years. Despite these reductions, our SSP payment levels are among the highest in the nation. The federal statutes regarding the retention of payment and living categories and the pass along requirements have always been detrimental to California as they have kept our program unnecessarily complicated and, in fact have rewarded those States which chose not to grant COLAS. As a result of the passage of the OBRA of 1993, these restrictive federal mandates have become even more detrimental to California. We are required to pay administrative costs based upon the complexity of our program, yet are not allowed to simplify this program. California urges the Committee to support amendment of the federal pass along statutes to require that the minimum SSP payment level be the average 1983 national SSP payment level.

These restrictive federal mandates were not part of the original SSI/SSP contract between the States and the Social Security Administration (SSA). In fact, the absorption of SSP-related administration costs by the SSA in return for the SSA's authority to subtract a recipient's countable income from the SSI portion of the benefit first were key factors in California's decision to enter into this contract. Although the contract provides that no changes can be made to its provisions without the mutual consent of both the States and the SSA, the reality is that the amendments noted above were enacted without the States' consents.

The mandatory payment of administrative costs by the States is especially unfair in light of the history of this program. Under the pre-1974 state programs for the aged, blind, and disabled, the Federal Government offered grants-in-aid on a matching basis for administrative costs. In addition, a recipient's countable income was shared equally between the Federal and non-Federal governments. Federal financing of these programs was provided through an open-ended appropriation from general revenues.

Finally, the restrictive mandates currently in effect for SSI/SSP, coupled with the repeal of some of the program's original protections for states, i.e. repeal of federal fiscal liability, have resulted in the loss of control of States' expenditures. California urges the Committee to support the reinstatement of countable income and administrative cost sharing for the SSP Program between the States and the Federal Government.

DRUG ADDICT/ALCOHOLIC SSI/SSP RECIPIENTS

In order to receive SSI/SSP benefits, Federal law/regulation requires SSI/SSP recipients who are drug or alcohol addicts (DA/A) to have a representative payee and to attend appropriate treatment, if available. In addition, when an applicant's eligibility determination requires several months of review, approved applicants are eligible to receive large retroactive benefit payments.

REPRESENTATIVE PAYEE

SSA has great difficulty locating responsible persons or organizations to act as representative payee for DA/A recipients. Consequently, representative payees can be a recipient's alcoholic friend or drug dealer. This has led to unfavorable public opinion and media coverage regarding SSI/SSP monies being paid to drug dealers and other questionable persons.

California urges the Committee to amend the representative payee requirements to open the program to more private, religious, or public entities (such as county welfare or social services departments) to act as representative payees for recipients. The recent provision for a small payment for services rendered should encourage responsible agencies to act as representative payees which will ultimately benefit both the recipients and the taxpayers.

TREATMENT

In California, SSA contracts with an outside Referral and Monitoring Agency (RMA) to oversee DA/A recipients' treatment plans and to monitor recipients' attendance. It is also required to report non-compliance on a timely basis to SSA.

The actual provision of treatment can be academic, as it is easy for recipients to avoid treatment. According to Federal regulations, treatment must be both available and appropriate. Any treatment facility whose access requires the use of public transportation may be deemed "unavailable" because the recipient has to pay for transportation. If the appropriate treatment is determined to be in-patient treatment and there is no bed available without fee, the treatment is considered to be "unavailable". If the facility requests a nominal fee or co-pay, for any type of treatment, it may be deemed "inappropriate" because recipients cannot be required to pay for treatment. In such cases, the recipient states that it is "too difficult" to attend a treatment program and SSA will waive that provision without suspension of benefits. As a result, it is probable that these recipients are using public funds to continue their abusive habits while successfully avoiding all treatment, with no detrimental consequences.

California urges the Committee to consider holding retroactive benefits for recipients in a special treatment account which would be used to defray the costs of both transportation to and from the treatment sessions and any nominal costs or co-pays, if any, of such treatments. Any funds not used for this purpose would be held until such time as the recipient is no longer disabled primarily due to drug addiction or alcohol abuse and can be considered "recovered" sufficiently to manage his/her own affairs. At that time, any remaining retroactive benefits could be distributed, first to the counties for recovery of any general assistance through the Interim Assistance Reimbursement Program, and then to the recipient to assist with ongoing living expenses. Such accounts would be set up, monitored and administered by the RMA as part of the monitoring function.

We also recommend that before SSI/SSP payments can begin for DA/A recipients, they would be required to be registered into and regularly attending an approved treatment program. The RMA would have a greater responsibility for screening applicants, enrolling them in an appropriate treatment program, and monitoring them to assure their required attendance. The RMA would also be responsible for immediate action should it determine that the recipient is not meeting his/her required treatment program.

California also urges that monitoring requirements be tightened and strengthened to ensure compliance. Current monitoring requirements include consequences for non-compliance which can be avoided by a recipient's claiming of hardship. The RMA may or may not report such non-compliance on a timely basis and SSA may or may not react on a timely basis. While recent budget cuts and resulting work backlogs have affected this aspect of the SSI/SSP program, we have received allegations that the RMA seldom responds to non-compliance reports. Although suspension from the program for non-compliance is currently required, this is not always done. California urges the Committee to require the RMA to submit a monthly report on each DA/A recipient, indicating their compliance or non-compliance for that month, rather than a cumulative statistical report.

In the event of continued non-compliance, current regulations require a recipient's permanent suspension from the program. As this is not always done on a timely basis, California requests closer supervision by SSA to insure compliance with existing regulations.

A reasonable time limit should be imposed for a DA&A recipient's successful completion of treatment. This can be determined by the case worker or professional assigned to the individual's treatment program and would allow recipients to progress at their own pace. The payment of benefits would be contingent upon a recipient's continued progress, up to a maximum of 24 months.

REFUGEE/IMMIGRANT FRAUD

California's SSP Program will distribute $2.1 billion in state funds this year through SSA. At this point, we do not believe the federal agencies responsible for fraud prevention, detection, and prosecution are taking effective action.

The Social Security Administration (SSA) has acknowledged that numerous allegations exist regarding SSI/SSP fraud in the refugee/immigrant communities. In a news article entitled "The Big Refugee Rip-Off" printed in The Orange County Register's, Sunday, May 16, 1993 edition, Louis D. Enoff, Acting Commissioner of the Social Security Administration is quoted as saying SSA "first heard reports of refugees being coached to collect benefits illegally from a manager in Social Security's San Francisco region in 1988." He stated that he turned over the allegations to the U.S. Office of the Inspector General. Enoff was also quoted as saying "his agency is swamped handling new claims and that there is little time and not enough staff to review people already collecting benefits."

The article further reported that "middlemen" who are experts on the ins and outs of government programs allegedly contact refugees/immigrants and teach them to pretend they are mentally disabled in order to qualify for SSI/SSP. One excerpt depicted a Cambodian couple who went to a middleman looking for financial security and were told by the middleman, "I need to teach you how to lie." For $200 and a promise of half their first disability check, the middleman delivered his first lesson. Because of the SSA's lack of adequate bilingual staff, the middlemen are accepted by SSA offices to serve as translators during the medical examinations and other application-related appointments. Physicians and clinics were also alleged to assist in fraud by falsifying medical records and diagnoses." As a result of the news article and other reports of fraud received by the state, the State of California's Department of Justice (DOJ) recently conducted undercover investigations which resulted in the arrests of several middlemen suspected of assisting individuals in fraudulently obtaining entitlement to SSI disability and Medicaid benefits.

It should be emphasized that fraud in the SSI/SSP Program cannot be attributed solely to immigrants. In fact, California has identified multiple areas of fraud that are not specific to any particular population group. The State is extremely concerned that this issue has been virtually ignored by the Federal Government despite contractual mandates. For example, Article II, Section I. of the SSI/SSP Contract between the SSA and the State of California requires the Secretary, i.e. the Federal Government, to "detect and investigate potential fraud or program abuse cases and make prompt reports to the State on such cases." This contractual responsibility for SSI/SSP fraud audits and investigation rests with the U.S. Department of Health and Human Services (DHHS), Office of Inspector General (OIG). However, OIG has only 28 special agents in its Region IX field offices to cover California and four other western states. In addition, these investigators are responsible for not only the SSI/SSP Program, but all of DHHS' programs including Title XIX Medicaid, Title IV-E Foster Care, Title II Social Security Retirement and Disability benefits, etc. To date, there has not been a Federal OIG agent assigned solely to the SSI/SSP Program. The current Commissioner of SSA's Region IX has stated that although Federal instructions require that SSA fraud cases be investigated by the OIG, "we have had little success in persuading OIG to pursue investigation of these cases." Even if OIG were to investigate SSI/SSP fraud cases, the U.S. Attorney's Office's policy is to not accept cases with losses less than $20,000. And while this fact alone is disturbing, the reality is that cases with losses less than $100,000 are not accepted for prosecution.

It is worthwhile to note that the Food Stamp Program, a 100 percent federally funded program, and the Aid to Families with Dependent Children (AFDC) Program, a federal/state funded program with roughly the same State General Fund expenditures ($2.1 billion) as SSP, have a highly visible $60 million fraud prevention program in place, involving over 700 welfare fraud investigators in 58 county welfare departments or in district attorney offices under a contract with the county welfare department. This program is currently funded with 75 percent Federal funds for the fraud investigators' costs. The remaining non-federal costs are paid, depending on the cost types, with either 100 percent State funds or shared between the counties and the State.

In light of the fact that SSI/SSP fraud investigation is the responsibility of the federal government and is not being carried out, California is currently examining several avenues for addressing this issue. Any proposals developed by the State will be presented to SSA for discussion regarding possible support and assistance.

SUMMARY

California urges the Committee to support the proposals detailed in this statement of testimony. In summary, we are proposing to:

- Reinstate the equal sharing of countable income between the States and the Federal Government for purposes of SSI/SSP grant amounts.
- Reinstate federal matching funds for costs associated with the administration of the SSP Program.
- Allow States to simplify and increase their SSP Program integrity by the repeal of restrictions regarding the reduction of payment and living categories.
- Amend the required SSP payment minimum to the average 1983 national SSP payment level.
- Use drug or alcohol addicted recipients' retroactive SSI/SSP benefits for their mandatory treatment-related costs.
- Require drug or alcohol addicted SSI/SSP applicants' attendance in approved treatment programs prior to approval of benefits.
- Impose a reasonable time limit for a drug or alcohol addicted SSI/SSP recipient's successful completion of treatment.
- Enforce and strengthen existing monitoring and other regulations pertinent to drug or alcohol addicted SSI/SSP recipients.
- Allow more public, private, and religious entities to act as representative payees for drug or alcohol addicted SSI/SSP recipients.

The CDSS is very concerned regarding the current federal laws and regulations which govern the SSI/SSP Program. Amendments to federal statutes have resulted in the state's loss of control over costs related to the SSP Program. It is imperative that we regain this control and that the Committee recognize that the good faith under which States agreed to participate in the SSP Program has been disregarded. We ask that the Committee support the proposals outlined above and wish to express our appreciation for the opportunity to be heard on these matters.

Testimony on
Modernization of the Supplemental
Security Income Program

Submitted to
Subcommittee on Human Resources
Committee on Ways and Means
U.S. House of Represenatives

By
Daniel Alvarez, Sr., Commissioner
Department of Human Services
City of Chicago
(312) 744-3111

October 28, 1993

Mr. Chairman, I greatly appreciate the opportunity to submit testimony regarding Supplemental Security Income and the homeless population of Chicago.

My name is Daniel Alvarez, Sr. I am the Commissioner of the Department of Human Services of the City of Chicago. My department plays a primary role in securing shelter and services for homeless people in Chicago. This winter, we will be helping to fund approximately 4600 beds throughout the city.

For the many people who are forced by circumstances to use our programs for the homeless, and for many of our other clients, too, Supplemental Security Income could be the program that transforms their lives. In fact, I think it is fair to say that, as originally conceived, SSI would have guaranteed that all aged, blind, or otherwise disabled persons would receive incomes no lower than the official poverty level. Unfortunately, because that original promise remains to be fulfilled, thousands of SSI-eligible Chicagoans struggle to survive either with no support from SSI, or with cash benefits that fall significantly below the poverty line. Many of them are clients of my department.

In my experience, SSI suffers from three major defects, each of which, I am gratified to note, has been highlighted in the SSI Modernization Project.

The most serious deficiency of SSI is that so many people who are probably eligible to receive benefits are not enrolled. In Chicago it may be that half of those eligible remain outside the program, perhaps 120,000 people who, with adequate outreach, could be receiving benefits. And to look at it from a different, but equally shocking angle, perhaps half the homeless population of Chicago is eligible but unenrolled.

The second serious shortcoming of SSI is the unconscionably long waiting time that must be endured by those who do apply for SSI, approximately half a year. To force destitute, disabled persons to endure six months with virtually no support, as is the case in Illinois, is to invite the most awful consequences. The backlog of unprocessed applications has become scandalous.

Thirdly, even for those fortunate enough to apply for and receive SSI benefits, the maximum cash payment is so low that recipients remain mired in poverty, dependent on ad hoc or episodic supplementary support from other sources.

Taken together these three deficiencies visit significant hardship on large numbers of people. They also, however, help to undermine entire communities.

Over the past two decades a number of Chicago's low-income communities have experienced a concentration and intensification of poverty that has left them ill-equipped to assist their most needy members. Among the causes of this devastating transformation are the loss of inner city jobs, private and public disinvestment in low-income communities, and in Illinois, the State's elimination of General Assistance and acquiescence in the erosion of the real (inflation-adjusted) value of AFDC cash benefits. With the loss of income has come a weakening of the churches, community organizations and informal networks of friends and relatives that can constitute an informal social security system in low-income communities.

In Chicago's deeply impoverished communities improvement in SSI could take on special importance. For individual households, the absence of alternative or supplementary sources of income would make an adequate SSI cash benefit a veritable lifeline. For the community, the cumulative effect of a significantly increased stream of SSI income would help to underwrite the revitalization of presently enfeebled community institutions.

To these ends, I make the following recommendations.

1a. We need much more outreach to the homeless population; it must be continuous, to reach the newly and periodically homeless, it must include the willingness and capacity to "walk the client through the process," because many homeless persons require that, and it must reach beyond the shelters in order to serve the people who will not use them.

b. We need many more personnel to process the claims of the people who do apply; the backlog that now forces applicants to wait approximately half a year imposes a nearly unbearable burden on them, driving them deeper into poverty and compounding their problems.

2. We need SSI payments that are large enough to lift and keep recipients out of poverty; if SSI means anything, it means that the United States has promised its aged, blind, and disabled citizens that they can count on adequate income.

Mr. Chairman, implementing these three policies would make a major contribution to alleviating homelessness in Chicago. It would extend adequate benefits to about 120,000 additional already eligible people, and increase the level of cash assistance by perhaps 50% for the approximately 120,000 clients already enrolled. Nearly a quarter of a million households would thus benefit immediately and directly, and the fabric of community institutions would gain strength in response to the indirect effects of the added income.

It is no accident that as our social safety net has grown weaker, our problems of poverty and homelessness have grown worse. Correspondingly, we are not powerless to ameliorate these conditions. SSI exists for just such purposes. It is up to us, all of us, to make sure that SSI fulfills its promise and serves those purposes.

Thank you.

TESTIMONY OF LINDA R. WOLF JONES
COMMUNITY SERVICE SOCIETY OF NEW YORK

Thank you for this opportunity to submit testimony for the printed record on the subject of the Supplemental Security Income program (SSI).

The Community Service Society of New York is an organization that has been working actively to improve the conditions of the poor for almost 150 years. One of the ways in which we carry out that mission is through analysis and advocacy of social policies in such fields as housing, education and income security. It is our concern for the economic well-being of the nation's poor in general, and the urban poor in particular, that underlies this statement to the Subcommittee.

Mr. Chairman, welcome back. Almost exactly ten years ago - July 18, 1983 - I testified before you on welfare and urban poverty when the panel was the Subcommittee on Public Assistance and Unemployment Compensation. It is dismaying to have to note that none of the problems have gone away in the intervening ten years. If anything, the problems associated with poverty have gotten worse and most of the programs to deal with them are even more inadequate now than they were back then.

The Supplemental Security Income program was designed and implemented in the early 1970s to replace a haphazard system of state programs for the aged, blind and disabled poor. Currently, more than five million people receive monthly federal payments from the SSI program. Roughly 40 percent of them also receive a federally-administered supplemental state payment each month. When the three payment categories of federal only, federal plus federally-administered state supplement, and federally-administered state supplement only are taken into consideration, the SSI program is responsible for mailing monthly checks to more than five and a half million people, all of whom would be desperately poor without the benefits that they receive.

Financially, poor people who have applied and been found eligible for the SSI program have fared better than other categorical groups of the poor, such as female-headed families and non-aged, non-disabled adults. That is not to say that SSI beneficiaries have fared well, certainly not by middle class standards. However, as public assistance programs go, the SSI program is not a bad one. All else being equal (that is, in the absence of major, eligibility-level changes in their disability or other life circumstances), recipients have, for the most part, been able to count on continuing eligibility, regular receipt of benefits, regular cost-of-living increases, and a minimum of bureaucratic hassle when compared to such programs as Aid to Families with Dependent Children (AFDC). Nevertheless, as the experts on the SSI Modernization Project determined after extensive review and deliberations, there are many ways in which the program could be strengthened to serve more needy people and to serve both applicants and beneficiaries much better than it does at present.

In the press release announcing these hearings, you asked for testimony relating to the recommendations made by the SSI Modernization Panel in its August 1992 report. We reviewed that report and commended the panel of experts in writing for producing a comprehensive and sensitive evaluation of the SSI program. The report offers a thoughtful range of strategies to provide more timely and sufficient benefits to the population the program was designed to serve. However, we also believe, as we indicated in our letter to the Modernization Project's staff director last November, that in its thoroughness and sensitivity in advocating for the needs of the SSI population, the panel has produced recommendations that, taken in their entirety, may be too far-reaching for the American economy of the 1990s.

Overall, CSS supports the report's unifying themes and priorities, and the specific recommendations it presents to address the goals of equity, efficiency, outreach, and coordination with other social welfare programs. Certainly, we have no theoretical argument with the importance of the four priority needs identified in the report: increased staffing, higher benefit levels, elimination of benefit reductions based on in-kind support and maintenance, and improved resource limits and exclusions. A majority of the experts on the panel concluded that these four changes were all so important and deserving of attention that they could not even prioritize them.

Increased staffing would alleviate the obstacles now encountered by applicants with disability claims as well as by other applicants and recipients who need to be in contact with the bureaucracy. The General Accounting Office testified in March of this year before the Subcommittee on Social Security that there are "inordinate delays in processing disability claims". (The disability determination process is the same for both Social Security and SSI and is carried out by the same staff.) Although the Social Security Administration has made some efforts in the direction of reducing the processing delays, the claims backlog continues to be considerable and new claims continue to pile up on top of existing ones for months at a time. Inadequate staff resources also impacts on the ability of applicants to receive the kind of one-on-one help that they may need in order to file a claim, particularly if their disabilities are mental or psychological rather than physical. Finally, the need to shift resources into initial claims determinations has also impacted on the Social Security Administration's ability to carry out other functions, such as continuing disability reviews.

The advantages of higher benefit levels are obvious and need no elaboration here. In February 1993, the average federally-administered SSI payment was $368 per month, or $4,416 per year. (Aged recipients tend to receive less than the average; disabled recipients tend to receive more.) The maximum federal SSI benefit for an individual living alone was $434 per month, or $5,208 per year. By comparison, the U.S. Department of Census poverty threshold for an individual at the beginning of 1993 (preliminary 1992 figures) was $7,141. An individual who was receiving the maximum federal benefit and had no other income would be living at an income level equivalent to 72.9 percent of the official poverty standard.

Similarly, the elimination of benefit reductions based on in-kind support and maintenance would be of vast help in assuring more adequate income for the aged, blind and disabled poor. Currently, any SSI recipient who receives in-kind support and maintenance suffers a one-third benefit reduction; the maximum federal payment at that point declines to $289.34 per month. Eliminating the provision altogether would provide sorely needed income while getting rid of a difficult to administer, complex, demeaning and frequently inequitable program requirement.

Finally the priority recommendation for improved resource limits and exclusions reflects the inadequacy of the current limits and the inadequacy and complexity of the current exclusions. At the present time, countable resources are limited to $2,000 for an individual and $3,000 for a couple. Surely it can be argued that someone who has $100 over the limit and no income is needy at a level commensurate with the original purposes of the SSI program.

Without listing all of the additional recommendations of the Modernization Panel, suffice it to say that, for the most part, they are equally sensible, equally well-argued and equally worthy of serious attention and consideration. The panel's experts have done a truly admirable job of uncovering the deficiencies of the SSI program, analyzing the needs of recipients vis-a-vis the program, and laying out the changes that would make the program more responsive to those needs. Their basic argument is compelling. In addition, public reaction to it is probably further enhanced by the fact that not only are SSI recipients unquestionably poor, but they have an exacerbating condition in the form of old age, blindness or disability.

In the best of all possible worlds, CSS would strongly support the introduction of the majority of suggested improvements as quickly as possible, including all four of the top priorities which I have already mentioned (increased staffing, higher benefit levels, elimination of benefit reductions based on in-kind support and maintenance, and improved resource limits and exclusions). Implementation of the package of suggested program changes would greatly improve the lives of the more than five and a half million poor people already on SSI, the hundreds of thousands of applicants whose cases are backlogged, and the half million more who would become eligible if the changes were made. We recognize the income needs of the aged and disabled poor, appreciate the report's recommendations for dealing with those needs, and will do our part in advocating for legislative attention to them.

There is, however, another side to the issue that moderates our enthusiasm - not for the report, but for any advocacy that would press for the immediate and unfettered implementation of its recommendations. We recognize, however painfully, that today's prevailing fiscal constraints force an unfortunate competition among often equally necessary domestic programs. We understand that limited resources not only make the far-reaching program change that is called for in the recommendations unlikely at the present time, but - even were the funding available - it would probably come at the expense of cutbacks in other public assistance and social welfare programs, particularly those programs which are considered to serve less "worthy" populations. We are particularly concerned about this possibility in light of the discussions on how to "end welfare as we know it" that have already begun within the Clinton Administration.

It is because of this harsh reality - a shrinking zero-sum game for social programs - that we feel compelled to support the view put forward in the report by panel members Bowler, Fulton, Hess, Nathan and Smeeding that changes be phased in, with immediate attention given to increasing staff, eliminating administrative complexities (including elimination of benefit reductions due to in-kind support and maintenance), and instituting a plan for gradually increasing benefits and expanding eligibility. These changes would get us started in the right direction without being so costly as to force us to turn our attention away from other, equally needy groups in the population.

Specifically, the concerns of the group which I will call Bowler, et al. bring in a note of practicality and political awareness that heightens, rather than diminishes, the value of the report and its recommendations. One could almost sum up their three concerns as cost, cost and cost. First, they point out that the cost of all of the recommended options would, by the end of five years, double the current federal expenditure on the program and would have a significant impact on state and local government expenditures as well. Second, in terms of top priorities, they indicate a preference for "short-term action lower-cost changes" over "an extremely expensive option on increasing benefits." Third, acknowledging the expense associated with the larger panel's recommendations, they argue that "proposals on the scope and phasing of SSI changes must fully take into account their cumulative effect and the fact that other pressing domestic problems also have priority claims on substantial additional resources." It is this third concern that I have also tried to underline in my own remarks, since it reflects in large part the CSS position based on our reading and assessment of the panel's recommendations.

In summary, we greatly appreciate the work done by the panel of experts who gave their time and effort to the SSI Modernization Project; we commend their thoroughness and applaud their recommendations. We look forward to a world in which none of us have to suffer the indignity of poverty and in which the appropriate combination of work and social programs provides an adequate level of income and a decent living standard for all. In the interim, until resources for domestic social programs are expanded in pursuit of that goal, we believe that the funds available for these programs must be utilized equitably to meet the sometimes competing needs of the aged and disabled, poor children and families, unemployed heads of households, and other disadvantaged members of society.

Again, thank you for this opportunity to submit our comments on the SSI Modernization Project Final Report. We look forward to continuing to work with you and with the Subcommittee staff on SSI and other issues of mutual concern.

TESTIMONY OF FRANK J. MECCA
COUNTY WELFARE DIRECTORS ASSOCIATION OF CALIFORNIA

The County Welfare Directors Association of California (CWDA) is a non-profit association of the 58 county welfare/social services agencies in California. CWDA represents county welfare/social services agencies on a variety of program, legislative, and fiscal issues before the California Legislature, California agencies and before the U.S. Congress and appropriate federal agencies. County welfare departments in California administer most of the public assistance and social service programs in the state, worth some $10 billion to all levels of government. Counties also pay a significant nonfederal share of cost of these programs, including AFDC, JOBS/GAIN, Food Stamps, Medicaid, Child Welfare Services, Foster Care, In-Home Support Services, Adult Protective Services and refugee assistance programs. California counties are also responsible for the provision of General Assistance and basic health care to indigent Californian's who have no other means of support, independent of state or federal regulations or funding.

CWDA's Interest in SSI Reform

In the State of California, counties are statutorily required under the California Welfare and Institutions Code to "relieve and support" the basic subsistence and health care needs of all indigent Californians who have no other means of support. Recipients of AFDC, Medicaid, and SSI are not eligible for General Assistance. In order to minimize undue hardship to indigents while their applications for aid are being processed, many entitlement programs such as AFDC, Food Stamps, Medicaid and General Assistance have processing time limits and provide for expedited benefits. However, there are no processing time limits for applications for SSI. Therefore, while otherwise indigent applicants for SSI are waiting long periods of time for approval, they are eligible for General Assistance. Therefore, county welfare departments in California in effect administer an "SSI interim assistance" program in the form of General Assistance.

Processing Delays for SSI

Processing time for SSI applications has steadily increased in California over the past several years from an average of three months to the **current average of nine months.** If the application is denied, the multiple level appeal process can take as long or longer. It is not uncommon for applicants to finally receive approval two or three years after the initial application. CWDA believes that the fundamental problem, as detailed in the Supplemental Security Income Modernization Project: Final Report of the Experts, is insufficient staff in the Social Security Administration District Offices to handle the growing volume of applications. According to the Modernization Report, over 17,000 positions were eliminated from the Social Security Administration's budget between 1984 and 1990. These positions have not been replaced. The elimination of positions has had the expected effect. Between 1987 and 1990, the Social Security Administration's ongoing backlog increased by more than 250 percent. The national backlog is estimated to reach 1.4 million cases by the end of 1993; California has more pending disability cases (around 182,000 and growing) than any other state. As processing delays increase, so increases the number of General Assistance recipients in California.

It is our experience that staff cutbacks and growing backlogs are also compromising the depth and thoroughness of the reviews of initial applications for SSI, resulting in more denials, and causing a dramatic increase in the number of appeals. Overworked SSA officials find themselves in a catch-22: the more time spent reviewing, analyzing, and following-up on initial applications, the higher the backlog grows. We find that many applications which are initially denied and ultimately granted during the appeal process, would have been initially approved if SSA district office staff had the time to thoroughly review, evaluate and follow-up on initial applications.

- **CWDA therefore recommends that Congress and the President augment the number of trained staff in the Social Security Administration to ensure that the SSA has sufficient staff to provide thorough reviews of initial applications for SSI.**

If the application is denied, most frequently because the "disability is not severe enough," there are several stages of appeal. The appeal process begins with "reconsideration," which is a paper review of the applicant's documentation, and continues through a more formal appeal process which includes a hearing before an Administrative Law Judge, and an Appeal Council Review. The final appeal for an applicant would be before the Federal District Court.

Of the 2,258,980 initial determinations made on disability claims in the Fiscal Year 1992, 43 percent were allowed and 57 percent were denied. Only 49 percent of initially denied applicants requested reconsideration and 17 percent of those who sought reconsideration were allowed while 83 percent were denied. 73 percent of those denied reconsideration appealed before Administrative Law Judges, who reversed 68 percent of the cases and granted benefits. Given that such a large percentage of reconsiderations are denied, then ultimately approved by an ALJ, the reconsideration process appears to be more of an "endurance test" than a useful stage in the appeal process.

- **CWDA therefore recommends that the unproductive and time-consuming reconsideration process should be eliminated.** This is consistent with Vice President Gore's report on reinventing government, which has proposed the elimination of unnecessary paperwork and processes.

A large number of indigent people have no resources or income on which to live while the SSI application process is pending. County General Assistance (GA) is often issued to provide for basic needs during this time period. If ultimately approved for SSI, a retroactive Medi-Cal card will be issued to cover allowable medical claims that were incurred during that period. The SSI program reimburses the County for these so-called "Interim Assistance" payments out of any retroactive benefits the applicant is granted, when and if the application is approved.

However, counties currently bear the full administrative cost of the Interim Assistance Case while the SSI application is pending. These costs include the eligibility intake and ongoing processing for the Interim Assistance case, as well as the cost of SSI advocacy. Advocacy activities are necessary, particularly for the mentally and emotionally impaired, and includes everything from assistance with completing forms, to gathering existing medical reports, and providing transportation for SSI appointments. As the length of time increases for SSI processing, these costs escalate accordingly. Financially strapped counties can ill afford to cover expenses due to the inability of SSI to process applications within reasonable time frames. As the time for processing cases lengthens, counties carry an enormous burden of costs and resources to meet the needs of this population.

- **CWDA therefore recommends that SSA reimburse counties and local governments for the administrative costs associated with Interim Assistance cases that get approved for SSI.**

Modernization of Definitions of Disability

Current definitions of disability for purposes of SSI eligibility have not been "modernized" or changed to reflect technological or societal changes that have occurred in medicine and social trends for the past several decades. SSA needs to consider modifying the definitions and criteria used to establish disability to address current medical and societal dynamics, and advances in physical and mental health diagnostics. For example, Chronic Fatigue Syndrome is not a recognized diagnosis for SSI determination of disability, yet it is accepted as a disabling condition by the medical community. Some individuals meet most or all of the requirements under the SSI disability evaluation criteria yet are disapproved at alarming rates. If the definition of disability was modernized to include current diagnostic practice, some clients that are currently denied SSI would become eligible. CWDA believes that modernization of definitions of disability is absolutely critical if the SSI Program is to continue to meet its intent and purpose.

- **CWDA believes that the SSA undertake a process to modernize and update definitions of disability to reflect social, medical and diagnostic changes that have taken place over the past several decades.**

With the war on drugs a tragic failure, the federal and state governments have forsaken a vulnerable population, leaving counties with the responsibility to assist increasing caseloads with dwindling resources of charitable and nonprofit human services agencies.

- **We propose that the federal government refocus the "war on drugs" by shifting a portion of the resources that are currently spent on interdiction to support and expand treatment programs for the indigent substance abusing population.**

These individuals should be held responsible for attending and receiving treatment, which would necessitate a periodic evaluation that could include an assessment of their ability to be self-sufficient.

Sullivan v. Zebley

On a national level, major progress has occurred with respect to meeting the needs of disabled children thanks to disability statutory changes in the SS Children's disability area and the Social Security Administration's implementation of the Sullivan v. Zebley U.S. Supreme Court decision. This case modified standards of assessing eligibility for SSI children's benefits.

Timing for Administration and Congressional review of the SSI program is critical in recognition of the needs of children in the Title IV-B Child Welfare Services and Title IV-E Foster Care system. County child welfare professionals in California estimate that 80 percent of their interventions involve families where substance abuse or usage is a significantly related factor. Counties report that endangerment due to parental neglect, incapacity or absence are the principal findings used by juvenile courts to place children in foster care when a parent with a drug problem cannot provide appropriate care and supervision.

The SSI program represents a major resource for parents who come to the attention of the child welfare services system and whose children are placed in out-of-home care for their protection. The majority of foster children do return home to their biological parents, and disabled children do require ongoing specialized medical attention. SSI benefits and medical care can represent the financial stability and medical resources that enable parents to care for their children. The extensive medical and psychological evaluation and assessment necessary to determine SSI eligibility provides the "work-up" necessary to provide ongoing treatment.

To improve the interaction between the Federal SSI and Title IV-E foster care programs, CWDA recommends some necessary changes in the children's disability area, including concurrent SSI/Title IV-E Payments and SSI Payments for eligible children residing in emergency shelter care.

Concurrent Payments

Existing HHS policy announcements prohibit concurrent payments from the Title IV-E Foster Care and Title XVI Supplemental Security (SSI). Receipt of payment is restricted to one or the other of these programs, as selected by the individual recipient. In instances where a child is eligible for both SSI and Title IV-E Foster Care, the state/county agency may utilize funds from only one of the programs. In many instances, the costs of care of the eligible child will exceed the SSI rate.

- **CWDA recommends a change in federal policies to allow states to utilize Title IV-E Foster Care to supplement an eligible child's Title XVI Supplemental Security Income up to the amount of the foster care rate. This would require the allowance of concurrent but not duplicate payments.**

Emergency Shelter Care

Under the Title XVI Supplemental Security Income (SSI) program regulations, SSI payments may not be made to individuals residing in public institutions, with certain exceptions. These exceptions, detailed in Section 416.211, basically include medical facilities, board and care home serving 16 or fewer residents, educational or vocational facilities, and emergency shelters for the homeless. Children are admitted to emergency shelter care for their own protection because they have been victims of abuse and neglect. Many children are admitted to these shelters for assessment for casework and foster care placement planning. For most of them, the length of stay in the shelter is brief, as the children are then returned home, to relatives, or placed in an appropriate foster care setting. However, these public shelter facilities do not qualify for SSI payments.

Under the Title XVI program regulations, individuals residing in semi-public institutions are eligible to receive SSI. These regulations, like the standards for disability for SSI eligible prior to the Zebley decision, appear to have been intended to apply to adults. The existing standards regarding public institutions should not apply to both adults and children.

Eleven counties in California operate emergency shelter care facilities. These counties represent over 70 percent of the statewide Child Welfare Services caseload. The remaining counties accommodate all children's needs through alternative out-of-home care settings, such as foster family homes or group care settings. This means that some counties are unable to equally access the same resources -- SSI -- for disabled children as are other counties.

Because the children who enter public emergency shelter care facilities are often most in need of the type of care and assessment provided by the facility, as opposed to foster family care, it is likely that a greater proportion of these children are eligible for SSI than the estimated proportion of children in foster care who are eligible for SSI. These children would also be in need of the benefits which accrue to children in foster care receiving SSI.

- **CWDA recommends that SSA modify existing Title XVI Supplemental Security regulations to include an exception for children who are temporarily placed in publicly operated emergency shelters. This exception can be linked to services provided under Title IV-B Child Welfare Services, Section 425 of the Social Security Act.**

Conclusion

CWDA appreciates the opportunity to testify on this important matter and offer our resources to the committee as it continues to explore SSI modernization.

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July 21, 1993

Ms. Janice Mayas
Chief Counsel and Staff Director
Committee on Ways and Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

**RE: Press Release No. 7 dated 7/02/93
of the Sub-committee on Human Resources
Committee on Ways and Means**

Dear Counsel Mayas:

I am responding to the above-captioned Press Release, particularly, in regard to Item No. 2, The effect of the Supreme Court's decision in Sullivan v. Zebley and Item No. 4, Certain criteria for establishing trusts.

The Zebley decision was certainly a boon to disabled children. Prior to that decision, it was virtually impossible for disabled children to qualify for SSI benefits. I am certain that there are abuses within the system as with all programs. However, the experience in my practice, a major portion of which is Social Security, indicates to me that the Zebley decision was extremely fair and allowed those children in need to receive benefits.

Many of the Zebley children are, not only disabled, they have catastrophic disabilities, which will require long-term and usually life-long care, well beyond the expected productive life for their parents, who are normally the main care givers. The creation of "Zebley trusts" in order to circumvent the $2,000.00 asset restrictions has been an absolute necessity. There should be regulations, which will allow for the creation of trusts for the benefit of these catastrophically injured children in order to alleviate the psychological, financial and physical burden upon the parents.

The asset cap that currently exists precludes, in my opinion, the creation of an effective trust system, which will guarantee the care for these children throughout their adult life. The end result is that there is the prospect that these children will become a greater financial burden to society as their parents and family members either lose or can no longer provide the financial and physical care necessary for the child's maintenance.

As I noted earlier, there will be certain abuses, but I believe that careful monitoring and sufficiently worded regulations will limit these abuses. The vast majority of Claimants are in dire need of assistance and this issue must be rectified.

If you have any further question or any further comments, please contact me.

Very truly yours,

DUNLAVEY, WARD & PAGLIARI

MICHAEL E. DUNLAVEY, ESQUIRE

MED/lrm

cc: NOSSCR
6 Prospect Street
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WRITTEN STATEMENT OF GARY FLACK

I appreciate the opportunity to submit a written statement to the Subcommittee On Human Resources of the House Ways and Means Committee. In reviewing the July 2, 1993 Press Release No. 7, I noticed that the scope of the hearing does not specifically include how SSI benefits are calculated for veterans' families. Although this does not affect many people, I believe the Social Security Administration's method for doing this is unfair and should be corrected. Perhaps that was considered by the SSI Modernization Panel. In the event that it is not, I wanted to bring this little problem to your attention. I should state at the outset that in my law practice, I regularly represent Social Security claimants and help them obtain benefits to which they are entitled. One such client, Bessie Bouldware, has the problem that I describe in this written statement.

Social Security Ruling 82-31 ("SSR 82-31") is inconsistent not only with Social Security regulations, but also is inconsistent with 42 U.S.C. §1382a(a)(2)(B). Paxton v. Secretary of HHS, 856 F.2d 1352 (9th Cir. 1988) framed the discussion thusly:

> In 1981, the Secretary changed the Social Security Administration's (SSA) policy regarding VA benefits paid for dependents. As of November 1981, the Secretary began to regard that portion of VA benefits paid to a veteran for the support of the veteran's dependent as countable unearned income to the dependent for the purpose of computing the dependent's SSI benefits. The Secretary issued this policy in the form of an interpretive ruling. Title XVI: SSI Treatment of Veterans Administration Payments to SSI Eligibles/Fiduciaries, 82-31 S.S.R. 291 (Cum. Ed. 1982) [hereinafter SSR 82-31]. Under SSR 82-31, the dependent's portion of VA benefits is now automatically used to reduce the dependent's SSI benefits.
>
> The Secretary adopted this new policy in response to court decisions, including our opinion in Whaley v. Schweiker, 663 F.2d 871 (9th Cir. 1981). SSR 82-31. In Whaley, we held that the dependent's portion of VA pension benefits may not be counted as income to the veteran for the purpose of computing and reducing the veteran's SSI benefits. 663 F.2d at 875.

* * *

Shortly after Whaley was decided, the Secretary issued SSR 82-31, indicating that VA benefits paid to a veteran for the support of the veteran's dependent would be counted as income to the dependent for SSI purposes. Pursuant to SSR 82-31, Mr. Paxton's VA pension benefits were used to reduce Mrs. Paxton's SSI benefits.

* * *

In SSR 82-31, the Secretary adopts a blanket policy of counting that portion of VA benefits paid to a veteran for the support of the veteran's dependent as unearned income to the dependent for the purpose of calculating and reducing the dependent's SSI benefits. This sweeping approach is inconsistent with the SSI regulations and the detailed approach they take to defining income. See generally 20 C.F.R. §§ 416.1100 to 416.1182 (1988) ("Subpart K-Income").

First, SSR 82-31 creates an unsupported exception to the rule that "[a]nnunities, pensions, and other periodic payments" counted as unearned income usually relate to the claimant's prior work or service. 20 C.F.R. § 416.1121(a). As we noted earlier, many types of payments are not considered unearned income. Section 416.1121(a) states that periodic payments counted as unearned income are "usually related to prior work or service."

VA benefits paid to a veteran for the support of the veteran's dependent are related to the veteran's prior service, but they are not related to the claimant's (the dependent's) prior service. Nonetheless, SSR 82-31 counts these periodic payments as unearned income to the claimant (the dependent). The Secretary has given no explanation for this deviation from the general rule.

Second, SSR 82-31 flatly contradicts the SSI regulation that describes "[w]hat is not income." 20 C.F.R. § 416.1103. Section 416.1103(g) explains that when someone other than the SSI claimant uses money to pay the claimant's bills, that money is not counted as unearned income to the claimant. Rather, the food, clothing, or shelter the claimant receives in exchange for the payment may be considered in-kind income to the claimant:

> If your daughter uses her own money to pay the grocer to provide you with food, the payment itself is not your income because you do not receive it. However, because of your daughter's payment, the grocer provides you with food: the food is in-kind income to you.

20 C.F.R. § 416.1103(g) examples (emphasis added).

* * *

Third, SSR 82-31 does not accord with the Secretary's own admission that VA benefits based on need may not be "deemed" the income of the veteran's dependent. Within a family, "[t]he first step in deeming is determining how much income [the claimant's] ineligible spouse [or] ineligible parent . . . has." 20 C.F.R. § 416.1161. The key rule governing the first step is that SSA does not consider available for deeming all of the spouse's or parent's income. *Id*. Specifically, SSA does not include as income available for deeming "[a]ny public income-maintenance payments (§ 416.1142(a)) [the claimant's] ineligible spouse or parent receives." § 416.1161(a)(2) (emphasis added).

The SSI regulations list several programs that make public income-maintenance payments. 20 C.F.R. § 416.1142(a). One type of public-income maintenance payment is a payment made under "U.S. Veterans Administration programs (those payments based on need)." § 416.1142(a)(7).

* * *

SSR 82-31 automatically counts the dependent's portion of VA benefits as unearned income to the veteran's dependent. The SSI regulations reveal that the dependent's portion of VA benefits may never be counted directly as unearned income to the dependent, and may only sometimes indirectly be deemed or counted as

> in-kind income to the dependent. SSR 82-31 is therefore inconsistent with the SSI regulations.

Paxton 1354-1359 footnotes omitted. This is the only Court of Appeals decision on this issue. The Paxton rationale is sound and should be accepted by the Social Security Administration. Most district courts which have considered this problem have similarly resolved it.

White v. Sullivan, 813 F.Supp. 1059 (D.Vt. 1992) concluded that Social Security Ruling 82-31 was not consistent with the Social Security Act, 42 U.S.C. § 1382a(a)(2)(B) in that the "augmented" VA pension is not "received" by SSI claimants. White declared the Ruling to be invalid as applied to a class of all applicants and recipients residing in Vermont. The court enjoined the Secretary from applying Social Security Ruling 82-31 to class members. The White court noted that VA pensions are paid to the veteran and not to his dependent (SSI applicant). The dependent did not necessarily "receive" the augmented portion of VA benefits for the purposes of 42 U.S.C. § 1382(a)(2)(B). Id. at 1065. Therefore, the Secretary may not count these funds as unearned income when calculating such claimant's SSI entitlement. Since the veteran may spend the augmented portion of his VA pension to meet his own needs, the SSI claimant does not necessarily receive any economic benefit from the VA payments. Accordingly, the dependent VA increment is not unearned income to the dependent for SSI purposes. Stated another way, the court reasoned that the SSI claimant never attained dominion over the augmented portion of the VA benefits and could therefore never necessarily apply these funds to meet his or her basic needs. The White decision also noted other conflicts between SSR 82-13 and other regulations of the Secretary. Id. at 1066.

Inman v. Sullivan, 809 F.Supp. 659 (S.D.Ind. 1992) similarly held for the SSI claimant. It declared SSR 82-31 invalid. It began its analysis by concluding that the SSI claimant does not receive the augmented portion of the VA benefits. It recognized the argument accepted by the Paxton court that when unearned income is used for calculating SSI eligibility, the amounts are "usually related to claimant's prior work or service" 20 C.F.R. § 416.1121(a). However, the augmented portion the veteran receives is due to his prior service, not his dependent's. SSR 82-31 provides no rationale for this exception to the Secretary's more general regulations.

Sprouse v. Sullivan, 738 F.Supp. 999 (E.D.Va. 1990) adopted the Magistrate's Report and Recommendation. It relied on the Tsosie v. Califano, 651 F.2d 719 (10th Cir. 1981), and upheld the Secretary's position. Tsosie did not consider Social Security Ruling 82-31. Indeed, Tsosie was one of the reasons that the SSR 82-31 came into existence. It is curious the Sprouse decision is so poorly grounded.

Ryder v. Sullivan, 804 F.Supp. 1365 (D. Col. 1992) is a very short decision that rules in favor of the SSI claimant primarily in reliance on Paxton. Although Colorado is in the Tenth Circuit, Ryder relied on the Ninth Circuit Paxton decision instead of the earlier Tsosie decision.

Kennedy v. Sullivan, cited in Inman apparently rules that Social Security Ruling 82-31 is invalid. See Inman at 662. Kennedy is a class action. 138 F.R.D. 484 (N.D.W.Va. 1991).

The validity of Social Security Ruling 82-31 also has been undermined by a nationwide class action, Anderson, et al. v. Sullivan, No. CV-88-036-GF (D. Mont. Nov. 21, 1989). Pursuant to this action, the Secretary was ordered to promulgate regulations that provide that the augmented portion of veteran's pension is not to be counted as unearned income to either the veteran or the veteran's surviving spouse. The new regulations' rescission of part of SSR 82-31 undermine the validity of the remainder Social Security Ruling 82-31.

I am uncertain whether it is appropriate to have legislation resolve this administrative error. However, in an effort to "create dialogue," I bring this problem to your attention. The proper calculation of SSI benefits when an applicant's spouse receives "augmented VA benefits" is being poorly handled by the Social Security Administration. The Social Security Administration should rescind Social Security Ruling 82-31.

GATEWAY
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October 27, 1993

Janice Mays
Chief Counsel and
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Dear Ms. Mays:

The following statement is submitted by Gateway Foundation for the printed record of the hearing on Supplemental Security Income:

As we approach national health care reform, we must look at the 5.5 million people who are addicted to alcohol and other drugs in the United States. It is estimated the total economic cost of smoking, drinking and drugs was a staggering $238 billion in 1990 alone, as reported in the October 22, 1993 CHICAGO TRIBUNE.

While these statistics are startling, even more shocking is that Supplemental Security Income -- a recovering addict's only financial aid to assist in the transition back into society -- is being threatened with discontinuation.

As it stands now, a substance abuser, deemed to be severely disabled because of a prolonged history of substance abuse, is entitled to collect SSI. A condition of receiving benefits, the recipient must undergo treatment in an approved program. Herein begins the problems.

Substance abusers are not always referred to treatment in a timely manner, often a result of lacking funds for such treatment, or a lack of knowledge of existing programs. Gateway Foundation alone has 950 people on a waiting list for treatment, with an additional 9,000 waiting at other programs throughout Illinois. However, Gateway is very successful with clients who receive SSI. This is evidenced by our many recovering staff members whose SSI payments enabled them to become productive members of society.

(more)

If SSI payments were easier to obtain, disbursed in a timely manner, and if they were discontinued when appropriate, the system would justly help thousands more to lead drug-free lives.

In contrast, the system fails us when a recovering substance abuser who has been out of treatment for some time receives a lump-sum disbursement for thousands of dollars. SSI payments can often do more harm in this instance. Better tracking, management, and disbursement of payments would not only ensure proper use of funds, but would get more people into the treatment centers where help, hope and recovery are possible.

Attached is the story of Rose, a former addict, Gateway graduate and employee. Her story exemplifies how SSI helps people in their transition into society. She had a 20 year heroin addiction, a 2 month old baby, and very little hope. With 15 months of extended care treatment at Gateway Foundation, she learned the skills to be a responsible member of society. She now works at Gateway as a client advocate and helps others qualify for SSI, others who stand in shoes she knows all too well.

SSI provides the means for people to enter treatment; it enables them to become eligible for Medicaid. This becomes the only payment option for treatment for thousands like Rose who can successfully recover.

With extended care treatment, success rates are even higher. Research has proven that the amount of time in treatment is a major variable in recovery. SSI payments during the period of disability allow many the opportunity to get extended care treatment and develop the necessary skills to beat alcohol and other drug addiction and live productive, healthy, drug-free lives.

Sincerely,

Michael Darcy

Michael Darcy
President

Five years ago I entered treatment for a 20 year heroin addiction. I will not recount all of the ugliness that most addicts and those around them suffer, suffice it to say that recovery had truly become a life or death condition. I also had a two month old daughter who would have open heart surgery at nine months of age in order to survive, probably attributable to the fact that my disease was out of control. I didn't really believe that I could recover. But there was help for me. That help came through long-term residential rehabilitation treatment. Under the guidance and supervision I received in 15 months of treatment, I was able to address many of the issues I needed to allow me to attempt a drug-free life and become a responsible member of society. Thanks to Gateway Foundation's client advocate who assisted me in applying for Social Security benefits, after I completed treatment, I was awarded just about enough money to cover my bill for treatment, approximately $2,500.00. After treatment, I regained custody of my daughter who continues to have some medical issues which require close monitoring....

Needless to say, had I been saddled with a $2,500.00 bill at the onset of our new life, in addition to the pressures of learning how to live without the use of drugs, my daughter and I may not be where we are today.

Today I work in the capacity of a client advocate. I now am in a position to assist new residents in applying for SSI benefits, many of whom are mothers with children and facing the same predicaments I have lived through. Most of us have had no previous work history and little education. I do not need to tell you the disproportionate amount of our population which lives below the poverty level.

If these benefits were not available to help us at least make the transition of addict to responsible individual, faced with the overwhelming task of resuming responsibility for ourselves and our children, many of us would resort back to "what we know". Simply put, the Department of Corrections would be caring for the mothers and the Department of Children and Family Services for the children.

(more)

It is unrealistic for our government to think that eliminating the SSI benefits given to those of us who desire to break out of a cycle of drugs and crime (and they go hand in hand) and who utilize these benefits in a fashion in which they were intended to be of some help, so that those who would abuse them would be unable to do so, is an option. This is truly throwing the baby out with the bath water.

###

WRITTEN TESTIMONY OF:
JOEL M. CARP
ASSOCIATE EXECUTIVE DIRECTOR
JEWISH FEDERATION OF METROPOLITAN CHICAGO

Congressman Ford - Chairman of the Subcommittee on Human Resources, and distinguished members of the Committee, as a member of the Chicagoland SSI Coalition and as a representative of the Jewish Federation of Metropolitan Chicago, I am pleased to have the opportunity to share the Jewish community of Chicago's experiences and thoughts concerning Supplemental Security Income (SSI) with you.

Since 1971, the Jewish Federation of Metropolitan Chicago has resettled almost 20,000 (more than 13,000 since 1987) Jewish refugees from the former Soviet Union through a program involving eleven of our affiliated and beneficiary agencies, including two hospitals in the Chicago area. One of the Federation's affiliate agencies, the Council for Jewish Elderly (CJE), serves more than 8,000 older adults each year and provides a variety of services aimed at maintaining independence and community living. These services are provided to individuals of all income levels and physical abilities on an as needed basis.

Many of the clients served by CJE are either low income and receiving benefits, or are potentially eligible for benefits from the Supplemental Security Income (SSI) program. Almost without exception, these elderly immigrants have left the former Soviet Union to accompany or rejoin family members living in the United States.

The main issue facing CJE's clients who receive SSI is that of income security. SSI was designed as a means tested "safety net" program, but has failed to fulfill it's mission to protect lower income seniors from destitution. With the current Federal benefit standard at 75 percent of the poverty level and the resource limit at $2,000, it is very difficult for a senior on SSI to afford the basic necessities of food, clothing and shelter. In a few short months, when the poverty levels are adjusted, the gap between the SSI benefit standard and the minimum required to be at the poverty level will widen. SSI recipients will receive only a 2.6 percent cost-of-living increase effective January 1, 1994, the smallest increase since 1987 and the second lowest in two decades.

Most of the elderly refugee population resettled in the U.S. qualify for SSI through the SSI - Aged Program, some through the SSI - Disability Program. We are aware of the concerns of Congress regarding inappropriate access of immigrants to the SSI - Disability Program, in some areas of the country. <u>This is not the case in Illinois</u>. Further, immigrants should not be unfairly blamed for the shortcomings of an outdated administrative system badly in need of "modernization", for the inadequacies of state or locally managed programs. The system needs to be looked at in terms of <u>protecting not further limiting</u> access to the SSI program.

We fully support the program improvements proposed by the SSI Modernization Panel intended to improve the quality of care and services to persons who are aged, blind, or disabled. We would like to especially emphasize several of those recommendations.

- <u>Increase Social Security Administration (SSA) staffing by 6,000</u>. Increased staffing would assist in resolving the backlog of SSI claims and would increase the efficiency and effectiveness of program administration. Further, it would allow the SSA to implement several of the SSI Modernization Panel's recommendations. One such recommendation involved conducting face to face interviews before claims can be denied on the basis of disability. These interviews should be conducted by trained disability experts who are SSA field office employees. We would also recommend that face to face interviews be conducted in certain cases where discrepancy or doubt exists <u>before</u> claims are approved.

- Increase the Federal benefit standard for SSI over a period of five years so that it reaches 120 percent of the poverty guidelines by the fifth year. It is simply unjust and indefensible to keep such an at-risk population destitute and on the brink of homelessness as a consequence of public policy.

- Change the resources test from $2,000 for an individual and $3,000 for a couple to $7,000 for an individual and $10,500 for a couple and streamline the exclusions. The increased resource limits combined with fewer restrictions would not only assist SSI beneficiaries but also assist the SSA in more efficiently and effectively managing use of staff time and resources while making SSI more accessible to those eligible.

- Repeal the law which requires that receipt of in-kind support and maintenance (food, clothing and shelter) must be considered as income. The current standard undermines the continued voluntary support by family members and community based organizations. Additionally, elimination of this law would further decrease administrative complexity and cost.

- Lower the age requirement for SSI from the current 65 to age 62 over a three year period. Many individuals who emigrated to this country from the former Soviet Union and who are between the ages of 62 and 65 were already retired in their homeland. Most importantly, in today's job market, there is less and less chance of obtaining gainful employment in the U.S after age 60. In addition, lowering the age limit to 62, creates greater consistency with social insurance retirement programs, and benefits all individuals eligible for SSI.

- Establish a specific funding stream to assure continuation of outreach activities. Additional funding to develop more outreach projects, especially for the elderly and limited English speaking populations, would help to ameliorate the issue of individuals paying "middlemen" in order to apply for benefits.

As you are aware, many Americans are becoming increasingly anxious about the economic stability of the United States. In the media, immigrants and refugees have been wrongly portrayed as the cause of the social and economic problems of this country. The fact is that there is hard data consisting of tax and economic studies, labor force analyses, and employment data that clearly shows just the opposite. In Illinois, for example, for every $1 invested in refugee employment and training programs, we save $2.50 in welfare costs. However, the negative publicity, combined with the reality of federal and state budget deficits and stubbornly high unemployment rates, has contributed to a growing resentment of refugees and immigrants and subsequent outbreak of racially motivated hate crimes across the United States.

In addition to mass media, public policy plays a tremendous role in shaping public opinion. We urge you to reconsider the very dangerous method currently being proposed for financing the extension of unemployment security benefits. We agree that unemployment benefits should be extended, but not at the expense of persons in poverty. The impact of preventing legal aliens' access to SSI for five years strikes most heavily on U.S. citizens who sponsor their elderly immigrant parents and then struggle to support them. Limits to access not only hurts the family but also increases the burden on states and localities to pay for other welfare programs for elderly permanent residents who have nowhere else to turn.

There is no question that immigrants and refugees have helped to periodically revitalize our economy through job creation, workforce participation, payment of taxes and cultural enrichment. Indeed, this is the very history of our country.

The diversity that results from immigration is a unique source of strength for our nation, particularly at a time when we need to enhance our competitive edge in the global marketplace. It is in our national interest to welcome the families of those who work hard and contribute so much to our country.

We encourage you to take a stand on this issue and correct what is wrong, without wronging what is right and just. Thank you for the opportunity to share our concerns with you.

Testimony for Subcommittee on Human Resources
Ways & Means Committee
U.S. House of Representatives
October 14, 1993

Submitted by Rhoda Schulzinger, Director of Children's SSI Campaign and Joseph Manes, Co-Director of Government Relations

The Judge David L. Bazelon Center for Mental Health Law is a national nonprofit advocacy organization, formed in 1972 and until 1993 called the Mental Health Law Project. For over a decade, the Center has worked to improve access to the SSI program for children with disabilities. Our testimony will concentrate on three themes: (1) how families use SSI benefits (2) misperceptions in the education community about SSI and (3) how Congress might reduce barriers to children's SSI benefits. But first, we want to describe our Children's SSI Campaign.

Currently, we are in the third year of a national outreach campaign to find and refer children who may be eligible for SSI benefits because of their physical, mental or emotional disability. We organized the Children's SSI Campaign to help publicize significant changes in the children's disability rules that enable more children to qualify for benefits. The campaign is a joint effort with Community Legal Services of Philadelphia, the Youth Law Center and National Center for Youth Law in San Francisco and Rural Legal Services of Tennessee and is funded by four private sources: The Robert Wood Johnson, The Nathan Cummings and The Annie E. Casey Foundations and The Pew Charitable Trusts.

The Children's SSI Campaign has enlisted a wide range of people working with potentially eligible families -- social service workers; elected and appointed officials; nurses and doctors; teachers and early intervention specialists; community leaders; parents; and children's and disability advocates across the country. Bazelon Center staff coordinates activities with more than 50 national organizations to inform their members about changes in the children's SSI eligibility rules and to recommend ways to assist eligible families. We also provide technical assistance and information to non-profit and state agencies in over 20 states.

In December 1991, around the time the campaign began, there were 438,853 children receiving SSI benefits. In May 1993, there were 720,458 children receiving benefits, an addition of 281,605 children which represents a 64% increase in enrollment. Some of the increase is attributable to the re-evaluation of children mandated by the U.S. Supreme Court in the <u>Zebley</u> class action lawsuit. A portion of the increase are the children who now qualify under updated medical criteria and a new disability determination process. And the rest of the increase is due to increased publicity and outreach efforts.

When we began the campaign, we estimated that 1 million children were eligible, but 58% of them were not receiving benefits. Since that time, changes in the financial eligibility rules for children under 18 increased the number of families who qualify. In addition, the most recent data from the U.S. Census Bureau indicates that child poverty is more prevalent than earlier estimated. Consequently, we believe that there are additional hundreds of thousands of eligible children who have not applied for benefits.

How Families Use SSI Benefits

The Committee should note that SSA reported in December 1992, the average federal monthly payment for SSI children with disabilities was $387. This amount is almost 92% of the maximum monthly payment, indicative of the low overall family income of participants in this means-tested program.

In recent months, stories have appeared in the press in several states alleging that parents are misusing the monthly payments intended to help their children. Obviously, we are unable to affirm or refute the validity of unsubstantiated allegations. Rather, we would like to balance the stories in the press with family experiences brought to the attention of the Children's SSI Campaign staff.

The campaign staff regularly hear from families who are struggling to meet daily expenses and the costs of their child's special needs. Some parents are using the cash to cover the costs of shelter, food, home modifications and the costs of their child's special needs. For example, the child with cystic fibrosis, learning disabilities, attention deficit disorder and serious allergies who has a monthly pharmacy bill of over $2000. The family whose child has cerebral palsy who used the benefits to buy a van specially equipped with a chair lift so the child can go to doctor's appointments, receive regular therapy and accompany the family on weekend outings. The family who takes their child to a clinic 15 times a year and can only afford the $25 co-payment for each visit to continue treatment for the child's spina bifida because of her SSI benefits.

Most frequently, we hear from families who need the SSI check to pay for items not covered by Medicaid. Despite the promise of the Medicaid EPSDT provisions, there are not enough Medicaid providers for children with special health care needs and state agencies frequently deny requests for special equipment and medical supplies. Among the items that families must buy are creams for debilitating skin conditions, diapers for older children, respite care and special learning toys.

Other families relate stories of how they must supplement services available from local school districts. A family reports that their child who has a significant hearing disability, attention deficit disorder and an IQ of 72 can receive speech and language therapy only twice a week through his school. But the child's therapist recommends more frequent assistance so the family pays $220 a month for private tutoring to ensure that the child will maintain his progress at school. Other families use the SSI check to pay for summer programs because the local school district has nothing to offer their children who have special needs.

The stories we hear on a daily basis underscore the importance of allowing families to make their own decisions about how to spend SSI benefits.

Furthermore, we believe that the Social Security Administration has provided sufficient protections against improper use of benefits through their representative payee regulations. The representative payee is the person who receives the SSI check on behalf of the eligible child and the payee must report every year to Social Security how the SSI money is spent for the child. If someone believes that SSI funds are used improperly by a child's representative payee, they can call the local Social Security office. Social Security will investigate alleged abuse of funds and, if proven, will appoint a new representative payee for the child.

Misperceptions about SSI in the Education Community

When the disability determination process for children changed, SSA expanded the list of people who can submit evidence for a child's application. As a result, teachers and school psychologists are now asked to provide information about their students who are applying for SSI. However, there appears to be widespread confusion about the disability process within the education community.

Once SSA has proof of a medical condition, the child is assessed to determine if the condition significantly interferes with his or her ability to develop or to engage in activities other children the same age normally do. It is at this stage that educators are asked to provide their observations about their students' functional abilities. However, many educators have little or no knowledge of SSA's disability determination process. For example, most do not know that the regulations require proof of an underlying medical condition. Most educators do not understand that the definition of disability used by SSA and that used by school districts are quite different. As a consequence, they do not know that a child may meet the goals of his or her individual education plan (IEP), but still qualify as "disabled" under Social Security's rules.

School personnel often do not realize that they are only one source of information to support an application. By law, the disability examiner must collect evidence from many people who observe the child over a period of time -- parents, doctors, family friends and all types of therapists. By collecting evidence from many sources, the examiner ensures that different people verify the severity of a child's disability. Before making the final eligibility decision, the disability examiner must determine that any test results are consistent with other evidence about the child's behavior and daily activities. If there are inconsistencies, the regulations require the examiner to obtain more documentation of the child's development and functioning to resolve the differences.

Many children with behavioral disorders have serious underlying physical or psychological problems that may not be known to a classroom teacher. Children with minor behavioral problems will not qualify for SSI. To be eligible, children must have a severe mental or physical condition that substantially interferes with age-appropriate development and functioning. Younger children must prove that they are not meeting age-appropriate developmental milestones and older children must prove that they cannot perform age-appropriate daily activities.

Reducing Barriers to Children's SSI Benefits

The SSI children's program has grown rapidly in the last few years as the Zebley population has finally received appropriate review and as the eligibility rules were revised. However, we believe that there are still hundreds of thousands eligible children who are not receiving benefits. The Committee should eliminate the continuing barriers in law and practice that prevent eligible children from receiving assistance which could improve their lives.

In 1989, the Ways and Means Committee recognized the gap between the number of children receiving SSI benefits and those potentially eligible. In OBRA '89, Congress mandated that SSA engage in "ongoing" outreach to children (Section 1635). Unfortunately, the Congressional mandate has yet to be implemented at the local district office level. Although the efforts to find Zebley class members was significant, on-going outreach to find newly eligible children is not part of SSA's daily routine.

As best we can tell, the "ongoing program of outreach" required by law has resulted in publication of a few pamphlets and posters, the designation of a coordinator in each region and a few demonstration projects. To fully implement the Congressional mandate, we believe that SSA must do more.

We recommend legislation to require SSA to establish an Office of Outreach Coordination to integrate the disparate efforts by the Office of Disability Policy, the Office of Public Relations and the Office of SSI Operations. The Office of Outreach Coordination would have the responsibility to create a focused and consistent program of outreach to children and other populations with high eligibility potential such as Native American families, homeless families and rural populations. The coordination office would be authorized to make grants and contracts with private and public organizations for a wide range of outreach techniques. The office would also serve as a clearinghouse of information on the most successful strategies.

There are other ways that the Committee could help improve access to benefits for eligible children. The August 1992 report of the Panel of Experts to the SSI Modernization Project, led by Dr. Arthur S. Flemming contains made a number of recommendations to improve the program to better meet the needs of eligible recipients. Although there were dozens of recommendations, the following five benefit children and we endorse them wholeheartedly.

1. Modify the rules for deeming family resources to a child with a disability to recognize other children in the family.

The SSI Modernization Panel of Experts recommended a change in the resource deeming rules to permit a $2000 resource allocation for each additional child in the family. The current limits on allowable resources do not consider the overall size of the family. As a result, families with several children cannot save for education, emergencies or numerous other needs without endangering the SSI benefits of the child with a disability. Furthermore, since deeming rules do not apply to a child who is institutionalized, the inadequacy of the current resource allocation encourages institutionalization as the only way the low-income family can obtain medical care for their child with a disability while also meeting the needs of the family's other children.

By contrast, the income deeming rules permit the family to allocate a portion of their income to each child without a disability living in the household. The allocation recognizes that daily expenses increase with the number of family members. For 1993, $218 of monthly income is allocated for each child without a disability living in the household and the amount is adjusted annually.

2. Disregard special expenses for care of a child with a disability.

The Panel recommended that SSA disregard the portion of family income used to pay for special expenses related to the child's disability. The disregard would recognize that families with children who have a disability have extraordinary expenses that are not offset by the SSI benefit. The special expenses could include communication devices or other adaptive equipment, medical equipment and medications, specialized transportation, respite care and special dietary needs. For example, one mother testified before the Panel that the cost of disposable diapers for her 13-year old child was $175 a month. One-time costs, such as making the house accessible, could be amortized over the life of the improvement.

3. Change the way certain unearned income is treated.

The SSI parental income deeming rules treat "earned" income (such as wages) more favorably than "unearned" income (such as Social Security benefits, veterans' benefits and interest payments). The Panel recommended that Unemployment Insurance (UI) benefits, workers' compensation and disability insurance benefits received by parents of a child with a disability be treated as earned rather than unearned income. These benefits are intended as a substitute for earnings while the wage-earner is unable to work.

SSA's parental deeming rules counts a higher proportion of the parent's unearned income as "available" to the child than earned income. As a result, the child's benefit is lower if the family income is unearned rather than if the same amount were earned. For example, in a two-parent family with earned income of $1000, the child with a disability would receive the current maximum benefit of $434. In a family with unearned income of $1000, the child's benefit would be $126.

If a parent loses his or her job and begins receiving unemployment benefits or is injured on the job and receives workers' compensation, the effect on the child's SSI benefit can be devastating. When the family is undergoing financial difficulties because of the wage-earner's unemployment or injury, social policy should not penalize it further with a reduction or loss of children's SSI benefits.

Representative Stark's bill, HR 3009 introduced August 6, 1993, includes a provision similar to the recommendation of the Modernization Panel which we strongly endorse.

4. Assure all SSI children have Medicaid protection.

Since access to regular health care is so important to a individual with a disability, the Panel recommended that all SSI recipients, adults and children, be automatically eligible for Medicaid regardless of the state in which they live.

In 31 states and the District of Columbia, an individual who is eligible for SSI benefits is automatically enrolled in Medicaid. In seven states, SSI-eligible individuals are automatically eligible for Medicaid, but must fill out a separate application: Alaska, Idaho, Kansas, New Hampshire, Nevada and Utah. Studies indicate that the need to file a separate application represents a barrier to children obtaining health benefits.

Twelve states, representing approximately 20% of SSI children, have established separate, and more restrictive, income, resources and/or disability criteria for Medicaid eligibility based on criteria that were in effect in these states on January 1, 1972. These "209(b)" states are Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma and Virginia.

5. Protect Medicaid during months when parents are "over-income."

The Panel's recommendations would "deem" an individual eligible for SSI for purpose of retaining Medicaid coverage in months when five weekly (or three bi-weekly) paychecks resulted in the parent being "over-income." Currently, when the child is ineligible for SSI for a month because the parent earned too much, the child also can lose Medicaid coverage for the month.

The two recommendations on Medicaid require a collaboration with the Energy and Commerce Committee.

As the Committee reviews the SSI program, we ask you to examine the continuing problems faced by families who have a child with a serious disability or chronic illness. We urge the Committee to eliminate the continuing barriers which make access to benefits difficult. SSI benefit payments are a vital element in holding families together and enabling children to obtain medical care and services which can ultimately lead to independence and productive lives as adults.

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STATEMENT OF U.S. SENATOR HERB KOHL (D-WI)
Before the House Ways and Means Committee,
Subcommittee on Human Resources
October 14, 1993

FIRST OF ALL, CHAIRMAN FORD, I WANT TO COMMEND YOU FOR HOLDING THIS HEARING ON THE SUPPLEMENTAL SECURITY INCOME PROGRAM. I APPEAR BEFORE YOU TODAY AS AN ADVOCATE OF THE DISABLED, BUT ALSO AS A SENATOR CONCERNED ABOUT HOW WE ARE SPENDING OUR FEDERAL TAX DOLLARS.

I WANT TO BE CLEAR AT THE OUTSET, THAT I SUPPORT THE INTENTIONS OF THE SSI PROGRAM, ESPECIALLY AS IT RELATES TO DISABLED CHILDREN AND THEIR FAMILIES WHO ARE TRULY IN NEED OF THESE BENEFITS. HOWEVER, I DO HAVE SOME GRAVE CONCERNS ABOUT HOW EFFECTIVELY AND EFFICIENTLY THIS PROGRAM IS BEING CARRIED OUT.

WITHIN THE PAST YEAR, MY OFFICE HAS RECEIVED NUMEROUS COMPLAINTS AND CONCERNS ABOUT THE SSI PROGRAM. INITIALLY, THE CONCERNS WERE JUST FROM WISCONSIN, BUT NOW WE ARE SEEING THEM FROM ALL CORNERS OF THE COUNTRY.

IN JUNE I CONTACTED HEALTH AND HUMAN SERVICES SECRETARY DONNA SHALALA, AND REQUESTED THAT HER OFFICE OF THE INSPECTOR GENERAL LOOK INTO THESE COMPLAINTS. MANY OF THE CONCERNS WERE ANECDOTAL IN NATURE, AND I FEEL IT IMPORTANT THAT WE QUANTIFY ANY PROBLEMS IF THEY EXIST, BEFORE WE MAKE ANY CHANGES IN THE PROGRAM. AT THIS POINT, THE O-I-G AUDIT IS ONGOING, AND I ANXIOUSLY AWAIT THE RESULTS OF THE REVIEW.

WHILE THE FINAL VERDICT ON THE SSI COMPLAINTS IS NOT YET IN, I DO WANT TO SHARE WITH YOU, THE COMMON CONCERNS ABOUT SSI EXPRESSED TO MY OFFICE. FIRST, THERE ARE REPORTS THAT SOME "UNQUALIFIED" CHILDREN ARE SOMEHOW MANAGING TO SKIRT THE SYSTEM, AND QUALIFY FOR BENEFITS THEY DO NOT NEED OR DESERVE. THERE ARE EVEN ACCUSATIONS THAT SOME PARENTS MAY BE "COACHING" THEIR CHILDREN TO MISBEHAVE IN SCHOOL AND PURPOSELY FAIL TESTS, ALL IN AN ATTEMPT TO GET SSI BENEFITS.

DISABILITY ADVOCATES SAY THIS SCENARIO IS HIGHLY UNLIKELY, THAT THERE ARE TOO MANY CHECKS ALONG THE WAY THAT WOULD CATCH ANYONE TRYING TO FAKE THEIR WAY INTO QUALIFYING FOR SSI BENEFITS. THAT MAY BE SO, BUT WE ARE HEARING ABOUT COMPLAINTS OF "COACHING" FROM ALL OVER THE COUNTRY. EVEN IF MANY OF THESE "COACHED" ATTEMPTS ARE ULTIMATELY UNSUCCESSFUL, IT IS CLEAR THAT SOME PEOPLE ARE AT LEAST <u>TRYING</u> TO CHEAT THE SYSTEM. AGAIN, THIS IS SOMETHING I HOPE BECOMES CLEARER IN THE O-I-G AUDIT.

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THE SECOND COMPLAINT IS REALLY THE OPPOSITE OF THE FIRST. WE ARE HEARING COMPLAINTS THAT SOME CLEARLY DISABLED YOUNGSTERS, ARE STILL BEING UNFAIRLY DENIED BENEFITS. I AM FAMILIAR WITH A CASE FROM MILWAUKEE INVOLVING A YOUNG CHILD WITH SEVERE ASTHMA WHO FROM ALL INDICATIONS CLEARLY DESERVED SSI BENEFITS, YET WAS DENIED. HIS MOTHER HAD TO SEEK LEGAL HELP, AND FINALLY AFTER TWO APPEALS, THE BENEFITS WERE APPROVED.

WHILE THE ULTIMATE GOAL OF PROVIDING HELP TO THIS CHILD WAS REACHED, I AM CONCERNED THAT HE AND HIS MOTHER HAD TO UNDERGO LENGTHY AND UNNECESSARY APPEALS. IT IS MY HOPE THE O-I-G AUDIT, AS WELL AS AN INTERNAL SOCIAL SECURITY ADMINISTRATION REVIEW, WILL GIVE US A CLEARER PICTURE ON HOW MANY OTHER CHILDREN ARE BEING WRONGLY DENIED OR WRONGLY APPROVED. AS WE ALL KNOW, THE SUPREME COURT DECISION IN THE ZEBLEY CASE MEANT EXTENSIVE CHANGES IN THE RULES, AS WELL AS A MASSIVE, SIXFOLD INCREASE IN SSI APPLICATIONS. I AM SURE THAT BOTH OF THOSE EVENTS ARE THE DRIVING FORCE BEHIND SOME OF THE SCREENING PROBLEMS.

THE THIRD AND PERHAPS MOST PERVASIVE COMPLAINT WE SEE, DEALS WITH HOW SSI BENEFITS ARE BEING SPENT. AS I UNDERSTAND IT, PARENTS HAVE A GREAT DEAL OF LATITUDE ON HOW THEY SPEND THE BENEFIT CHECKS. I BELIEVE PARENTAL DISCRETION IS VERY IMPORTANT, BECAUSE THE SPECIFIC NEEDS OF DISABLED CHILDREN VARY GREATLY. FOR EXAMPLE, A CHILD WITH CEREBRAL PALSY HAS FAR DIFFERENT NEEDS THAN A CHILD WITH ATTENTION DEFICIT DISORDER, SO PARENTAL FLEXIBILITY IS CRUCIAL.

BUT WHILE DISCRETION IS IMPORTANT, IT CAN ALSO OPEN THE DOOR TO ABUSES. I AM AWARE OF A CASE IN MICHIGAN, WHERE A PARENT BOUGHT A MOTOR HOME WITH THE SSI BACK PAYMENTS, THEN TOOK HER CHILDREN OUT OF SCHOOL FOR A CROSS COUNTRY TRIP. WHAT POSSIBLE BENEFIT COULD BE DERIVED FROM THESE CHILDREN MISSING SCHOOL FOR SEVERAL WEEKS? THIS IS CLEARLY NOT WHAT SSI IS FOR.

MY OFFICE HAS RECEIVED NUMEROUS OTHER REPORTS OF HIGHLY QUESTIONABLE EXPENDITURES AND THAT CONCERNS ME BECAUSE SSI IS SUPPOSED TO BENEFIT THE CHILD. SOME PSYCHOLOGISTS HAVE EVEN TOLD US THAT CHILDREN QUIT THEIR COUNSELING UPON BEING APPROVED FOR SSI. TO ME THAT IS COUNTERPRODUCTIVE TO THE GOALS OF THE PROGRAM. IN SHORT WE NEED A BETTER WAY TO MONITOR EXPENDITURES, AND ALSO GIVE PARENTS GREATER GUIDANCE IN HOW TO SEEK HELP FOR THEIR YOUNGSTERS ONCE BENEFITS ARE APPROVED.

ONE VERY CLEAR PROBLEM IN THE AREA OF EXPENDITURES INVOLVES THE LARGE LUMP SUM BENEFITS PAYABLE UNDER THE ZEBLEY DECISION. IN SOME CASES THE CHILD RECEIVES UP TO $30 THOUSAND IN BACK BENEFITS, BECAUSE THE SUPREME COURT RULED THEY WERE WRONGLY DENIED A DECADE AGO. THE PROBLEM IS THAT SSI RULES SAY THE PARENTS MUST SPEND NEARLY ALL OF THAT MONEY WITHIN SIX MONTHS, OR RISK LOSING CONTINUING BENEFITS. I KNOW THERE ARE TRUST OPTIONS, BUT WE ARE TALKING ABOUT LOW INCOME RECIPIENTS WHO MAY NOT HAVE THE LEGAL KNOWLEDGE OR ACCESS TO COMPLICATED TRUST AGREEMENTS.

WE SIMPLY HAVE TO MAKE A MORE USER FRIENDLY TRUST ARRANGEMENT

AVAILABLE, SO THAT PARENTS CAN SET MONEY ASIDE FOR FUTURE BENEFIT OF THE CHILD. AS IT STANDS NOW, WE ARE SIMPLY ENCOURAGING THEM TO SPEND A LARGE SUM OF MONEY, AS QUICKLY AS POSSIBLE, AND IN DOING SO THEY AREN'T ALWAYS SPENDING THE MONEY WISELY OR IN THE CHILD'S BEST INTERESTS.

OVERALL, I BELIEVE SSI IS A WELL INTENTIONED PROGRAM, AND WHEN IT BENEFITS A DISABLED CHILD IT IS A GOOD PROGRAM. BUT BASED ON THE NUMBER OF CONCERNS RAISED, IT IS MY BELIEF THAT THE SSI PROGRAM IS NOT WITHOUT PROBLEMS. IT WAS MY GOAL WHEN I ASKED FOR THE O-I-G AUDIT, THAT WE FIND OUT JUST HOW WIDE SPREAD THESE PROBLEMS ARE, AND TAKE APPROPRIATE ACTION.

WITH THAT IN MIND, I ANXIOUSLY AWAIT THE INSPECTOR GENERAL'S FINDINGS SO THAT WE MIGHT TAKE WHATEVER CORRECTIVE STEPS ARE NECESSARY. IN DOING SO, IT IS MY HOPE THAT WE ALL KEEP IN MIND OUR ULTIMATE GOAL, THAT IS THE WELL BEING OF OUR DISABLED POPULATION, ESPECIALLY CHILDREN IN NEED.

MR. CHAIRMAN THAT CONCLUDES MY REMARKS, AND I AGAIN WANT TO THANK YOU AND THE SUBCOMMITTEE FOR ADDRESSING THIS IMPORTANT ISSUE.

Statement of Honorable Carrie P. Meek
Subcommittee on Human Resources
October 14, 1993

Mr. Chairman, I want to commend you for holding this hearing today. It is all too easy for SSI to be pushed aside while so many other important issues come to the forefront, and I appreciate the opportunity to testify about this program and about the legislation I have introduced.

When I came to Congress earlier this year, one of my goals was to work on behalf of those who are most in need. I was particularly concerned about the plight of poor elderly women. I learned that for many of these women SSI was a critical source of support even though it only provided enough income to bring them to less than 75% of the poverty guidelines. I was pleased to learn of the work of the Supplemental Security Income Modernization Project and the excellent report done by the experts led by the distinguished Arthur S. Flemming. I believe that the recommendations of the report must be implemented, and that is why I introduced legislation, H.R. 2676, which incorporates some of the most important ones.

SSI is the only federal program that seeks to provide a minimum income to some of our impoverished people. It serves the aged, blind, and disabled, and we should be proud of the accomplishments of the program in providing some measure of dignity to the lives of millions of Americans. SSI has fallen well short of the goal, however, that was expressed in the report of the Senate Finance Committee in 1972 when SSI was established. The committee foresaw a program that would "provide positive assurance the Nation's aged, blind and disabled people would no longer have to subsist on below-poverty-level incomes." Twenty-one years later, we are well short of that goal.

The Modernization Project's major recommendation is to phase in an increase in benefit levels over five years, so that incomes would reach 120% of HHS poverty guidelines. I have included this recommendation in my bill and this is the centerpiece of SSI reform. There is ample precedent for using standards higher than 100% of poverty guidelines. Food stamp eligibility, for example, is as high as 130%. The report of the experts provides additional examples.

The SSI benefit standard in 1992 was 74.4% of poverty guidelines for an individual and 82.7% for a couple. I maintain that this is barely sufficient. If our goal is to lift the aged, blind, and disabled out of poverty, then we should do so. Witnesses who provided testimony to the panel of experts recounted numerous stories of SSI recipients who had to choose among necessities. One health care professional said the following:

> The SSI eligibility limits and living-expense allowances can be dangerous to health, in my view. The program excludes too many needy persons and gives too little to those it includes. . . . To eat nutritiously, some may scrimp on

> necessities of life other then food. Some often try to stretch out their drug supplies by taking less than the recommended doses. They live in dangerous housing: accidents are waiting to happen because of poorly maintained structures and poor lighting. At risk of hypothermia, they have trouble paying the bills for cooling and auxiliary heating. They have heart trouble and they live in walk-ups. Taking a bus ride is risky and taxis are too expensive if they need to reach a medical clinic.

Mr. Chairman, this is not the picture Congress had in mind when SSI was established more than twenty years ago.

Because of these low eligibility and benefit levels, exclusions from resources have proliferated in order to help people maintain eligibility. The result is a very complicated system that makes administration of the program more costly. The experts recommended increasing resource eligibility standards and simultaneously reducing the number of exclusions. My bill eliminates some of the exclusions, but I would encourage the subcommittee to do a complete review. I addressed only those exclusions included in Title XVI of the Social Security Act, but many others exist. With adequate resource limits and realistic income eligibility levels, most exclusions would not be necessary.

I also strongly support the recommendation to eliminate in-kind support from the determination of income. Such support is food, shelter, or clothing given to a person or received by that person because someone else paid for it. Receiving such support can result in a recipient's benefit being reduced by one-third. The experts were concerned that this provision discourages family members from providing help and that the policy is confusing to both beneficiaries and Social Security staff.

Another recommendation encompassed by my legislation is the enhancement of work incentive provisions. My bill would allow SSI beneficiaries to earn $2400 annually without having benefits reduced. For every three dollars earned above this level, benefits will be reduced by one dollar. Work incentives provide opportunities for SSI recipients to achieve a greater measure of independence and perhaps eventually end the reliance on public assistance. In recent years, the disabled in particular have taken greater advantage of the opportunity to work. In 1991, 6.3% of recipients with disabilities received income from working.

The last major change included in H.R. 2676 is the reduction of the age limit for eligibility on the basis of age from 65 to 62, phased in over a three year period. The experts recommended this reduction to make it consistent with other Social Security programs which permit retirement benefits at age 62. This lower age would provide greater security for the elderly, for whom it is difficult to find work.

I recognize that the greatest barrier to enacting the recommendations of the SSI Modernization Project panel of experts is the cost. The report noted that the cost of all the recommendations over five years would be $38.8 billion, most of which would result from the increase in benefits. This is not, however, a reason to ignore the findings of this distinguished panel. Justice requires that we provide incomes that permit these persons to live in dignity. We can take some consolation from the fact that we are providing help to the aged, blind, and disabled, but we are nonetheless keeping them below the poverty level. We can and must do better.

The experts recognized the difficulty posed by the cost of their proposals. They were counting on a follow-up commission to examine the financing of this reform effort. Unfortunately, the Social Security commissioner under the previous administration never appointed a financing commission and the Clinton Administration has only recently nominated a replacement. It is my hope that the new commissioner will take up this cause and convene a new group of experts to propose a financing mechanism.

Mr. Chairman, SSI is important to those who are the most vulnerable in our society. It is a vital safety net particularly for women and minorities who find themselves without other means of support in their old age or because of disability. I urge you to make this hearing a first step towards the enactment of SSI reform legislation as recommended by the SSI Modernization Project experts. It is time to live up to the promise.

TESTIMONY OF MS. SYDNEY TALLY HICKEY
and
SERGEANT MAJOR MICHAEL F. OUELLETTE, U.S. ARMY, RETIRED
THE MILITARY COALITION

Mr. Chairman. The testimony presented today has been prepared by Ms. Sydney Tally Hickey, Associate Director of Government Relations, National Military Family Association (NMFA), and Retired Army Sergeant Major Michael F. Ouellette, Director of Legislative Affairs, Non Commissioned Officers Association of the USA (NCOA).

NMFA is a volunteer, non profit organization composed of members from the seven uniformed services, active duty, retired, reserve and their family members and survivors. NMFA's sole focus is the military family and its goals are to influence the development and implementation of policies which will improve the lives of those families.

NCOA is a congressionally-chartered organization with a membership in excess of 160,000 noncommissioned and petty officers serving in every component of the five (5) Armed Forces of the United States; active, national guard, reserve, retired and veterans.

This testimony has been endorsed by The Military Coalition representing 24 military associations with approximately 3.5 million members. A list of the member organizations is enclosed.

BACKGROUND

Disabled children of low income military families stationed overseas became eligible for Supplemental Security Income (SSI) benefits because of the actions of this subcommittee and the passage of the Omnibus Budget Reconciliation Act of 1990. Prior to that time, these families and their qualifying children lost their eligibility simply because they were overseas on the orders of the U. S. Government.

Representative Jim Slattery (KS) responded to the plight of a young soldier on orders to Germany accompanied by a disabled daughter who qualified for SSI benefits. Rep. Slattery's legislation which permitted the military member with a qualifying disabled child to continue to receive SSI benefits while stationed overseas and was adopted by this subcommittee and incorporated into OBRA 1990.

P.L. 103-66 further addressed specific problems facing military families when it extended the overseas provision to military families stationed in Puerto Rico or territories or possessions of the United States. The law also clarified another provision in the SSI code that had unfairly penalized military families. Although military families certainly consider the military member to still be a part of the family when he or she was absent on an unaccompanied tour or on orders for duty at a distance from the family residence, SSI regulations did not. P.L. 103-66 has corrected this inequity.

CONCERNS

More recently, a number of other problems have become apparent with the administration of the SSI program for military families. One is the inability to determine initial eligibility for SSI when stationed outside of the United States. Correction of this problem is addressed in legislation (H.R. 480) introduced by Representative Slattery. When a child is born overseas with a disability or when a disability is first diagnosed while the family is overseas, the child and the family cannot apply for SSI eligibility. The military member must request a humanitarian short tour and return to the United States simply to establish a home and have SSI eligibility determined. The only other alternative is for the family to attempt to complete their overseas tour of duty without the needed economic relief of SSI benefits. Since social workers employed by the military and military physicians are available at duty stations outside the United States, it would seem reasonable to allow these professionals to make a temporary determination of SSI eligibility using criteria and forms required by the Social Security Administration.

The second problem concerns adult military family members who are eligible for SSI benefits within the United States. but not when stationed with their military sponsor outside the United States. These adult family members can be the spouse of the military member or, very occasionally, the dependent parent of a military member. Each military service has an Exceptional Family Member Program (EFMP). All servicemembers with a disabled family member are required to register their family with the EFMP. Registered families are screened before they are sent to duty stations to ascertain that needed medical and other services are available for the disabled family member. This is particularly true for duty stations outside the United States where services from the private sector may be limited or non-existent. If the required services are not available, either the military member is assigned to another duty station where the needed services exist or is assigned outside the United States in an unaccompanied tour status. It is obvious that the number of servicemembers with a disabled adult family member, a family income low enough to qualify for SSI benefits, and who would be stationed outside the United States accompanied by the disabled adult family members would be minuscule. However, the importance of SSI benefits to the economic well being of the family is no less for these military member than those with disabled children.

DISCUSSION

NMFA, NCOA and the other member organizations of The Military Coalition are most grateful to this subcommittee and Congressman Slattery for their outstanding efforts in rectifying many of the inequities military families have had to endure. Nonetheless, we remain amazed that our government would ever penalize military families simply because they were following orders! As the military services are drawn down in numbers, the abilities and skills of each military member becomes even more vitally important. This Country cannot afford to lose for a day or a week or a month a member who is critical to the mission of his/her unit. We also do not believe the citizens of this Country expect military families to be excluded from the benefits of such programs as SSI simply because the services of the military member are needed at a duty station outside the United States.

RECOMMENDATION

NMFA and NCOA respectfully recommend that the provisions of H.R. 480 be approved by this Subcommittee and that adult disabled dependent family members also be able to qualify for SSI benefits when stationed outside the United States with their military sponsor.
Thank You.

THE MILITARY COALITION Summer 1993

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NAMI

TESTIMONY FOR THE HEARING RECORD
FOR THE SUBCOMMITTEE ON HUMAN RESOURCES
COMMITTEE ON WAYS AND MEANS
REGARDING THE SUPPLEMENTAL SECURITY INCOME PROGRAM
IN CONJUNCTION WITH THE SUBCOMMITTEE'S HEARING
OCTOBER 14, 1993
Office of Government Relations

* *

The National Alliance for the Mentally Ill (NAMI) is a national self-help organization of families of persons with severe mental illnesses, i.e. schizophrenia, affective disorders, bipolar disorder, etc. -- families who, next to the consumers, have suffered the most emotionally and financially through their personal involvement and support of a son or a daughter, a sibling or a spouse, or even a parent afflicted with these devastating brain diseases -- dedicated families who continue as volunteers to achieve NAMI's mission to improve the quality of life for all persons with severe mental illnesses and ultimately to eradicate these tragic brain diseases.

NAMI's membership totals over 140,000 persons consisting of families of persons with severe mental illnesses, as well as recovering consumers themselves. NAMI's organization consists of a national office in Arlington, Virginia; 50 state offices; and over 1000 local affiliates.

NAMI sees the Supplemental Security Income (SSI) program as critically important to the well-being of persons with severe mental illness. SSI's income maintenance function and its categorical eligibility relationship to Medicaid make it central to government assistance for this vulnerable population. Accordingly, the NAMI Board has resolved these principles regarding SSI in our "Policy Platform" (ratified in December, 1992).

"NAMI calls for immediate federal legislation to:

*"Increase the ***monthly cash benefit*** of Supplemental Security Income (SSI), at least to the federal poverty level

***"Increase *incentives to work* while retaining benefits**

***"Increase the amount of *assets* an individual may possess to retain eligibility**

***"Eliminate *"in-kind" contributions* from counting against the income limits**

***"Expedite the *appeals* process**

***"*Coordinate eligibility* criteria for Medicaid, Social Security Disability Insurance (SSDI), and SSI**

***"Recruit, train, and monitor *representative payees* for persons without traditional sources of support**

***"Address the complex problems associated with reaching *homeless* individuals who are mentally ill**

***"Increase SSI *staffing levels and training* to accomplish these objectives."**

NAMI's justification for these recommendations, and their correlation to the major chapter topics in the Modernization Project's August 1992 "Final Report of the Experts" follow.

BENEFIT PAYMENT ISSUES - CHAPTER II

***"Increase the *monthly cash benefit* of Supplemental Security Income (SSI), at least to the federal poverty level"**

NAMI's main concerns are about adult relatives or friends: children, spouses, siblings. It has been more important to NAMI families not to have the income stream reduced, suspended or terminated -- without an orderly process that can be comprehended and managed by persons whose reason for disability is severe mental illness (or their advocates).

NAMI also believes that monthly benefits should continue for at least three months during hospitalizations of persons with severe mental illness -- without the currently required written statement from an attending physician. In the real world, it is extremely difficult to train the physicians in the legislative/regulatory objectives of this requirement, and in its vital importance to the patient's continued stability, post-discharge. The consequences of not having the documentation from the physician can be homelessness, and re-institutionalization -- both of which are more costly to society.

Persons with severe mental illness can have cognitive deficiencies among their disabling conditions, even during stable and productive periods of their lives. Retrospective accounting and the way it affects their income stream can be at least unmanageable for them, and at worst harmful. NAMI supports returning the program to prospective accounting.

NEEDS-BASED ISSUES - CHAPTER III

•"Increase the amount of *assets* an individual may possess to retain eligibility"

NAMI's aging parents, especially, are concerned about the needs of their adult children with severe mental illness after their own deaths. Policies regarding resources and unearned income should allow properly constructed trusts (where the principal is not available as a resource to the beneficiary) and the supplemental income they can provide, without having the categorical eligibility for Medicaid be extinguished. Additionally, resources accumulated for the "plan for achieving self-support" (PASS) should not be counted against eligibility for Medicaid in states using their own rules for determination.

NAMI also supports the majority recommendations with respect to parent-to-child deeming: use of the single formula now employed when parent(s) have both earned and unearned income; consider income intended to replace earned income (unemployment compensation, etc.) as earned income; and deduct itemized expenses incurred because of the child's disabling condition before deeming of parents' income.

•"Eliminate *"in-kind" contributions* from counting against the income limits"

NAMI understands that exempting food, clothing, or shelter furnished to persons with severe mental illness by not-for-profit community organizations is a benefit to the individuals. But, when setting policy for in-kind support & maintenance, NAMI strongly believes that since the current $97.38/week *is clearly insufficient to sustain independence, taking $32.13 of it away because the same in-kind* contribution was made by family is counterproductive. There are even instances in which the "family" is an elderly widow who likely needs the additional third of the benefit to meet the family shelter expenses. At the very least, *pro rata* contribution to household expenses should become a rebuttable presumption.

DISABILITY & WORK INCENTIVES - CHAPTER IV

•"Increase *incentives to work* while retaining benefits"

Persons with severe mental illness rely almost exclusively on Medicaid in many instances - for costly prescribed medications that maintain their stability and prevent their institutionalization, or reinstitutionalization. Loss of access to these medications can produce catastrophe for persons with severe mental illness.

Accordingly, with respect to work incentives, NAMI recommends alterations in the interaction of "substantial gainful activity" with eligibility for the SSI program, and the Section 1619 -- a and b provisions for maintaining Medicaid coverage as earnings rise.

•"Expedite the *appeals* process"

NAMI advocates for a population whose disability is not always or uniformly apparent. Furthermore, the individuals applying often lack the very organizational skills and access to documents that would make them more successful applicants. Professional evidence and family or advocate assistance is very frequently necessary.

In the Modernization Panel's discussion of the definition of disability, relative to the "substantial gainful activity" test, panelists almost unanimously recommend that the dollar amount alone is not a reasonable determinant. If the generation of $500/month in earned income by a given beneficiary requires substantial support services, this in itself is ample demonstration of this beneficiary's disability. NAMI agrees that the definition should be so understood.

With respect to disability determinations for children, NAMI applauds the actions taken by SSA following *Zebley*, but agrees there is still a need for disability criteria that would more easily permit assumed disability -- and therefore Medicaid coverage -- for very young children. Payments should not be limited to the six months currently allowed for "presumptive payments", but the existing provision not considering them as overpayments should also be extended.

NAMI also agrees that time limits should be set for decisions on eligibility and appeals. Failure to meet these should be linked to non-recoverable payments to applicants.

Finally, NAMI strongly concurs with the requirement for a face-to-face interview preceding denial, and the correlative need for staff specially trained to deal with persons whose primary cause of disability is severe mental illness.

AGENCY SERVICE ISSUES - CHAPTER VI

***"Recruit, train, and monitor *representative payees* for persons without traditional sources of support"**

Another outgrowth of NAMI's concern for adults whose family predeceases them is the matter of trustworthy, accountable representative payment system for persons whose disability keeps them from adequately managing their own finances. Proper Protection & Advocacy procedures must be maintained while a person is being determined incapable of handling his/her own resources.

***"Address the complex problems associated with reaching *homeless* individuals who are mentally ill"**

When persons with severe mental illness lose their access to treatment, for whatever reason, they often become homeless. NAMI is supportive of suggestions that procedures be put in place to meet the needs peculiar to this population: pay benefits while they're in public shelters; establish alternate permanent addresses for their payments, use trained staff and expedited procedures to register them without all required documentation, etc.

***"Increase SSI *staffing levels and training* to accomplish these objectives."**

In the debate on staffing issues, NAMI supports the addition of at least 6,000 staff members to SSA's program of Supplemental Security Income. The Social Security Administration is to be commended for the humane and forward-looking programs it now has in place. The letters of agreement into which local SSA offices can enter with psychiatric inpatient institutions is one such example. This program can prevent rapid relapse of persons with severe mental illness upon discharge from an inpatient stay by having an income stream and Medicaid coverage already in place. But it can only work if sufficient numbers of staff are available and trained.

The out-going Commissioner testified before a Ways & Means Subcommittee that 5,000 more slots would do the job. NAMI believes that with the other reforms we've supported here: face-to-face hearings, specially trained workers available at all area offices, and sufficient staff to make the hospital discharge letters of agreement really work -- at least the full 6,000 additional FTE's are necessary.

LINKAGE OF SSI TO MEDICAID - CHAPTER VII

***"*Coordinate eligibility* criteria for Medicaid, Social Security Disability Insurance (SSDI), and SSI"**

NAMI's positions on this principle are partly included in the recommendations on Chapter IV. The objective is of course to avoid "notches" in initial or continuing eligibility where these programs intersect.

Uniform eligibility criteria would build confidence among beneficiaries that, despite benefit dollar reductions because of increased earnings, the point at which all benefits would terminate would not be different for each program and thereby more incomprehensible.

NAMI also recommends making categorical eligibility for Medicaid national, so that persons with mental illness who move from state to state can retain the opportunity to reconnect with treatment, irrespective of in what state they happen to find themselves.

NAMI shares the hopes of SSA and the Modernization Panel that many of the recommendations can be turned into reality in the near future by actions of the Congress and the Administration.

POOLED TRUSTS

- **Issue has gained relevance since Modernization comments**

In addition to the organizational positions taken above in connection with the modernization project, NAMI urges the Subcommittee to accept the recommendations regarding codification of the Social Security Administration policy on trusts, modified to track the action taken by Congress in P. L. 103-66, OBRA, '93. Oral testimony on these points was presented by other witnesses -- principally the ARC.

Medicaid amendments in this Act exempt from adverse effect on Medicaid eligibility of the grantors transfers by a parent to a trust for the benefit of a disabled child, of any age; and transfers to a trust for a disabled person under age 65 -- ***including a pooled trust.*** It is presumed that the eligibility of the trust beneficiary will be treated as under current SSI policy: only direct payments from the trust to the individual can affect benefits or eligibility. Upon the individual beneficiary's death, the amount recovered from pooled trusts by state Medicaid may be limited "subject to any agreed upon amount or percentage of remaining funds which must be paid to the general pooled trust funds, as determined by the trust agreement".

NAMI believes with the ARC that codification will allow parents, family members, and friends to rely more securely on the rules for making arrangements, which will last long after the parent (or other grantor) is no longer living, to benefit the disabled individual who needs on-going assistance -- without jeopardizing their SSI or Medicaid eligibility.

TESTIMONY BY ROBERT BURGESS
NATIONAL ASSOCIATION OF DISABILITY EXAMINERS

The National Association of Disability Examiners (NADE) appreciate this opportunity to offer our views on issues affecting the Supplemental Security Income program.

NADE is a professional association whose membership includes individuals engaged in all aspects of the Social Security and Supplemental Security Income disability programs. Although the majority of our members are employed in the DDSs, our membership also includes physicians, attorneys, advocates, rehabilitation counselors and others interested and involved in disability evaluation. The diversity of our membership provides us with a unique perspective; an ability to view problems and proposed solutions both from a practical, "hands on" standpoint and also as they affect the applicant and the disability program itself.

(1) RECOMMENDATIONS MADE BY THE SSI MODERNIZATION PANEL

The SSI Modernization Panel offered a number of recommendations to improve the SSI program. Many of those involved the disability program, including a recommendation to review the definition of disability itself and several recommendations to revise the evaluation process. We would like to comment on those recommendations.

RESOURCES

We strongly agree with the panel members and other experts who expressed the view that "...the real problem was the budget-driven underfunding of agency operations...without added resources, lasting improvements are not possible no matter how much effort is directed toward altering administrative processes or reassigning priorities which, in turn, can only reduce backlogs at the expense of other program "necessities".

DEFINITION OF DISABILITY

NADE recognizes the need to remove beneficiaries from the rolls by virtue of return to work and supports efforts aimed at rehabilitation. However, we agree that individuals who are able to work only by virtue of substantial support services are not performing "substantial gainful activity" and are still disabled. It is appropriate to change the definition of "substantial gainful activity" to recognize this. We do not, at this time, recommend changing the definition of disability itself.

APPEALS

NADE can not support elimination of the reconsideration level of appeal. To do so would negatively affect the DDSs, many of whom have specialized recon units; the ALJs, by increasing their workload; and the thousands of applicants whose claims are allowed at this level. We have long supported <u>strengthening</u> this step rather than eliminating it. The current reversal rate at this level is not insignificant. However, enhancement of the reconsideration process could increase the reversal rate and reduce the burden at the Administrative Law Judge level. We would support providing a face-to-face evidentiary hearing at the <u>reconsideration</u> level coupled with providing increased discretion to the decision maker. To offer this hearing at the <u>initial</u> level would be cost prohibitive and counterproductive and any face-to-face interviews held without additional discretion given to the DDS decision-maker will have little effect on the outcome of the decision and will add substantial cost and time to the process.

TIME LIMITS ON DISABILITY CLAIMS AND APPEALS

NADE strongly opposes establishment of arbitrary time limits for completing SSI cases under appeal and for making initial determinations on new disability claims. As we have stated in past testimonies, such a requirement could encourage claimants to not cooperate in the documentation of their claim. they would have no incentive to keep scheduled consultative examinations or provide the agency with the information necessary to document their claims.

Additionally, it is highly likely that the majority of these cases in which benefits were begun prior to making a final determination would ultimately be denied. Denials, in general, require more documentation and therefore, more time. An allowance can be made as soon as the decision has been documented, whether or not all information has been obtained, whereas under current provisions we must wait until all documentation has been received before processing a denial. Timely decisions are important but program integrity demands that those decisions also be accurate and well documented and not based on an arbitrary time frame.

OUTREACH ACTIVITIES

NADE agrees with the views expressed by the SSI Modernization Panel and other experts that SSI Outreach Activities must be appropriately funded. Those most in need of outreach to provide access to the SSI program are often those with the fewest resources.

Because of this, without adequate funding "successful" outreach results in unmanageably high backlogs and unacceptably long delays in development and adjudication. Years of "downsizing", combined with increasing workloads have hampered effective <u>implementation</u> of outreach activities. Applicants receive less assistance in processing their claims; DDSs are not able to educate medical sources about the need for information or are unable to recruit consultants willing to see claimants with unresponsive or no sources. Medical sources are reluctant to provide information when they are not familiar with the needs and requirements of the program. Adequate funding is essential if outreach activities are to be truly beneficial to those they are intended to help.

(2) <u>THE EFFECT OF THE SUPREME COURT'S DECISION IN SULLIVAN v. ZEBLEY</u>

NADE members share many of the concerns expressed by educators and others that providing SSI payments to children may, in some cases, cause harm. We, too, are aware of anecdotal evidence that suggests children are not benefiting from these funds. While we cannot comment on the validity of these at this time we do not believe they should be discounted as "myths". We do know that these claims have had a significant impact on the disability process. Not only have applications increased dramatically, these claims almost always require more documentation than most adult claims and from a wider variety of sources, many of whom are not familiar with the SSI program or who, for whatever, reason, are unwilling to provide information. We are concerned with the extent to which "allowance rates" have been used as a measure of a state's compliance with the regulations despite the fact that previous studies have shown that allowance rates are not a reliable measure of accuracy. To require states with "low" allowance rates to re-adjudicate all denials (and to do this only on childhood claims) is to foster the perception that the only "correct" decision is an allowance and that children's claims should be evaluated more liberally than adult claims.

While we do not disagree with the Zebley decision itself we are concerned that it be implemented appropriately in a way that does not disadvantage children. We are encouraged by the recent initiatives of impartial parties such as the Office of Inspector General and the General Accounting Office to review this program -- it's implementation and impact.

(3) <u>ELIGIBILITY REQUIREMENTS FOR IMMIGRANTS AND SUBSTANCE ABUSERS</u>

Substance abuse has been widely accepted in the medical community as a illness which can lead to a disabling condition. However, here too, NADE members are aware of widespread anecdotal evidence that suggests payments are harming, rather than helping, beneficiaries. The Regulations do require appointment of a representative payee and referral for treatment (and compliance with that treatment). Unfortunately funding and staffing shortages have limited SSA's ability to monitor both the effectiveness of the representative payee and the beneficiary's compliance with treatment. this monitoring is essential and must be appropriately funded if program integrity is to be maintained.

Thank you for the opportunity to offer these comments for your consideration as Congress studies the complex issues facing the disability program today.

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October 28, 1993

The Honorable Harold Ford
Chairman, Subcommittee on Human Resources
Committee on Ways and Means
United States House of Representatives
B-317 Rayburn House Office Building
Washington, DC 20515

Re: Oversight Hearing on Supplemental Security Income

Dear Mr. Chairman:

National Selected Morticians ("NSM"), a national trade association of some 950 funeral firms located throughout the United States and in various foreign countries, submits this letter for the record in the above hearing. NSM maintains its headquarters offices at 5 Revere Drive, Northbrook, Illinois 60602.

The present SSI system provides that irrevocable funds for funeral and related expenses are not to be treated as resources in determining benefits. In addition, the SSI program currently allows a $1,500 burial fund and a burial space exclusion for revocable arrangements. Interest and accruals on burial space and a burial fund are also excluded. These exclusions have worked well in practice and are manifestly in the public interest in making possible a dignified funeral and burial for elderly and disabled individuals who are without resources at the time of death.

Most of NSM's members make available to consumers prefunded arrangements under which funeral goods and services are later furnished at the time of death. Currently, these arrangements are funded in a variety of ways, including trusts and insurance. Regardless of the financing instrument, SSI resource exclusions apply. NSM believes that all present resource exclusions for funeral and burial funds should be retained.

In the case of consumers without adequate resources, unless such prepaid arrangements have been made prior to death, funeral expenses are generally borne by state or local authorities. There can be little question that, if the current SSI resource exclusions for funeral and burial funds are eliminated, state and local expenditures for indigent funerals will of necessity increase enormously -- to the great detriment not only of state and local governments but to thousands of aging poor who would be relegated to a form of potters' field treatment not of their choosing. Thus, in our view, this result cannot be justified by the perceived necessity of "streamlining" of resource exclusions. The idea that these exclusions should be eliminated in the name of simplification, without compelling factual evidence that their administration has become unworkable, is a fallacious one and should be recognized as such. Indeed, if the proposed deletion of these exclusions should become a reality, the new administrative task of valuing assets previously excluded alone would probably be as burdensome and expensive.

We are especially concerned by the suggestion in the Panel's report that the proposed increases in resource limits will be enough to permit recipients of excluded resources to keep them. As we see it, this is a major flaw in the report and would appear to ignore compelling evidence to the contrary. As reported by reliable statistical sources, the average cost of a funeral and in-ground burial is about $5,000. A cemetery lot and marker add a still further amount. It thus is difficult to imagine that, as a practical matter, the new resource limits will counterbalance the elimination of these exclusions.

We are also puzzled, as the Subcommittee must be, that the report apparently considers it in the public interest to deny aging poor of the fruits of earlier prudent pre-planning of the funeral arrangements they prefer and, instead, to penalize them for it. The typical SSI recipient, like everyone else, wishes to have a funeral and final disposition of his/her persuasion and choice. By removing the exclusions, this important part of an individual's life would be effectively removed. As Chairman Flemming said in his letter transmitting the report, "I am struck by the fact that this nation does not have a well-coordinated policy for poor persons as individuals." The removal of the exclusions in question would certainly compound that policy failure.

Further, we note that tens of thousands of SSI recipients currently have pre-funded arrangements. If the exclusions are eliminated, the impact on these recipients will be catastrophic. The probability is that thousands of them will be disqualified and immediately forced onto local welfare roles. This impairment of the safety net would hardly seem in the national interest.

The report's recommendation that an overall increase in allowable resources will offset or cure the loss of the exclusion in question is unsound, if not totally incorrect, for the reasons already noted. A further consideration is that, in all likelihood, the increase recommended would be quickly depleted by impoverished recipients desiring more of perceived day-to-day necessities, without consideration by most of them of the expenses needed later at the time of death. In today's economic climate, this result is one to be expected and would be entirely understandable. That is why designated exclusions, such as the present allowance for a burial fund and burial space, are more effective as a practical matter than a general increase in resources. The present exclusions were crafted in a similar factual setting by Congress in 1982 for the very purpose of allowing SSI recipients to provide for final expenses through prepaid funeral contracts without forfeiting the right to receive benefits. To abandon this approach -- as the report seeks -- would seem directly contrary to the policy of Congress to support the aging poor in a prudent and reasonable manner. The Congress was correct in its 1982 analysis in this regard, and it should stay the course now by rejecting the Modernization Panel's recommendation to eliminate the exclusion of funds set aside for funerals and burials.

Finally, we support and agree with the comments of representatives of the National Funeral Directors Association who appeared and testified before the Subcommittee on October 14, 1993, and we specifically incorporate by reference the statement made by Mr. Larry K. McElwain on behalf of that Association.

Respectfully submitted,

Fred L. Bates

Fred L. Bates
Executive Director
National Selected Morticians

Dave Murchison

David C. Murchison
Legal Counsel

OVERSIGHT HEARING ON SUPPLEMENTAL SECURITY INCOME

STATEMENT OF:

New Jersey State Funeral Directors Association, Inc.

PREPARED FOR:

Subcommittee on Human Resources
Committee on Ways and Means
United States House of Representatives

October 21, 1993

SUMMARY OF COMMENTS:

Advocating the retention of specific resource exclusions for prepaid funerals and burials.

……

Introduction

These comments are filed in response to the solicitation for comments by the Subcommittee on Human Resources, Committee of Ways and Means, U.S. House of Representatives, which conducted an oversight hearing on October 14, 1993.

The comments specifically address the Supplemental Security Income (SSI) Modernization Project Final Report by the Experts published by the Social Security Administration (SSA) in the Federal Register on September 4, 1992 (57 FR 40732).

The New Jersey State Funeral Directors Association (NJSFDA) is a non-profit, 501(c)(6), state-wide professional and business association of 757 funeral directors. All of the members of the New Jersey State Funeral Directors Association are also members of the National Funeral Directors Association, which has also filed comments.

The New Jersey State Funeral Directors Association entirely concurs and supports the conclusions and the recommendations of the National Funeral Directors Association, which generally focus on the need to retain the specific resource exclusion for prepaid funerals and burials. The following comments are designed to complement those remarks and provide some state-level perspective on the issues with which we are concerned.

……

Who Will Bury the Dead?

We note that the final report of SSI Modernization Project did not address the question of societal responsibility for caring for the dead, except to the extent that we can presume that the proposed single lump sum cash resource exclusion of $7,000 ($12,000 for a couple) was intended to do so. It is our belief that this approach will not deal with this "forgotten need" as adequately and effectively as the presently defined and specific funeral resource exclusion already does .

Accordingly, we wish to express here our very deep concern, that in the consideration of the overwhelming demands by the living on the SSA, and on the SSI program they are charged with responsibility for administering, the need to humanely and realistically deal with the responsibility for the dead has been forgotten. The Final Report did not in one place address this issue except to say that previously identified resource exclusions would be eliminated in favor of a "simplified" methodology.

Unfortunately, death and its attendant needs, like human service programs generally, does not lend itself to simplification. It was the recognition of this human fact that led to the creation of the funeral and burial resource exclusion in the first place, when the Social Security Act was amended as part of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982.

Why Was the Funeral and Burial Resource Exclusion Created?

As so aptly summarized by the SSA in its SSI Program Circular of February 3, 1988, "It was the judgment of Congress that persons should not have to choose between lifesaving welfare assistance and giving up their plan for the disposition of their bodily remains."

Congress enacted the 1982 TEFRA amendment after a well publicized case in which a Virginia woman was denied SSI eligibility because of the existence of a burial plot in a cemetery.

Clearly, the absence of a resource exclusion for prepaid funeral and burials was recognized as a significant policy omission that needed addressing, and that providing for same was an important priority of both the Congress and the SSA.

Even prior to TEFRA enactment on September 3, 1982, SSA issued an interim rule in the August 17, 1982 Federal Register (47 FR 35948), recognizing that "burial plots or prepaid (that is, fully paid or currently being paid) burial contracts ... will not realistically be used by an SSI applicant or recipient to meet his or her current subsistence needs. *We have found this to be true because most persons who make arrangements for their burial often will not change such arrangements under any circumstances.* (47 FR 35948)

An additional interim rule followed in the December 8, 1982 Federal Register (47 FR 55212), after the TEFRA position was actually enacted, with the initial final rule being published on December 28, 1983 (48 FR 57125).

This resource exclusion was not created by advocates of funeral service, but rather was generated as an administrative response to an acute and human problem. The recognition of the legitimacy of, and necessity for, this exclusion has increased dramatically since 1982, as has the general public awareness of the demographics of aging and the growth of the SSI and Medicaid programs.

The Impact of Funeral and Burial Exclusions at the State Level

Public assistance payments for funerals and burials at the state and local level have always been on the edge of crisis, with this crisis intensifying since the mid 1980's in response to an acceleration both of need, caused by the growth of Medicaid eligible individuals (based on SSI eligibility standards) and the increased mortality rates among public aid recipients due to Acquired Immune Deficiency Syndrome (AIDS), Tuberculosis (TB) and other disease phenomena, and of price. As an example, in the State of New Jersey, where the state generally provides more adequate funeral payment assistance than most states, the current allowance pays only 53% of the actual retail costs of a "minimum" funeral, and only 43% of the related cemetery costs. (New Jersey State Funeral Directors Association, private study, August 1992). But increasingly, New Jersey (as an example) has disallowed funeral assistance eligibility for derivatives of the basic Medicaid program on the basis that the out of pocket cash requirements simply could not be supported by the state budget.

As a result, in seeking to address the long term needs of funeral and burial payments, the states, funeral directors, elder care advocates, hospice groups, social workers, nursing homes -- the whole community that is responsible for the practical reality and demands of death -- has been advocating and educating the need to engage in reasonable financial planning through the establishment of prepaid funeral and burial accounts, because of the certainty that state cash payment assistance programs are financially inadequate and cover a declining percentage of the total public assistance community.

It is essential to recognize that the SSI eligibility standards that today provide for a prepaid funeral and cemetery exclusion, in and of themselves, and as they apply as the state eligibility standards for Medicaid, are the only adequate mechanism that exists in the United States today to practically and feasibly deal with aggregating, labeling and segregating out financial resources to bury the dead who were recipients of public assistance.

The elimination of this resource exclusion, the failure to separately provide for this purpose that was recognized in 1982 as a compelling and special need, will result in a disheartening and inhumane indifference to the care and disposition of the bodily remains of our financially unfortunate citizens.

A Resource Exclusion with a Purpose

We expect part of the interest in resource simplification is to eliminate the potential for resource exclusion abuse. Accordingly, the experts expressed an indifference to distinctions between accessible and inaccessible assets.

However, in doing this it seems that a more valuable distinction may be had from examining the purpose for which the resource exchange or change in accessibility occurred; e.g., a resource exchange (or trust to effect same) to provide a reversionary interest in a future funeral and burial, the purpose of which is agreed to be a useful public policy purpose, would be allowed, whereas an irrevocable exchange merely for the purposes of SSI eligibility would not be.

This is a more meaningful approach to this problem than today's current SSI policy where a resource transfer outside of two years prior to eligibility is not considered, thus permitting the types of abusive estate planning that has been a chronic concern of SSA.

We argue then, that SSA policy should support resource exclusion by purpose, and avoid generalizations of dollar amounts ($7,000 for an individual, $12,000 for a couple) as being intended to cover all needs. We agree that it probably makes some sense to generally increase the personal allowance set asides, but it cannot be thought that these amounts will adequately provide for funeral expenses. This is particularly so because of the fixed character of the dollar exclusions, and the ever changing prices of consumer goods and services such as funerals and burials.

The current policy on prepaid funerals and burials is working -- whether funded by the use of life insurance or trusts -- and should be retained in this fashion. There is no evidence of abuse. The original regulations prescribed no limit and set no parameters (except on revocable trusts) or terms and conditions, although the Secretary (of SSA) has the authority to do so. The Secretary, in the ten years of the program, has not apparently seen the need.

The Program that Took Ten Years to Implement

The SSI (and Medicaid) funeral and burial resource exclusion program has taken a full decade to implement, and we consider that the full understanding of the program by all levels involved in program administration, did not really occur until 1992.

Ten years .... ten years for a good idea to achieve reality. Ten years for the basic rules to filter down from the SSA to its own staff; to the state Medicaid policy writers and hence to the eligibility case workers; to the social service staffs of nursing homes, hospitals, hospice, funeral homes. Ten years to determine if what the Congress and the SSA really intended is what was being implemented on the regional and local level.

The SSI and Medicaid programs are massive, in terms of staff, dollars and eligible recipients. We recognize the inherent responsibility to improve, review and constantly rework such a program in its broadest respects.

But we wish it understood that this small part of this huge program -- the funeral and burial resource exclusion -- which imposes no out of pocket cash costs on the state or federal governments -- has been successful, finally, at a not insignificant cost of labor and effort to implement it.

To change it now would undo a significant amount of good, and would provide no solution for the future burial of the SSI and Medicaid dead.

Conclusion

Our greatest concern is that the need of caring for the dead is being overlooked and forgotten, and that absolutely no consideration has even been given to it in the rush to broadly redefine the methods of administering resource exclusions.

If we achieve the recognition of the need to deal with the practical funeral and social requirements of death, then a practical assessment in our view would keep intact the present funeral and burial resource exclusions for all of the reasons that they were developed in the first place in 1982.

In the intervening ten years since Congress and the SSA adopted the funeral and burial resource exclusions, nothing has changed, except that now -- through the SSI eligibility standards -- we have a working solution to a real need.

The program of funeral and burial resource exclusions works.

We respectfully advocate its retention as is.

SARAH B. PATTERSON
ATTORNEY ▪ AT ▪ LAW
Practice limited to Social Security and SSI Cases

Fifth Floor
44 Montgomery Street
San Francisco, CA 94104

July 25, 1993

Hon Harold E Ford
Chairman, Subcommittee on Ways and Means
U S House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

Dear Representative Ford

I am writing to submit a statement for inclusion in the record of the hearing you are going to hold on the SSI program My remarks are limited to the topic of SSI benefits for substance abusers

I have been practicing law for 17 years, and my practice is limited to representing claimants in Social Security disability and SSI cases I practiced for many years in Louisville, KY, and three years ago opened a practice in San Francisco The difference in my practice here is dramatic The cases in San Francisco (and this seems to be the experience of most attorneys here as well as the experience of the SSA district offices) is that the vast majority of the cases are drug and alcohol disabilities, many of them from our vast homeless population My conversations with other lawyers around the country indicate that this is growing in all major cities In California, at least, these claimants are often people who, in another era, would have been in mental hospitals due to serious psychiatric disorders

I believe the current Social Security regulations are adequate in addressing substance abuse The cases I have here are most frequently claimants who are "dual diagnosed," meaning they are both mentally ill and have substance abuse issues Often, especially here where mental health services for the poor are virtually nonexistent, these mentally-ill people are self medicating with street drugs and /or alcohol My clients report they cannot be seen for mental heath treatment unless they are actively suicidal The health care systems are simply overwhelmed, and further draconian budget cuts are in store

The streets in our Tenderloin neighborhood remind me of the bar in Star Wars I ask myself what has become of us, that Mother Teresa is sending missionary nuns from Calcutta to work in the Tenderloin in San Francisco

To me, the problem is not that we are giving money to addicts or alcoholics As a taxpayer, I am

[illegible] wealth of Kentucky, admitted to the Northern District of California Federal [illegible]

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as reluctant as anyone to think of my tax dollars going to buy vodka or crack. If the system would work the way it is designed to, the recipients of benefits would all have responsible payees, and they would all as a consequence have housing because their payees would see to that. And they would all be in decent treatment.

Restricting addiction disabilities will only push the problem to another segment of the overloaded system Jails in California feel the brunt of the "deinstitutuionalization" of the mentally ill. The Social Security system is feeling it as well. The population bulge of 40-50 year old people is hitting Social Security as they begin physical and mental deterioration, often accelerated by substance abuse. Young people can drink a quart of vodka a day, but when you are 45 and have been doing it for 20 years, the body and the brain give out In some cases it induces mental illness and organic brain damage, or the mental illness induces the drug addiction.. The end result is the same

Substance abuse treatment is the health care issue of the 90's Social Security has an opportunity to have some positive impact on this problem by making certain that qualified recipients of disability benefits receive adequate mental health care for substance abuse problems This is not a"quality of life" issue, - to use a phrase common to insurance companies denying mental health coverage This is an issue that affects the quality of life in our cities, and the health of the cities themselves. Solving the drug problem is on the agenda of many agencies and administrations, and this is but one face of the problem..

The American Medical Association did not recognize alcoholism as a disease until the mid - 1950's It took 40 years for Social Security to catch up by placing substance abuse in its Listings of Impairments. Certainly there are misuses of this category of disability, as there may be of others That is what the system is designed to catch, and it catches and discards hundreds of thousands of them. Some cases, however, are deemed severe enough for disability benefits.

Requirements for treatment in such cases are essential In my experience the treatment is **not** available, and the monitoring is **not** in place. The answer to this is to **fund the treatment and the monitoring**. It is not to deny benefits to people with a severe and uncontrolled mental illness. It is almost inevitable that a backlash will be created by those who don't understand the nature of addiction The nature of addiction is the loss of choice about use of substances. People can recover, but it is a slow and painstaking process that some people cannot endure.

I encourage all my clients to get into recovery programs. I see some of them months later- some of the ones for whom it has worked. Their SSI money has gone to pay for residential care and halfway houses. When it works, it is a miracle and beautiful to behold. I have a fifty-year old client in a treatment house who is learning to read for the first time Some of them stop drinking only to have even more serious psychiatric problems surface If treatment is not in place for these illnesses, their sobriety is simply history

Addicts are human beings in incredible pain As a society we cannot be in a position of treating them like animals who do not even deserve housing or simple health care No one chooses to turn six $10 tricks a day to support a coke habit if they have any choice. This is not a criminal, this is a sick person. No one lives in alleys and bushes, or sleeps in doorways in ragged blankets and panhandles for food if they have the choices that you and I have But addiction affects many families, even those like yours and mine. It kills It maims It destroys lives as surely as any physical disease, but generates little of the compassion we reserve for physical illness

The **vision** of the system is to provide monitoring and treatment for the most severely mentally ill of our street people. Let us not condemn the parts of the system that are identifying people in need of monitoring and substance abuse treatment Let us rather work harder to get the rest of the treatment design into play, to provide more and better payee services, more and better treatment facilities and more careful monitoring with continuation of benefits contingent on participation in treatment.

Respectfully,

Sarah B Patterson

Sarah B Patterson
Attorney at Law

WAYS AND MEANS COMMITTEE
U.S. HOUSE OF REPRESENTATIVES
1102 LONGWORTH H.O.B.
WASHINGTON, D.C. 20515

OCTOBER 22, 1993

My name is Stephanie Shelton. My address is 2502 Wintergreen Avenue Forestville, Maryland 20747. My phone number is (301) 736-6364. I am a twenty-six-year-old woman. I am writing the Committee for Ways and Means because it is necessary for me to explain the difficult situation I have been dealing with for a long period of time. I would appreciate your time and consideration in this matter.

I was diagnosed at the age of eight with mild mental retardation. Ever since that time, I have been living with a relative; presently with my maternal grandmother. My present goals include leading a fairly independent life without having to rely on my family for everything and I would like to get a better paying job. However, serious obstacles prevent me from reaching these goals.

In September, 1991, I went to the Camp Springs Social Security office to apply for Supplemental Security Income (SSI). This was the first time I had ever attempted to receive assistance from the government. One of the employees at the office seemed very optimistic about my situation. She said that I had a very good chance of receiving SSI, given my circumstances. Unfortunately, such optimism and high expectations did not produce any results. I was rejected from receiving SSI. Then, I was told that I could reapply.

Four to five months later, I applied again and was rejected for a second time. The letter I received explained that, since I had worked for five years at Hardee's fast food restaurant, I showed a capacity to work and support myself. May I ask how I can support herself with $100.00 a week? I do not think I could pay rent, let alone food, medication, doctors' appointments, and clothing expenses with that amount of money. So, I asked for a hearing in January or February, 1993. I have not received a response from the Social Security office for approximately eight to nine months. I have made two calls within that time frame, but nothing resulted from those inquiries. At this point, my goals will not be reached, given the indifference of the Social Security Administration.

Presently, I am working at Roy Roger's fast food restaurant in Edgewater, Maryland. After taxes, I bring in approximately $128.00 a week. I earn $4.30 per hour (minimum wage). In the last few years, I have been living with my 73 year old maternal grandmother, who can barely make it on her own. Neither one of us owns a vehicle and our total resources are meager.

For the two years I have attempted to receive SSI (September, 1991 to present). Regretably, I have only been working ten out of those twenty-four months. In May, 1992, I finally was hired at "Hot Dogs and More" up the street from where I live. The owner decided not to hire me back after five months of working there. They had remodeled the restaurant, telling each one of us to reapply once the restaurant was finished being remodeled. I did just that, with no response from the owner; not a letter or phone call. From October, 1992 to July, 1993, I was jobless again. Without transportation, I walked to every fast food and convenience store nearby, applying for jobs, with no success. Unfortunately, I have not been able to be a cashier because counting money is difficult for me. Therefore, options as to what I can do in a fast food restaurant are minimal. So, too, the possibility of making more money is slim to none.

I am still waiting for a response from the Social Security office to which I applied for a hearing and I am trying my best to make due with the scarce resources available to me. I have many concerns at the moment. Not only do I fear losing my grandmother in the future, I am afraid of what will happen to me if my grandmother is not around in the future. I am certainly in a "Catch 22" situation with little hope for a brighter future.

On October 18, 1993, I received more discouraging news. They wrote to say that my Medical Assistance would be cut off that same week because my eligibility was taken away "due to more income than is allowed." That just makes matters worse for me.

I am writing this letter about the goals and obstacles I face in my life in the hope that you might understand how difficult my situation is at the moment. Receiving Supplemental Security Income (SSI) would help me improve the quality of my life by enabling me to have a positive attitude about my future and giving me the opportunity to make choices about where to live. Without this needed resource, there is no chance for improvement in my life situation and a very good chance that I may become a burden to others. Please consider my story so that the Congress may be aware of this most unfortunate situation I face today. Thank you for your time and consideration.

Sincerely,

Stephanie Shelton
Recorder
Margaret Veeling

#17testimony

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August 2, 1993

Ms. Janice Mays
Chief Counsel and Staff Director
Committee on Ways and Means,
U.S. House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

Re: Oversight hearing on SSI

Dear Ms. Mays:

We are writing on behalf of the South Carolina Trial Lawyers Association in response to the notice published July 2, 1993, announcing an oversight hearing on Supplemental Security Income.

We will address the issues as they are set forth in the announcement:

1. With regard to recommendations made by the SSI modernization panel . . .

> The chances of any applicant, whether for SSI or disability benefits, is greatly enhanced by attorney representation.
>
> Unfortunately, unlike the disability law, there is no provision in SSI to withhold a portion of retroactive benefits to satisfy attorney's fees.
>
> We submit the time for amending SSI legislation to provide for withholding 25% of retroactive benefits for attorney's fees is long overdue. There is no rational justification for this disparity between Title II and Title XVI.
>
> SSI applicants are typically the most needy of the disabled, and it is unfair to deny them attorney representation.

We recognize many SSI claimants are represented by Legal Aid attorneys. However, Legal Aid, in most states, is not in a position, financially, to develop cases, and most cases require additional development.

Also, amending the attorney fee provisions in SSI, as suggested, would draw private attorneys into this field and reduce the case load of the already overworked Legal Aid organizations.

For the reasons stated, we urge the Committee to consider implementing legislation to amend current SSI law with regard to attorney's fees.

Recognizing it could take years to obtain legislative amendment, we suggest that, in the interim, SSA approve a policy of mailing retroactive SSI checks to claimants' attorneys, upon written direction from claimants. Such a practice was followed, though not widely publicized, by SSA until a few years ago, when it was arbitrarily stopped.

SSA currently takes the position that mailing retroactive SSI checks to attorneys designated by claimants violates the regulatory prohibition against assignments. Such is subject to interpretation. For many years, SSA did not view such transactions as assignments.

2. The effect of *Zebley* . . .

We are aware there are some who feel children are still discriminated against in the post-*Zebley* era. SCTLA, however, feels that the law is now equitable and that restructuring it to favor children would discriminate against adults. We feel the present law is fair and adequate.

3. Eligibility requirements for immigrants and substance abusers . . .

a. As to whether immigrants should qualify for

SSI, we feel immigration, in general, needs to be more tightly regulated, and that potential SSI recipients should not be permitted to immigrate into the United States.

b. SCTLA feels strongly that anyone convicted of defrauding the government, with regard to SSI or any other program, should be strictly dealt with by the criminal justice system. There are already adequate laws to handle this.

c. With regard to substance abusers, we oppose efforts to restrict or deny SSI benefits to these unfortunate individuals, political and public opinion notwithstanding.

Substance abuse is now accepted by the medical community as a medical/nervous disorder. Substance abusers are entitled to disability benefits. Since SSI parallels the disability law, it would be discriminatory to disqualify substance abusers from receiving SSI.

4. Criteria for establishing trusts . . .

The wealthy are permitted to establish trusts to protect assets and income, so why should the poor be denied the same legal right?

As a practical matter, relatives of SSI recipients, if denied the right to establish trusts to shield income and assets from the SSI means test, will resort to disinheritance. What purpose is then served?

The present law, with regard to trusts, however, is confusing, and we urge SSA to publish definitive criteria to guide lawyers who attempt to draw such trusts.

Thank you for the opportunity to contribute input to these very important issues which will be before the subcommittee in the upcoming hearing. If we can be of further assistance, please advise.

Yours truly,

Will T. D

Will T. Dunn, Jr.
Chairman, SS Section SCTLA

Doug Patrick

Douglas F. Patrick
President, SCTLA

WTDjr/DFP/nrg

TESTIMONY OF
THE HONORABLE PETE STARK
BEFORE THE
COMMITTEE ON WAYS AND MEANS
SUBCOMMITTEE ON HUMAN RESOURCES
OCTOBER 14, 1993

Mr. Chairman and Members of the Subcommittee: Thank you for holding this hearing.

I would like to publicly thank the members of the SSI Modernization Project for the time and careful attention they gave to reviewing the structure and purpose of the Supplemental Security Income (SSI) program. Their report is comprehensive and specific. It gives this committee and the administration many recommendations which deserve our attention and our response.

I intend to focus on two topics contained in the Project report - funding for outreach activities and work incentives. I have introduced several bills which address these issues.

For some time I have thought that one of the quickest and most economical ways of signing eligible people up for the SSI Program would be to use staff of nonprofit organizations who work with the poor. Many of these people already are very knowledgeable about the program and have the trust of potential SSI recipients. If they aided people in filling out the forms and collected the necessary documentation, they would cut down on the time overworked SSA staff would have to spend with the potential SSI applicants. In return for the time spent by staff, the nonprofit would receive a fixed amount of money for each person that turned out to be eligible for the SSI program. My bill, HR 2325, creates two demonstration projects, one in a poor urban area and one in a poor rural area, to test this idea.

The second topic - work incentives for people on SSI - is addressed in HR 3264. This legislation is the result of many hours of reflection and discussion by numerous people with real grass roots connections. The experts who worked on the Modernization Project and the people who worked with a member of my staff to craft the legislative language know the anxiety and frustration experienced by people with disabilities as they struggle to go back to work .

The number of people with disabilities who benefit from work incentives provisions passed by Congress continues to slowly increase. By making improvements in the work incentives, we have the opportunity to expand the number of working people and their contributions to society. For many people with disabilities, returning to work increases their independence and sense of self-worth.

The provisions of HR 3264 include the following issues:

- access to work incentives under SSI for Social Security Disability Insurance-only recipients who lose eligibility for SSDI benefits because of work,
- eligibility of certain individuals with disabilities for coverage under Medicaid home and community-based care waivers,
- disregard deemed income of ineligible spouse when determining continued Medicaid eligibility under section 1619 (b),
- continuation of Medicaid for the aged who lose SSI due to excess earnings,
- time limits for approval by the SSA of self-support plans,
- regulations regarding completion of self-support plans,
- exclusion of income and resources under self-support plans in determining Medicaid eligibility in "section 209(b)" States,
- expansion of self-support plans to include housing goals,
- self-support plans for the aged,
- treatment of unemployment compensation, worker's compensation, and sick pay as earned income for SSI purposes,
- treatment of certain grant, scholarship, or fellowship income as earned income for SSI purposes, and
- SSI eligibility for students temporarily abroad.

A section-by-section analysis of the provisions of HR 3264 is included with my testimony and indicates the variety of ways we can open doors for people on SSI to become more self-sufficient.

Again, thank you, Mr. Chairman, for this hearing. I hope the subcommittee will be able to take action on these pieces of legislation.

WORK INCENTIVES AMENDMENTS OF 1993

H.R. 3264

Section-by-Section Explanation

TITLE I. ACCESS TO SSI WORK INCENTIVES

Section 101. Access to Work Incentives Under SSI for SSDI-only Recipients Who Lose Eligibility for SSDI Benefits Because of Work

Under current law, an individual must have been eligible for at least one month of regular SSI benefits prior to being eligible under the Section 1619 work incentive provisions, including continued Medicaid.

This provision makes it possible for an individual who is eligible for disability benefits under the Title II Social Security Disability Insurance (SSDI) program and loses eligibility because of earnings to become immediately eligible for the SSI Section 1619 work incentives without having been eligible for at least one month of regular SSI benefits.

The work incentives for people on SSDI are time-limited and do not allow for people with limited work ability to go in and out of the job market. People on SSDI can go back to work and still receive benefits throughout a nine-month (not necessarily consecutive) trial work period, plus an additional three-month grace period. If earnings exceed $200 for a month, the month usually counts as a month of trial work. After the trial work period plus the three-month grace period, SSDI benefits are suspended, if earnings continue to be at the Substantial Gainful Activity (SGA) level. During a 36-month Extended Period of Eligibility (EPE), SSDI benefits can be reinstated for any month that earnings do not exceed the SGA level. Also, Medicare coverage can continue for the same length of time.

When persons lose SSDI benefits, they may have more resources than are allowed under the SSI eligibility rules. Because it would be helpful for people to have access to the SSI Section 1619 work incentives, this amendment provides a time period for people to spend down certain excess resources while they begin to work under the Section 1619 work incentives provisions. Individuals would have 12 months to spend down, beginning 3 months after the end of an individual's trial work period, which is to say after the three-month grace period following the trial work period. For example, if a person has $2500 in resources when they begin to work under the Section 1619 work incentive provisions, they would have 12 months to spend the $500 which is the amount over the SSI resource limit.

The individual would have to apply for SSI under this provision no later than 3 months after receiving notification from the SSA that they were no longer eligible for SSDI benefits.

It may happen that after an individual moves from receiving SSDI benefits to receiving SSI benefits, the person's earnings drop below the SSDI SGA level. This could trigger the resumption of SSDI benefits. The amendment provides that, if this happens during the SSDI program's 36 month EPE, such earnings will not eliminate eligibility for Medicaid under Section 1619(b).

This provision is based on a recommendation made by members of the SSI Modernization Project.

Title II. Work Incentives Waiver Authority

Section 201. Eligibility of Certain Individuals with Disabilities for Coverage Under Medicaid Home and Community-Based Care Waivers

Under the Section 1915(c) waiver authority in Medicaid law, States with approved applications may provide home and community-based care to persons who, without these services, would require institutional care that would be covered by Medicaid. The purpose is to prevent or postpone institutionalization of persons who could be served in the community. To that end, 1915(c) waivers permit States to cover services that go beyond the medical and medically-related benefits that have been the principal focus of Medicaid law. With approved waiver programs, States are authorized to cover a wide variety of nonmedical, social and supportive services that have been shown to be critical in allowing persons to remain in the community. These include personal care services, case management, homemaker/home health aide services, adult day health services, habilitation services, respite services and other services requested by the State and approved by the Secretary of HHS. For the chronically mentally ill, the waiver program also authorizes day treatment or other partial hospitalization, psychosocial rehabilitation services, and clinic services (whether or not furnished by a facility).

However, some individuals with deteriorating physical disability conditions, such as Muscular Dystrophy, who are currently working but need Personal Assistance Services to enable them to continue to work, are denied eligibility for Medicaid on the basis of disability because they have earnings in excess of the SGA earnings test for disability.

The intent of this section is to allow a state to initiate a request for an addition to the waiver or waivers that they have under the home and community-based care waivers in Title XIX. This could be an add-on to current or future home and community-based waiver projects in a state.

States would be allowed to have a waiver of the definition of disability under Medicaid related to the SGA earnings test for purposes of the home and community-based care waiver programs. Specifically, a state would be allowed to serve individuals who have earnings which exceed the SGA earnings test for initial eligibility on the basis of disability. Such individuals would have to qualify under the medical criteria for disability for Medicaid. They would also have to meet the requirements under the Medicaid home and community-based care waiver program that their impairments be so severe that they require the level of care provided in a skilled nursing facility or an intermediate care facility.

Eligibility for the waiver program is limited to individuals with incomes less than 300% of the federal SSI benefit standard. The earned income disregards do not apply in determining an individuals continued eligibility under the 300% limit. This amendment would allow a state under such a waiver to apply the SSI earned income disregard.

Section 202. Waiver Authority

Under current SSI law, the first $20 of any income in a month is disregarded in determining SSI benefits. In addition, $65 of earnings and one-half the remaining earnings is disregarded in determining benefits. Under this amendment, at the request of a state, the Secretary of HHS may provide for SSI applicants and recipients in that state - instead of $65 and one-half of remaining earnings being disregarded - $200 plus one-third of the remaining earnings be disregarded.

This section is in response to the portion of the SSI Modernization Project report which calls for SSI work incentives demonstration projects. The Panel called for both work incentives demonstrations and, at the same time, they recommended eventual permanent changes in the SSI earned income disregards to $200 plus one-third of the remaining earnings.

The amendment provides that such SSI work incentives demonstrations be at the request of the state because of the potential impact of changes in SSI eligibility on State Medicaid programs.

Title III. Amendments to Work Incentive Provisions

Section 301. Disregard Deemed Income of Ineligible Spouse When Determining Continued Medicaid Eligibility Under Section 1619(b)

Under current law and regulations, if an SSI recipient who is working and benefiting from the Section 1619 work incentives marries, the income deemed from an ineligible spouse may increase their income to the point that they do not meet the requirement in Section 1619(b) that they would be eligible for cash benefits but for earnings. This amendment would disregard the income of the ineligible spouse in determining eligibility under Section 1619(b) for Medicaid.

This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 302. Work Incentives for Persons Eligible on the Basis o Age

Under present law, the continuation of Medicaid (without a spend down) under Section 1619(b) when income exceeds the income disregard break even point only applies to persons eligible on the basis of disability. This amendment would provide that such policy would apply under a new Section 1619(e) for persons eligible on the basis of age.

This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 303. Self Support Plans Not Disapproved Within 30 day to be Deemed Approved

This provision would provide that unless the Social Security Administration acts within 30 days of an individual submitting a Plan for Achieving Self Support (PASS) to the Social Security Administration the PASS plan would be deemed to be in effect. It does make it clear that after the deemed approval that the Secretary can subsequently disapprove the PASS prospectively. The individual will have six months to spend down accumulated funds.

This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 304. Regulations Regarding Completion of Plan for Achieving Self Support

Under current regulations, a PASS can be for up to four years in length. This amendment would require the Secretary to have regulations which would vary according to "the difficulty of achieving self support based on the nature and severity of the disability."

This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 305. Exclusion of Income and Resources Under Plans fo Achieving Self Support in Determining Medicaid Eligibility in Section 209(b) States

Under present law, there is no explicit language in the SSI law that a State which has elected the 209(b) option, that is, does not utilize the SSI criteria to provide automatic eligibility for Medicaid for SSI recipients, be required to disregard under that State's Medicaid eligibility criteria the same income and resources disregarded under a SSI PASS plan. This can have the effect of negating the incentive to work under the SSI work incentives. This amendment would require 209(b) states to disregard income and resources disregarded for SSI eligibility to be disregarded under a state's Medicaid eligibility criteria.

This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 306. Expansion of Self Support Plans to Include Housin Goals

Under present law, income of a SSI recipient which is identified and earmarked for eventual use under a PASS is not considered to be countable income or resources in determining eligibility for or amount of SSI. That is, earned income and other income received by persons with disabilities can be placed in a special bank account and that income is not considered in determining initial eligibility for SSI or the amount of income counted in determining their monthly benefit under SSI. Also, what they save can exceed the SSI resources limit if there is a Plan to be funded by the special PASS savings account.

The disregard under a PASS is to finance such items as educational costs related to a person's career goals or adapting a van to one's physical limitations in order to drive to work.

However, for persons with severe disabilities their ability to achieve other goals are often precluded because of the resource limitations in current SSI law. While individuals are allowed to own their own homes and not be denied eligibility for SSI, the $2,000 limit on liquid resources in SSI law prevents an SSI recipient from accumulating resources to be used to achieve more independent housing. Also, individuals are precluded from accumulating resources to have the cash for the initial costs of moving into their own apartment or home or for special remodeling or refurbishing of their housing to accommodate it to their special needs or even accumulating funds for a down payment toward owning their own home.

This amendment to SSI PASS provisions would provide that a Plan for Achieving Self Support could be for the purpose of achieving a "career goal or a housing goal". That is, it would add to the current income disregards and disregards for countable resources under the SSI program the disregard of the income received in a month and resources saved which are for the purpose of enabling an individual to achieve a housing goal.

As in the case of a PASS under current law, a PASS which deals with achieving greater independence in housing must be developed by the individual. The plan also would have to be approved by the SSA and the goals have to relate to enabling the individual to live as independently as possible.

The funds saved would have to be identifiable and apart from other bank accounts as in the case of a current PASS. The length of time for a plan for greater independence in housing would be flexible according to the goals and needs of the individual. The maximum amount an individual would be allowed to accumulate under a PASS concentrating on a housing goal would depend on the goal and what is realistic and necessary based on housing and security costs in a community and the special housing needs of the individual.

Section 307. Self Support Plans for the Aged

The amendment would provide that Impairment Related Work Expenses (IRWE) and the PASS provisions (including the addition to PASS for a housing goal) would also apply to persons who are eligible on the basis of age as well as persons with disabilities.

This amendment is based on the recommendation made by members of the SSI Modernization Project that the work incentives be extended to the aged.

Section 308. Additional State Supplementation Requirement

States have the explicit option not to have their SSI state supplement apply for persons who are eligible only on the basis of Section 1619. This amendment would provide that if a state has an agreement with the SSA for federal administration of state supplements, they must provide for

state supplements to apply to Section 1619 eligible individuals. There is no other mechanism for enforcement of such a requirement other than the federal/state agreements for federal administration of state supplementation.
This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 309. Treatment of Unemployment Compensation, Worker's Compensation, and Sick Pay as Earned Income for SSI Purposes

Under present law, an SSI recipient could lose eligibility for SSI and Medicaid if they have worked and become eligible for Unemployment Compensation and other work-related benefits such as worker's compensation and sick pay because such income is treated as unearned income with only a $20 disregard. This amendment would provide for the treatment of these work-related benefits as earned income with the $65 plus one-half the remaining earnings disregarded.
This amendment is based on a recommendation made by members of the SSI Modernization Project.

Section 310. Treatment of Certain Grant, Scholarship or Fellow Income as Earned Income

Under present law, SSI excludes from being counted as income any portion of any grant, scholarship or fellowship received for use in paying the cost of tuition and fees at any educational institution. However, such funds received by a person with a disability not used for those purposes are treated as unearned income and only the first $20 a month is disregarded. The amendment would treat such funds not used to pay for tuition and fees as earned income with the earned income disregard of $65 plus one-half the remaining earnings disregarded. The main impact would be to keep such students eligible for Medicaid under the provisions of Section 1619(b).

Section 311. SSI Eligibility for Students Temporarily Abroad

Under present law, if an SSI recipient is out of the United States for an entire calendar month they lose their eligibility for SSI benefits. When they return, they must be in the United States for no less than 30 days to again become eligible for SSI benefits. This causes severe problems for a small number of individuals with disabilities who are pursuing their education which includes study in other countries. This amendment would allow the SSA to waive that requirement when it would cause severe disruption for persons with disabilities who are pursuing an education to further their career.

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