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WORK INCENTIVES FOR BLIND AND DISABLED SOCIAL SECURITY BENEFICIARIES

HEARING

BEFORE THE

SUBCOMMITTEE ON SOCIAL SECURITY

OF THE

COMMITTEE ON WAYS AND MEANS

HOUSE OF REPRESENTATIVES

ONE HUNDRED SIXTH CONGRESS

SECOND SESSION

MARCH 23, 2000

Serial 106–56

Printed for the use of the Committee on Ways and Means

U.S. GOVERNMENT PRINTING OFFICE
66–686 CC WASHINGTON : 2000

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WORK INCENTIVES FOR BLIND AND DISABLED SOCIAL SECURITY BENEFICIARIES

THURSDAY, MARCH 23, 2000

HOUSE OF REPRESENTATIVES,
COMMITTEE ON WAYS AND MEANS,
SUBCOMMITTEE ON SOCIAL SECURITY,
Washington, DC.

The Subcommittee met, pursuant to notice, at 10:00 a.m., in room 1100 Longworth House Office Building, Hon. E. Clay Shaw, Jr. (Chairman of the Subcommittee) presiding.

[Advisories announcing the hearing follow:]

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

SUBCOMMITTEE ON SOCIAL SECURITY

FOR IMMEDIATE RELEASE
March 15, 2000
No. SS–12

Shaw Announces Hearing on Work Incentives for Blind and Disabled Social Security Beneficiaries

Congressman E. Clay Shaw, Jr., (R–FL), Chairman, Subcommittee on Social Security of the Committee on Ways and Means, today announced that the Subcommittee will hold a hearing examining work incentives in the Social Security disability program for those who are blind and those with other disabilities. **The hearing will take place on Thursday, March 23, 2000, in room B–318 Rayburn House Office Building, beginning at 10:00 a.m.**

In view of the limited time available to hear witnesses, oral testimony at this hearing will be from invited witnesses only. Witnesses will include policy experts and advocates for blind and disabled individuals as well as beneficiaries who have been affected by these policies. However, any individual or organization not scheduled for an oral appearance may submit a written statement for consideration by the Committee and for inclusion in the printed record of the hearing.

BACKGROUND:

Social Security provides benefits for individuals who are blind or disabled and unable to work because of their medical conditions. To qualify for benefits, an individual must be unable to perform work for pay due to any medically determinable physical or mental impairment. A person is considered able to work or engage in substantial gainful activity (SGA) if earning at or above a certain dollar level (known as the SGA level). The SGA test applies to both determining initial and continuing eligibility for benefits.

Prior to 1977, all disability beneficiaries, as well as blind beneficiaries, were subject to the same SGA limit, established in regulation by the Social Security Administration. The Social Security Amendments of 1977 (P.L. 95–216) increased the amount of the SGA limit for blind beneficiaries to the same amount as the age 65 earnings limit, but did not change the SGA limit for all other disabled beneficiaries. The Contract with America Advancement Act of 1996 (P.L. 104–121) increased the age 65 earnings limit, but did not change current law with respect to the blind.

In 2000, the SGA limit for blind beneficiaries is $1,170 per month and this amount is indexed annually for wage growth. The limit for non-blind disability beneficiaries was increased from $500 to $700 per month in July 1999, after remaining at the same level for the past 10 years.

In announcing the hearing, Chairman Shaw stated: “We should do all we can so every disabled worker has opportunities and incentives to stay in the workforce. Everyone wants that. That is what the Ticket to Work legislation passed last year was all about. But we need to do more. This hearing will help to show us the way.”

FOCUS OF THE HEARING:

The hearing will focus on the role of earnings in determining initial and continuing eligibility for disability benefits, a review of the differences in current law for blind individuals and those who have other disabilities, and an assessment of costs and employment experiences of individuals who are blind and individuals with other disabilities.

DETAILS FOR SUBMISSION OF WRITTEN COMMENTS:

Any person or organization wishing to submit a written statement for the printed record of the hearing should *submit six (6) single-spaced copies of their statement, along with an IBM compatible 3.5-inch diskette in WordPerfect or MS Word format, with their name, address, and hearing date noted on a label,* by the *close of business*, Thursday, April 6, 2000, to A.L. Singleton, Chief of Staff, 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 at the hearing, they may deliver 200 additional copies for this purpose to the Subcommittee on Social Security office, room B–316 Rayburn House Office Building, by close of business the day before 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 submitted on an IBM compatible 3.5-inch diskette in WordPerfect or MS Word format, typed in single space and may not exceed a total of 10 pages including attachments. Witnesses are advised that the Committee will rely on electronic submissions for printing the official hearing record.

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. A witness appearing at a public hearing, or submitting a statement for the record of a public hearing, or submitting written comments in response to a published request for comments by the Committee, must include on his statement or submission a list of all clients, persons, or organizations on whose behalf the witness appears.

4. A supplemental sheet must accompany each statement listing the name, company, address, telephone and fax numbers where the witness or the designated representative may be reached. 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.

Note: All Committe advisories and news releases are avaailable on the World Wide Web at “HTTP://WAYSANDMEANS.HOUSE.GOV”.

The Committee seeks to make its facilities accessible to persons with disabilities. If you are in need of special accommodations, please call 202–225–1721 or 202–226–3411 TTD/TTY in advance of the event (four business days notice is requested). Questions with regard to special accommodation needs in general (including availability of Committee materials in alternative formats) may be directed to the Committee as noted above.

NOTICE—CHANGE IN LOCATION

ADVISORY

FROM THE COMMITTEE ON WAYS AND MEANS

SUBCOMMITTEE ON SOCIAL SECURITY

FOR IMMEDIATE RELEASE CONTACT: (202) 225–9263
March 16, 2000
No. SS–12-Revised

Change in Location for Subcommittee Hearing on Work Incentives for Blind and Disabled Social Security Beneficiaries Thursday, March 23, 2000

Congressman Clay Shaw, Jr., (R–FL), Chairman of the Ways and Means Subcommittee on Social Security, today announced that the Subcommittee hearing on examining work incentives in the Social Security disability program for those who are blind and those with other disabilities, previously scheduled for Thursday, March 23, 2000, at 10:00 a.m., in room B–318 of the Rayburn House Office Building, **will now be held in the main Committee hearing room, 1100 Longworth House Office Building.**

All other details for the hearing remain the same. (See Subcommittee press release No. SS–12, dated March 15, 2000.)

Chairman SHAW. Today, the Subcommittee is considering how best to encourage work and earnings for a special group, and that is people with disabilities. We have already taken some major steps to encourage work through last year's Ticket to Work law. This law will better help beneficiaries prepare for work and keep jobs. It extends health care coverage, encourages service providers to focus on results, and maintains the safety net for those who need it. But we can't stop there. Fortunately, as we consider ways to further improve the disability program, there is much we already agree on. Let us focus on that.

We all agree that federal programs should promote work and self-sufficiency. We all agree everyone should be offered a "hand up" rather than a "handout". And we all agree disability programs must protect those who are simply too disabled to work.

Our commitment to the Ticket law establishes exactly that, but each of us must also consider some tough questions as we listen to today's witnesses. For example, are proposed changes consistent with the purposes of the disability program? Are they fair to all disabled beneficiaries as well as to current workers whose hard-earned wages support the program? And will they threaten the disability program's safety net, which already will start running in the red by 2006?

Despite these challenges, I am convinced that we can do more to encourage work. Ronald Reagan once said, "The very key to our success has been our ability, foremost among nations, to preserve our lasting values by making change work for us rather than against us". Especially with complicated government disability programs, such change never occurs easily. But that is all the more reason for us to dig in and get to the bottom of the issues that have kept others from doing more to help every disabled person who wants to work.

And I will now yield such time as he may consume to the gentleman from California, Mr. Matsui.

Mr. MATSUI. Thank you very much, Mr. Chairman, I appreciate your yielding to me, and appreciate the fact that you are holding this hearing.

Over the past year, the Congress has made significant bipartisan progress in ensuring that the Social Security program encourages people to participate fully in the nation's economy and provides them with incentives to join, return to or remain in the workforce.

At the end of last year, the Congress passed on a bipartisan basis and the President signed into law the Ticket to Work and Work Incentives Act. The Ticket to Work Act assists disability beneficiaries attempting to return to work or who are struggling to remain in the workforce by expanding their access to public and private vocation rehabilitation providers, extending the period for which they are eligible for Medicare coverage, and creating new options for states to allow individuals with disabilities to purchase Medicaid.

Just three weeks ago, the House unanimously passed a bipartisan legislation to repeal the Earnings Test for Social Security beneficiaries who have attained the normal age of retirement. H.R. 5 allows the most experienced members of our workforce, our nation's senior citizens, to continue work without experiencing a reduction in their Social Security benefits. Despite this progress, we can still do more to look at Social Security programs to see where we can improve the ability of beneficiaries to take part in the workforce.

As we all know, we are in an environment of budget constraints. On the one hand, we have a limit on budget surplus and budget resolutions that we are going to discuss today that will challenge our ability to fund health, education and social programs while allowing for tax cuts. And on the other hand, we have a Social Security surplus that we will set aside for debt reduction and help us pay for the benefits in the future.

We are determined to do our best for Social Security recipients and to explore ways to improve their ability to participate in the labor force while working within our budget limits. One such avenue is a requirement in the Ticket to Work and the Work Incentives Act that the Social Security Administration conduct demonstration projects on possible modification on earnings limitation for the disabled.

In addition, the bill mandates a GAO study on the topic as well. The information that we will receive on these two initiatives will be very useful and helpful to our investigation into the costs and effectiveness of various incentive policies.

Today, I look forward to the testimony of the representatives from the Social Security Administration and the GAO, and I am eager to hear from disability beneficiaries about the impact that possible work incentive policies may have on them.

In the end, enhanced work incentives in the Social Security program benefit more than the disability community themselves, they benefit the country as a whole.

I look forward to working with Chairman Shaw and the other members of the Subcommittee to make the most of this very, very important opportunity. Thank you.

Chairman SHAW. Thank you, Bob.

Because of the length of our agenda today, I am going to try to hold all the witnesses within the five-minute limit. Each person to testify this morning, we have your full statement that will be made a part of the record, and we would hope that you can summarize within the time allotted, and I would hope we can have everyone's cooperation on that.

Our first witness is Member from the State of Maryland. Mr. Ehrlich.

STATEMENT OF THE HON. ROBERT L. EHRLICH, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MARYLAND

Mr. EHRLICH. Thank you, Mr. Chairman. I will certainly hold to the daily rule with respect to the five-minute limitation. I really appreciate the opportunity to briefly highlight my written testimony which I submitted for the record, and I am not going to read it.

Members of this Committee, particularly the Chairman, know this issue very well. And, again, I thank you for this opportunity today.

Very briefly, Mr. Chairman, a couple of points I would like to hit with respect to history and the facts and the sponsorship, and then a final plea with regard to this particular issue.

The Chairman and Members of the Subcommittee are well aware of the history of the Social Security limitation and the linkage between seniors and the blind. It occurred in the 1970s, the original linkage came out of this Committee.

As part of the Contract With America, in fact, the senior citizens' earnings limitation was phased in over five years from $11,000 to $30,000. At that time, however, not because of any compelling policy reasons, but because of the need to balance the budget, there was a de-linkage. Seniors and the blind were de-linked.

It has been that case now for the past four years. This year, given the great work of this Committee, the Subcommittee and the full Committee, and now the House, with respect to the seniors' limitation, I thought the time would be good with respect to doing something for the blind.

The Chairman is well aware that at least past leadership has made representations to the blind community with regard to "fixing" this linkage problem, and I am truly hopeful that the Chairman, the Subcommittee and the full Committee will follow through on that promise made a number of years ago.

The Chairman is well familiar with the facts. During a time of technological innovation, a steaming economy, very low unemployment, the blind suffer from a 70-percent unemployment rate. The primary reason, in my view and in the view of the folks you are going to hear today, is the "disincentives" built into the code with respect to this earnings limitation.

H.R 1601 has over 280 bipartisan co-sponsors in this House. Nineteen Members of the Ways and Means Committee co-sponsor this bill.

Mr. Chairman, we can talk about policy. We can talk about equity. I believe that to at least re-link the blind with the seniors regardless of what happens with regard to the senior bill, whether that is a clean bill or whether it comes back from the Senate with a phase-in, or whatever, is the right thing to do. These are people who want to work. Given the technology we have in this country today, they can work. I think this Congress should all be about empowering people who simply want to work, and whether it is the Social Security Act, whether it is our Code that provides the disincentive, I believe it is incumbent upon this Congress to remove those disincentives from the law.

I truly thank you for your interest. I know your personal interest in this issue. I thank you for the time today, and I am going to let the folks who are impacted by this inequity in our law testify before the Committee. And, again, I thank you, and yield back.

[The prepared statement follows:]

Statement of the Hon. Robert L. Ehrlich, Jr., a Representative in Congress from the State of Maryland

Good morning, Mr. Chairman and Members of the Subcommittee. I appreciate the opportunity to talk to you about eliminating a work disincentive for blind Americans. As many of you know, I have repeatedly introduced and pushed for passage of legislation to restore work incentives for the blind. Last year I introduced H.R. 1601, the Blind Empowerment Act (BEA). This bipartisan bill has more than 280 co-sponsors. This legislation could positively impact as many as a quarter million blind Americans.

For nearly twenty years, the blind and senior citizens were linked for the purposes of the Social Security Earnings Test. In 1996, this historic link was broken, not to make a significant policy change, but to balance the budget. Under that legislation, Congress provided seniors with an opportunity to increase their earnings to $30,000 by 2002 without losing their Social Security benefits; however, blind individuals were limited to earnings of approximately $14,000 in calendar year 2000. Blind individuals who earn more than this earnings limit threshold lose all of their benefits. In contrast, a senior citizen in the same situation has their benefits reduced at a rate of $1 for every $3 earned over the limit.

To be sure, this lower threshold and complete loss of benefits for the blind creates major disincentives to work. Presently, the unemployment rate for the blind is approximately 70%. In effect, Congress penalizes blind workers for trying to improve their quality of life for themselves and their families. This is unacceptable. Congress should encourage, not discourage, blind individuals to work.

My legislation (H.R. 1601) accomplishes this. Specifically, my bill removes the existing disincentives by re-linking the blind with the seniors. Most importantly, H.R. 1601 restores fairness for the blind by honoring the co-sponsors' pledge for parity with senior workers.

The Ways and Means Committee recently voted to repeal the earnings limitation for seniors. Shortly thereafter, the House overwhelmingly affirmed this repeal and the Senate has likewise done the same. I strongly support the repeal of the seniors earnings limitation. I do believe, however, that Congress has a responsibility to restore fairness and work incentives for the blind. By adopting H.R. 1601 this Committee can accomplish this goal. I urge you to take this opportunity and help blind Americans to reach their full working potential. I pledge to continue my efforts on behalf of all blind Americans.

Again, Mr. Chairman, thank you for affording me the opportunity to testify before the Social Security Subcommittee.

Chairman SHAW. Thank you, Bob. Mr. Matsui?

Mr. MATSUI. I have no questions. I would like to thank Mr. Ehrlich.

Chairman SHAW. Mr. Doggett?

Mr. DOGGETT. No questions.

Chairman SHAW. Well, I do know you have talked to me on numerous occasions. I know your interest in this issue, and we appreciate your being here this morning.

Mr. EHRLICH. Thank you, Mr. Chairman. I am going to get to my Commerce markup before the Chairman gets angry at me. Thank you.

Chairman SHAW. We next have a panel of witnesses from the Social Security Administration. We have Dr. Susan Daniels, Deputy Commissioner, Disability and Income Security Programs; and from the U.S. General Accounting Office, Barbara Bovbjerg, Associate Director, Education, Workforce and Income Security Issues, Health, Education and Human Services Division; and she is accompanied by Carol Petersen, who is the Assistant Director of the Education, Workforce and Income Security Issues, Health, Education and Human Services Division.

Dr. Daniels, I beg your pardon. I put everybody together, and that is not the way it is supposed to be this morning. So, everyone can remain at the table, but we will start out with Dr. Daniels and go to questioning, and then get to the other witnesses from the United States General Accounting Office. Dr. Daniels.

STATEMENT OF SUSAN DANIELS, PH.D., DEPUTY COMMISSIONER, DISABILITY AND INCOME SECURITY PROGRAMS, SOCIAL SECURITY ADMINISTRATION

Dr. DANIELS. Mr. Chairman, there certainly are enough chairs up here, so anyone could join if they would like to.

Mr. Chairman, Members of the Subcommittee, thank you so much for inviting me here today to talk about the work incentives for blind individuals and other people with disabilities.

The Social Security Act defines disability as the inability to engage in any substantial gainful activity (SGA) due to a medically determinable physical or mental impairment. We use how much a person earns as a guideline for evaluating whether work is substantial and gainful, and whether we may consider them eligible for benefits.

Blindness, sometimes referred to as statutory blindness, is the only impairment defined in the Act itself; all other impairments are defined by regulation.

The Social Security Administration has approximately 120,000 statutorily blind individuals on our rolls, about 100,000 of them on Disability Insurance.

How do we determine if a person is actually working? For most individuals, that is done through regulation, and since July 1999 the SGA amount has been $700. For individuals who are blind, the Act itself specifies the computation of the SGA amount, and since January 2000 that has been $1,170 a month. Prior to 1978, the SGA amount for the blind and nonblind were identical. The Social Security amendments of 1977 linked the SGA amount for individuals who are blind and the retirement earnings test. The SGA amount for individuals who are blind and the retirement earnings test rose from $334 a month in 1978 to $980 a month in 1995. For the nonblind, the SGA amount rose from $260 a month in 1978 to $500 a month in 1995.

The Contract With America Advancement Act in 1996 significantly increased the retirement earnings test and de-linked the SGA amount for individuals who are blind from that test, and it indexed the then-SGA amount for individuals who are blind to average wage growth. Meanwhile, SSA increased the SGA for nonblind individuals to $700 a month last summer.

The Social Security disability programs that we administer may not be the exclusive and permanent source of income for all beneficiaries, but they can be a stepping stone to improve the economic conditions of people with disabilities through Return to Work initiatives.

There are several work incentives in both the SSI program and in the Disability Insurance program, which were further enhanced by the Ticket to Work and Work Incentives Improvement Act of 1999.

We also refer individuals with disabilities to private and public vocational rehabilitation programs. Last year, Social Security reimbursed State Vocational Rehabilitation agencies $120 million for the rehabilitation of over 11,000 beneficiaries.

As you well know, you have worked two hard years on producing legislation to improve the work incentives. Your success culminated in the President signing the Ticket to Work and Work Incentives Improvement Act into law last December. I want to express my thanks to you, Mr. Chairman, and to all members of this Committee for getting that important piece of work done. It is really a magnificent bill.

A quick review. We now have tools in place under the Ticket to Work program in Social Security to extend Part A Medicare premium-free for individuals who return to work for eight and a half years; a quick reinstatement of benefits if working and the workplace doesn't work out for beneficiaries; and, finally, the Medicaid buy-in for states to increase economic and health security in the states.

H.R. 1601 and S. 285 would reset the SGA amount for blind people back to the retirement earnings test amount. Currently, the earnings retirement test is $1,417 a month. If these bills are enacted in the year 2000, the five-year cost would be about a billion dollars and the long-term cost .01 percent of payroll, an impact on the long-term solvency of the trust fund.

H.R. 5 as passed by the House and the Senate would eliminate the retirement earnings test completely. The President has promised to sign a clean bill to eliminate the retirement earnings test.

Obviously, such enactment, combined with the previously discussed legislation, would completely eliminate the SGA for blind individuals, thus making all statutorily blind people eligible for our programs.

Who would benefit? Such a significant policy change would benefit primarily those individuals who are currently blind and working because they would become immediately eligible for Social Security Disability.

In the year 2000, if this bill was enacted, the five-year cost would be $2.6 billion and the long-term costs .03 percent of payroll, an even greater impact on the trust fund.

As we think about changes, a few questions should be kept in mind. Have we given the time and the resources and support we need to achieve and measure the new work incentives you passed last year? Are additional ones needed now? If we eliminate work as a criteria for benefits, we create a new program that pays people based on a significant limitation. Which limitation should that be? Which impairments would be covered? Should this supplement extend to nonworking age people, say, children or the elderly who are in great need? And what is the long-term effect on the solvency of Social Security, and how will it be financed?

A policy change of great significance is possible but is likely to require a long period of conversation and significant financial analysis.

Mr. Chairman, we want to build the momentum provided by the enactment of the Ticket to Work bill to increase incentives for people with disabilities to work. Commissioner Apfel has reaffirmed our commitment to make every effort to bring as many Americans with disabilities into the workforce as possible.

I would be delighted to take your questions. Thank you.

[The prepared statement follows:]

Statement of Susan Daniels, Ph.D., Deputy Commissioner, Disability and Income Security Programs, Social Security Administration

Thank you for inviting me to discuss current work incentives for blind individuals and other people with disabilities. This is an important issue, and the Social Security Administration looks forward to working with you on finding ways to help more Americans with disabilities successfully return to work.

Today I would like to discuss the definition of disability and how work activity for both blind and non-blind individuals relates to it; our current work incentives and the recent changes in the law; and some pending proposals in that area.

Definition of Disability

The Social Security Act (the Act) defines disability as the inability to engage in any substantial gainful activity (SGA) because of a medically determinable physical or mental impairment(s):

- That can be expected to result in death, or
- That has lasted or, that we can expect to last for a continuous period of not less than 12 months.

We use earnings guidelines to evaluate whether the work activity is SGA and whether we may consider someone disabled under the law. While this is only one of the tests used to decide if a person is disabled, it is a critical threshold in disability evaluation.

Blindness (sometimes referred to as statutory blindness) is the only impairment defined in the Act; all other impairments are defined in regulations. Blindness is defined as central visual acuity of 20/200 or less in the better eye with best correction, or a limitation in the field of vision in the better eye so that the widest diameter of the visual field subtends an angle of 20 degrees or less (tunnel vision).

Blind individuals do not have to meet the “regency of work” test (generally, work in 20 out of the last 40 quarters) to be eligible for disability benefits. Approximately 120,000 of our beneficiaries meet the statutory definition of blindness. (About 50,000 are Supplemental Security Income beneficiaries aged 18 to 64; approximately 100,000 are Social Security beneficiaries; about 30,000 are concurrently receiving benefits under both programs.)

Substantial Gainful Activity (SGA)

The Act requires the Commissioner to prescribe in regulations the criteria for determining when earnings demonstrate an individual’s ability to engage in SGA. The Act also specifies that a different definition of SGA applies to blind individuals. With an impairment other than blindness, effective July 1999 earnings over $700 a month generally demonstrate SGA. For someone who is blind, effective January 2000, earnings over $1,170 a month generally demonstrate SGA.

Prior to 1978, the SGA amount was the same for both blind and non-blind individuals. The Social Security Amendments of 1977 made the SGA threshold for blind individuals the same as the monthly exempt amount under the retirement earnings test (RET) for individuals at or above the normal retirement age (NRA), an amount which has generally been indexed that amount to average wage growth. At the time, Senator Birch Bayh indicated that blindness was a “distinct and unique condition” and that “The blind, as a group, suffer largely artificial impediments when they seek to enter and compete in the labor market.” The two thresholds (the exempt amount and SGA) rose together from $334 a month in 1978 to $940 a month in 1995, while the non-blind SGA amount rose from $260 a month in 1978 to $500 a month in 1990.

The Contract with America Advancement Act of 1996, enacted March 29, 1996, significantly increased the RET exempt amount (rising to $2,500 a month in 2002 for individuals at NRA). It de-coupled the SGA amount for blind individuals from the RET, and instead continued to index the then-existing SGA amount for average wage growth. Meanwhile, SSA increased the regular SGA amount in regulations to $700 a month effective July 1999.

For individuals who are blind and age 55 or older, if their work requires a lower level of skill and ability than the work that they did before age 55, benefits are suspended, not terminated, when earnings demonstrate SGA. Benefits are then payable for any subsequent month that earnings fall below SGA.

Work Incentive Provisions

Congress enacted work incentive provisions that were strongly supported by the Administration to provide beneficiaries with the support they need to move from benefit dependency to independence. Work incentives assist beneficiaries with disabilities to enter or reenter the workforce by protecting entitlement to cash payments and/or health care until this goal is achieved.

Some work incentives are common to both the Social Security Disability Insurance (SSDI) and Supplemental Security Income Program (SSI), while some are unique to one program or the other. Because even the common work incentives may be treated differently by either program, I would like to briefly discuss work incentives as each program treats them. I would also like to point out the special work incentives that apply only to blind beneficiaries of either program. SSDI Work Incentives

There are several work incentives for SSDI beneficiaries built into the Act, most notably impairment-related work expenses (IRWE), the trial work period (TWP), the extended period of eligibility for reinstatement of benefits (EPE), and continuation of Medicare. These are dependent upon the disabled beneficiary continuing to have a disabling impairment.

When determining SGA, we deduct from gross earnings the cost of certain impairment-related work expenses. We deduct beneficiaries’ IRWE paid during a period of work when:

- The item or service enables them to work;
- They need the item or service because of their disabling impairment;
- They pay the cost and are not reimbursed by another source (e.g., Medicare, Medicaid, private insurance);
- The expense is “reasonable”—that is, it represents the standard charge for the item or service in their community.

The TWP allows disabled beneficiaries to test their ability to work for at least 9 months. During the TWP, beneficiaries receive full benefits regardless of how high earnings might be. The TWP continues until the accumulation of 9 months (not necessarily consecutive) of “services” performed within a rolling 60-consecutive-month period. We use this “services” rule only to control when the TWP stops. “Services” means any activity in employment or self-employment for pay or profit or of the kind normally done for pay or profit (whether or not it is SGA). We currently consider work to be services if earning are more than $200 a month (or more than 40 self-employed hours in a month).

Once benefits have been ceased due to SGA, the EPE allows automatic reinstatement of benefit payments for any month in which earnings fall below SGA. Benefits can be reinstated anytime during the 36-month period following the end of the TWP, and will continue as long as requirements are met. Currently, Medicare coverage continues during this period and for three additional months. At that point, disabled individuals can buy Medicare coverage. Effective October 1, 2000, based on the new Ticket to Work Incentives Improvement Act, premium-free Medicare is extended an additional 4 years.

In addition to providing incentives to work, we also refer disabled beneficiaries to their local State Vocational Rehabilitation VR agency, or to other service providers in the public and private sector who try to help beneficiaries return to work. In fiscal year 1999, SSA paid State VR agencies about $120 million for their services provided to

over 11,000 beneficiaries with disabilities who worked at least 9 months at the substantial gainful activity level. Although this was a record year for reimbursements, we look forward to much more progress in this area.

SSI Work Incentives

Some general information about the SSI program is useful to explain the work incentive provisions as they apply to that program. The SSI program differs from Social Security in that the monthly Federal benefit standard (currently, $512 for an individual and $769 for an individual with an eligible spouse) is reduced dollar-for-dollar by the amount of the individual's "countable" income—i.e., income less all applicable exclusions. The result of this computation determines whether the individual (or couple) is eligible and the amount of the benefit payable.

SSI law defines two kinds of income: earned and unearned. Earned income is wages, net income from self-employment, remuneration for work in a sheltered workshop, royalties on published work, and honoraria for services. All other income (including income received in kind) is unearned.

When determining an individual's countable income, exclusions are taken for various types of income. There is a general $20 exclusion, generally applied to an individual's for unearned income. In the case of earned income, we exclude a portion of the $20 general exclusion that has not been used, and then exclude the first $65 and one-half of the remainder of the earnings. This greater exclusion for earned income acts as a work incentive for all SSI recipients.

In determining the benefits of disabled individuals, we exclude IRWEs. For the disabled, we exclude work expenses directly related to the individual's disability, such as attendant care services, assistance in travelling to and from work and personal assistance related to work. I will discuss allowable deductions for blind SSI beneficiaries in greater detail later.

Under SSI we also exclude income set aside or being used to pursue a plan for achieving self-support (PASS) that has been established by a disabled or blind person. These plans are established to help blind and disabled individuals become self-supporting by excluding income that is set aside to help the individual reach a specific occupational goal. In December 1999, there were 1,045 SSI recipients with a PASS established, although not all of those individuals reported earnings for that month.

Finally, the laws governing SSI contain provisions that enable blind and disabled individuals to continue working and receiving income beyond the limit that would normally result in ineligibility.

Under section 1619(a), a disabled beneficiary who would cease to be eligible because of earnings over the SGA limit (currently $700 a month) can continue to receive cash benefits until the amount of earnings would cause him or her to be ineligible for benefits under SSI income counting rules. Being a recipient of this special benefit equals being an "SSI recipient" for Medicaid eligibility purposes.

Section 1619(b) provides "SSI recipient" status for Medicaid eligibility purposes for certain SSI recipients. These individuals have earnings which preclude the payment of an SSI benefit but are not sufficient to provide a reasonable equivalent of the SSI, social services, and Medicaid benefits that the individuals would have in the absence of earnings. For these individuals, the loss of the social service and Medicaid benefits would seriously inhibit their ability to continue working. However, these individuals have to be otherwise eligible except for their earnings.

According to SSAs Office of Research, Evaluation and Statistics, there were approximately 340,000 SSI disability beneficiaries (or 6.4 percent) who were working

In December 1999. About 70,000 of these individuals were receiving benefits under section 1619(b). These beneficiaries do not receive an SSI payment but retain their Medicaid coverage. Almost three-fourths of those who received this type of SSI benefit had amounts of earned income below the substantial gainful activity level.

Blind Work Incentives

I have already discussed how the SGA level differs for blind beneficiaries and how it applies to SSDI beneficiaries who are blind and age 55 or older. SSA also does not count any earned income a blind SSI beneficiary receives that is used to meet any expenses needed to earn that income in determining SSI eligibility and payment amount. Unlike IRWE, blind work expenses (BWE) do not have to be related to blindness. As a result, any expense reasonably attributable to work is to be excluded, dollar for dollar, not simply those related to the impairment.

Some examples include guide dog expenses; transportation to and from work; Federal, state, and local income taxes; Social Security taxes, attendant care services, professional association fees; and union dues.

Ticket to Work and Work Incentives Improvement Act of 1999

As you know, the President signed the Ticket to Work and Work Incentives Improvement Act of 1999 (the "Ticket") into law last December. I want to express my thanks, Mr. Chairman, to you, and the members of the Subcommittee, for your support in getting the "Ticket" passed. This legislation will help disabled individuals who want to work by lessening their fears about losing health care coverage and income during attempts to work.It improves and expands their VR choices, providing enhanced work incentives, outreach activities and new service structures.

The provisions most pertinent to today's discussion include:

- The Ticket to Work and Self-Sufficiency Program—which provides beneficiaries with opportunities to get vocational rehabilitation services, employment services or other support services from approved providers that they can choose, and which will be phased in beginning 2001.
- Part A premium-free Medicare coverage for disability beneficiaries who return to work is extended for four and one-half years beyond the current limit effective Oct. 1, 2000.
- Quick reinstatement within five years without filing a new application for beneficiaries with a disabling condition whose benefits have ended because of earnings from work.
- Prohibition against initiation of a continuing disability review (CDR) while a beneficiary is—using a ticket—or based on the work activity of an individual receiving benefits for at least 24 months.

Ever since the "Ticket" was enacted, we have been actively engaged in the hard work of implementing its various provisions. We again look forward to working with you as the different provisions take shape and begin to show the results we anticipate—more people with disabilities entering or reentering the workforce.

Pending Legislation

Legislation has been introduced in both the House (H.R. 1601) and the Senate (S. 285) that would equate the SGA amount for blind individuals with the RET exempt amount at NRA. Currently that amount is $1,417 a month, which is scheduled to rise to $2,500 a month in 2002 (30,000 per year), and to be indexed to average wage growth thereafter. I would like to point out that approximately 60 percent of workers today earn $30,000 per year or less. If these bills were enacted effective 2000, we estimate 5-year costs of $0.9 billion and long-term costs to the Social Security trust funds at −0.01 percent of taxable payroll; in other words, passage of such a provision would have a detrimental impact on long-term solvency. Any consideration of these proposals should be done in the context of Social Security solvency legislation.

H.R. 5 as passed by the House would eliminate the RET at NRA effective this year. As you know, the President has promised to sign a clean bill to eliminate the RET at NRA. Obviously, such enactment would affect the preceding SGA proposal; that proposal, if combined with H.R. 5, would completely eliminate the SGA amount for blind individuals, thus permitting a blind individual to earn any amount and still be eligible for benefits. Under this scenario, effective 2000, we estimate 5-year costs of $2.6 billion and long-term costs at −0.03 percent of taxable payroll, an even greater negative impact on long-term solvency. Note that the elimination of the RET at NRA has no impact on long-term solvency, but there are additional Medicare and Medicaid costs as well.

Conclusion

Mr. Chairman, we want to build on the momentum provided by the enactment of the "Ticket" and to increase incentives to work for all people with disabilities. Our commitment is to make every effort to enrich the lives of people with disabilities and to help those who want to work do so.

As Commissioner Apfel testified before this Subcommittee last year, as a nation, we are best served when all our citizens have the opportunity to contribute their talents, ideas, and energy to the workforce. We look forward to working together with the Subcommittee and Congress to achieve the proper equilibrium of equity and actuarial balance in the area of disability work incentives. I will be happy to answer any questions the Members may have.

Chairman SHAW. Thank you. Mr. Matsui?

Mr. MATSUI. Thank you, Mr. Chairman. Dr. Daniels, thank you for your testimony, it is very helpful, obviously. You indicated that if we raise the earnings limit for the disabled to $17,000 a year—from $700 to whatever the current level would be, the level before the new bill becomes law, it would be .03 in terms of the negative impact on solvency of the Social Security system?

Dr. DANIELS. That is the estimate if we eliminate the SGA amount just for our blind beneficiaries.

Mr. MATSUI. It is my understanding that the actuaries, however, do take into consideration that there would be indexing of that earnings limit in terms of doing a calculation over a 75-year period, is that correct?

Dr. DANIELS. Well, yes. The notion of substantial gainful activity, just that notion itself, has to continue in actuarial terms to change and grow over time, or else it would lose all meaning because wages grow over time.

Mr. MATSUI. So they do expect—the actuaries, in their calculations over the 75-year period, do expect it to grow or increase over time?

Dr. DANIELS. That is correct.

Mr. MATSUI. So, if we begin today—and the only reason—because it is such a small amount, given the fact that the CPI is so small, obviously it is good for our economy—probably not good for, obviously, people that are receiving fixed benefits—but if you begin indexing, then this would have no impact on the solvency of the Social Security trust fund in terms of where we are today, over a 75-year period?

Dr. DANIELS. Well, what the actuaries actually do is assume the current law. And so they look at what the growth would be in SGA given current law which is right now indexing the SGA for blind individuals as currently indexed to average wage growth, but if we eliminated it, then there would be an even larger number of people eligible for the program.

Mr. MATSUI. You are talking about eliminating the earnings limit?

Dr. DANIELS. Eliminating the substantial gainful activity test, right.

Mr. MATSUI. Oh, but I wasn't suggesting—I was suggesting in my question that if you indexed it—

Dr. DANIELS. It is indexed today.

Mr. MATSUI. It is indexed today?

Dr. DANIELS. Yes, it is. The blind SGA is currently indexed to average wage growth.

Mr. MATSUI. Well, I thought it stated at $700.

Dr. DANIELS. No, $700 is for those individuals who are not blind.

Mr. MATSUI. For individuals who are—

Dr. DANIELS. Not blind. The SGA is $700 a month.

Mr. MATSUI. Okay. But if you indexed it for both the blind and the nonblind, would it then have an impact on the trust fund?

Dr. DANIELS. It would have an immediate and small impact because there is an assumption that SGA will grow as wages grow. So the long-term impact is very negligible to index the SGA.

Mr. MATSUI. That is because—again, I want to go back and repeat myself—because the actuaries take into consideration the indexation on the basis of wages.

Dr. DANIELS. Absolutely.

Mr. MATSUI. So it shouldn't have any impact. It shouldn't even be a negligible impact.

Dr. DANIELS. I can't believe it took us this long to get to agreeing with your statement. Yes.

Mr. MATSUI. Now, I guess if we would have been indexing when we decoupled the blind from those 65 and older—I don't know what the inflation rate would have been over that last few years, but it probably would have been somewhat substantial, and I would imagine this would make some sense to do—it obviously may not make a lot of folks happy—but at least it would be a start. Is that something that you—and I know you can't make a policy decision—obviously, this is a new discussion—but at least would that be something that you would consider recommending as a solution to this?

Dr. DANIELS. Well, we are not taking a position today—

Mr. MATSUI. I understand that.

Dr. DANIELS.—but what I can say to you is just to keep in mind that the blind SGA is currently indexed by statute—

Mr. MATSUI. Right, but not the balance of the disabled.

Dr. DANIELS.—but the balance of our beneficiaries have an SGA amount fixed at $700 a month, which can be changed by regulation.

Mr. MATSUI. Right. Okay. Well, I don't have anymore questions in this area. I sense that the real way we probably will have to address these issues when we deal with Social Security comprehensively, that is my belief given the fact that we have a lockbox, and then given the fact that the surplus is not as large at this time, and we obviously don't want to use on-budget surpluses. Is that a correct analysis of the position today?

Dr. DANIELS. The President is very eager to sign a clean bill on the retirement earnings test, and a decision to change substantially the role and function of the disability program, which the SGA is a very significant part of, is possible, but requires a great deal of conversation and financial analysis.

Mr. MATSUI. Thank you. Thank you very much.

Dr. DANIELS. You are welcome, Mr. Matsui. Thank you.

Chairman SHAW. Dr. Daniels, I have a number of questions here that have been supplied by staff that I would like to read to you, and if you could answer, we would appreciate it.

What is substantial gainful activity? You mentioned that SGA is a "critical threshold" in disability evaluation. Would you explain what we mean when we talk about substantial gainful activity? What would it mean to have a "disability" program that does not consider ability to work and the earnings as a test of whether someone is disabled?

Dr. DANIELS. Well, I think it is really—the words "substantial gainful activity" are a lot of big legal words for the notion of work and ensuring work.

When individuals pay Social Security payroll taxes, what they are getting is not only an opportunity to have income when they retire, but if they are unable to work because of a disability, an opportunity to have their income replaced. So the notion is that people of working age should work if they can, but if they can't they are insured against the loss of income due to disability.

So, our first question when we evaluate whether or not a person is eligible for Disability Insurance benefits, is to ask it they are working. And SGA is just a way of determining if a person is really earning a real income, not just a token income from some hobby or some small activity, but substantial activity that produces a real income.

That amount is set for blind individuals by statute, by the Act itself. For all other people with disabilities who apply, we set that amount by regulation. We assume that if a person today is earning less than $700 a month, they are not doing substantial gainful activity, or that is they are not really working enough to support themselves. And if they have a mental or physical impairment, they become eligible for the program.

For individuals who are blind, however, the amount is $1,170 a month because that is what the statute has established. We do not set that by regulation.

So, basically, the question is, do we want to have a test for work? Do we want to say that we provide income security for individuals because they are unable to work in their working years? And that pretty much is the question about SGA.

Now, it is possible to have a program where people simply get a benefit based on a limitation that they might have and whether or not they work, but that has never been the role of the Social Security Disability Insurance program. That would be a supplement—or sometimes in other countries called the "disability allowance." That is a different kind of program, and the effect of removing SGA is basically to say that an individual with a significant impairment would simply be eligible based on that impairment, whether or not he or she is they are able to work.

Chairman SHAW. Thank you. Mr. Collins?

Mr. COLLINS. Dr. Daniels, how does the SGA differ from the earnings limit for seniors?

Dr. DANIELS. Well, today, it is not linked. In 1996, with the Contract with America Advancement Act, the SGA for blind individuals and the retirement earnings test were de-linked. They were no longer tracking together in the legislation. But the SGA for blind individuals was indexed to average wage growth. And the growth of the retirement earnings test from 1996 to the year 2002 was greater than it would have been had it been indexed.

So, in other words, the individuals who are blind, their SGA is not growing as fast as the retirement earnings test under current law.

Mr. COLLINS. What is the difference in the principle behind it—not the dollar amount? Why is one set at one rate, or fee, or check, or benefit, than another one? Why do you do these things?

Dr. DANIELS. Well, I think that would be a good question for me to ask you because I didn't do those.

Mr. COLLINS. Why did I do that?

Dr. DANIELS. I don't know why you did, but let me see—let me take a good guess, Mr. Collins. When we think about social insurance, we are thinking about individuals paying in together so that they can insure themselves against loss of income either due to aging because they are elderly, or due to disability, the inability to work during their working years. And I think that is a very wonderful idea, that we all pull together to take care of those who need income when they are elderly and should expect to get some of that back, or who in their working years are unable to work.

Now, when we say that we would eliminate a retirement earnings test for the elderly, what we are saying is that even if you don't have to work or you are retired, you can work if you can. But we know that a lot of people, as they get older, find it very difficult to work full-time or to work consistently, and we are not expecting people who are retirement age to actually be able to continue to work full-time; whereas, with the younger population, we expect all those who can work, to work.

And so the SGA amount for people in their working ages can be different because its purpose is to say that we only give our benefits to individuals who are not able to work with their impairment.

Now, some people are able, regardless of their impairment, to work, but some are not. And so SGA—the substantial gainful activity test—becomes a way of saying, "Well, if you can work, you should work; but, if you can't, this program is here to help you".

Mr. COLLINS. I have talked to constituents who are blind, and they have expressed they don't feel like there should be a total repeal, that there should be some limit, do you agree with that?

Dr. DANIELS. Well, I certainly think that some people believe that if you go to work, the way the program has a "financial cliff"—after a year your benefits completely end—is quite problematic. And in the Ticket to Work and Work Incentives Improvement Act that you passed last year, you directed the Social Security Administration to do some demonstrations, to test out different ways of making that "cliff" a "ramp" so that people could ease off, and we are preparing—very, very actively preparing to begin those demonstrations. I hope in the next few years we will have a good answer for you on that question.

Mr. COLLINS. Well, that seems to be the answer because I see where, with the cliff, it totally can disrupt an individual's life. Okay. Thank you, ma'am.

Chairman SHAW. Mr. McCrery?

Mr. MCCRERY. Thank you, Mr. Chairman. I know we have a vote, and I apologize for being late.

Chairman SHAW. Do you wait until after the vote, or do you want to go ahead now?

Mr. MCCRERY. Well, I am mainly interested—and I understand Mr. Matsui pursued this, I am sorry I wasn't here—but I would like for you to explain, if you can, why there is a difference in the amount of income allowed blind disabled and the amount of income allowed nonblind disabled, if you can. Could you touch on that? The rationale, the policy rationale for that.

Dr. DANIELS. Well, the rationale and the why might not be exactly the same. The why is that the SGA for blind individuals is set in the statute itself, by law. The SGA, substantial gainful activity, amount for nonblind beneficiaries is set in regulation. Now, that is the way the current provisions are structured.

So the reason that the SGA for the blind is what it is and indexed to average wage growth is because the Act says it should be, and the Act is silent on the SGA amount for nonblind, or how it is handled in terms of growth. So, that is the technical answer. If that satisfies you, that is fine.

Mr. MCCRERY. No, it doesn't.

Dr. DANIELS. There is a philosophical answer as well, and that has to do with the function of the retirement earnings test and the function of SGA. SGA assumes, or the Disability Insurance program assumes that people of working age who can work, should work. But we know that some people can't work. Some people can't work because of impairments—that is, they have a health condition or a functional limitation that makes it impossible for them to work. Those people receive Disability Insurance. They receive that when they are unable to work, and that is a great safety net because that happens to many workers, that they are unable to work. However, it is not the same thing as being retired. It is not the same policy.

We provide retirement income to people when they reach a certain age, based on the average—

Mr. MCCRERY. Maybe I didn't make myself clear. I am interested—

Chairman SHAW. Let me interrupt, if I may. If you could mull over that question, we will come right back. We are going to have to recess—

Mr. MCCRERY. Let me restate the question so she can mull over the question that I want her to answer. The thing I am interested in is the difference between the earnings limit, if you will, or the SGA limit for blind disabled as opposed to nonblind disabled. Never mind the Social Security retirement, I understand why there is a difference there. I want to know the policy rationale for the difference between blind disabled and nonblind disabled, and what each of those categories can earn without losing their benefits.

Dr. DANIELS. I will focus on that when you come back.

Chairman SHAW. And with that, stay tuned for that answer. We will return in approximately 15 minutes.[Recess.]

Chairman SHAW. We had a real cliffhanger, and we were waiting for Dr. Daniels to reply to Mr. McCrery.

Dr. DANIELS. I guess the question is, is this my final answer, right? [Laughter.]

Dr. DANIELS. Mr. McCrery, I gave some thought to the question that you asked, and I actually consulted here with my colleagues and some members of the advocacy community, and I think here the answer goes something like this.

The SGA for blind and nonblind were the same from the beginning of this program to 1978. And that is when the split began.

I would imagine when the time of the split was made—and I wasn't there, and I wasn't in Congress at the time—but I would imagine that what that split represented to the Congressmen who made that split was a recognition that individuals with blindness have very significant and very serious impediments in getting in the workforce, and great need.

Now, it would be hard today, looking at the changes in technology and the advancements in education for people with disabilities to actually—and I think you will hear testimony today about whether or not research supports that assumption—but I would imagine that this was done in good will—that is, to recognize and support some people who have a very, very significant impairment, and it was probably done on the basis of that good will and that notion that they are unique and uniquely disabled and uniquely disadvantaged by their impairment.

Mr. MCCRERY. Well, thank you for that answer. Have you thought about the fact that blindness is easily—the disability of blindness is easily ascertained, it is easily discovered, it is easily provable, as opposed to some other forms of disability that are more subjective in terms of medical analysis? Is that possibly part of—

Dr. DANIELS. There are some impairments that are very easy to discern, even to the layman. For instance, I use a scooter and that is fairly easy to discern. And people who have very significant hearing impairments are very easy to discern. And there are other impairments that are more difficult to discern—heart condition, diabetes, et cetera.

I don't know if that would explain the difference in the amount itself, or linking one to the retirement earnings test and not another. But I imagine it was done on the basis of some notion of good will and assistance to people who are obviously in need.

Mr. MCCRERY. Do you support the difference? Do you think that there is—would you recommend to us policymakers that we maintain a difference in the earnings limit, so to speak, for blind disabled and nonblind disabled?

Dr. DANIELS. I think that the road you are going down now is the most judicious, to listen to the constituencies and to hear from people about this difference, and to have the GAO look at the research.

I will not be in the same position to have gathered all that information that you have. We have not taken, in the Administration, a position on this, but you are certainly going to hear from your customers, from people with disabilities of various kinds, and from the GAO, and I think that is the way to go. Take a look at it from all sides, and make up your own mind.

Mr. MCCRERY. Thank you, Ms. Daniels.

Chairman SHAW. Mr. Portman.

Mr. PORTMAN. Thank you, Mr. Chairman, and commend you for what you did last year on the Ticket to Work, which was very helpful, but I know you would like to do more to ensure that all disincentives are removed to work.

Dr. Daniels, I was just listening to your response to Mr. McCrery. I am not sure that I understand the Administration's position, and looking at your testimony I wanted to ask a question, if I could. I don't think you will need a lifeline for this one.

Dr. DANIELS. Thank you. My mother is standing by.

Mr. PORTMAN. Okay. You can call or you can poll the audience, but—[Laughter.]

Mr. PORTMAN. This is sick, isn't it? We are all spending our time watching these shows instead of watching C–SPAN and these interesting hearings.

Does the Administration take a position with regard to differential treatment? I know you say you haven't done some of the research and so on, but in looking at your testimony, it says "Our commitment is to make ever effort to enrich the lives of all people with disabilities and to help all those who want to work to do so".

And I just wonder, are you implying there that all people with disability should be treated equally when it comes to incentives to work and, if so, do you have any specific suggestions for this Subcommittee as we grapple with this issue? What is the Administration's position?

Dr. DANIELS. Well, the Administration has no position on this particular piece of legislation, but there is some guidance, I think, that I can offer you in terms of thinking about it.

You have asked the right questions, I think, of the GAO, and I think your question of me, is this disparate treatment fair? It is not necessarily fair to treat everyone alike. Some people have greater need. And we recognize that in the SSI program when people are able to work some, their check is reduced $1.00 for every $2.00 that they earn, and that is a recognition that some people can do more for themselves.

We don't think that "identical" is the same thing as "fair". You are about to evaluate whether or not this disparate treatment is based on some rational facts about the special circumstances of individuals who are blind. That makes sense to me. And you will draw your own conclusions about that. I think that the worst thing to do is to think that "identical" is the same thing as "fair," and I don't think it is.

Mr. PORTMAN. Well, I appreciate that guidance. I think it would be helpful if we could get a specific answer to this legislation from the Administration because you all do have a lot of research and resources, and have obviously the responsibility of administering these programs.

I would just make the general comment that just as we have run into the earnings limit issue with Social Security, ages 65 to 70, so we have run into it on this issue. And back home we have a wonderful organization called the Clovernook Center for the Blind, and they do a lot of work. They produce for the Federal Government and for the private sector lots of material including Braille editions of general readership magazines that go around the country. And they have had a hard time keeping and attracting blind and disabled employees because people worry about how it will affect their Social Security Disability benefits, which is very similar to what we all hear back home on the earnings limit on Social Security.

And just last week, in fact, two constituents came to see me, both of whom are active members of the American Council of the Blind and are blind themselves, and talked about that in very personal terms. They want to work, but they feel they can't afford to.

So, I do think this is an issue that the Ticket to Work helps a lot, but our work is not yet done. And, again, I think it would be very helpful if the Administration could give us some more specific guidance as we work through this. Thank you, Mr. Chairman.

Chairman SHAW. Mr. Hulshof.

Mr. HULSHOF. Thank you, Mr. Chairman. Dr. Daniels, welcome. I want to make a point, and I think it is worth noting, that individuals with disabilities can actually earn more than the limits but then stay eligible, and the reason is that they can subtract work expenses that are related to their disability in determining their earnings subject to the limit, although this sounds to me like an administrative nightmare.

I guess my question is, first of all, how many individuals who are blind take advantage of these deductions to earn more than the $1170 a month limit, do you know offhand?

Dr. DANIELS. Actually, I do know, and I have it on a sheet of paper here and I am going to take a look at it and answer that question for you. But the blind work incentive deduction is a little bit more liberal than the other, for the impairment-related work expenses. The impairment-related work expenses for nonblind have to be impairment-related whereas the work expenses for individuals who are blind can be any work expense. So, it can be a reader, or the care of a guide dog, or special transportation, but it also can be union dues, or uniforms, or any of the expenses of work can also be deducted. So that is a more liberal standard than for the nonblind.

Hold on a second, I am going to look that up for you. It is hard to compare apples and oranges here because we have work incentives in the SSI program, work incentives in the Disability Insurance program, and we have concurrent beneficiaries, so you are right, it is a pretty complicated picture.

But we have about 75 percent of blind DI individuals are not posting any kinds of earnings and are probably not using any of the work incentives, and about 13 percent of them are posting earnings under $6,000 a year. Nine percent are posting earnings at about between $6–12,000 a year, and 3 percent are posting earnings over $12,000 a year. So, 75 percent of our blind beneficiaries are not using the work incentives at all.

Mr. HULSHOF. Does SSA ever determine that expenses are “not reasonable” and, if so, what happens then?

Dr. DANIELS. Well, certainly, when they are not reasonable, but we would then give an explanation to the beneficiary of why an expense is not considered reasonable.

But we really do want to encourage people to tell us what their expenses are so that we can assist them in getting the maximum from the work incentives, and as good a start on that employment track as we can help them do.

Mr. HULSHOF. Do you have, maybe in the numbers in front of you, how many people actually file for these work incentives? I mean, you have told us how many qualify. Do you happen to have those numbers, or can you get them to us later?

Dr. DANIELS. Yes, we can get them to you for the record, as best we can.

[The information follows:]

For work expenses for either DI or SSI beneficiaries, no formal claim is filed that SSA would keep track of. These issues come up in the ordinary course of claims development and work reviews. We can deduct all, some, or none of the claimed expenses, but we do not track these categories. Often, the amount of expenses would be immaterial to the case, such as when earnings are below SGA without considering expenses. In any event, processing instructions indicate that the work expense provisions should be liberally construed.

In December 1999, about 4,000 SSI recipients reduced their countable earnings through the Blind Work Expense provision. The average amount of the blind work expense was approximately $250.

Mr. HULSHOF. The other issue as we have been talking about, in 1977 the separate substantial gainful activity limit was established, and the new limit was increased annually for the blind to reflect average wage growth, and because average wages grow faster than prices, this SGA limit also has grown faster than inflation. In contrast, the SGA limit for individuals with other disabilities is not automatically adjusted either for prices or wages, and as a result the SGA limit for those who are not blind has fallen behind.

Now, I recognize that the Administration just increased that limit from $500 to $700 a month last year. When was the last increase prior to 1999, if you know, Dr. Daniels?

Dr. DANIELS. Yes, I do know, it was in 1990. It was raised from—the two most recent changes was from 1980 to 1990, it went from $300 to $500. It was $300 in the entire decade of 1980. In 1990, it went to $500, and in 1999 to $700.

Mr. HULSHOF. And do you anticipate any further increases for those who are not blind?

Dr. DANIELS. When we put out the regulation, the Notice of Proposed Rulemaking for raising the SGA to $700, we asked individuals for comments on all other aspects of SGA for nonblind, and we received many, many comments. Those are under consideration and analysis, at this time.

Mr. HULSHOF. Thank you, Dr. Daniels. Thank you, Mr. Chairman.

Mr. MCCRERY. Mr. Chairman, may I follow up just very quickly?

Chairman SHAW. Yes, go ahead.

Mr. MCCRERY. Did the Administration make a cost estimate when you increased it from $500 a month to $700 a month?

Dr. DANIELS. Yes, we did.

Mr. MCCRERY. And what was that?

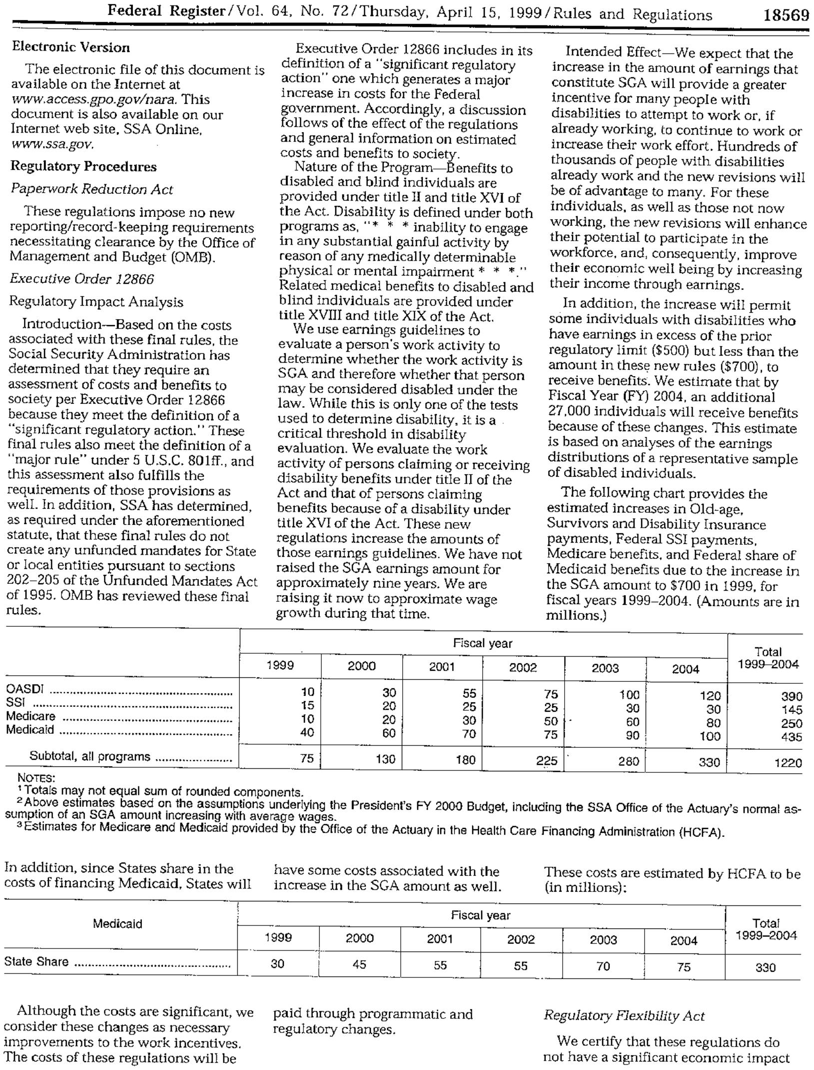
Dr. DANIELS. I am going to have to look over here to my colleagues because I have a number in mind, but I want to check it.

We did make a cost estimate it was included in the baseline, in OMB.

Mr. MCCRERY. Can you get for us maybe the analysis and show us how much that cost was estimated to cost over, say, five years or ten years?

Dr. DANIELS. Okay. We certainly will, we will submit it for the record.

[This information follows:]



Federal Register/Vol. 64, No. 72/Thursday, April 15, 1999/Rules and Regulations 18569

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Regulatory Procedures

Paperwork Reduction Act

These regulations impose no new reporting/record-keeping requirements necessitating clearance by the Office of Management and Budget (OMB).

Executive Order 12866

Regulatory Impact Analysis

Introduction—Based on the costs associated with these final rules, the Social Security Administration has determined that they require an assessment of costs and benefits to society per Executive Order 12866 because they meet the definition of a "significant regulatory action." These final rules also meet the definition of a "major rule" under 5 U.S.C. 801ff., and this assessment also fulfills the requirements of those provisions as well. In addition, SSA has determined, as required under the aforementioned statute, that these final rules do not create any unfunded mandates for State or local entities pursuant to sections 202–205 of the Unfunded Mandates Act of 1995. OMB has reviewed these final rules.

Executive Order 12866 includes in its definition of a "significant regulatory action" one which generates a major increase in costs for the Federal government. Accordingly, a discussion follows of the effect of the regulations and general information on estimated costs and benefits to society.

Nature of the Program—Benefits to disabled and blind individuals are provided under title II and title XVI of the Act. Disability is defined under both programs as, "* * * inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment * * *." Related medical benefits to disabled and blind individuals are provided under title XVIII and title XIX of the Act.

We use earnings guidelines to evaluate a person's work activity to determine whether the work activity is SGA and therefore whether that person may be considered disabled under the law. While this is only one of the tests used to determine disability, it is a critical threshold in disability evaluation. We evaluate the work activity of persons claiming or receiving disability benefits under title II of the Act and that of persons claiming benefits because of a disability under title XVI of the Act. These new regulations increase the amounts of those earnings guidelines. We have not raised the SGA earnings amount for approximately nine years. We are raising it now to approximate wage growth during that time.

Intended Effect—We expect that the increase in the amount of earnings that constitute SGA will provide a greater incentive for many people with disabilities to attempt to work or, if already working, to continue to work or increase their work effort. Hundreds of thousands of people with disabilities already work and the new revisions will be of advantage to many. For these individuals, as well as those not now working, the new revisions will enhance their potential to participate in the workforce, and, consequently, improve their economic well being by increasing their income through earnings.

In addition, the increase will permit some individuals with disabilities who have earnings in excess of the prior regulatory limit ($500) but less than the amount in these new rules ($700), to receive benefits. We estimate that by Fiscal Year (FY) 2004, an additional 27,000 individuals will receive benefits because of these changes. This estimate is based on analyses of the earnings distributions of a representative sample of disabled individuals.

The following chart provides the estimated increases in Old-age, Survivors and Disability Insurance payments, Federal SSI payments, Medicare benefits, and Federal share of Medicaid benefits due to the increase in the SGA amount to $700 in 1999, for fiscal years 1999–2004. (Amounts are in millions.)

	Fiscal year						Total 1999–2004
	1999	2000	2001	2002	2003	2004	
OASDI	10	30	55	75	100	120	390
SSI	15	20	25	25	30	30	145
Medicare	10	20	30	50	60	80	250
Medicaid	40	60	70	75	90	100	435
Subtotal, all programs	75	130	180	225	280	330	1220

NOTES:

[1] Totals may not equal sum of rounded components.

[2] Above estimates based on the assumptions underlying the President's FY 2000 Budget, including the SSA Office of the Actuary's normal assumption of an SGA amount increasing with average wages.

[3] Estimates for Medicare and Medicaid provided by the Office of the Actuary in the Health Care Financing Administration (HCFA).

In addition, since States share in the costs of financing Medicaid, States will have some costs associated with the increase in the SGA amount as well. These costs are estimated by HCFA to be (in millions):

Medicaid	Fiscal year						Total 1999–2004
	1999	2000	2001	2002	2003	2004	
State Share	30	45	55	55	70	75	330

Although the costs are significant, we consider these changes as necessary improvements to the work incentives. The costs of these regulations will be paid through programmatic and regulatory changes.

Regulatory Flexibility Act

We certify that these regulations do not have a significant economic impact

Mr. MCCRERY. Thank you.

Chairman SHAW. Thank you, Dr. Daniels. We appreciate your being here with us. As usual, you gave us a very open and very clear view of your responsibility.

[The following questions submitted by Chairman Shaw, and Dr. Daniels' responses, are as follows:]

1. About 100,000 individuals who are blind receive DI benefits. About 12% earn more than $500 per month; only 1% return to work each year. So if SGA was repealed for those who are blind, no more than 12,000 and probably more like 1,000 people on the rolls would be helped. Is that a fair as-

sessment? How many individuals who are blind are currently working and NOT receiving disability benefits? If SGA, were repealed, how many individuals would be eligible for DI benefits? Is it fair to say that repealing SGA would primarily help those who are NOT now receiving disability benefits? Does that make sense, given the DI program's financial prospects?

It is fair to say that removing the SGA limit for blind individuals would have only a small program effect with respect to current DI beneficiaries.The much more substantial program effect is the entry onto the rolls of new beneficiaries.

It is difficult to estimate the number of blind individuals who are currently working and not receiving DI benefits. According to the testimony of the General Accounting Office, about 30 percent of working-age blind individuals are employed.

We estimate that removing the SGA limit for blind individuals would cause an additional 55,000 people to become eligible for DI benefits, with 5-year costs of $2.6 billion and long-term costs of 0.03 percent of taxable payroll, which would have a distinct negative impact on long-term solvency. Almost all of this would go to individuals not currently receiving DI benefits. As to whether such a change should be considered, any consideration of this and other program changes should be done in the context of Social Security solvency legislation.

2. One of the work incentive provisions in current law is the ability to subtract the value of impairment-related work expenses from earnings before determining whether these earnings are substantial gainful activity. How many SSDI beneficiaries receive the benefit of this work incentive provision? Of this number, how many are statutorily blind?

We do not track that data. We know from reports from our field office employees that only a relatively small number of DI beneficiaries use impairment-related work expenses to reduce their earnings below SGA, too small a number to justify building a special system to capture this information.

Chairman SHAW. We now have the next panel which I inappropriately called up a few moments ago. Barbara Bovbjerg is the Associate Director, Education, Workforce and Income Security Issues, and we have her accompanied by Carol Petersen, if the witnesses would take their seats. And I apologize again for trying to put everybody on the same panel. That was not my intention, it was my not looking at a few asterisks on the schedule which separated the two panels. You may proceed.

STATEMENT OF BARBARA D. BOVBJERG, ASSOCIATE DIRECTOR, EDUCATION, WORKFORCE AND INCOME SECURITY ISSUES, HEALTH, EDUCATION AND HUMAN SERVICES DIVISION, U.S. GENERAL ACCOUNTING OFFICE; ACCOMPANIED BY CAROL PETERSEN, ASSISTANT DIRECTOR, EDUCATION, WORKFORCE AND INCOME SECURITY ISSUES; HEALTH, EDUCATION AND HUMAN SERVICES DIVISION

Ms. BOVBJERG. Good morning, Mr. Chairman, Members of the Subcommittee. I am Barbara Bovbjerg, from the GAO, and I am happy to be here today with my colleague, Carol Petersen, to discuss the Disability Insurance program's substantial gainful activity level for the blind.

The DI program requires disabled applicants to demonstrate they cannot earn more than the SGA both to enter DI and to remain in the program. Since 1977, the SGA for the blind has been higher than for those with other disabilities, and consideration is being given to raising the SGA level further.

I would like today to focus on two aspects of this question. First, to what extent the blind face different employment circumstances than those with other disabilities; and, second, the potential impact of raising or eliminating the SGA for the blind on work effort, trust fund costs, and the DI program overall. My testimony is based on prior work that we have done on circumstances of blind beneficiaries and on our overall body of work in the disability program.

First, the blind and barriers to employment. Proponents for higher SGA levels for the blind have suggested three ways in which the blind are at a greater disadvantage than other disabled individuals—lower employment rates, lower wages when they are employed, and higher work-related costs. They believe that these relative disadvantages are so great that the SGA for the blind should be higher to make the difficult search for employment more attractive to blind beneficiaries.

There are few empirical studies that consider whether the blind are indeed more disadvantaged than those with other disabilities. And among those few studies, there is little to suggest that the blind are unique among the disabled population. My written statement presents the data we found, and it suggests that many disabled individuals, blind and nonblind, face barriers to obtaining well-paying jobs, and many experience significant work-related costs.

I would like to turn now to the potential effects of raising the SGA for the blind on work effort, cost to the program and the trust fund, and on the nature of the program itself.

Increasing the SGA may indeed motivate current blind beneficiaries to seek and obtain work, and this should represent a positive step toward increased integration with society and the enhanced self-esteem associated with the work experience. But raising the SGA would also make the DI program more generous and thus more costly. This is because the number of beneficiaries could be expected to rise. Some disabled individuals already working would join or rejoin the rolls, and those already on the rolls would retain eligibility longer than would otherwise be the case.

As beneficiary rolls grow, DI costs would rise, and that is worse than the projected financial outlook for the Social Security trust funds. For example, if the SGA for the blind is reset to today's retirement earnings limit of $17,000 a year—and I say today knowing that we are about to change that—Social Security actuaries estimate that it would cost the trust funds $2.7 billion over the next ten years.

Although this worsens 75-year solvency projections for the trust funds only relatively slightly, it still would worsen the financial outlook in a system already facing a $3 trillion actuarial deficit. Eliminating rather than raising the SGA would, of course, have even greater financial impact. Actuaries estimate that these costs would rise $6.8 billion over a ten-year period.

Eliminating the SGA also has the potential to change the DI program in fundamental ways. Historically, the program has insured workers against reduced earnings due to impairment. Without an SGA standard, DI benefits would be offered to blind individuals regardless of their earnings. Although this measure may encourage current beneficiaries who can work to work and earn more, it would pay the same benefits to people who earn a lot as to those who earn a little or nothing.

Breaking the connection between ability to work and eligibility to receive DI benefits would represent a fundamental change in the nation's Disability Insurance policy and should be recognized as such.

In conclusion, raising the SGA for the blind could increase work participation among blind beneficiaries, but would raise program costs and could widen differences in the program's treatment of the blind and the nonblind, even though both groups face barriers to obtaining well paying jobs. Eliminating the SGA for the blind would have these same effects, but more broadly, and would fundamentally change the program.

There are a number of ways to approach incentives to work, some of which are being tested as part of the Ticket to Work and Work Incentives Improvement Act. Such other incentive approaches also have the potential to increase work among disabled individuals without altering the fundamental purpose of the DI program structure and deserve consideration as well.

That concludes my statement, Mr. Chairman. Dr. Petersen and I are available to answer any questions.

[The prepared statement follows:]

Statement of Barbara D. Bovbjerg, Associate Director, Education, Workforce and Income Security Issues, Health, Education and Human Services Division, U.S. General Accounting Office

Thank you for inviting me here today to discuss the substantial gainful activity (SGA) level established for blind beneficiaries of Social Security Disability Insurance (DI). The DI program provides monthly cash benefits to workers who have become severely disabled and to their dependents and survivors. In addition, Medicare coverage is provided to DI beneficiaries after they have received cash benefits for 24 months. In fiscal year 1999, about 6.5 million beneficiaries received DI benefits amounting to $50.4 billion. Of these, about 100,000 qualified because of statutory blindness. [1] The average benefit paid to disabled workers was $734 a month in December 1999. In addition to providing evidence establishing their medical impairment, individuals must demonstrate that they are not earning above a certain amount—known as the SGA level—in order to qualify for and maintain eligibility for DI benefits.[2] Since 1977, the SGA levels have been higher for blind than for nonblind DI beneficiaries, and until recently the level for the blind was set equal to the earnings limit for Social Security retirees.

Today I would like to focus my remarks on (1) the differences in employment circumstances affecting people with blindness compared with those affecting people with other disabilities and (2) the potential impact of changes in SGA levels on the DI program and on the Social Security trust funds. My testimony updates and expands on our prior work on the circumstances of blind beneficiaries and on our body of work examining the DI program and SGA levels.[3]

In summary, higher SGA levels have been established for blind beneficiaries primarily on the basis of the assumption that certain adverse economic consequences associated with blindness are unique. Few empirical studies have compared the work-related experiences of blind individuals with those of people who have other disabilities. However, the studies that we reviewed showed many disabled individuals—blind and nonblind—face adverse employment circumstances. Although raising SGA levels for the blind—or even eliminating them—could encourage more blind beneficiaries to work, such changes would perpetuate differences in the treatment of blind and nonblind beneficiaries and could slightly worsen the Social Security trust funds' financial outlook. Moreover, eliminating the SGA level, by removing the

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[1] To meet the statutory definition of blindness for Social Security purposes, a person must have either central visual acuity of 20/200 or less in the better eye with the use of a correcting lens or a limitation in the fields of vision so that the widest diameter of the visual field subtends an angle of 20 degrees or less.

[2] Individuals with disabilities other than blindness must also demonstrate an inability to engage in substantial gainful activity.

[3] See *DI Substantial Gainful Activity Levels* (GAO/HEHS–96–109R, Mar. 20, 1996). Other related GAO products are listed at the end of this testimony.

connection between benefit eligibility determination and the inability to work, would fundamentally alter the purpose of the DI program.

BACKGROUND

From its origin in 1956, the purpose of the DI program has been to provide compensation for the reduced earnings of individuals who, having worked long enough and recently enough to become insured, have lost their ability to work. [4] The program is administered by the Social Security Administration (SSA) and is funded through payroll deductions paid into a trust fund by employers and workers (currently 1.8 percent of payroll for DI).

To qualify for benefits, an individual must have a medically determinable physical or mental impairment that (1) has lasted or is expected to last at least 1 year or result in death and (2) prevents the individual from engaging in substantial gainful activity.[5] Individuals are considered to be engaged in substantial gainful activity if they have countable earnings at or above a certain dollar level. To calculate countable earnings, SSA deducts from gross earnings the cost of items that, because of the impairment, a person needs to work (for example, attendant care services performed in the work setting, wheelchairs, or Braille devices).[6] In addition to determining initial eligibility, the SGA test also applies to determining continuing eligibility for benefits. Beyond a trial work period during which DI beneficiaries are allowed to keep any level of earnings, benefit payments are terminated once SSA determines that a beneficiary's countable earnings exceed the SGA level.

The Social Security Act did not initially distinguish between the SGA levels for blind and nonblind DI beneficiaries.[7] This was changed in 1977 when the Social Security Financing Amendments (P.L. 95–216) set the SGA level for individuals who are blind equal to the monthly earnings limit set for Social Security retirees aged 65 to 69.[8] This link also meant that the SGA level for the blind would be indexed to the average wage index (AWI), a measure of average wages of all employees in the country. Linking the SGA level for the blind to the retirement earnings limit meant that whenever the limit was changed, the SGA level for the blind would change to an equal amount.

The provision for linking the blind SGA level to the retirement earnings limit remained in effect until the Senior Citizens' Right to Work Act of 1996 (P.L. 104–121) was enacted. This act mandated a substantial increase in the monthly earnings limits for Social Security retirees over a 5-year period and removed the link between the retirement earnings limit and the SGA level for the blind but retained the SGA level that was in place at that time as well as the annual indexing to the AWI. Currently, the SGA level for the blind is $1,170 a month of countable earnings.

On March 1, 2000, the House passed H.R. 5, the Senior Citizens' Freedom to Work Act of 2000, which, if enacted into law, would eliminate the earnings limit for retirees between the normal retirement age (currently age 65) and age 70.[9] The Senate passed its version of the bill on March 22, 2000. Currently, recipients aged 65 to 69 can earn up to $17,000 a year without having their benefits affected.[10] For earnings above this limit, Social Security benefits are reduced $1 for every $3 in earnings. The application of this earnings test is generally a deferral of benefit payments to a later time when earnings cease or are lessened. Thus, future benefit levels may be increased as a result of having benefits withheld under the earnings limit. According to SSA's actuarial estimates, eliminating the earnings limit for those reaching the normal retirement age would increase Social Security costs over approximately 20 years but would be negligible over a 75-year period. H.R. 5 explicitly exempts blind DI beneficiaries from the provision that would eliminate the earnings limit.

For individuals who have disabilities other than blindness, the Social Security Act gives the Commissioner of Social Security the authority to prescribe the SGA level by regulation. Over the years, SSA has increased the SGA level a number of times,

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[4] The DI program was established under title II of the Social Security Act

[5] To qualify for benefits, individuals with blindness need only show that they are not earning at the SGA level. Individuals with disabilities other than blindness must also demonstrate an inability to engage in substantial gainful activity.

[6] Deductions can be made only if (1) the cost of the item or service is paid by the person with the disability and (2) the person has not been, and will not be, reimbursed for the expense.

[7] SGA levels were first published in regulations in 1961 and at that time were set at $100 a month of countable earnings.

[8] The 1977 law did not affect SGA levels for nonblind DI beneficiaries.

[9] There is a different earnings limit, as well as a different benefit reduction rate, for retirees aged 62 to 64.

[10] The earnings limit does not apply to those over age 69, and it is increased each year on the basis of indexing to average wages in the economy.

the latest increase occurring in July 1999 when the level for nonblind individuals was raised from $500 to $700 a month of countable earnings. The SGA level for nonblind beneficiaries is not indexed. The current SGA level for the blind of $1,170 a month is about 67 percent greater than the $700 level for people with disabilities other than blindness.

Under the current program, a DI beneficiary may earn any amount for 9 months within a 60-month period and still receive full cash and health benefits. At the end of this trial work period, if a beneficiary's countable earnings exceed the SGA level, cash benefits continue for an additional 3-month grace period and then stop, causing a precipitous drop in monthly income from full cash benefits to none. Such a drop in income is a considerable disincentive to work. Indeed, less than 1 percent of DI beneficiaries return to work each year.

In addition to identifying this "income cliff," our prior work has identified other program design and implementation weaknesses—such as limited referral to vocational rehabilitation services and the eventual loss of medical coverage after cash benefits end—that have been disincentives to work. [11] To help reduce such disincentives, the Congress has, over the years, established various work incentive provisions to safeguard cash and medical benefits while a beneficiary tries to return to work, and recently, SSA has begun to place greater emphasis on assisting beneficiaries in returning to work.

In addition, the Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106–170) is expected to enhance certain work incentives for people with disabilities through such measures as expanding eligibility for Medicare, creating a Ticket to Work voucher program that will allow people with disabilities a greater choice of vocational rehabilitation and employment service providers, and establishing new demonstration projects for the working disabled. This increased focus on work reflects a shift in societal attitudes, as embodied in the Americans With Disabilities Act, toward goals of economic self-sufficiency and the right of people with disabilities to full participation in society. In addition, medical advances, new technologies, and changes in the nature of work now provide people with disabilities more opportunities to work than ever before.

MANY DISABLED WORKERS FACE ADVERSE EMPLOYMENT CIRCUMSTANCES

Proponents of a higher SGA level for the blind believe that blind individuals are at a greater disadvantage, particularly from an economic standpoint, than individuals with other disabilities. According to these proponents, the disadvantages facing blind people include (1) greater employment discrimination resulting in low employment rates; (2) greater likelihood that when able to find work, it will be in a low-wage job; and (3) extra costs for supportive services or equipment that are necessary for the blind to find and maintain employment and conduct other daily activities.

Few empirical studies rigorously compare the experience of blind individuals in terms of employment, earnings, and work-related expenses with the experience of those who have other disabilities. The readily available studies that we reviewed relied on data from the mid–1990s. These studies indicate that many disabled workers—blind and nonblind—face adverse employment circumstances and high job-related expenses.

Estimates from the 1997 Disability Statistics Report, published by the National Institute on Disability and Rehabilitation Research, show that although the 1994 labor force participation rates for adults with visual impairments aged 18 to 64 were low in comparison with the rates for some impairments, these rates were higher than the labor force participation rates for those with other impairments, such as mental illness or emphysema (see table 1).[12]

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[11] See *SSA Disability: Program Redesign Necessary to Encourage Return to Work* (GAO/HEHS–96–62, Apr. 24, 1996).

[12] L. Trupin and others, *Trends in Labor Force Participation Among Persons with Disabilities, 1983–1994,* Disability Statistics Report (Washington, D.C.: U.S. Department of Education, National Institute on Disability and Rehabilitation Research, 1997). This report is based on the most recent available data from the National Health Interview Survey (NHIS). The NHIS, conducted annually by the Census Bureau for the National Center for Health Statistics, is a cross-sectional survey of the civilian noninstitutionalized population of the United States. The labor force participation rate is the primary measure in labor market analysis. It is a measure of everyone in the labor force, including people who have a job, are on temporary layoff, or are looking for work.

Table 1: Labor Force Participation Rates Across Various Impairment Types

Impairment type	Participation rate (percentage)
No disability	83.0
Deafness or hearing impairment in one ear only	80.0
Orthopedic impairments of lower extremity	69.4
Blindness or visual impairment in one eye	69.0
Orthopedic impairments of shoulder and/or upper extremities	68.6
Orthopedic impairments of back or neck	62.5
Intervertebral disc disorders	59.8
Visual impairment in both eyes	59.8
Orthopedic impairment of hip or pelvis	59.3
Hearing impairment in both ears	58.7
Amyothrophic lateral sclerosis	50.1
Malignant neoplasm of female breast	46.4
Toxic poisoning and other adverse effects	46.2
Osteoarthrosis and allied disorders	45.2
Malignant neoplasm of respiratory and intrathoracic organs	45.0
Rheumatoid arthritis and other inflammatory polyarthropathies	44.0
Heart disease, excluding hypertension	41.5
Hypertensive disease	38.2
Multiple sclerosis	36.9
Absence or loss, lower extremity	35.0
Mental retardation/Down syndrome	33.5
Affective psychoses	30.9
Chronic liver disease and cirrhosis	30.7
Cerebral palsy	30.7
Blindness in both eyes	28.9
Mental illness	27.2
Emphysema	27.1
Depressive disorders	25.4
Cerebrovascular disease	23.3
Nephritis, nephrotic syndrome, and nephrosis	20.1
Schizophrenic psychoses	11.9

Source: 1994 NHIS data, reported by National Institute on Disability and Rehabilitation Research.

Data patterns from the 1994–95 Survey of Income and Program Participation (SIPP) are consistent with this finding.[13] The SIPP provides estimates of employment rates and earnings levels of individuals disaggregated by various functional limitations. As shown in table 2, employment rates and earnings of adults (aged 21 to 64) with severe functional limitations were significantly lower than those for adults with no disability. Adults with limitations involving sight had a somewhat higher employment rate than those with limitations involving lifting, walking, or climbing stairs but had a significantly lower employment rate than for those unable to hear normal conversations. Monthly earnings levels of individuals with severe sight limitations were about the same or slightly lower than the monthly earnings for individuals with severe limitations in walking, lifting, and hearing.

Table 2: Employment Rates and Earnings Across Various Functional Limitations

Functional limitation	Percentage employed	Earnings
No disability	82.1	$2,153
Unable to hear normal conversation	59.7	2,047
Unable to see words and letters	30.8	1,252
Unable to lift and carry 10 pounds	27.0	1,536
Unable to climb stairs without resting	25.5	1,257

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[13] John M. McNeil, *Americans With Disabilities: 1994–95,* Current Population Reports, Household Economic Studies, P70–61 (Washington, D.C.: U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, 1997). The SIPP, an ongoing study by the Bureau of the Census of the economic well-being of the civilian noninstitutionalized population, is a nationally representative sample of approximately 30,000 households. Information about disability was collected during the period October 1994–January 1995, which represents the most current available SIPP data regarding employment and earnings of people with disabilities.

Table 2: Employment Rates and Earnings Across Various Functional Limitations—Continued

Functional limitation	Percentage employed	Earnings
Unable to walk three city blocks	22.5	1,346

Source: 1994–95 SIPP data, Census Bureau

Other studies conducted by researchers in academic institutions and by organizations representing the disabled have provided some information on the work-related costs faced by those with disabilities. While comparisons of results across these studies is difficult given the varying focus, methodology, and measures used in each study, the results, in general, indicate that individuals with disabilities other than blindness also incur high work-related costs.

For example, the American Foundation for the Blind and Mississippi State University found that legally blind individuals spent an average of $884 per year on readers, $57 per year on tapes related to reading, $50 per year on recruiting new readers, $469 per year on work-based adaptive devices, and $150 per year on mobility aids. Also, over 50 percent of the legally blind spent less than $500 for devices used at work.[14] In comparison, the literature we reviewed and researchers we contacted indicate that people with severe mental illness may also require many work-related services, including on-the-job coaching, money management assistance, and mental health services. Cost estimates ranged from $1,400 to $3,600 annually for supportive employment services and $3,200 to $7,000 annually for mental health services.[15] In addition, researchers have noted that people with hearing impairments incur costs for interpreter services, telecommunications devices for the deaf, answering machines and ancillary services, retrofitting of items that use sound to operate, and the care of hearing dogs. Researchers have pointed out that most of these items require significant initial and continuing investment.[16]

INCREASING OR ELIMINATING SGA LEVELS COULD INCREASE WORK BUT WOULD HAVE COSTS

Recently, proposals have been put forth that would either raise or eliminate the SGA level for the blind. In particular, proposals raising the SGA level for blind individuals have been focused on restoring the link between this level and the retirement earnings limit that existed from 1977 to 1996.[17] Restoring this link would allow working beneficiaries to keep more of their benefits, thereby reducing a significant disincentive to work. However, SSA estimates of the impact of these possible changes indicate that they all would have some negative effect on DI costs and the actuarial balance of the Old-Age, Survivors, and Disability Insurance (OASDI) trust funds. Moreover, if enacted, the proposals to eliminate the SGA requirement, by removing the connection between benefit eligibility determination and the inability to work, would fundamentally alter the purpose of the DI program.

Increasing or Eliminating the Blind SGA Level Could Increase Work Effort but Would Raise Program Costs

Under the current DI program, earning even one dollar above the SGA level for a sustained period results in loss of DI cash income and Medicare benefits. The prospect of losing cash and health benefits can reduce motivation to work, especially when low-wage jobs are the likely outcome. Increasing or eliminating the SGA level for the blind would reduce this disincentive to work and thus could result in more work effort by blind beneficiaries. However, by making the program more generous, this change would also increase the number of beneficiaries through the effects of both increased entry to and decreased exit from the program. Some working individuals not currently on the DI rolls would be newly eligible to enter the program, and those already on the rolls would be able to increase their work and earnings without losing their eligibility and thus would not exit the program.

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[14] C. Kirchner and others, *Lifestyles of Employed Legally Blind People: A Study of Expenditures and Time Use,* Technical Report (Mississippi State, Miss.: Mississippi State University, Rehabilitation Research and Training Center on Blindness and Low Vision, 1992).

[15] G. Bond and others, “Toward a Framework for Evaluating Cost and Benefits of Psychiatric Rehabilitation: Three Case Examples,” *Journal of Vocational Rehabilitation,* Vol. 5 (1995).

[16] W.A. Welsh, “The Economic Impact of Deafness,” *Journal of the American Deafness and Rehabilitation Association,* Vol. 24, No. 3 and 4 (Jan./Apr., 1991).

[17] S. 285 and H.R. 1601, introduced on January 21, 1999, and April 28, 1999, respectively, both propose to “restore the link between the maximum amount of earnings by blind individuals permitted without demonstrating ability to engage in substantial gainful activity and the exempt amount permitted in determining excess earnings under the earnings test.”

The extent to which these increased entry and decreased exit effects occur will affect DI benefit costs and OASDI trust fund balances. SSA's Office of the Actuary has estimated the financial impact of several options for increasing or eliminating the SGA level for the blind. Ten-year estimates of increased DI benefit payments range from $2.7 billion, if the SGA level for the blind is set equal to the current-law earnings limit for retirees, to $6.8 billion, if the SGA level for the blind is completely eliminated.[18]

Table 3 shows that increasing the SGA level for the blind also would have varying effects on the OASDI actuarial balance, depending upon the proposed option.[19] In discussing these proposed increases, it is important to view their effect on trust fund costs within the context of an already large Social Security shortfall. Under current SSA actuarial projections, the OASDI trust funds will be exhausted in 2034, with the Old-Age and Survivors Insurance trust fund being depleted in 2036 and the DI trust fund being depleted in 2020.[20] Over a 75-year period, the OASDI deficit is currently estimated to be 2.07 percent of taxable payroll—approximately $3 trillion.

Setting the blind SGA level equal to the current-law earnings limit for retirees ($1,416.67 per month)[21] would have a negligible effect, less than 0.005 percent of taxable payroll,[22] on the OASDI actuarial balance. However, other options for increasing or eliminating the SGA level for the blind could reduce the actuarial balance, up to .01 and .03 percent of taxable payroll. Although these proposed increases would have a relatively small impact on the actuarial balance, the trust fund shortfall would be exacerbated under any increase to the SGA level.

Table 3: Estimated Change in the OASDI Actuarial Balance as a Result of Changes in the Blind SGA Level

SGA option	SGA level	Impact on OASDI actuarial balance (as a percentage of taxable payroll)
Set the SGA level for blind individuals equal to the 2000 earnings limit for retirees,[a] and index thereafter	Beginning in 2000, increase the SGA level from $1,170 to $1,416.67, and index thereafter	Less than −0.005
Set the SGA level for blind individuals equal to the 2000 earnings limit for retirees,[a] allowing it to rise to the 2002 limit, and index thereafter	Beginning in 2000, increase the SGA level from $1,170 to $1,416.67, then raise the SGA level through 2002 to $2,500, and index thereafter	–0.01
Eliminate the SGA level	Permit blind individuals to earn any amount and still retain full DI benefits	–0.03

Note: Although the DI actuarial balance is affected by changes in SGA levels, SSA estimated the effect on only the OASDI actuarial balance.

[a] This earnings limit refers to that set for Social Security retirees aged 65 to 69.

Source: SSA Office of the Chief Actuary.

Some advocacy and interest groups representing people with disabilities other than blindness have proposed establishing a uniform SGA level for both blind and nonblind individuals. Because relatively few DI beneficiaries are blind, the DI benefit cost of raising or eliminating the SGA level for the nonblind would be even higher than it would be for the blind, although DI benefit cost estimates for either of these changes were not available from SSA at the time of our review.

However, SSA has estimated the financial impact on the OASDI actuarial balance of various options affecting the nonblind SGA level. Changes in the nonblind SGA

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[18] The short-range estimates cover the period 2000–09.

[19] Although the DI trust fund is affected by changes in SGA levels, SSA only estimated the effects on the combined OASDI trust funds.

[20] The combined OASDI trust funds will be in cash surplus until 2014. At that point, the trust funds will start redeeming some of their assets to obtain the funds necessary to pay benefits, and expenditures will begin to exceed revenues. By 2034, the trust funds will be exhausted; that is, OASDI will meet only 71 percent of its benefit obligations.

[21] This earnings limit refers to that set for Social Security retirees aged 65 to 69.

[22] Taxable payroll is the amount of wages or self-employment income that is subject to the Social Security tax. For long-range forecasting, Social Security's income and costs are expressed as a percentage of taxable payroll. Measuring the program's income and outgo over long periods (75 years) by describing what portion of taxable earnings they represent is more meaningful than using dollar amounts, because the value of the dollar changes over time.

level would have greater adverse effects on the OASDI trust funds than would changes in the blind SGA level. For example, table 4 shows that raising the current nonblind SGA level of $700 a month to that of the blind SGA level of $1,170 a month would significantly affect the OASDI actuarial balance. These effects would be even greater if the SGA level for the nonblind were set equal to the current-law earnings limit for retirees or were completely eliminated. Such changes would represent a significant worsening of an already dire situation.

Table 4: Estimated Change in the OASDI Actuarial Balance as a Result of Changes in the Nonblind SGA Level

SGA option	SGA level	Impact on OASDI actuarial balance (as a percentage of taxable payroll)
Set the SGA level for nonblind individuals equal to the current SGA level for blind individuals	Beginning in 2000, increase the SGA level from $700 to $1,170, and index thereafter	−0.09
Set the SGA level for nonblind individuals equal to the 2000 earnings limit for retirees,[a] and index thereafter	Beginning in 2000, increase the SGA level from $700 to $1,416.67, and index thereafter	−0.15
Set the SGA level for nonblind individuals equal to the 2000 earnings limit for retirees,[a] allowing it to rise to the 2002 limit, and index thereafter. Beginning in 2000, increase the SGA level from $700 to $1,416.67, then raise the SGA level through 2002 to $2,500, and index thereafter	−0.44	
Eliminate the SGA level	Permit nonblind individuals to earn any amount and still retain full DI benefits	Not estimated [b]

Note: Although the DI actuarial balance is affected by changes in SGA levels, SSA estimated the effect on only the OASDI actuarial balance.

[a] This earnings limit refers to that set for Social Security retirees aged 65 to 69.

[b] Although not estimated, eliminating the nonblind SGA level would have the greatest adverse effect on the OASDI actuarial balance.

Source: SSA Office of the Chief Actuary.

Proposals to Eliminate the SGA Level Would Alter the Fundamental Role of the DI Program

Elimination of SGA levels for blind or other disabled individuals would fundamentally alter the purpose of the DI program. The DI program's historic role of providing compensation for reduced earnings due to a disability and the program's emerging role of facilitating severely disabled individuals in their return-to-work efforts are both based on the concept of assisting individuals whose impairments have adversely affected their work capabilities. The very definition of disability includes the requirement that a person be unable to perform substantial work, and the purpose of the SGA level is to determine if, regardless of one's medical condition, a person demonstrates by working that he or she is not in fact work-disabled. Without an SGA standard, cash benefits would be offered to individuals incurring a physical or mental disability regardless of their earnings. Removing the connection between benefit eligibility determination and the inability to work would fundamentally alter the program's emphasis.

CONCLUSIONS

Current proposals ranging from increasing the SGA level for the blind to eliminating it completely would have the likely effect of increasing beneficiaries' work effort but would raise program costs and could widen the differences in the program's treatment of blind and nonblind beneficiaries, even though both groups face adverse employment circumstances. Moreover, raising the SGA level for the blind could result in further calls to increase the SGA level for nonblind beneficiaries, leading to significantly higher program costs and adverse effects on trust fund solvency. In addition, eliminating the SGA level would fundamentally alter the purpose of the DI program. Other changes to the work incentives—some of which are being implemented or will be tested by SSA as a result of the Ticket to Work and Work Incentives Improvement Act of 1999—are likely to increase work without fundamentally changing the nature of the DI program.

Mr. Chairman, this concludes my prepared statement. At this time, I will be happy to answer any questions you or other Members of the Subcommittee may have.

CONTACT AND ACKNOWLEDGMENT

For information regarding this testimony, please contact Barbara Bovbjerg at (202) 512–7215 or bovbjergb.hehs@gao.gov. Individuals making key contributions to this testimony include Carol Dawn Petersen, Mark Trapani, Gretta L. Goodwin, and Michael J. Collins.

RELATED GAO PRODUCTS

Social Security Disability: Multiple Factors Affect Return to Work (GAO/T–HEHS–99–82, Mar. 11, 1999).

Social Security Disability Insurance: Factors Affecting Beneficiaries' Return to Work (GAO/T–HEHS–98–230, July 29, 1998).

Social Security Disability Insurance: Multiple Factors Affect Beneficiaries' Ability to Return to Work (GAO/HEHS–98–39, Jan. 12, 1998).

Social Security Disability: Improving Return-to-Work Outcomes Important, but Trade-Offs and Challenges Exist (GAO/T–HEHS–97–186, July 23, 1997).

Social Security: Disability Programs Lag in Promoting Return to Work (GAO/HEHS–97–46, Mar. 17, 1997).

SSA Disability: Return-to-Work Strategies From Other Systems May Improve Federal Programs (GAO/HEHS–96–133, July 11, 1996).

Social Security: Disability Programs Lag in Promoting Return to Work (GAO/HEHS–96–62, June 5, 1996).

SSA Disability: Program Redesign Necessary to Encourage Return to Work (GAO/HEHS–96–62, Apr. 24, 1996).

Chairman SHAW. Ms. Petersen, do you have a statement?

Dr. PETERSEN. No, I don't.

Chairman SHAW. Mr. Matsui.

Mr. MATSUI. Thank you, Mr. Chairman. I want to thank you for your testimony, Ms. Bovbjerg, for it is very clear and precise and I think pretty much lays it out.

And I know that you probably don't want to make any conclusions here, but are you kind of concluding that for us to really do something, we have to really deal with the fact that maybe we need a comprehensive solution to the Social Security problem; otherwise, we make the Social Security problem worse before we make it better?

Ms. BOVBJERG. Well, I acknowledge that the cost would be small, but it is going in the wrong direction if you are trying to deal with this $3 trillion problem.

Mr. MATSUI. I am not suggesting the cost is so small we should just do it, but I am just saying that, frankly, the way—I think the way we structured our debate—both parties have structured our debate in terms of not tampering with the Social Security surplus, and obviously the on-budget surplus can be used, but we certainly don't intend to move SSI disability and take from that at this moment, anyway. We are left in the position of having to deal with this comprehensively. Is that kind of where we are?

Ms. BOVBJERG. I think that is a good summary, yes.

Mr. MATSUI. In terms of the actual increase in employment for many of the disabled if we do raise the earnings limit, do we get credit for that at all in terms of the budgetary impacts and others?

Ms. BOVBJERG. I am not sure that it would score, and I can't speak to that, you would have to ask my colleagues at the Congressional Budget Office.

Mr. MATSUI. I doubt it would score, that is—

Ms. BOVBJERG. You know that there would be a net effect that some people would work more if the SGA were higher or eliminated, who are currently on the rolls, but there are other people who are not currently on the rolls because they work, who would work less because they would then get benefits plus whatever they were earning.

Mr. MATSUI. Well, I want to thank you for your testimony. As I said, I think you have laid it out very well. It is a decision that we have to make and, obviously, we are kind of caught in a dilemma right now, all of us are.

Ms. BOVBJERG. If we can provide any help, we will.

Mr. MATSUI. I appreciate that. Thank you.

Chairman SHAW. Mr. Collins?

Mr. COLLINS. No questions.

Chairman SHAW. Mr. McCrery.

Mr. MCCRERY. Would you pronounce your name for me?

Ms. BOVBJERG. It is a hard one, it is "Boberg", like "iceberg".

Mr. MCCRERY. Thank you. I have other questions.

Ms. BOVBJERG. I am glad you asked one I could answer.

Mr. MCCRERY. You said in your testimony that if we were to do away with the SGA limit for the blind, that by removing the connection between eligibility and the inability to work would fundamentally alter the purpose of the disability program. I agree with you. But I would like for you to expound on that. How would it fundamentally alter the purpose of the disability program?

Ms. BOVBJERG. Well, first, it would sever the linkage between eligibility and inability to work—that is, to engage in substantial gainful activity. This is a linkage that is intrinsic to the current program. Eligibility for benefits at that point would be determined solely on a medical or functional basis. Everyone meeting those criteria would receive benefits, regardless of how much they work and how much they earn. That removes the concept of disability insurance from the disability program by doing that, and makes it more of a payment for physical impairment. That is something the Congress could decide to do, but as Dr. Daniels stated, I think that is such a significant policy change that certainly we would want to know more about the implications of that on finance and disability policy.

Mr. MCCRERY. In other words, if we were to do away with any kind of earnings limitation, it would undermine the original purpose of the disability program.

Ms. BOVBJERG. Yes, sir.

Mr. MCCRERY. Can you state for us your impression of what the original purpose of the disability program was?

Ms. BOVBJERG. Well, I can, and I hope that Carol will chime in if I don't get everything here, but the Disability program is to insure people who become disabled—who have been in the workforce, who become disabled-against an inability to—and I hate to keep using these words—to engage in substantial gainful activity or an inability to support themselves in some way that we have defined.

Mr. MCCRERY. So, in other words, it was not the Disability program under Social Security—was not intended to simply provide a payment to somebody who becomes disabled, it was to provide a safety net, if you will, for income that if a person is so disabled that he can't work or that his work is very limited, then we want to provide some income so that person can provide food and shelter and so forth, is that correct?

Ms. BOVBJERG. That is right, and I think that there are statements made by members of Congress at the time that the Disability law was passed that say that very explicitly, that we understand that this means that only people with impairments who cannot work will get benefits. That was made very clear.

Mr. MCCRERY. Well, Mr. Chairman, I agree with the analysis—Ms. Bovbjerg—and I think it would fundamentally alter the definition and the purpose of the Disability program if we were to simply do away with any earnings limitation at all, and to do that for the blind disabled may not cost that much to the Federal fisc, but again we get to this question of what would be the rationale, the policy rationale, for not doing the same thing for other categories of disabled, and if we do it for all then it is going to be a huge cost and it would not serve the same purpose that was originally intended by the Congress when this program was created.

So, I think that is a fundamental question that the GAO at least has answered correctly, and I think this Subcommittee and full Committee and full Congress ought to answer the same way. Thank you.

Chairman SHAW. Ms. Bovbjerg, did you touch on the effect that his question would have on the trust fund?

Ms. BOVBJERG. Well, I can tell you that we have received from the actuary information that eliminating the SGA for the blind would reduce—would have an impact, an actuarial impact, the 75-year impact of .03 percent of taxable payroll, which is about $40 billion over 75 years. $40 billion even in the context of $3 trillion is still significant.

Chairman SHAW. If you could address that same question as to what effect it would have on the date that the trust fund runs negative. Now I think it is 2006 on the disability side.

Ms. BOVBJERG. We can get that.

Chairman. SHAW. If you could supply that for the Committee, that is something that I think is a concern of everyone on the Committee. Mr. Hulshof.

Mr. HULSHOF. Thanks, Mr. Chairman. Ms. Bovbjerg, on page 4 of your written testimony and in your oral statement, you talk about the disadvantages that blind people face according to the proponents, and you mentioned that there are really few empirical studies that rigorously compare the experiences of blind individuals as compared with the experience of others. And I have read your synopsis of the 1997 Disability Statistics Report. I know Mississippi State also has a published report.

Are there empirical studies currently being conducted that could rigorously take a look at this to determine, that you are aware of?

Dr. PETERSEN. In the short period of time we had to prepare for this testimony, these were the studies that we could identify, and we could not find any systematic studies looking at costs that exist to date.

Mr. HULSHOF. Could you just briefly—I know your time was limited in your five minutes, but could you maybe expound on what the studies—I mean, I have read this—but could you just summarize for me what at least these studies indicate regarding the blind versus nonblind?

Ms. BOVBJERG. Well, we have three pieces that we have brought into the testimony, and some of this is from work that we did in 1996 on some of these same issues—one involved labor participation rates, another is employment rates and wages, and another piece is on work-related costs. And what you see there is there are differences among impairments, but that really it seemed to us that the point was that different impairments have tremendously adverse employment circumstances. This is not something that is unique to the blind.

And we want to emphasize that we are not saying it is easy to be disabled and get a job, that is not what we are saying, but we are saying that we have not found evidence that the blind are unique in this regard.

Mr. HULSHOF. Regarding those work-related costs, whether for the blind or for those individuals with other disabilities, are they most often borne by the worker? Are they borne by the employer? I mean, how are those costs actually—who bears the brunt of those costs?

Dr. PETERSEN. It varies. Some can be borne by the employer, other costs are borne by the individuals themselves.

Mr. HULSHOF. I think that is all I have. Thank you, Mr. Chairman.

Chairman SHAW. Thank you very much. We appreciate your being with us. If you could supply us with the information I asked you about the trust fund, I would greatly appreciate it. It would add a lot to the discussion. Thank you.

[Questions submitted by Chairman Shaw, and Ms. Bovbjerg's answers, follow:]

Barbara Bovbjerg, General Accounting Office, Response to Questions for the Record

1. Could you elaborate on the types of adverse circumstances faced in today's society by individuals with disabilities?

Research has shown that many disabled individuals-blind and nonblind-face a number of adverse employment circumstances when attempting to return to work. First, employers may be reluctant to hire individuals with disabilities. Although the Americans with Disabilities Act prohibits employment discrimination against the disabled, there is still a stigma associated with disability that may influence employers. This stigma may be related to the misconception that a disabling impairment always adversely affects the individual's productivity. Another cause of employment discrimination may arise from the fact that a disabled employee may require workplace accommodations, which the employer may be unwilling to provide.

Second, for those individuals who do seek employment, the number and type of jobs available may be limited due to the disabling condition. Sometimes a disabling condition will lower a worker's productivity when he or she is unable to perform the same essential tasks of the job as before the disability. This decreased productivity may limit the pool of available jobs to those that require less skill and thus provide lower wages.

Finally, disabled workers incur costs that a non-disabled worker does not incur for supportive devices, equipment, and other work-related services necessary for employment. Examples of these costs include readers and mobility aids for the blind, mental health services for people with severe mental illness, and interpreter services and hearing dogs for the deaf. Most of this assistance requires significant initial and continuing investment.

2. What proportion of beneficiaries work and, among those, what proportion approach substantial gainful activity (SGA) limits?

The Social Security Administration (SSA) has estimated that one half of one percent of all beneficiaries leave the program each year because of work, but this figure does not include beneficiaries who work but do not earn enough to be terminated from the program. According to agency officials we interviewed, SSA is unable to accurately determine the total number of disabled beneficiaries who work. Furthermore, SSA does not have the capability to generate a reliable and valid estimate of the number of disabled beneficiaries who work because the agency data systems cannot distinguish a beneficiary terminated due to a medical improvement from one who is terminated because of work. In addition, an agency official told us that SSA's data systems cannot distinguish work-related earnings from other disability-related payments.

In addition to being unable to accurately determine the number of disabled beneficiaries who work, SSA is unable to accurately determine how many working beneficiaries have earnings that approach the SGA limit. Because an individual can earn any amount in a month without losing benefits when he or she is in a trial work period, SSA does not track the individual's earnings during this period. Once the individual finishes the trial work period, SSA verifies earnings and if the individual is earning above SGA then benefits continue for a three-month grace period and then cease. If an individual has monthly earnings below SGA at the end of the trial work period, then SSA assumes his or her earnings remain below SGA until the individual reports this information or if the agency's data systems identify earnings above the SGA limit.

Although the agency's data systems can identify earnings above the SGA level, there are some limitations associated with this process. Some income classified as earnings may not be from work. In addition, earnings are only reported on a yearly basis, so SSA's data systems will only catch those individuals who earn 12 times the SGA level, which is stated in monthly terms. Therefore, beyond the trial work period, it is possible for an individual to earn above the SGA level for some months, but still retain benefits as long as yearly earnings are less than 12 times the SGA level. An agency official told us that there is no computerized method to identify earnings on a monthly basis.

3. Is raising the SGA limits the right public policy?

Raising the SGA limits for disabled beneficiaries would reduce disincentives to work and could result in greater work effort by beneficiaries. However, as we mentioned in our testimony of March 23, 2000, by making the program more generous, this change would also increase the number of beneficiaries through the effects of both increased entry to and decreased exit from the program. Some working individuals not currently on the Disability Insurance (DI) rolls would be newly eligible to enter the program, and those already on the rolls would be able to increase their work and earnings without losing their eligibility and thus would not exit the program.

The extent to which these increased entry and decreased exit effects occur will affect DI benefit costs and Social Security trust fund balances. SSA's Office of the Actuary has estimated that raising the SGA limit for the blind to the current-law earnings limit for retirees is estimated to increase DI benefit payments by $2.7 billion over a ten-year period. Since relatively few DI beneficiaries are blind, the DI benefit cost of raising the SGA limit for nonblind beneficiaries would be even higher. Raising the SGA limit for all DI beneficiaries would lead to significantly higher program costs and adverse effects on trust fund solvency.

Whether raising the SGA limit represents good policy goes beyond the financial considerations. Fundamental policy weaknesses in the DI program continue to persist. As we have reported in the past, these weaknesses include an eligibility determination process that concentrates on applicants' incapacities, an "all-or-nothing" benefits structure, and return-to-work services offered only after a lengthy determination process. To address these policy weaknesses, we continue to believe—as we recommended in 1996—that SSA should place greater priority on helping disabled beneficiaries return to work. We also recommended that the agency develop a comprehensive strategy to achieve this goal. While SSA has taken actions that place a greater emphasis on return to work, it has yet to adopt an overall strategy for implementing a new approach.

In developing a return-to-work strategy, SSA can draw upon the experiences of other systems to identify elements of a new federal disability system that could help each individual realize his or her productive potential without jeopardizing the availability of benefits for people who cannot work. Having identified these elements, SSA would then be in a position to determine the legislative and regulatory changes needed to test and evaluate the effectiveness of these practices in the federal disability system. After obtaining this information, policymakers will be in a position to determine whether raising the SGA is good public policy.

Chairman SHAW. The next panel we have, includes Ms. Brenda Gillis, a Social Security Beneficiary, and she is from Stuart, Florida, which is just a few miles north of my district; Joanne Wilson, who is the Director of the Louisiana Center for the Blind; Dr. Brenda Cavanaugh, Research Director for the Rehabilitation Research and Training Center on Blindness and Low Vision, of Mississippi State University; James Gashel, Director of Governmental Affairs, National Federation of the Blind, from Baltimore, Maryland.

Mr. MCCRERY. Mr. Chairman, while our panelists are begin seated, if I might take just a minute to introduce Joanne Wilson, from Louisiana. Ms. Wilson has been very active with the Association for the Blind in Louisiana for a number of years, and has constantly worked on behalf of the blind in our state. She has met with me on a number of occasions since I have been in Congress, and has always been extremely helpful in providing good information and, I will say, as much as any other advocate that I have come in contact with over the last 12 years, she has been honest, straightforward, and tried to do her best to not only represent those that she is advocating for, but to be forthright and up-front with the facts and policy rationale, and for that I appreciate it very much. And we are, I think, honored to have somebody of her stature in the blind community here to testify today, and I hope the Subcommittee will pay attention to what Ms. Wilson has to say.

Chairman SHAW. Indeed, we will, and thank you very much. Again, I will repeat, we have everyone's full statement to be made part of the record, and we invite the witnesses to summarize as they see fit, and we will start with Ms. Gillis.

STATEMENT OF BRENDA-ANN GILLIS, SOCIAL SECURITY BENEFICIARY, STUART, FLORIDA

Ms. GILLIS. Good morning. I would like to thank the Committee for inviting me here to testify today. This is a very nerve-wracking experience, but I am honored to be here.

My father always told me that when you need to consider things in life, especially difficult decisions, you should first try to walk in that person's moccasins. So, I suppose my role here today is to try to express to you what my moccasins feel like and encourage you to try to walk in them with me for a few moments.

I am relatively new to blindness. I was declared legally blind in 1994 when my son was two years old. It was a very difficult transition for me, and to this day I still need some blindness skills that I haven't quite mastered yet. Braille is one of them. Otherwise, I would have note cards and be much more organized.

I worked my whole life. I was encouraged to do so from the time I was 15. I picked corn and tomatoes in south Jersey, and I knew that by doing that I was contributing to my government, to my community, and to my future retirement benefits.

When I was declared legally blind, I had held a job that I had enjoyed for 11 years, as the Parish Administrator for the Episcopal Church. In that job, I earned a $30,000-a-year wage and was provided with $5700 a year in medical benefits, and I had $4900 a year contributed into a retirement pension by my parish.

As my sight diminished through the retinitis pigmentosa, which is a degenerative disease of my retina which has slowly robbed my vision and tunneled it down to the point where one day I will have no vision left, I began to realize that it was unfair to my parish for me to continue in my employment as I did not have all the skills I needed, the equipment I needed, and I was rapidly approaching a point in my life where I would no longer be able to drive. After almost having an accident with my three-month-old son in the car, I decided to give up my driving privilege.

As time wore on, my job became more and more difficult for me to do effectively, so I resigned that position. At that point, I applied for Social Security Disability benefits. While I awaited a determination from Social Security as to my eligibility, my family faced the foreclosure of our home. It was a very scary time, having such a young child in the home, and I really didn't know where to turn.

It was shortly thereafter that I became associated with the National Federation of the Blind, and I have since touted this relationship as the best career move I have ever made. I finally found a group of professionals who treated me as an equal and didn't judge me on the basis of my inability to see.

I struggled quite often with my family and friends, not knowing how to handle me under my new set of circumstances. And, finally, the disability benefits arrived. I began my own business. I own Letter Perfect in Stuart, Florida, and do secretarial duties on the side. However, because of the earnings limit imposed upon me as a recipient of SSDI, I have to be very careful as to the types of jobs that I accept and the duration of those jobs and how they affect that income at the end of the month.

The reason for this is, if I earn $14,000 a year, I lose $20,000 of benefits. The loss of that income would then once again place me in the position of facing foreclosure on my home. It is very difficult to juggle in one's mind how to manage a business under these circumstances.

I very much want to work. I do not view my vision loss and my blindness as a reason not to be employed. So, with my benefits at $1715 a month, I encourage you to raise the earnings limit so that I could go back to work and augment my retirement and be made whole with the middle class. I guess that's all. I just heard my tone back here.

My retirement benefit is important to me, and at the current rate I cannot augment that in any way. So, I implore you to consider raising the earnings limit for the blind so that I can compete with the other members of the middle class. I thank you for the time to speak.

[The prepared statement follows:]

Statement of Brenda-Ann Gillis, Stuart, Florida (Social Security Beneficiary)

My name is Brenda-Ann Gillis. I am a 35 year-old wife, mother, business owner and advocate for the blind community of Martin County, Florida. I have lived in my single family home since June of 1986.

First, I would like to thank the committee members for allowing me to share my story. The earnings limit has a direct negative impact on my life and that of my family. I hope that my testimony will illustrate the difficult economic choices blind individuals must face when contemplating work.

Background

I was born with retinitus pigmantosa (RP). My condition was not diagnosed until I entered college in the fall of 1982. Because of the degenerative nature of the disease, my vision was not noticeably affected for some time after the initial diagnosis. As a result, I was able to graduate from college and begin my working career without using any of the adaptive techniques that a blind individual uses. After college a local print shop employed me as their office manager. Eventually I accepted a position as a parish administrator for the Episcopal Church and worked there from 1985 to 1996. As time went on, I found my vision getting worse and worse. Finally I was declared to be “legally blind.” It was difficult to do my job without knowing how to “function” as a blind person. As a result, I had to leave my job.

After leaving my job I applied for Social Security Disability Insurance (SSDI) benefits to which I was entitled. Unfortunately an eligibility determination did not come soon enough. My loss of income resulted in a possible foreclosure on our home. While awaiting a determination by the Social Security Administration, I sought service from the Division of Blind Services in West Palm Beach. I was able to locate an employer who was willing to employ me as a “work at home” sub-contractor and began to operate my own business. Eventually I was awarded disability benefits. My disability benefit coupled with my part-time job, however, does not compensate for the loss of the previous income.

I was frustrated with my new circumstances. I had never noted as a sighted member of society, that the stereotypes associated with blind persons were a large and seemingly unfair invisible barrier that could not be moved or altered with any measure of ease. For me, I had been a visible and active member of my community, but on that day when I was presented with a white cane all my accomplishments of my past seemed to disappear and even my closest friends were struggling with how to handle the person I had become. It was at that point that the decision was made to either give up or start fighting and this is when I came to learn of the National Federation of the Blind. The relationship I have developed with this organization since that time is in my opinion the best career move I ever made. I had finally found a group of professionals who acknowledged the skills and intelligence that I had always possessed but were no longer recognized by my sighted colleagues. So, I set to work at the business of “Changing What it Means to be Blind” everywhere I turned. In the furniture store when the sales woman inquired as to why my friend would bring a blind person to shop for furniture, my friend replied, “. . I bring her along to evaluate comfort and texture.” In a restaurant when the hostess literally grabbed my head and proceeded to demonstrate the proximity of the sconce on the wall to ensure that I would not injure myself. I made a point of contacting the management and requesting the opportunity to come back and place his staff under occlusion and allow them to experience a meal without sight. My resume to employers does not begin with the line “I am a blind applicant,” but when I arrive for interviews the position has undoubtedly been filled in the time it took me to travel to their office. Why then do we always seem to seek new and innovative ways to oppress blind individuals? Is there not enough in the way of daily challenges for our lawmakers to feel it necessary to exclude the blind when they discuss our ability to work and earn a decent living? Please do not take these comments to infer that you are not sensitive, as I am sure you are, but quite frankly, even I did not contemplate the impact being blind has on one’s life until I myself became blind.

Earnings Limit Work Disincentive

The reality for me is that I simply do not view myself as less employable now than I was in 1985 when I was considered to be a “sighted” member of society. The loss of my eyesight did not affect my ability to reason, manage, perform or communicate. My brain did not die. I truly wish to work. I truly am concerned about the need for me to provide for my retirement, my son’s education and actively participate in my community. Unfortunately, because I happen to be blind, some of these goals are not prudent given the current restrictions posed upon my family and myself. The reality is that given the present earnings limits for blind individuals, it is not practical for me to seek employment. Presently I receive monthly checks in the amount of $933.00 for myself, $498.00 for my dependent son and a disability pension from church insurance in the amount of $292.00. This totals $1,715 in monthly benefits of which I pay federal taxes on only one half of the $933.00 and 100% on the $292.00 of 1099–R income. By not working I additionally save the expense of childcare, transportation and insurance, together with all the other routine incidentals associated with leaving my home to work in an office environment. Under this present set of circumstances, I would have to secure a job that paid $35,500 per year to simply break even. At that rate of pay, which would require employment that a blind individual would have to maneuver to secure, I would have no extra money to save for retirement. By not working, the prospect of retirement becomes even dimmer since I am not continuing to contribute to the system which will eventually be charged with providing my only source of income. It has come to my attention that upon reaching the age of 65 my disability pension will be reduced from $292 to $63 per month. When my son turns sixteen I will lose $498 per month. While I am bright enough to comprehend the economic impact of my present circumstances on my eventual retirement, there is simply no way in my mind to prevent the inevitable. If I were to take a job for the average wage of approximately $23,000 per year in our area, I would not only lose my monthly benefits, but I would further be asked to pay taxes of 100% on this earned income. The bottom line is at that rate I would once again face the foreclosure of the mortgage on my home and still have no free dollars to invest in the augmentation of my retirement income. Work at this point would force me to significantly decrease my monthly cash flow.

In closing, I wish to share a bit of reality with those of you who enjoy the privilege of being sighted and all that goes with it. In addition to the inconceivable notion that you would no longer be able to “see” the beauty of all that God has created for our enjoyment, you would also lose the respect you have earned from your peers despite your accomplishments. You would lose the self-esteem that comes with the pride of being employed and rewarded for a job well done. You would lose the privilege of driving and subsequently the loss of your personal freedom to travel when and where you wish to go. And you would face on a daily basis the uninformed and sorely uneducated general public who would view you as a person who deserves their pity and constant assistance. If you were blind, I am certain that you would evaluate your situation and do as I have done, pick yourself up and start fighting for the truth to be revealed. You would realize without a doubt that the only way to effect change under such circumstances is to teach by your example, to earn respect through your accomplishments; and you would be forever transformed into the mind set that the democratic process requires your personal involvement.

Conclusion

Therefore, I ask that you thoughtfully consider what your life would be like if you woke one day to find yourself in my moccasins. Would you view your circumstances as a really good reason to continue in the status quo and never consider the possibility of obtaining a job? Would you view the work disincentives imposed upon you by your government as fair and just? Would you be content to live in this manner when you know the best way to change public perceptions is by doing precisely what others may think is simply not possible for you to do?

If it is your intention to provide an environment that fosters the pursuit of life, liberty, and happiness, then you have no choice than to find a way for blind persons to earn a comfortable way of life. Solutions must be found to make it feasible for us to contribute to our communities and our self-esteem. As the population of the blind and visually impaired grows across our nation we must find ways to ensure that they are accepted as functional members of society and not simply brushed aside or ignored as a dirty little secret. It is inconceivable to me to imagine that here in the land of freedom, the home of the brave, we find ourselves too fearful of the consequences to do what we know in our hearts to be the right thing. If we are to tout the virtues of independence then we need to ensure that every citizen is afforded the independence necessary to succeed and prosper here and now in the United States. This is precisely why I traveled here today. I truly appreciate the opportunity to express to each of you why it is imperative that you increase the earnings limits of the blind to the extent that the blind of our nation can be made whole. If provided a limit of earnings that will afford me the opportunity to actually seek employment that would place me in a position of equality with the middle-class citizens who are considered to be “able-bodied,” then I promise to each of you I would happily welcome the chance to avail myself to being the responsible citizen who works hard to earn all the benefits and privileges associated with living in our free country. It has truly been an honor to address you today, and I will leave our Capitol now with the knowledge that you have carefully listened to my personal story and will seriously consider the impact the choices you make today will have on at least one blind person from the state of Florida who stood before you praying that you will listen to your hearts and do that which is only right and just. Thank you.

Chairman SHAW. Thank you, Ms. Gillis. Ms. Wilson.

STATEMENT OF JOANNE WILSON, DIRECTOR, LOUISIANA CENTER FOR THE BLIND, RUSTON, LOUISIANA

Ms. WILSON. Thank you, Congressman McCrery, for your kind words. I want to talk to you today about fleas and about blind people. Scientists have taken fleas and they have put them in a jar and put a lid on that jar, and the fleas would try and jump out of the jar. And after hitting their heads on the lid several times, they would realize they could only jump just so high, right under where that lid would be.

Now, if the scientists take the lid off the jar, the fleas will continue to jump just so high, just right below where that lid was, and never realize that if they made one more jump they would be set free.

This is very much like what happens to blind people. I run the Louisiana Center for the Blind. I have been doing that for 15 years now. We bring in students from all over Louisiana and all over the country, who say they want to go back to work, that they are coming there for training so they can go back to work. We have had 521 students now enrolled at our Center.

I recently did statistics that said that 41 percent of those students came in on Social Security Disability, and out of that 41 percent, unfortunately, only 15 percent ultimately left the Social Security rolls and went back to full-time competitive employment. Some of the others went to work, but just under the earnings limit.

Now, I thought, 15 percent, we are doing something wrong, until I found figures that in the general disability population it is less than 5 percent that ultimately leave the Social Security disability rolls and go back to work.

We are thought of as one of the best agencies in this country for rehabilitation, but yet we are not getting to some of these folks. The Ticket to Work program has some good things in it, but it is not hitting the real problem that is faced by blind people. In most polls and anybody that you ask, cancer, AIDS and blindness are the three most dreaded things that could happen to you.

The real problem with getting blind people off of Social Security disability is a psychological one. It is a fear of risk. The real problem of blindness is not the loss of eyesight, it is the misconceptions and stereotype notions that exist about blindness, and these stereotype notions exist with the sighted public, but they also exist with the blind. Blind people themselves really don't believe in what they can do. When they leave our center, they know what they should do, but they don't really know in their hearts what they could do.

Just last Tuesday, I met with our students and I told them I was coming for this testimony, and I said to them, "I want to speak to you, you that are getting Social Security Disability. Tell me how you are thinking".

Jack immediately piped up and said, "Well, you know, I am kind of old, and I don't want to go back to work, and it is time for the younger folks to take my place, and I don't need all that pressure". And another student said, "Wait a minute, Jack, how old are you?" And he said, "Well, I am 40". And they all started laughing, and they said, "Jack, what is the real problem?" The real problem, after we prodded a little bit, was Jack didn't really believe that he could go back to work, that he could take the risk and become competitive again.

Brenda, one of our students, said, "Well, it is really hard for me to give up the certainty of a check when I have two children, and rent to pay, and food to put on the table. I just can't take the risk when I know I am going to get probably a minimum wage job".

Janice spoke up and said, "I can't afford to go back to work. By the time the taxes are taken off and the huge cost of transportation and accessible means of working as a blind person, I can't afford to go back to work. It doesn't pay for me to work".

The stories went on and on, but what is happening is that we are denying people that have paid into the system, that have paid into the system and that have talents and experiences and things to give back. We are denying society the opportunity for those talents to be utilized and for them to become taxpaying citizens.

I ask for all of you—I know we have the votes, if we could just get it up for a vote—to help us take off the lid, take off the lid for blind people so we really don't have these psychological and emotional barriers caused by Social Security work incentives, and we could really get back to work. Thank you.

[The prepared statement follows:]

Statement of Joanne Wilson, Director, Louisiana Center for the Blind, Ruston, Louisiana

My name is Joanne Wilson. I am director of the Louisiana Center for the Blind in Ruston, Louisiana. My address at the Louisiana Center is 101 South Trenton, Ruston, Louisiana 71270. The telephone number at the Center is (318) 251–2891.

I want to thank the distinguished members of this Committee for an opportunity to testify regarding the issue of Social Security earnings limitations for the blind.

Approximately 15 years ago we opened the Louisiana Center for the Blind as a private, non-profit rehabilitation training facility for blind and visually impaired adults. With support from the membership of the National Federation of the Blind of Louisiana, we willingly undertook the imposing task of opening a facility that would provide training for blind and visually impaired individuals. Foremost in our thought was that if we were to ever gain the acceptance of a society which for centuries had regarded blind people as severely limited and unable to lead full lives which include productive work and full participation in the affairs of their communities, then we needed to establish ourselves within those communities as respectable citizens, with the same hopes and expectations as our sighted peers. We knew that with proper training and opportunity a blind person could become a contributing member of our complex society, but such achievement had to begin with instilling a positive philosophy about blindness in blind people themselves.

What is of paramount importance for your deliberations today is understanding that for a blind person, the **real** problem of blindness is not the loss of sight, although this is significant. Rather, it is the attitudes which exist, both among the sighted public and among the blind themselves concerning blindness and the ability of the blind to compete with their sighted counterparts.

Certainly, it is well documented that historically blind individuals have always been last in line when they must compete with the general public for services, and more often than not they are denied access to employment and full societal access. While training facilities like the Louisiana Center for the Blind and others across the country can address societal attitudes, employment is a persistent problem. Many members of the public have long assumed that blind people could not engage in productive work, at least not at a level that would allow them to be economically self-sufficient. To many in our society, a legally blind person is *presumed to be unemployed, if not unemployable.* Imagine, if you will, being a blind person growing up in a society that has embraced this notion wholeheartedly, with its formidable misconceptions about who you are and what you are able to do. Every fiber of your being would long for the opportunity to compete for a job and succeed or fail on your abilities—not on preconceived notions about your blindness.

Emerging from a long history of dependence and lack of opportunity to escape from it, with its stifling of the human spirit and its degrading effect on self-esteem, has presented a tremendous challenge to individuals who are blind. They know that most employers can see and cannot imagine even being able to get to the job (let alone doing the job) without their sight. In this respect, blindness is unlike most other disabilities in that the effects of not seeing are believed to be all-pervasive. We as blind people have struggled mightily for the small advances we have made, yet clearly individuals who are blind are not yet realizing the "American Dream" even in the best of economic times.

The nation's policy is to promote opportunity. In the Rehabilitation Act of 1973, for example, Congress defined the purpose and mission of the rehabilitation program as follows:

"Sec. 2. (B)(1) to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society. . .
"(2) to ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities. . ."

Inclusion of the Rehabilitation program in the Workforce Investment Act of 1998 reinforces the intent of Congress that persons with disabilities can and *should* participate fully in the American labor force. However, according to a study published in *Americans with Disabilities: 1991–1992 U.S. Bureau of the Census, Current population Reports (870–33),* Washington, DC: U.S. Government Printing Office, the employment rate among those with visual disabilities is approximately 26%, with the remaining 74% either "out of the labor force" or "unemployed." Since clearly Congress has provided a system to promote inclusion of persons with disabilities in meaningful employment, why then does such an alarming rate of unemployment among the blind persist?

It is well documented that a major disincentive to the blind considering work is the loss of cash benefits under Social Security Disability Insurance. This program provides support to meet subsistence-level needs, and eligibility for this assistance is virtually automatic for a blind person. Although the benefit payments are modest compared to earnings from most (even entry-level) employment, the security it provides is highly valued. The fear of losing those benefits is great, due primarily to uncertainty about the impact of working on benefits and the belief that future assistance may not be available if work stops. Blind people are aware that, under the current limitations, one dollar over the earnings limit for the blind will result in complete loss of cash benefits. Think, if you will, about your own work here. Clearly if work defines us, as many contend, blind and visually impaired persons do not find it easy under the current limitations to resist becoming "underachievers" or "second-class" participants in America's workforce.

In my position as director of a training facility, I have personally counseled with hundreds of individuals who are convinced that they must remain dependents of, rather than contributors to, the system. Examples which immediately come to mind are two individuals who became blind in mid-career. In both instances, their blindness was sudden because of medical conditions which did not affect them in any other way-only their vision was affected. Both were professionals with established careers, who realized that in order to regain their confidence and possess the ability to travel and care for themselves independently, they needed to learn alternative techniques of doing so as blind persons. Incidentally, not only did they need to learn skills, but they also needed desperately to re-gain their self-esteem. After completing training, they fully expected to return to their respective fields, James as a construction engineer with 25 years' experience building major highways across the country and Robert as an claims adjuster with a national insurance corporation. However, when job placement efforts began near the end of their training, it became apparent that their respective companies were not interested in their knowledge and experience but rather were consumed with imagined barriers and false misconceptions about the abilities of these two formerly valued employees who were now blind.

At that point they faced a dilemma: Should they return to work for mediocre wages which wouldn't cover their mortgages, or should they become dependent upon Social Security benefits, which would at least provide some reliable income for their families? Senior citizens in similar situations do not have to make this choice. Why then, should a blind person? Had these individuals been given an opportunity to work, even at modest wages, and to keep their earnings without loss of Social Security benefits, I could tell you today that they are contributing to and not drawing support from the system. Sadly, I cannot do that. They returned home with their hopes and careers dashed, facing uncertainty about their ability to care for their families.

When I think of James and Robert, I am reminded on the other hand of two elderly individuals I know-both of them quite financially secure, who decided because of boredom to return to work when they were well into their 70's. An attorney and a rancher, respectively, they have generously endowed universities and institutions with their gifts, yet they still earn Social Security benefits, earn wages which are never questioned, and complain when Medicare doesn't cover the cost of a medical procedure. No earnings limitations are imposed on the elderly. The system did not encourage these two to stay dependent and to remain idle from fear of losing everything. Nor did it strip them of their dignity as it did James and Robert. My question then, is why earnings limitations are imposed on the blind. Is it because our aspirations and our sense of personal responsibility are those of such a relatively small number that they go unnoticed? If that is the case, I ask you to consider these two facts: Blind individuals do compose only a very small segment of our society. If 74% of that small number are either "out of the labor force" or "unemployed," then the current system with its disincentives to work has failed.

Removing attitudinal barriers, raising expectations on the part of employers and individuals who are blind, and instilling the work ethic in those who have experienced little opportunity for meaningful work-these are the needs and challenges which we address today. Eliminating the earnings limit for blind individuals will ensure that more blind Americans have the opportunity to participate in the workforce, express their strong work ethic, and exercise personal responsibility as they long to do. We ask that you help us achieve our goal to be recognized as contributing members of society and to gain respect for our abilities by giving them free rein to help build a more productive nation. Thank you.

Chairman SHAW. Thank you, Ms. Wilson. Dr. Cavenaugh.

STATEMENT OF BRENDA S. CAVENAUGH, PH.D., RESEARCH DIRECTOR, REHABILITATION RESEARCH AND TRAINING CENTER ON BLINDNESS AND LOW VISION, MISSISSIPPI STATE UNIVERSITY

Ms. CAVENAUGH. Good morning, Mr. Chairman, Members of the Subcommittee. Thank you for the opportunity to testify. I have worked in blindness rehabilitation since 1972. Today, my testimony is based upon findings from research conducted at the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University. The RRTC, was established in 1981, through the support of the National Institute on Disability and Rehabilitation Research. We are the only NIDRR-funded center studying blindness and low vision. Our mission is to conduct research activities focused on improving the employment and independent living outcomes of consumers who are blind.

I would like to present findings on the costs and employment experiences of blind individuals. First, findings from an analysis of data on consumers served in the State-Federal Vocational Rehabilitation Program, will be presented, followed by findings a national survey of blind consumers.

The Rehabilitation Act of 1973, as amended, authorizes the allocation of federal funds on a formula basis to the states and territories for the administration of a vocational rehabilitation VR program to assist individuals with disabilities in preparing for and engaging in gainful employment. State VR agencies provide a wide variety of services. The following findings are based on data from the 1998 Rehabilitation Services Administration, RSA, 911 National database of all clients/consumers exiting the VR program from the 50 states and from the District of Columbia.

The number of persons who had been accepted for and received services who exited the program in 1998 was around 360,000. Four percent of those 360,000 consumers were legally blind, and about 96% or 345,000 had other disabilities.

When comparing competitive closure rates of consumers—and I am using RSA's definition of competitive employment which includes those consumers with competitive employment closures, self-employment closures, or business enterprise program closures—35 percent of blind people were closed in competitive employment, 60 percent of other people with other disabilities were closed in competitive employment.

In comparing costs, the mean cost of services of blind persons with competitive employment outcomes was approximately $8,200. The mean cost of services for consumers with other disabilities was approximately around $3500. The average mean number of services for blind persons was approximately 6; the mean number of services for other persons with disabilities was around 4.5. The mean length of services of legally blind consumers was about 4 years; for people with other disabilities, the length of services was approximately 3 years.

Included in my written testimony is a list of 17 services that people can receive through the State-Federal VR program. I have included the percentage of legally blind people receiving each service, and the percentage of people with other disabilities receiving each service.

This information indicates that blind people are five times more likely to receive rehabilitation engineering services. They are three to four times more likely to receive assistive technology devices and assistive technology services—services that are critical to maintaining employment.

To further investigate differences in cost of services, I categorized people with disabilities into 16 sub-groups. Again, the cost for legally blind people was $8200. Cost of services was highest for people who are deaf-blind—approximately, $8600. Cost of services was least expensive for people with nervous system disorders—approximately $2700.

To summarize, the mean cost for serving blind people is double the cost for serving other persons with disabilities. In addition to services noted above, blind people are twice as likely to need adjustment training, twice as likely to need personal assistance, and unlike other impairment-related services such as occupational or physical therapy, blindness-specific services and equipment—critical to acquiring and maintaining employment—are rarely, if ever, reimbursable through Medicare or other health plans. Additionally, these are generally not one-time expenses. For example, blind persons must purchase new—or upgrade, if it is an option—speech, Braille, and large-print computer access technology when new versions of mainstream computer operating systems and software are released. Orientation and mobility services may be required when employment settings change.

Finally, with respect to findings from the national telephone survey. Legally blind persons were asked if specialized technology assistive technology was needed to perform their job effectively, eightly nine percent of the participants said yes. When asked if they would like a regular job, 92 percent of those participants who were unemployed said yes, they wanted a job.

In conclusion, blind people want to work. Blind people require specialized skills, services, technology, and equipment not covered by insurance. Many blind people can pay for these expenses because this higher SGA level. Thank you.

[The prepared statement follows:]

Statement of Brenda S. Cavenaugh, Ph.D., Research Director, Rehabilitation Research and Training Center on Blindness and Low Vision, Mississippi State University

Good morning, Mr. Chairman and Members of the Subcommittee. Thank you for inviting me to testify on issues related to work incentives for blind and disabled Social Security beneficiaries. I have worked in vocational rehabilitation since 1972 and am currently the Research Director at the Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision at Mississippi State University. The RRTC was established in October, 1981, through support from the National Institute on Disability and Rehabilitation Research (NIDRR) of the U. S. Department of Education. As the only NIDRR-funded RRTC studying blindness and low vision, our primary mission is to conduct research, training, and dissemination activities focused on improving the employment and independent living outcomes of consumers who are blind or severely visually impaired. Dr. J. Elton Moore serves as our Executive Director.

Today, I will be reporting findings on the costs and employment experiences of individuals who are blind or severely visually impaired (hereafter referred to as blind persons). First, results of analysis of national data on consumers served in the state-federal vocational rehabilitation (VR) program will be presented. These findings indicate that although the substantial gainful activity (SGA) level for blind beneficiaries is higher than the SGA level of other disabled persons ($1170 vs. $700 per month), blind persons must purchase specialized blindness-related services and equipment which are not reimbursable through Medicare or other health plans. Further, these are critical to their achieving and sustaining employment. Second, preliminary results from a national survey on the employment status of working-age persons who are blind will be presented. These findings provide more detailed information on the relationship of work disincentives and employment.

Analysis of State-Federal Vocational Rehabilitation Data

The Rehabilitation Act of 1973, as amended, authorizes the allocation of federal funds on a formula basis to the states and territories for the administration and operation of a vocational rehabilitation (VR) program to assist individuals with disabilities in preparing for and engaging in gainful employment. State VR agencies provide a wide range of services (e.g., physical restoration, counseling and guidance, vocational training, maintenance, job referral, job placement, rehabilitation engineering, assistive technology) to assist people with disabilities in becoming employed. VR program data were derived from the 1998 Rehabilitation Services Administration (RSA) 911 National data base. All cases *exiting* from the VR program from the 50 states and the District of Columbia were used in the analysis.

Consumers Exiting VR program after "Individualized Plan for Employment" Initiated (Includes both "rehabilitated" and "not rehabilitated" closures)

Total Served	n = 359,913
Legally blind consumers	n = 14,732 (4%)

Consumers with other disabilities	n = 345,181 (96%)

Consumers Exiting VR program "Rehabilitated" with Competitive Employment Outcomes includes competitive, self-employment, or state-agency-managed business enterprise work statuses

Competitive Outcomes	n = 212,082
Legally blind consumers	n = 5,201 (35% of 14,732)
Consumers with other disabilities	n = 206,881 (60% of 345,181)

Service Intensity Variables (computed only for consumers with competitive employment outcomes)

Mean Cost of Services.	
Legally blind consumers	$8,184
Consumers with other disabilities	$3,488

Mean Number of Services.	
Legally blind consumers	6.0 services
Consumers with other disabilities	4.5 services

Mean Duration of Services.	
Legally blind consumers	4.0 years
Consumers with other disabilities	3.0 years

The Rehabilitation Services Administration defines cost of services as the total amount of money spent by the State VR agency in providing or arranging for services on behalf of the consumer. Expenditures are "life-of-the-case" costs and do not refer to any particular year. In addition, the RSA requires the VR agency to include information on whether the client did, or did not, receive a specific service sometime during the VR process. To further explore possible reasons for differences in costs and numbers of services between blind consumers and those with other disabilities, percentages from cross-tabulations were computed. Results from this analysis are reported in Table 1.

Table 1: Percent Receiving Services by Disability

Types of Services	Legally Blind	Other Disability
Assessment	84%	82%
Physical Restoration	39%	29%
University Training	10%	16%
Business or Vocational Training	7%	14%
Adjustment Training	50%	20%
On-the-job Training	5%	7%
Miscellaneous Training	24%	16%

Table 1: Percent Receiving Services by Disability—Continued

Types of Services	Legally Blind	Other Disability
Counseling and Guidance	79%	76%
Job Referral	18%	38%
Job Placement	15%	29%
Transportation	30%	30%
Maintenance	14%	16%
Personal Assistance (includes reader)	12%	2%
Rehabilitation Engineering	12%	2%
Assistive Technology Devices	42%	8%
Assistive Technology Services	45%	12%
Other Services	42%	23%

Comparisons among "other disability" group. To explore differences within the "other disability" group, those consumers with competitive sector outcomes ((n = 206,881) were further categorized into disability sub-groups. Sample size, cost of services and percent competitively closed (i.e. competitive, self-employed, and BE closures) are reported in Table 2.

Table 2: Disability by Cost of Services and Percent Competitive Employment

Disabling Condition	Mean Cost of Services	Competitive Closure
Deaf-blind (n=166)	$8,602	45%
Legally blind (n = 5,201)	8,230	35%
Orthopedic conditions (n = 44,229)	4,608	62%
Genitourinary system (n = 2,249)	4,557	70%
Visual impairments, but not legally blind (n = 5,242)	4,418	57%
Neoplasms (n = 846)	4,404	65%
Traumatic brain injuries (n = 3,990)	4,393	55%
Allergic endocrine, nutritional diseases (n = 3,557)	4,112	62%
Hearing impairments (n = 15,458)	3,761	72%
Speech impairments (n = 591)	3,682	68%
Respiratory conditions (n = 787)	3,492	56%
Diseases of the blood (n = 4,524)	3,204	67%
Mental and emotional conditions (n = 85,265)	3,155	56%
Digestive system conditions (n = 3,345)	3,111	83%
Cardiac and circulatory conditions (n = 3,537)	2,920	64%
Nervous system disorders (n = 23,961)	2,688	63%

Conclusions

- Mean cost of VR services for legally blind consumers reaching competitive employment outcomes is more than twice the cost of services for consumers with other disabilities ($8,184 vs. $3,488).
- When consumers with other disabilities are grouped into smaller categories of disability-specific conditions, only deaf-blind consumers (n = 166) have a higher mean cost of VR services when compared with legally blind consumers $8,602 vs. $8,230). Consumers with orthopedic conditions have the third highest cost of services ($4,608).
- Legally blind consumers are more than twice as likely than consumers with other disabilities to receive adjustment training and approximately four times more likely to receive personal assistance (includes reader services), rehabilitation engineering, assistive technology devices, and assistive technology services. (Adjustment training includes training in blindness-specific skills, such as Braille, orientation and mobility, and activities of daily living. Rehabilitation technology devices and training includes purchase of and training to use blindness-specific technology, such as computer speech, Braille, and large print plus low vision optical and non-optical devices.)
- *Unlike other impairment-related services such as occupational or physical therapy, blindness-specialized services and equipment—critical to acquiring and maintaining employment—are rarely, if ever, reimbursable through Medicare or other health plans.* Additionally, they are generally not "one-time" expenses. For example, blind persons must purchase new (or upgrade if an option) speech, Braille, and large print computer access technology when new versions of mainstream computer operating systems and software are released; orientation and mobility services may be required when employment settings change.

Factors Affecting Employment Status of Persons who are Blind: Preliminary Analysis of National Telephone Survey

Research Question:

What employment-related factors have the most impact on employment status and occupations of working age adults with blindness or visual impairment?

Participants:

Working-age adults who are legally blind (N = 279)

Sampling Frame

National Library Service (NLS) subscribers designated as blind or visually impaired

Sampling Design:

Systematic sampling with random start -every kth element in the total list chosen (first chosen at random). Sample size chosen to ensure findings are accurate within plus or minus five percentage points of the population parameters (95 percent confidence level). Sampling tolerances (intervals) range from 3–5 points, depending upon percentage result (worst case scenario 50% would be 5 points; best case 10% or 90% would be 3 points.

Selected Findings related to SSDI "Income Cliff":

When asked if "risk of losing benefits or insurance payments" was a employment barrier that they had personally encountered in trying to find a job, 27% of participants answered affirmatively.

When asked if "risk of losing benefits or insurance payments" was an important reason they were not working full-time, 34% of participants working part-time or unemployed answered affirmatively.

When asked if "risk of losing benefits or insurance payments" was an important reason they were not working full-time, 39% of participants working part-time answered affirmatively.

When asked if specialized assistive technology was needed to perform job effectively, 89% of participants answered affirmatively.

When asked if they would like a regular job, 92% of those participants who were unemployed, but not currently looking for employment, answered affirmatively.

References

Cavenaugh, B. S. (2000). [Analysis of Rehabilitation Services Administration R–911 National Data, Fiscal Year 1998]. Unpublished raw data.

Cavenaugh, B. S. (2000). [Analysis of National Telephone Survey on the Employment Status of Blind Persons]. Unpublished raw data.

The Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision at Mississippi State University was established in October, 1981, through support from the National Institute on Disability and Rehabilitation Research (NIDRR) of the U. S. Department of Education. As the nation's only RRTC studying blindness and low vision, our purpose is to enhance employment and independent living outcomes of consumers who are blind or severely visually impaired through the conduct of research, training, and dissemination activities.

Chairman SHAW. Thank you. Mr. Gashel.

STATEMENT OF JAMES GASHEL, DIRECTOR, GOVERNMENTAL AFFAIRS, NATIONAL FEDERATION OF THE BLIND, BALTIMORE, MARYLAND

Mr. GASHEL. Thank you, Mr. Chairman. I am appearing today on behalf of the National Federation of the Blind, and I appreciate the opportunity to testify.

It is no secret that the NFB has sought removal of the earnings limit just like seniors. We hold this view because the work and beneficiary status of the vast majority of blind people is just like seniors.

We had a policy in this country until yesterday, telling seniors not to work and paying them not to. Congress was right to end that policy. The earnings limit stifles initiative and kills the spirit.

It is one thing when this happens to someone at age 65, who has worked a lifetime and had opportunities throughout that lifetime. It is a different thing all together, and it is very sad, when this happens to a person who is blind at age 25, told not to expect very much of themselves for the future, and then to have that confirmed by the earnings limit.

I have witnessed this throughout my 30-year career in counseling blind people about going to work and helping them struggle with the earnings limit.

You should see the letters they receive from Social Security, from Susan Daniels over here. They don't thank you for going back to work. What do you think it says to a person when you get a letter from Social Security that goes like this: “We are writing to give you new information about the benefits you receive on this record, and the rest of this letter will tell you how we overpaid you $45,000”—or pick some other number, it is usually real high—“too much in benefits, and how you can pay us back.”

People are devastated by this. They are trapped in a system that doesn't help them go to work and doesn't really seem to want them to. It penalizes them if they do. Our country can do better. We are going to do better for seniors, and I think that reflects a great deal of credit on you.

I have been around this issue for many, many years, and I think that it is right—no person at age 65 will ever get an overpayment notice like that anymore, regardless of how much they earn.

I was present when Mr. Archer created the concept of the equivalent status through the identical earnings limit for seniors and the blind. He told me that he wanted to remove the limit all together, but he knew it wouldn't pass right then. His alternative was five mandated adjustments followed by automatic indexing applied to seniors and the blind. This did pass.

With removal of the earnings limit for seniors, a choice was made to exclude the blind, so what should the policy be? We have been fighting for years just like seniors, to have meaningful work incentives just like seniors, so blind people could go to work and not have any reason not to do so just like seniors. Is that wrong? Was Mr. Archer wrong when he thought that linkage up in 1977? Why isn't it right now if it was right then?

Frankly, I don't know what to say to blind people who are caught in the earnings limit trap. If Congress has really adopted a "just say no" stance, then I don't know how to answer that issue. I don't think people can accept the fact that it is right to pay benefits for someone who earns, let's say, as much as a member of Congress, over $140,000 a year, and then just say "no" to members of a group who are otherwise eligible, if they earn $14,000.

On the matter of disability and blindness, I am troubled by the fact that disability still means the inability to work. I honestly don't know another definition, but I worry that no progress will really be made on the earnings limit as long as there isn't a different definition.

With blindness, SGA is applied as a pure earnings limit, which could be changed without changing or redefining disability. I think Congress should look at doing it that way.

Mr. Chairman, the economics of the circumstances of the blind—low income, intermittent employment, and lots of unemployment—clearly justify removing limits and providing resources to members of this population. Our country would be richly rewarded if you would use your leadership to do this.

There will be no reward if the blind are simply held back and told that we have to wait again. This is not to say that something else should not be done apart from blindness relating to disability because that, too, should be done.

On behalf of the National Federation of the Blind, I thank you.

[The prepared statement follows:]

Statement of James Gashel, Director, Government Affairs, National Federation of the Blind, Baltimore, Maryland

Good morning, Mr. Chairman. My name is James Gashel. I am the Director of Governmental Affairs for the National Federation of the Blind.

The National Federation of the Blind (NFB) has a membership in excess of 50,000, representing all states, the District of Columbia, and Puerto Rico. All of our officers and the vast majority of our members are blind. Local chapters of the Federation can be found in most sizable population areas in the United States. In the words of our monthly publication, the Braille Monitor, "We are not an organization speaking for the blind; we are the blind speaking for themselves."

This hearing is being held in the wake of legislation passed to remove the earnings limit altogether for people who reach age 65. The NFB has sought identical treatment for blind people. In this statement I will explain how the blind person's earnings limit presently works and why we think it should be changed.

How the Blind Person's Earnings Limit Works:

At least two provisions of the Social Security Act work together to form what I have called "the blind person's earnings limit." These are section 216(i) (in which blindness is defined) and the second sentence of section 223(d)(4) (which specifies that earnings not exceeding the exempt amount for age–65 retirees are not considered to be substantial gainful activity (SGA) for someone who is blind). This latter provision has been amended to exclude the changes in the exempt amount made in 1996 and the removal of the earnings limit altogether.

This means that the blind person's earnings limit (or exempt amount—whichever term you like) is now set at $1,170.00 per month. This is $14,040.00 annually, indexed to coincide with average wage growth determined from year to year. As with seniors, only Congress can change this limit.

I have used the term "earnings limit," because this is the best way to describe the situation for the blind. The technical term formerly used for seniors was the "retirement test," but members of Congress and the public called it the earnings limit. With blindness, the technical term is the "substantial gainful activity test," but this too is just an earnings limit.

SGA is an earnings limit for the blind but an entirely different concept when used in determining disability. An SGA determination in disability cases is intertwined with the decision as to whether or not the person is disabled. The person found able to perform SGA is not disabled according to the law.

This is not how it works with blindness. I say this because of the plain language of section 216(i) of the Act:

". . .the term 'disability' means (A) inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months, or (B) blindness; and the term "blindness" means....."

This language is certainly not new. It has been in the law this way for at least 35 years. If blindness is established, the only remaining question is, do earnings (if any) exceed (or not exceed) SGA? If earnings exceed SGA, no benefit can be paid. Conversely, benefits are payable when earnings are below SGA. So—technical term or not—SGA is really an earnings limit imposed on the blind.

How the Earnings Limit Works as a Disincentive:

I have already said that only Congress can change the blind person's earnings limit, but why do so? In my mind, the foremost reason is that only 26 percent of blind adults age 18 to 65 are working to any extent at all. According to a November, 1999, report of the American Association of Retired Persons, 12 percent of persons age 65 and older work. So the vast majority of blind adults, 74 percent, are just like seniors in regard to work and beneficiary status.

There are many reasons why so few blind people work. Lack of self-confidence and lack of employers willing to hire them are two reasons. The imposition of the earnings limit is by far the reason most often given, however. I say this from 30 years' experience in counseling blind people to go to work.

Consider the economics in a fairly simple but typical case. Assume annual cash benefits of $9,000.00 or $750.00 per month. At this rate for a single person with no other income, the benefits are tax-free. Taking this into account, plus the expenses that also go with working (such as commuting and buying clothing appropriate to the workplace) $15,000.00 in gross pay would be needed to replace $9,000 in benefits.

Annual pay of $15,000.00 is $7.20 an hour. At $16,000.00 or $7.70 an hour, the average net gain for working full-time for an entire year would be about $1,000.00. Earnings below $15,000.00 will mean a loss. Some will do this, but most won't because they can't afford to lose income. If the beneficiary has dependents, the situation is even more troublesome.

With two dependents, the total benefits are likely to average $18,000.00 annually. Therefore, earnings of $15,000.00 or $16,000.00 (just above the limit) will not replace benefits. Using conservative assumptions, such as taxes figured at 25 percent of gross pay and child care for two children at $300.00 per month, I conclude that replacement of $18,000.00 in benefits would require about $33,000.00 in gross pay. When dependents are involved, the choice to work or not to work is far more constrained, and the amount needed to replace everyone's benefit far exceeds the blind person's earnings limit.

From this it is clear that a typical blind person is apt to face a severe income penalty with earnings at the entry level. Most people will not lose with gross pay above $33,000.00, but most blind people are not being offered that much money to start or return to work. So most blind people accept their benefits and often do intermittent work to supplement them. This way, with benefits of $9,000.00 and earnings of $13,000.00 (just under the earnings limit), the beneficiary can have $22,000.00 and often do better financially than accepting a full-time entry-level job.

This is the sad reality that most blind people face day after day: not getting ahead, just getting by. It would be one thing if employers were opening their arms to accept us, but that is not happening. For most blind people, just getting a chance to have a job is a job itself. This condition, combined with the earnings limit, leads to lost opportunities and lost potential for far too many blind people.

Creating Incentives:

Congress is very good at using laws—especially tax laws and Social Security—to create incentives. There are many examples of subsidies paid to certain groups or industries to achieve desirable national goals. The removal of the earnings limit to subsidize working seniors' wages is a relevant example. In this instance, one goal is to help employers maintain an experienced workforce. This responds to current needs, but many years ago when economic and employment conditions were different, the earnings limit was a means of encouraging seniors to vacate their jobs for younger workers.

This brings me to the earnings limit policy for the blind. What should the policy be? Frankly, the removal of the earnings limit at age 65 looks like a choice has been made to pay benefits to seniors who work and pay blind people on the condition that they don't work. Since both "retirement age" and "blindness" are defined—so establishing basic eligibility is really not the question—the policy of no limit for seniors compared to $14,040.00 for the blind is unjust. That point is not lost on blind people.

People have asked, "Would you really pay benefits to blind people who earn as much as a member of Congress?" My answer would be "yes." If benefits are paid to members of Congress (or others who earn as much as a member of Congress), then I would not exclude the blind. With the removal of the earnings limit, benefits will now be paid to thousands of seniors who will continue to work and earn as much as $141,300.00 and more. The goal achieved by this policy is valid, but continuing an earnings limit of $14,040.00 on work performed by the blind is not.

CONCLUSION:

Mr. Chairman, the economic circumstances of blindness—low incomes, intermittent work, and lots of unemployment—clearly justify removing limits and providing resources to members of this population. This is not to say that issues relating to disability apart from blindness don't deserve attention—they do. So, on behalf of the National Federation of the Blind, I urge you to examine the impact of the earnings limit with the wisdom, caring, and foresight shown in removing the limit for seniors. If you do that, I am confident that new opportunities will result from new incentives. I thank you.

Chairman SHAW. Thank you. Mr. Matsui.

Mr. MATSUI. Thank you, Mr. Chairman. I would like to thank all four of the panelists for their testimony, it was very precise and very moving.

Dr. Cavenaugh, you indicated that there was a difference in terms of expenses for those that are blind and other disabled, and you related a number of numbers. Could you perhaps—and not go into a lot of detail because it would probably take a long time—explain where the difference is and why the blind have a larger expense than the other disabled?

Dr. CAVENAUGH. The Rehabilitation Services Administration requires the state agencies to report "yes" or "no" if a person received a specific service during the VR process. RSA also requires data on total cost of services. So, we know the total cost of services and which services a consumer received. There are about 17 different types of services.

Using cross-tabulations, percentages, frequencies, I looked at the types of services different disability sub-groups actually received. First, I compared legally blind consumers with all other consumers. Then I grouped consumers with other disabilities into 16 subgroups. I again looked at the services received by consumers in these subgroups.

I found that blind people were receiving many more of those services which we would expect to be more expensive. Why is it two times more expensive for a legally blind person to go through the VR system? Well, I think it is to some extent because of the huge cost for rehabilitation engineering. For example, among legally blind people, 12 percent receive rehabilitation engineering; in the other disability group, about 2 percent receive rehabilitation engineering. Forty-two percent of legally blind people receive assistive technology devices; 8 percent of other disability groups receive technology devices. Forty-five percent of blind people receive assistive technology services; 12 percent of other people do.

So, from this data, that blind people are receiving those services that are more expensive and, unfortunately, these are services, as I earlier indicated that are necessary for finding employment and are also necessary for maintaining employment.

Legally blind consumers are twice as likely to receive adjustment services. Adjustment services include training in blindness-specific alternative techniques critial to living independently. So, I think cost of services is higher because blind clients receive these services more frequently than other VR consumers.

With respect to job placement services, other disability groups are twice as likely to receive job placement services. When I was a VR counselor, job placement services were provided by the rehabilitation counselor and were not included in cost of services. So, I think differences in costs can be explained by the types of services received.

Mr. MATSUI. Thank you, I appreciate that response. Mr. Gashel, how is your building coming along?

Mr. GASHEL. We are making good progress. We have raised about $3.5 million, but we have got to raise $18 before we—

Mr. MATSUI. You are moving along, anyway. It is coming along.

Mr. GASHEL. Yes, we are.

Mr. MATSUI. Congratulations.

Mr. GASHEL. Thanks for asking.

Mr. MATSUI. The unemployment rate among the blind is, what, 75 percent?

Mr. GASHEL. Seventy-four percent.

Mr. MATSUI. I want to ask a two-part question. If you raise the earnings limit and eliminate it completely, do you have any estimates what the unemployment rate would be for the blind? And, secondly, if you raised it to $17,000, do you have an estimate or studies that would indicate what the unemployment rate for the blind would be? Maybe you don't.

Mr. GASHEL. I think it would be a guess, but we are talking about 100,000 beneficiaries who would be the target group, and all of them are receiving benefits now, very few of them are working, as we have heard today. So, what you are trying to do is attract as many of them as possible into the workforce.

There are probably only about 30,000 blind people who are earning above the earnings limit, according to the information that we have assembled, so you are not going to add that many beneficiaries to the rolls, and it would be a great trade-off to attract, you know, 50,000 of these people, or even 30-40,000 of these people into the workforce who are not now paying in.

Now, if you figure—we could do the math sometime—but if you figure that those people are going to earn, say, average incomes of $25,000, they are going to pay taxes when they earn that money. Right now, they are just drawing benefits.

So, I think this is a great way for the program—just like seniors—to pay for itself.

Mr. MATSUI. Thank you, all of you.

Chairman SHAW. Mr. Collins.

Mr. COLLINS. You heard Dr. Daniels talk about a demonstration project. My question is going to be aimed at her comment, and the question is, what change would be better, a higher SGA or no "cliff", and that is open to all.

Mr. GASHEL. I would like to try first. I will go for it, Mr. Collins. Well, probably both. I think this is really an analogous situation to seniors, I hope that comes through. With seniors, you know, there was no cliff for a long time, and even a 2-for-1 offset wasn't considered enough of a work incentive, and so then they went to a 3-for-1 offset and that wasn't considered enough of a work incentive, and so now it is no limit.

I don't know why it would be any different for blind people, but some people have talked about a 2-for-1 offset. Well, that would be one way to look at it, or maybe a 3-for-1 as was done for seniors.

I certainly think that the threshold has to be higher. $11,000 wasn't a good enough threshold for seniors, and so now it is $17, and it will be nothing. So the threshold clearly has to be a lot higher than it is to help people get into the workforce. Average incomes are about $25,000, entry level incomes. Now, different jobs, of course, have different entry level incomes, but I think you have got to get above $25,000 for an entry level job to encourage people to enter the workforce.

Mr. COLLINS. Anyone else want to tackle that one?

Ms. WILSON. I wanted to make a comment on that, if I could. In my roomful of students last Tuesday, they all unanimously agreed that they were afraid to go off of Social Security Disability because they basically do not trust the system.

Don said, "I would be afraid to go off of it even though there are some of these incentives because I don't want to face Mrs. King, my Social Security worker again, she was just awful, and I don't want to get entrenched—have to deal with that system anymore than I do".

Fifteen years ago when we started the Louisiana Center for the Blind, we got a Social Security demonstration grant to prove some of the things that I think are, again, going to be coming around to be proven, and some of those demonstration grants have been going around for 15 years that I know of straight up from Social Security. Nothing much is changing, I think, because we are missing the point. We are going all around it, but we are not hitting the real basics, and that is the emotional thing.

I would love to see what blind people could really do and really work if they really had the real incentives to do it. I think we could change the whole way people view blindness.

Mr. COLLINS. If I understood you right then, you are kind of from the old school—a bird in the hand is worth two in the bush—stay on Social Security to keep from wrestling with the system itself, and the fear of losing income totally. Is that the way I interpret it? Ms. Gillis?

Ms. GILLIS. For me, in order to replace my benefit, I would have to secure a job for $35,500 a year. Those jobs are few and far between in Martin County. The entry level jobs there start at $23,000 a year, and I would need to work at a $35,500 a year level just to break even with where I am presently at. So that, to me, is scary. At that level, even if I broke even, I am still in the position I am in now where there are no extra dollars to augment my eventual retirement. And the scariest part of this, in my mind, is when I turn the magic age of 65 and my benefits all convert over, my benefits will be so reduced, my pension with the church which is $292 now will be reduced to $63. I don't know what Social Security will do with the $933 a month benefit, but I bet you it will be at least half of that, and that is a scary thing. And then what is my employment outlook when I am 65 and blind, when I get to that age, even though there is no limit, I will have been out of the workforce for almost 30 years. So that concerns me.

Mr. COLLINS. Thank you very much.

Chairman SHAW. Mr. McCrery.

Mr. MCCRERY. Ms. Gillis, would you explain to us why it would take a $35,000 a year job to replace what you are getting from Social Security?

Ms. GILLIS. With the additional expenses that I incur to go back to work—well, first of all, the taxability of the income. Presently, I pay tax on one-half of the $933 a month I receive for myself, and pay no income tax on the $498 I receive for my dependent son, and I pay tax on 100 percent of the $292 of 1099-R income on my tax return. When you factor in the difference of the taxability of the income, in itself, when I go back to work and my income is all earned income, that is all subject to taxes. So that is part of the problem.

I would have additional expenses that I would need to incur to secure the adaptive technology, the equipment, the maintenance thereof, the transportation, child care, the list goes on and on, all the incidentals associated with leaving my home and going back into the workforce.

Mr. MCCRERY. Anything else? You are not counting loss of medical benefits, are you?

Ms. GILLIS. Yes, the medical benefits, as well, Medicare. I am sorry.

Mr. MCCRERY. But you know you would continue to receive Medicare for nine years after you broach the earnings limit.

Ms. GILLIS. Right, and I would have to get additional medical insurance as well, yes.

Mr. MCCRERY. Within that nine-year period, yes, you would have to obtain other medical insurance, but your medical benefits would continue even after you lost your cash benefits under current law, do you know that?

Ms. GILLIS. I do now, sir. I am not an expert.

Mr. MCCRERY. I thought you might have been counting that in your estimate, and it doesn't exactly fit as neatly as that.

Ms. Wilson came to my office about a month ago and brought with her a group of about 15 blind individuals, and we talked for about an hour about this subject, and Ms. Wilson knows that I disagree with Mr. Gashel and Ms. Wilson on severing—I mean, on doing away with any earnings limitation for the disability program under Social Security. So, I am over that hurdle with Ms. Wilson. I haven't talked with Mr. Gashel about it.

I really believe, in brief, that the disability program under Social Security is completely different from the earned retirement benefits under Social Security, and I really think it is apples and oranges.

The incentives are the same, yes, I agree with that, and certainly, as Ms. Gillis has pointed out, if we keep this very low limit as a cliff, it serves definitely as a disincentive for people to work, no doubt about that. And I, and I think other members of this Subcommittee, would like to do something about that. I don't think the right thing to do, though, is just to say there is no earnings limit. That, as GAO testified, just fundamentally changes the purpose of a disability program under Social Security.

For example, if you have a blind individual who makes $100,000 a year, it doesn't make sense for him to receive disability benefits from the government, from the taxpayers. And you say, okay, $100,000—well, $80,000—$50,000—you know, where do you stop? I don't know. But I do think there is a need for an earnings limit when somebody has demonstrated an ability to earn enough clearly to take care of his needs, his family's needs, then the taxpayers don't need to supplement that.

But I think this issue of a cliff is something that we need to look at. I think that is the most detrimental part of this whole system. Ms. Gillis already testified, gosh, she has got to be very careful to not make just over that limit because, if she does, boom, she loses everything except her medical benefits.

So, I think one of the most important things we could do, Mr. Chairman, is to smooth out that cliff, to provide a slope so that Ms. Gillis doesn't have to watch everything so closely for fear of losing everything. She can smoothly transition into that slope and not have to be so precise about counting every penny, and I think that would be a big help.

I would like to raise the earnings limit and I think Dr. Cavenaugh has done this Subcommittee some service in pointing out some of the underlying rationale for the difference in treatment between blind disabled and nonblind disabled and, Dr. Cavenaugh, I appreciate your giving us those statistics which I think bolster the argument for separation of the two.

So, with that, Mr. Chairman, I see my time has expired. I appreciate your giving me the time, and thank all the witnesses for your testimony.

Chairman SHAW. Mr. Hulshof.

Mr. HULSHOF. Thank you, Mr. Chairman. Dr. Cavenaugh, in the interest of full disclosure, I have a degree from the University of Mississippi and, as you know, there is the intense rivalry between Ole Miss and Mississippi State. So, if you promise not to hold it against me, I promise not to hold it against you.

Dr. CAVENAUGH. You know what we do when we say the prayer at Mississippi State, do you know how we respond?

Mr. HULSHOF. How is that?

Dr. CAVENAUGH. Go to hell Ole Miss. We really don't mean it.

Mr. HULSHOF. I will resist the urge to respond in kind.

Dr. CAVENAUGH. Well, actually, we have stopped saying the prayer, so it doesn't happen anymore.

Mr. MCCRERY. We do the same thing at LSU, for that matter, so, Hulshof, you are in bad company here.

Mr. HULSHOF. I feel outnumbered by other SEC teams, but I do want to ask you just quickly, because we are also being called for a vote, in looking over your study, you mention that, or your conclusions that the cost of VR services for those legally blind are more than twice that of VR services for people with other disabilities, and I want to ask, does that category of other disabilities include people that are not on the Disability rolls?

Dr. CAVENAUGH. Yes, it does. There are people who are served in the State-Federal program who are not on the Disability rolls.

Mr. HULSHOF. Is that a fair comparison, because wouldn't you expect VR costs—and you have worked in VR, as you mentioned—wouldn't you expect VR costs to be lower for people who are not disabled enough to qualify for Disability benefits?

Dr. CAVENAUGH. Absolutely.

Mr. HULSHOF. We talked about, with the previous panel, that the SGA limit for those who are blind is about 67 percent higher for those with other disabilities. I assume your research findings justify that disparity?

Dr. CAVENAUGH. The disparity that—I am sorry, I didn't hear.

Mr. HULSHOF. Does your research—do you agree that is an appropriate—

Dr. CAVENAUGH. What is an appropriate?

Mr. HULSHOF.—that there is a 67 percent higher SGA limit for the blind as opposed to those that are other individuals with disabilities?

Dr. CAVENAUGH. Do I agree with the higher SGA level for blind people?

Mr. HULSHOF. Yes, ma'am.

Dr. CAVENAUGH. The data seem to indicate yes.

Mr. HULSHOF. What about, as Dr. Daniels mentioned for us, that any individual who is disabled can actually earn more than the SGA limits and still stay eligible because they can subtract work expenses that are related to their disability in determining the earnings subject to the limit. I mean, the fact that we are trying to help provide a deduction or subtraction of work-related expenses. Including that, does that also continue then to justify this disparity between individuals who are blind and those disabled who are not blind?

Dr. CAVENAUGH. Yes, I would think so. And I think my reasoning is, are we talking about those work-related expenses through Schedule A? You are talking about the IRS deductions?

Mr. HULSHOF. Yes.

Dr. CAVENAUGH. You have to make it first, and using Schedule A precludes people from taking the Standard Deduction, so I think there continues to be real problems. In response to your question regarding non-recipients, I could select out those VR clients receiving SSI or SSDI and I compare cost of services for blind persons versus consumers with other disabilities. I would expect similiar results to those I have reported.

Mr. HULSHOF. Mr. Chairman, I know we have got this vote on, so I yield back my time.

Chairman SHAW. Mr. Gashel, are you aware of a proposal that was in the President's budget to exempt the disabled employees and the sheltered workshops from receiving Social Security credits to withholding of FICA? I would like you to comment on that because I think it is important that everybody who is working continue to build up Social Security credits that will help them when they reach retirement.

Mr. GASHEL. Well, I agree with that, Mr. Chairman, and I think it is an outrageous proposal. I honestly don't know where it came from, but I can see some of the workshops that employ the disabled might want to exempt themselves from coverage under the—with FICA, paying into Social Security, because a lot of the people might be getting Supplemental Security Income anyway, but it is outrageous to end up denying people Social Security coverage.

It is kind of like, in our case, we get paid the sub-minimum wage in these workshops, too, which again is outrageous. So, I think that what we have got to do is look at blind and disabled people more along the lines of the way we look at other workers in this country, including seniors. We want people to work and we want them to earn as much as they possibly can, and we want them to earn Social Security credits. I think this proposal might end up having to come to this Subcommittee—I am glad you brought it up because I hope you don't approve anything like this.

Chairman SHAW. I am also concerned about the fact that so many of these sheltered workshops do not pay minimum wage. It is something that has come up in my office in talking with some of the blind representatives. Chris Cox brought it up to me. I see she is in the audience today. She brought it up to me in the office sometime ago. And it is something I would like to look into.

Do we have any data—and I address this to any of the witnesses at the table here—do we have any data as to what effect that would have on the employment of the blind within the workshops, if we were to do away with that exemption and provide that the workshops pay minimum wage just like everybody else?

Mr. GASHEL. You are going to have trouble believing this, but according to the people that pay the sub-minimum wages, there are only 150 blind people, nationwide, that are paid less than the minimum wage. So, really, we are talking almost academics here. It is close enough for government work to pay everybody at least the minimum wage.

Chairman SHAW. Yes, but I think it is insulting. I think it is insulting.

Mr. GASHEL. It is absolutely insulting. And so the impact would be 150 people. The guy who runs the workshop umbrella called National Industries for the Blind, is paid $200,000 a year, which is as much as the President. And I have said, you know, at a salary like that, he ought to be able to figure out a way to bring 150 blind people up to at least the minimum wage.

Chairman SHAW. I think you just figured out a way to do it.

Mr. GASHEL. I hope so.

Chairman SHAW. Well, we do have two votes on the Floor, which is going to take us away, so I am going to recess until 1:00 o'clock.

It is now a quarter after 12:00. We will come back at 1:00 o'clock. That will give everyone a chance to take a little break and have lunch and be back here. This panel is excused, we have completed, and we are down now to the final panel. Thank you. And I want to thank all you witnesses. Ms. Gillis, I was particularly impressed with your comment that to walk in your shoes. I think that we should pay heed to that and do that.

Ms. GILLIS. Thank you.

Chairman SHAW. Thank you for being here.

[Recess.]

[Questions submitted by Chairman Shaw to Ms. Cavenaugh, Mr. Gashel, Ms. Gillis, and Ms Wilson, and their respective answers, follow:]

Brenda Cavenaugh, Ph.D.
Rehabilitation Research and Training Center on Blindness and Low Vision
P.O. Box 6189
Mississippi State University, MS 39762

Dear Dr. Cavenaugh:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following questions:

1. Individuals who are disabled, including those who are blind, can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if a person who is blind earns $1,500 per month but has $500 in work expenses, their SGA is $1,000—below the $1,170 limit.) Are you familiar with the provision? Is it being used? How many individuals who are blind take advantage of these deductions? Is it effective? Should it be changed?
2. Your analysis of the costs of vocational rehabilitation services compares the costs of blind individuals with the costs of individuals with other disabilities. Do all of these blind individuals meet the definition of statutory blindness used by Social Security? Do all of the individuals with other disabilities have impairments that are severe enough to qualify for Social Security disability benefits? If you compared the costs of only those blind individuals who qualify for Social Security with those individuals with other disabilities who qualify for Social Security disability benefits, what would be the difference in these costs?

I thank you for taking the time to answer these questions for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

Honorable E. Clay Shaw, Jr.
Chairman, Subcommittee on Social Security
House of Representatives
Washington, DC 20515

Dear Congressman Shaw:

Thank you for the opportunity to further respond to your questions regarding work incentives for Social Security Disability Insurance (SSDI) beneficiaries who are blind.

In response to questions regarding my analysis of the costs of vocational rehabilitation (VR) services:

- Legally Blind consumers are those with "center visual acuity 20/200 or less in the better eye with best correction or widest diameter of visual field subtending an angle of no greater than 20 degrees." All blind individuals used in this analysis as reported in my March 23, 2000 testimony meet the definition of statutory blindness used by Social Security.

- Although the Rehabilitation Services Administration database used in this analysis does not include direct data indicating if VR consumers have impairments severe enough to qualify for SSDI, it does include information indicating if individuals received SSDI at application, at closure, or at any time during the VR process. With the expectation that an analysis of this specific population of SSDI beneficiaries would be helpful in answering your questions, I am attaching findings from this analysis.
- Based on an extensive search, I have not found any research that has shown that costs of VR services for those who qualify for SSDI are significantly different from those reported in my testimony of March 23, 2000 or in the enclosed attachment.

With respect to your other questions regarding work-related expenses:

- Although SSDI and Supplemental Security Income (SSI) beneficiaries can deduct Impairment Related Work Expenses (IRWEs) in determining earnings subject to SGA limits, an extensive review of the literature revealed no empirical data on the use of IRWE's by blind recipients. My personal experience has been that blind individuals are generally unaware of work-incentive provisions, such as IRWE, the Trial Work Period (TWP), and the Extended Period of Eligibility (EPE).
- Dr. John Hennessey, Office of Research and Statistics, Social Security Administration, has authored several publications focusing on factors (e.g., work incentives, job accommodations, VR, age, sex, race, and marital status) that Honorable E. Clay Shaw, Jr. affect the ability of SSDI recipients to sustain their work effort. In addition, researchers at the Rehabilitation Research and Training Center (RRTC) for Economic Policy for People with Disabilities, Cornell University, have investigated earnings and program participation rates of SSI recipients. You may want to contact Dr. Suzanne Bruyère, RRTC Director, at (607)255–7727 for information on related ongoing studies. My review indicated that neither of these sources reported findings on utilization of IRWE's across disability groups.

Please, do not hesitate to contact me it you have further questions. My telephone number is 662–325–2001. I can also be contacted by e-mail at bcavenaugh@colled.msstate.edu.

Sincerely,

BRENDA S. CAVENAUGH, PH.D., CRC
Research Director

Analysis of State-Federal Vocational Rehabilitation Data

The Rehabilitation Act of 1973, as amended, authorizes the allocation of federal funds on a formula basis to the states and territories for the administration and operation of a vocational rehabilitation (VR) program to assist individuals with disabilities in preparing for and engaging in gainful employment. State VR agencies provide a wide range of services (e.g., physical restoration, counseling and guidance, vocational training, maintenance, job referral, job placement, rehabilitation engineering, assistive technology) to assist people with disabilities in becoming employed. VR program data were derived from the 1998 Rehabilitation Services Administration (RSA) 911 National data base. All cases exiting from the VR program from the 50 states and the District of Columbia were used in the analysis.

Consumers Accepted for Service and Exiting VR program after Individualized Plan for Employment Initiated (Includes both "rehabilitated" and "not rehabilitated" closures)

	All Consumers	SSDI Recipients*
Total Served	359,913	53,416
Legally blind consumers	14,732	4,229
Consumers with other disabilities	345,181	49,187

Consumers Exiting VR program "Rehabilitated" with Competitive Employment Outcomes—includes competitive, self-employment, or state-agency-managed business enterprise (BE) work statuses

	All Consumers	SSDI Recipients
Competitive Employment Outcomes	212,082	25,123
Legally blind consumers	5,201	1,774
Consumers with other disabilities	206,881	23,349

Service Intensity Variables (computed for consumers with competitive employment outcomes)

	All Consumers	SSDI Recipients
Mean Cost of Services.		
Legally blind consumers	$8,184	$9,052
Consumers with other disabilities	$3,486	$4,767
Mean Number of Services.		
Legally blind consumers	6.0	6.7
Consumers with other disabilities	4.5	4.7
Mean Duration of Services (Yrs.).		
Legally blind consumers	4.0	3.8
Consumers with other disabilities	3.0	3.1

Disability by Mean Cost of Services

	All Consumers	SSDI Recipients
Deaf-blind (n = 166)	$8,602	$10,179
Legally blind (n = 5,201)	8,230	9,076
Orthopedic conditions (n = 44,229)	4,608	7,212
Genitourinary system (n = 2,249)	4,557	4,300
Visual impairments, not legally blind (n = 5,242)	4,418	6,970
Neoplasms (n = 846)	4,404	4,278
Traumatic brain injuries (n = 3,990)	4,393	5,877
Allergic endocrine, nutritional diseases (n = 3,557)	4,112	4,315
Hearing impairments (n = 15,458)	3,761	5,216

	All Consumers	SSDI Recipients
Speech impairments (n = 591)	3,682	5,999
Respiratory conditions (n = 787)	3,492	3,264
Diseases of the blood (n = 4,524)	3,204	3,252
Mental and emotional conditions (n = 85,265)	3,155	3,833
Digestive system conditions (n = 3,345)	3,111	3,483
Cardiac and circulatory conditions (n = 3,537) ..	2,920	4,043
Nervous system disorders (n = 23,961)	2,688	3,933

References

Cavenaugh, B. S. (2000). [Analysis of Rehabilitation Services Administration R–911 National Data, Fiscal Year 1998]. Unpublished raw data.

Cavenaugh, B. S. (2000). [Analysis of National Telephone Survey on the Employment Status of Blind Persons]. Unpublished raw data.

Mr. James Gashel
Director of Government Affairs
National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230

Dear Mr. Gashel:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following question:

Individuals who are disabled, including those who are blind, can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if a person who is blind earns $1,500 per month but has $500 in work expenses, their SGA is $1,000—below the $1,170 limit.) Are you familiar with the provision? Is it being used? How many individuals who are blind take advantage of these deductions? Is it effective? Should it be changed?

In your testimony, you indicate that one reason to increase the SGA limit is because of work-related expenses which make it less profitable to work. However, aren't work-related expenses excluded from the SGA limit?

I thank you for taking the time to answer this question for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 18, 2000

The Honorable E. Clay Shaw, Jr., Chairman
Subcommittee on Social Security
Committee on Ways and Means
United States House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

Thank you for your letter of April 26, 2000, including questions resulting from our recent hearing. I certainly appreciate you continuing interest in this matter as well as the opportunity to respond to the additional questions.

You ask if I am aware of allowed deductions for disability-related work expenses, how many blind people take advantage of these deductions, and whether the law should be changed. To answer the last question first, I certainly think the law should be changed. In the rest of this letter I will explain why.

According to the Social Security Administration, 120,000 blind persons receive disability insurance benefits. I saw an official estimate several years ago that about eleven percent of beneficiaries who are blind have earnings. This means that approximately 13,200 blind people work while continuing to receive benefits. Based on my experience, I would estimate that about 40 percent, or 5,300, claim impairment-related work expenses.

This means that 89 percent of blind beneficiaries don't work. Of those who do, the majority still don't claim impairment-related work expenses. Therefore, this is not a significant work incentive. At best, it only serves to compensate a few people for some of their work-related costs.

For the blind, I think there are several reasons why this deduction is not effective as a work incentive. Most work expenses cannot be counted. For example, the cost of transportation to and work does not count, since the Social Security Administration does not consider taking the public bust to be blindness-related. Costs that may relate to impairments, other than blindness, don't count if eligibility is based on blindness. Costs that are paid by an employer don't count either. So, the result is that most work-related expenses really don't count.

Also, the application of this deduction is very discretionary with the Social Security Administration. Therefore, beneficiaries are left with considerable uncertainly as to whether a particular deduction will be allowed or disallowed. No process for reliable and consistent advance determination exists.

Work incentives are only effective if they as seen as clearly addressing and favorably resolving perceived penalties. It is a fundamental principle that beneficiaries will not use what they cannot understand or do not trust. This-in addition to the narrow scope of the allowed deduction itself-is the primary reason why only a small minority of blind beneficiaries claim deduction for impairment-related work expenses.

I believe these comments provide answers to you questions about impairment-related work expenses, although no necessarily in the order of the questions themselves. The following comments will address you final question, which is: "Aren't work-related expenses excluded from the SGA limit?" The answer is "no." Only *impairment-related work* work expenses are excluded.

In one of her responses to a question during the hearing, Deputy Commissioner Susan Daniels said that all ordinary work expenses can be deducted from gross earnings for blind people. However, Dr. Daniels either misspoke or was confused. In either case her information was factually incorrect. This demonstrates the problem. If officials of the Social Security Administration cannot accurately explain the deductions that all allowed and not allowed, how can claimants be expected to know where they stand?

This is really the underlying problem which why work incentives are not used. They are just too complex for beneficiaries or their advocates to understand and for Social Security personnel to administer. As long as there are penalties to working and there is no certainty as to whether they will or will not be applied, beneficiaries will choose security over work.

I hope this information will be useful to you in your further deliberations on this issue. Please not that a letter (copy attached) which I sent to you after the hearing provides further information to consider. Essentially this letter explains that extra expenses were not used to justify the higher SGA level for the blind. In view of your questions, I though it might be helpful to include this explanation with this response.

Very truly yours,

JAMES GASHEL
Director of Governmental Affairs
NATIONAL FEDERATION OF THE BLIND

JG/mrb
Attachments

March 27, 2000

The Honorable E. Clay Shaw, Chairman
Subcommittee on Social Security
Committee on Ways and Means
House of Representative
Washington, D.C. 20515

Dear Mr. Chairman:

I am writing to provide additional information for the Subcommittee in light of testimony given at the March 23, 2000, hearing on work incentives for blind and disabled persons.

(1) There appears to be an assumption that the blind SGA law enacted in 1977, was based anticipated higher costs resulting from blindness. This is an important issue. Extra costs were not the basis for the higher SGA. I know this. I was present when Mr. Archer first expressed the idea that the earnings exemption threshold should be the same for the blind as it was for seniors, and I heard every word he said to explain this position.

The blind SGA law was an Archer amendment offered in conference in lieu of a Senate amendment which called for a complete removal of the earnings limit for the blind. The legislative history on this amendment consists solely of the discussion which occurred among the conferees who were meeting to reconcile the differences in the Senate- and House-passed versions of the 1977 Social Security financing bill.

Mr Archer propounded the provision which became law when the House confesses refused to go along with the Senate position. He was asked directly for the rationale of treating blind people differently from persons with other disabilities. His explanation did not include extra costs as the basis. He relied instead on the fact that blindness has its own definition apart from disability.

Mr. Archer said that determining the inability to work was not at issue in applying the definition of blindness. As he explained it, he viewed the legal status of the blind as similar to reaching age-65 in that both conditions are clearly defined. He contrasted this with disability and explained that the inability to perform SGA was at the heart of the definition, unlike blindness.

I was presented in Mr. Archer's office in January, 1995, when the subject of blindness, disability, and the earnings limit again arose. Valerie Nixon of the Subcommittee staff was also present. When Ms Nixon presented the view that blindness and disability are essentially equivalent, Mr. Archer returned to the same explanation he gave in 1977—that blindness is defined apart form disability, and the ability to work is not at issue.

I am not suggesting that Mr. Archer currently believes in removing the earnings limit for the blind. Apparently he does not, even though he expressed the desire to do so in 1977. My point is that Mr. Archer's reasoning for the blind SGA law had nothing to do with an excess cost justification. It was solely based on the view that—with blindness being defined—the payment or denial of benefits is really a pure earnings limit question.

The GAO questions the extra cost justification, but extra costs were not the justification. The assumption that they were seems to come from statements made by Senators on the floor when the amendment to remove the earnings limit for the blind was passed. I acknowledged that Senators may have attempted to cite extra costs, but their position did not prevail in the end. Mr. Archer's position that blindness and retirement age are defined, and an identical exemption of earnings would be appropriate, did prevail. This is an important distinction to make in giving further consideration to the blind person's earnings limit.

(2) The GAO has failed to acknowledge that major costs relating to disability, such as supported employment and extra medical expenses, are often covered by

federal or state programs. The record should be clear on this in the interest of accuracy, even though "whose costs are higher" was really not Mr. Archer's rationale in the first place.

(3) Dr. Daniels testified that expense deductions used to reduce gross earnings and determine SGA are different for the blind as compared to the disabled. She said that all reasonable work expenses can be deducted for the blind and only impairment-related work expenses can be deducted for the disabled.

This statement is incorrect. The work expense deducted for the blind and disabled is identical in the Disability Insurance program. Only impairment-related work expenses (more common for disability than for blindness) can be deducted. There is a difference in the deduction of expenses in the SSI, title XVI program, but that would not be relevant to SGA evaluation under title II.

(4) Concern was expressed that raising or eliminating the earnings limit altogether would change the nature of the Disability Insurance program. There is no question that the program would be changed, but the change would be essentially the same as removing the earnings limit at retirement age. With the removal of the earnings limit at age 65, the original purpose of the retirement program has now been changed. Before this change (and particularly before other changes made more gradually over the years), benefits were paid if a person actually retired-that is, stopped working.

The earnings limit was called the "retirement test." Anyone who continued to work beyond certain limits applied to earnings and amount of services performed was not "retired" and not eligible for benefits. The purpose of Social Security was partially to replace earnings lost due to retirement.

The concept has been changed altogether in the current program with no earnings limit. Benefits are not paid to anyone who reaches retirement age, regardless of whether or not the person retires. The same thing could be done in the case of blindness, since blindness is already defined as an eligibility condition. It is only the earnings limit that prevents actual payment of cash benefits and results in a severe work disincentive.

Thank you for the opportunity to present this additional information. The NFB is anxious to assist you on legislation to reduce the disincentive of the earnings limit.

Very truly yours,

JAMES GASHEL
Director of Governmental Affairs
NATIONAL FEDERATION OF THE BLIND

April 26, 2000

Ms. Brenda Gillis
c/o Kristen Cox
National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230

Dear Ms. Gillis:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following questions:

1. In your opinion, what is the role and purpose of the Disability Insurance program? Do you believe it is successful in achieving its purpose? What changes would you make?

2.Individuals who are disabled, including those who are blind, can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if a person who is blind earns $1,500 per month but has $500 in work expenses, their SGA is $1,000—below the $1,170 limit.) Are you familiar with the provision? Is it being used? How many individuals who are blind take advantage of these deductions? Is it effective? Should it be changed?

I thank you for taking the time to answer these questions for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 17, 2000

The Honorable E. Clay Shaw
Committee on ways and Means
United States House of Representatives
Washington, DC 20515

RE: Re: SSDI Program Inquiry

Dear Congressman Shaw:

In the words of Social Security's own publication, "Understanding the Benefits," the agency states, ". . .the disability is one of the most complicated of all Social Security programs." We can certainly agree on this point. Throughout this publication an SSDI recipient is instructed to request publication after publication from their local office for additional information. However, the "bible" for disabled persons who wish to work is publication 05–10095, "Working While Disabled . . . How We Can Help." The best part is that it only takes several months, countless phone calls and four to six weeks for mailing to obtain this "additional information," only to discover that if you are disabled due to blindness you require an additional booklet. These are the moccasins I told you about on March 23, 2000.

You have asked in your letter for me to tell you if I understand the purpose of the SSDI program and if I believe it is presently meeting its intended purpose. It is my opinion that the ultimate purpose is to provide financial security for individuals faced with life changing circumstances who are looking for a hand up, not a hand out. However, because of the reasons I have outlined below I do not believe the program is meeting it's intended purpose. Allow me to ask you to once again place yourself in my moccasins. Unlike the SSI program, SSDI is an insurance program for which I am eligible because I had worked in the past, paid into the system, and have qualified to have my contributions repaid to me in an amount determined by the credits earned. SSDI is not a gift of the Federal Government bestowed upon a disabled person because you want to help out; it is something I have earned.

Social Security representatives at a local level have demonstrated, in my opinion, that they know less about this program and how it pertains to blind workers than do I, the lay person. As a matter of fact, when I first applied for benefits they were denied because SSA failed to read the entire definition of "legal blindness" and this oversight delayed the start of my benefits by more than three months. Furthermore, I feel that our panel efficiently demonstrated to the sub-committee that blindness in and of itself is a unique condition that is easily defined.

When I was declared legally blind and began to receive my benefits, I was finally in a position where I could learn the new skills required to re-enter the workplace without fear of financial hardship. The first step was to obtain these new skills and the adaptive equipment and software that would make my "rehabilitation" possible. The Division of Blind Services (DBS), the Florida state agency in place to assist blind persons to this end, was my sole source of information and assistance. Because I desired to operate my own business, DBS was able to provide me with the adaptive technologies I would require to achieve this goal. Once I demonstrated that I was earning money, my case was closed and I was left to my own devices to become self-sufficient. After doing a little homework, I learned about earnings limits, reporting requirements and how they would affect my benefits. One of the requirements is to report to SSA my earnings during the "trial work period." At the end of the first month I called the local Social Security office and no one seemed to know what it was I was attempting to do nor did they seem to have a clue as to what form should be utilized. I was told they would make a note of my comments and there was no need for me to contact them again citing that the forms I needed would be sent to me in the mail. When my first year of operation had concluded and still no forms had arrived, I contacted Social Security again to report my work activity. Again I was simply told they would make a note in my file and they refused my offer to fax over my balance sheet and profit & loss statement for the year. This did not agree with what I had read in the SSA publication. Not knowing where to turn (if the supervisor was instructing me in this manner) I determined to follow the local office's instructions. This situation has not changed at any point during the past five years my business has been in operation. At this point I have assumed that when SSA finally gets around to reviewing my status in seven years, I will at that time be expected to produce my shoebox full of receipts and paperwork. Therefore, I look at the whole program and its requirements as being far too burdensome for the beneficiary. There is no systematic and easy method to report qualifying deductions, changes in income, and impairment related work expenses.

The reality for most blind individuals is that they will be worse off financially by working as compared to receiving SSDI benefits. The financial loss creates a persuasive work disincentive. Let's say for the purpose of discussion that instead of operating my own business, I had opted to go to work for ABC Distributors making $24,000 per year. The Division of Blind Services would provide to me the adaptive technology I required, supply a personal employment consultant to integrate the adaptive technology into my work situation and coach me on how to improve my productivity. The agency then closes my case and deems me rehabilitated. However, the time and energy that has gone into securing my employment, (paid for by the tax payers) it is likely that I would be worse off financially. This is true because the minute I earn over $1,170 per month gross I will lose all of my SSDI benefits. Not only do I lose my benefits, but also I now will incur additional expenses such as childcare and transportation specifically related to my employment.

Furthermore, by working at ABC Distributors 100% of my income would be taxable. Using a conservative tax rate of 25%, my net monthly income would be approximately $1,500 per month. My SSDI benefits totaled $1,715 per month. As you can see, I would net nearly 200 dollars less by working than staying at home and collecting benefits. This is true without considering the negative impact that work related expenses would have on my net earnings (not to be confused with impairment related work expenses). Let me also add here that it was pointed out to me that the costs associated with medical insurance should not be part of this equation as Medicare would still be available for nine years after benefits are discontinued. What the Congressman failed to point out is that an employed individual in this situation would have to pay a premium for those benefits. So while they may be an option, there is a definite cost associated to it. To complicate things further a blind worker still endures lack of "job security" in the workplace. But still we are grateful to have our jobs.

Now three years down the road the ABC Distributors Company decided to change accounting software. I come to work one day to discover that the screen reading software will not work with the new accounting package and a major incompatibility has cropped up overnight. This is not an uncommon scenario. I call the screen reader software manufacturer and they send someone out to see if their product can be adapted to function properly. In the best case I find myself unemployed for two or three weeks while the problem is resolved and I have a receipt of a hefty bill for their "on site" services. In the worst case, a solution cannot be found and I am now on the unemployment line again with that hefty bill still in hand. Under this latter situation, I am by myself reapplying for SSDI benefits and the process would start over again. A vicious cycle, wouldn't you agree?

As to your second question about "impairment related work expenses" and whether I believe that blind persons take advantage of them. Well, in my opinion based on my interpretation of the "rules" in this game, I truly believe that Ms. Daniels should read some of her Administration's publications and clear things up in her own mind before making blanket statements like those she made on March 23, 2000. It is my opinion that Ms. Daniels, like many of the SSA employees, do not fully understand the differences between the SSI and SSDI programs offered to disabled persons. While many of the expenses she referred to are "deductible" from the SGA under the SSI program, those same deductions do not always pass the test for SSDI. As I understand it, one can only deduct impairment related work expenses. If Mrs. Daniels does not fully understand work incentive under the SSDI program, you can imagine the confusion that exists among beneficiaries, like myself. For blind individuals, there are so few impairment related work expenses that one can legitimately deduct that they do not significantly impact one's income. This may be a different scenario for people who need full time attendant care or have other substantial costs related to work and impairment. As I mentioned above there doesn't seem to be an adequate way for the SSDI recipient to report them even if they do exist. Do blind persons take advantage of the "work incentive," as you like to call it? Well, the best answer I can give you is we sure try like hell.

The confusing and abundant policies surrounding SSDI often result in beneficiaries fearing the system itself. Blind people know that it is not a matter of "if" SSA will send a letter outlining how we can repay what they believe to be an "overpayment" of benefits—it's a matter of "when" we will receive it. And, let me assure you that if you opened your mailbox to find that you owe the federal government tens of thousands of dollars, you would carefully consider if the personal rewards and satisfaction you get from being employed is worth the financial risk. In fact, I have heard from many of my blind friends that even though they write and call SSA over and over to discontinue benefits, should they land a really good job, the checks keep coming month after month until that one day when the strong arm of SSA marches in to collect it all back.

In closing, think about your many blessings. You are sighted, able bodied and have a good job. Your life is not filled daily with the challenges of living with blindness and the stereotypes associated with your "condition" that you would experience each day you ventured out into the general public. You enjoy the privilege of driving where and when you want. You open your mailbox and go inside to read it, tossing the junk out without even opening the envelope. There is no need for you to invest thousands of dollars and countless hours learning new skills simply to find the important items or wait until Saturday when your neighbor has time to come over and read it all to you. What needs to be done with SSDI and what it will cost, I leave to you the expert. But I would make these two suggestions. First, create a system in which blind beneficiaries are not worse off financially for working. This primarily could be done by increasing the earnings limit to such an extent that you demonstrate a genuine effort to afford the blind community with a hand up not a hand out. Second, the SSDI system must be simple and easy for the lay person to understand. I ask that you stop the vicious circle of revolving through an endless stream of employed, unemployed, in this agency and then out to another. The blind community needs to have the opportunity to show the world blindness is not something to be feared and that it ultimately, in this day and age, has little impact on our ability to be productive and responsible citizens. There is far too much to do in this country to "Change What it Means to be Blind" and worrying about our financial security should not be one of the battles we must fight. I sincerely hope we can count on you to seek an appropriate solution and provide the blind citizens of our Nation a real incentive to work.

Faithfully,

BRENDA-ANN GILLIS
Stuart, FL 34997

April 26, 2000

Ms. Joanne Wilson
Director
Louisiana Center for the Blind
101 South Trenton St.
Ruston, LA 71270

Dear Ms. Wilson:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following questions:

1. Individuals who are disabled, including those who are blind, can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if a person who is blind earns $1,500 per month but has $500 in work expenses, their SGA is $1,000—below the $1,170 limit.) Are you familiar with the provision? Is it being used? How many individuals who are blind take advantage of these deductions? Is it effective? Should it be changed?

2. In your testimony, you ask why should a person who is blind have to make the choice between work or becoming dependent on Social Security benefits. You add that had these individuals been given an opportunity to work, even at modest wages, and to keep their earnings without loss of benefits, they would be contributing to and not drawing support from the system. Are you saying that individuals should be allowed to work and earn as much as they want, and still draw full benefits for a certain time limit? Or are you saying there should be no time limit, but individuals will choose to leave the rolls at some point?

I thank you for taking the time to answer these questions for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 18, 2000

The Honorable E. Clay Shaw, Jr.
Chairman
Subcommittee on Social Security
Committee on Ways and Means
United States House of Representatives
Washington, D.C. 20515

Dear Chairman Shaw:

Thank you for your letter of April 26, 2000, concerning work efforts of blind persons in the Social Security Disability Insurance program. The information below is provided in response to your specific questions:

1. You describe the policy of deducting disability-related work expenses and ask several questions. I am, of course, familiar with this policy. While the example you provide is plausible, it is far from typical for blind persons. This is because the deduction is limited to "impairment-related work expenses," excluding most costs that blind people will pay when they work. For example, transportation to and from work is often not deductible for blind persons because a specialized, disability-related service is not needed.

I don't have access to statistics. However, I doubt that this deduction is used very much. I say this because the "if's," "and's," and "but's," of the deduction are far too complex for most people to understand or apply. When a person could be working with gross earnings marginally above the SGA limit, there is usually a fear of taking a chance. Beneficiaries have good reasons for not relying upon what someone in the Social Security office might tell them. Therefore, they have no way of knowing whether or not a particular work-related expense deduction will be allowed or counted against them. For this reason the law should be changed. If deductions are part of the law, they should be straightforward, easy to understand, and not discretionary with the Social Security Administration.

2. You ask if blind persons should be able to work and retain benefits under a time limit, or whether they will leave the rolls on their own without a time limit. My answer is that work should not be penalized at any point. In other words, a policy that encourages work should not be withdrawn or time-limited. If a beneficiary works, the contributions made to the system are savings to the trust funds. The continued payment of benefits for people who work has been adopted as a policy for seniors. Frankly, I don't think the policy should really be any different for the blind. If Congress does adopt a different policy, however, it should clearly include a guarantee of not losing by working.

I hope this information helps. Please contact me if I can respond to any other questions.

Sincerely,

JOANNE WILSON, DIRECTOR
Louisiana Center for the Blind, Inc.

Chairman SHAW. This will be our final panel of the day. We have David Gallagher, Social Security Beneficiary, from Eastpointe, Michigan; William VanOoteghem, Father of Social Security Beneficiary, from Essexville, Michigan, on behalf of The Arc of the United States, and he is accompanied by Wendy VanOoteghem, who is a Social Security Beneficiary. We have Dr. Pamela Hanes, Associate Professor, Public Health and Preventive Medicine, Oregon Health Sciences University, and Tony Young, who is Co-

Chair, Social Security Task Force, Consortium for Citizens with Disabilities.

As with the other witnesses, we have your full statements which will be placed in the record, and we would invite you to proceed and summarize as you see fit. Mr. Gallagher.

STATEMENT OF DAVID E. GALLAGHER, SOCIAL SECURITY BENEFICIARY, AND CONSULTANT, LIFE IN TIME CONSULTATION SERVICES, INC., EASTPOINTE, MICHIGAN

Mr. GALLAGHER. Thank you. Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to share my testimony. This testimony is not just about me, but it is about many people who are consumers of mental health services.

I was diagnosed as having manic depressive disorder in February 1978. I have been hospitalized over 20 times since that time. I have a Master's Degree in social work from Wayne State University in Michigan, and I am currently working as a peer counselor at Northeast Drop-In Center, a place for mental health consumers to meet and receive services.

I am currently on Social Security Disability Insurance and Medicare, but I also pay for Blue Cross/Blue Shield Supplemental to pay for the things that Medicare does not pay for. The cost of mental illness is staggering.

My medications alone cost over $1,000 a month for the psychotropic medications, and another $49 a month for high blood pressure medication. These costs are pretty typical for a person with severe mental illness. I could not work without these medications. In addition, I have chronic renal failure, chronic bronchitis, I have had lymph nodes removed from my larynx twice, I have had a history of seizure disorder, I have had two mini-strokes, I am in need of extensive dental work, I have glaucoma which affects my night vision.

Although I have worked from the time I was 15, because of my mental illness I have not been able to work continuously at full-time employment. In spite of my illness, I have had periods where I have worked years at a time, but not always at the same job. In between, I have been hospitalized because of my illness. My current job as peer counselor is my longest history of employment, but currently it is only part-time. However, I could work more if I knew my benefits would not end right away, and I could work at an income level above poverty with full health benefits.

To be able to work full-time, I need full Blue Cross/Blue Shield insurance. Managed care coverage is not adequate due to the cost of medications and the need for mental health services both of which are costly and extremely limited by almost all health plans. Most importantly, medications are not covered by Medicare or my Blue Cross/Blue Shield Supplemental insurance. Another factor is because of our pre-existing conditions, most health insurance providers will not extend us coverage.

Consequently, due to the lack of parity, we are forced into continual dependency on Disability rolls. A key point I need to stress is that I was taken off Social Security Disability benefits after being on Disability for three years because Social Security said I was gainfully employed. I was making just $560 a month as a direct care staff person. This is not gainful employment for a person who has a thousand dollar prescription drug cost that no health plan pays for. Worse, because I am currently paying back Social Security Disability benefits because of the cost of my medication and because of the cost of my medication I have to continue to be on Social Security Disability. I am currently paying $100 a month to Social Security Administration because they said I was overpaid back when I was making $560 a month. I reported my earnings to Social Security Administration, so I don't know why I have an overpayment, but Social Security says I do.

These two issues, the restrictions on my earnings that keep a person from earning above what they need to make in order to live and the fact that consumers always feel that Social Security is out to get them when we try to do work is enough to keep people from doing the best they can do.

I do want to work, and so do many mental health consumers, but we are unable to work above the poverty level without losing our insurance benefits, then we have little choice but to stay on the rolls. I hope, and all consumers hope, that Congress fixes this program.

Honorable Chairperson, thank you for allowing me to speak. Have a wonderful day.

[The prepared statement and attachment follow:]

Statement of David E. Gallagher, Social Security Beneficiary, and Consultant Life in Time Consultation Services, Inc., Eastpointe, Michigan (Social Security Beneficiary)

Thank you for the opportunity to allow me to share my story. This testimony is not just about me, but it's about many people who are consumers of mental health services. I started out my journey with mental health when I was diagnosed as having manic-depression in February 1978. I have been hospitalized over twenty times since that time. My last hospitalization was in 1995. I spent over 13 months in Clinton Valley Center, a state hospital in Michigan. I was put in Clinton Valley when my Blue Cross/Blue Shield ran out. My last hospitalization was due to the fact that I had a blood clot in my leg and I had to have a DVT. Also, I had neuroleptic malignant syndrome, which caused my liver functions to fail and my kidneys to go toxic. I was pronounced dead twice. I am fortunate to be alive.

I have a family history of mental illness. My parents dealt with the suicide of my maternal grandfather when I was an infant. They were raised with a strong work ethic, they were a byproduct of an agrarian agricultural life style and then thrust into an industrial revolution. My father raised us as practicing Roman Catholics. My parents' struggle to give their three boys the best material things in life robbed them of their serenity and ultimately produced a family of overachievers. Throughout their heartache and pain they have tried to understand and cope to the best of their ability. And I love them for that.

By the time I graduated from high school, I was searching and seeking hope. My life had no plan. I wanted to marry my first love, but I was being prompted to "go to college and make something of myself." So off I went to Michigan State University with absolutely no idea what the college experience was all about. I had a three-hour orientation, and I was left to figure out the rest. Being alone with complete freedom, sometimes one makes bad choices. At the end of the year I was on social probation, academic probation, and was asked to leave the University. I left Michigan State University with a 1.9 grade point average.

That summer I worked for Ford Motor Company, a lifestyle I did not enjoy, so I enrolled in Eastern Michigan University. Again, I had a three-hour orientation and was off to school. I knew that I liked money so I thought I'd take business administration. I joined a social fraternity and soon I was active in everything. I was hypermanic, enjoying the attention, the prestige. I was out of balance. By the end of 1977 I was like a runaway locomotive. My grade point average at Eastern dropped to a 2.39. My need to be important and accepted by others drove a wedge between my girlfriend. Other people close to me were fearful of me.

There were many precipitating psychosocial stressors leading to my first hospitalization, in February 1978. I lost my part-time job, my funding sources dried up, my finals went poorly, and my parents decided that this would be an opportune time to practice tough love, which is a good concept when alternate supports are in place. I went to unemployment, I was turned down. I went to social services, I was turned down. I was physically, emotionally, socially, and spiritually bankrupt. And, in psychosis, I collapsed emotionally

From 1978 to 1980, I worked part-time at Kroger's and then I worked in the field of collections at a bank. I struggled to get back to school. I was fortunate that in 1980, Vocational Rehabilitations offered to sponsor me to go back to school if I could complete two semesters at Schoolcraft Community College, then they would re-evaluate the possibility of me finishing up my Bachelor's in Business Administration Degree. I was doing well; I had a good support system. I felt so good that I decided, against medical advice, that I did not need my Lithium or other neuroleptics. Within three months of discontinuation of my medication, I was hospitalized in a state institution for one of my longest periods ever. The years 1980 through 1985 involved a rapid succession of hospitalizations. I was put on Social Security Disability for approximately three years. I worked part-time at a Clark Gas station. When I felt strong enough, I worked in a flower delivery business full-time. Then Social Security Disability was discontinued.

In 1985 I started to play guitar at a mission in Detroit. Working with individuals who were homeless, I decided to be an advocate by becoming a social worker. The people I met that year had touched my heart. I formulated a plan, and started the process of getting admitted to Wayne State University School of Social Work. I filed for financial aid and applied for guaranteed student loans. In my personal statement to Wayne State's University School of Social Work, I stated the reason for my desire to become a social worker was that I am a consumer and I wanted to help other consumers. I had two entrance interviews for admission to the Bachelor of Social Work program. I felt discriminated against in the verbal questions asked of me. I really wanted to be a social worker, so I accepted the situation and the decision made. I was to go through the College of Life Long Learning process of admission, and take the Introduction to Social Work class as well as getting a recommendation from the professor. I took the class and received a 4.0 grade point average and the instructor sponsored my entrance into the program.

The university experience can be frustrating to the average person, let alone to a person who is perceived as different. I found in my personal situation that when I was open about my emotional recovery, many persons in academia were guarded, apprehensive, and at times obtrusive when it came to evaluating my ability to function as a student. It may be noted that during 1985 to 1990, when I attended Wayne State University, I was completely medically stabilized; I was not hospitalized during that period. I did find some supportive faculty at Wayne. One professor taught me the prevention model of social work. His teachings were in part responsible for the substance abuse prevention program I later designed and implemented at William Dickerson Detention Facility through People's Community Services of Metropolitan Detroit.

I graduated from Wayne State University in 1989 with a Bachelor's Degree in Social Work, and a grade point average of 3.18. The next year in the advanced standing program was like being in boot camp. I did not work, I lived off guaranteed student loans. I was totally immersed in social work, day in and day out. I knew that a failure at this level would devastate me.

Graduating from the Master's Program in 1990 was one of the highlights of my life. I graduated with a 3.54 grade point average. I had a new girlfriend. My family showed complete acceptance for the first time in my life. I was interviewing all around the state for jobs. I was doing consultant work. Once again, I tried being captain of my own ship, but I lacked humility. I concealed my feelings from my psychiatrist, because I truly enjoyed having / I the illusion of complete control.

I was hired as coordinator of an assertive community treatment team at a community mental health agency. They were looking for someone who had control capabilities. In the interview process, I told the director I was I being treated for manic-depressive disorder when he asked me, “ Is there anything you want to share about your personal life?” He hired me anyway. Life was great; I had a good job, a company car, good benefits. Boom, I started not sleeping! I did not tell my doctor. Eight business days after starting to work, I totaled out the company car. I broke my collarbone and was in full-blown mania.

While I was in the psychiatric hospital, I received notice that I was fired. After recovering from the broken collarbone and thirty days in the hospital, I was hired by another community mental health agency. The clinical supervisor was truly happy to have me on staff because of my background at Sinai, which was also her orientation towards therapy.

Soon after being hired, I confided in one of my coworkers that I was being treated for a bi-polar condition. It got back to my clinical supervisor. She called me into her office and told me that she had heard that I was a consumer of mental health and asked me if it was true. I said yes. She told me that due to the nature of my illness, it would be important that all the staff in our department know. She asked me to announce this at the next staff meeting. I told her no problem. So at the next staff meting, I explained the nature of my illness to approximately ten people, all professionals. Soon there were rumors that I was not doing my job. I was called into the clinical supervisor's office and told that someone had been listening in and documenting my sessions. I was never late for work, I never took time off from work, all my paperwork was up to date. Six weeks after being hired, I was fired without cause.

I was hospitalized for depression. When I got out of the hospital, I was broke, depressed and socially isolated. No one wanted to hire me, so I went to the Clark gas station, handed the manager my resume, told him that I could learn his computer cash register system and he hired me that day. It was a very humbling experience, but it paid some of the bills, brought up my self-esteem and got me out of the apartment. I sent out over **200** resumes. Finally, I was hired part-time contractually at a private practice doing individual and family counseling. I continued to work at the Clark gas station. With both jobs, I was able to pay the rent, but I was having a difficult time paying my health insurance and medical bills. This continued for 8 months.

I was hired at People's Community Services of metropolitan Detroit in 1991, to be a social group worker. Soon after, I became the supervisor for the Hamtramck programs. I was able to develop a social adjustment group at the consumer-run Northeast Drop-In Organization Center (NEDO). It was my pride and joy. Using the concepts of self-help, affirmation and empowerment from NEDO, I then developed the program and directed it at the detention facility.

When I was taken off social security benefits after being on disability for three years it was because they said it was because I gainfully employed. At the time I making just $560 a month as a direct care staff person. My main need was insurance benefits. I was a melarill and lithium patient for 20 years. Fortunately, the community mental health system was able to help me with my benefits.

Due to the fact that I am currently paying back social security benefits and the cost of medication, I have to continue to be on social security disability. I am currently paying back social security benefits of $100 a month to SSA because they said I was overpaid back when I was making $560 a month. I reported my earnings so I don't understand why I have an overpayment, but Social Security says I do.

The costs faced by consumers who want to work are enormous. Medications make it possible for me to work, but Medicare doesn't pay for them. So I have to pay for them. The cost of my current medication is as follows: Closeral is $800.00 a month, Depokote is $150.00 a month, Cogentine is $49.00 a month. My hypertension medication is $49.00 a month. My blood is drawn twice a month, I see a Psychiatrist twice a month, a case manager every three months and a Medical Doctor every three months.

I have chronic renal failure, chronic bronchitis, and I have had lymph nodes removed from my larynx twice. I have a history of a seizure disorder. I have had two mini-strokes. I am in need of extensive dental work. I have glaucoma that affects my night vision.

I currently have Medicare and Blue Cross/Blue Shield supplemental insurances. Without which I could not function. I do want to work but like many consumers who also want to work, we are unable to secure gainful employment above the poverty level with insurance benefits. Another factor is because of our pre-existing conditions most insurance providers will not extend us coverage. Consequentially, due to the lack of parity, we are forced into continual dependency on Medicare rolls.

My goal one day is to be an advocate for all consumers of mental health services. I no longer look at my illness as a debilitating situation, but rather a medical condition. It has become the motivation and catalyst for my desire to help others to understand themselves. I have found that by helping others, I help myself.

Many understanding and compassionate people have helped and inspired me along the way. Many medical doctors and the mental health professionals have contributed to the stabilization of my condition. These professionals went beyond the call of duty and I am truly grateful to them for their compassion to myself and others. My brother, Greg, has dedicated the last twenty years to being a mental health professional. He has reached countless thousands, directly and indirectly. His insight into the human psyche as well as his understanding of the need for advocacy has influenced the availability of least restrictive environments for consumers of mental health services. His faith in me gave me hope when I lacked all faith in myself I love him for that; I love him for his strength and his courage. My younger brother, Leonard has also been an encouragement to me. His past role as a consumer advocate combined with his doctoral training in neuropsychology has given him a unique perspective on recovery issues. I love him and I am encouraged to see him work through the trials and tribulations of his own life. Above everyone else, I would like to thank God, who has allowed me choices in life; He does not make junk. I have learned that He loves us all.

Additional Testimony of David Gallagher

Community Mental Health Organizations, and Client Centered planning, are at risk due to the current policies of our HMO's, PPO's, and EAP's. As an at risk agency, CMH's will be forced to reduce, restrict, and in some cases deny services to many who can not afford traditional treatment. Managed care will be devastating to many of the neediest clientele. Client centered planning is supposed to put the consumer in control of his/her treatment plan. Unfortunately client centered planning is not being followed in most cases. What is needed is more Consumer Advocates, especially, professionals who are themselves mentally ill.

As both a Consumer and a professional certified social worker I can afford the luxury of being an advocate no matter where I go or to whom I speak. I have learned to walk in other people's moccasins and have empathy for those who suffer the disease called mental illness. What will be needed is psychosocial rehabilitation combined with self-help initiatives. We need to aid and assist consumers of mental health through self help alternatives, consumer initiatives counseling and education. Our goal is to promote a better understanding of the potential of all persons who suffer from the condition called mental illness. Organizations are in place such as Manic Depressive Depressive Association (MDDA), International Association of Psychosocial Rehabilitation Services (IAPSRS), Schizophrenics Anonymous (S.A.), and Michigan Supported Education Program, (MSEP). They are just a few of the many support groups available.

The objective for the year 2002 will be to lower recidivism rates and optimize resources. The stigmatization that causes the Not In My Backyard (NIMBY) syndrome is going to have to be overcome. Revolving door hospitalization is going have to end. What we are finding is that our jails and prisons are being filled due to homelessness and valid medical needs. Misdemeanors are being committed just to get three squares and a cot. By the year 2002 each CMH should be required to have a Consumer run drop-in center. Utilizing the Fountain House Model, these outreaches fill in the gap where the CMH's currently are lacking. It may be noted that I am affiliated with North East Drop In Center (NEDO), and I also circulate with the Odyssey House Drop IN, and the Liberty Drop IN Center.

While education and counseling play a major role for the struggling consumer, it is imperative that pharmacology not be disregarded. The newer medications like Closeral, Depokote and Respitol work wonders with little side effects. With proper medication mental illness can be arrested and treated as any other physical disability. With the new millennium we must empower our consumers; they are a valuable resource. The American work ethic is very important to all. It gives a person a sense of accountability. In order for Workfare to work though, a living wage and a national insurance program will be needed. The programs will have to be innovative. Unlike Social Security Insurance, which is over three trillion dollars in debt, these programs will have to be self-sustained. Social Security was never set up to be lived on but to supplement ones income.

Our greatest resource is our intelligence and ability to learn. You can give a person fish for a day and he will eat for a day but if you teach a person how to fish he can eat for a life. All colleges must be cost affordable to be utilized by consumers. The need for tutors will be in demand for this special population. Drop In Centers should be on campus just as they are at Wayne County Community College and Henry Ford Community Colleges. Peer support groups should be available at all colleges.

By the year 2002 we will need more Occupational Therapists, Recreational Therapists, and Music Therapists. Lay people and para-professionals with shared life experiences will be in high demand. Due to the fact that many Consumers are dual diagnosed with substance abuse as a secondary diagnosis, self-help groups such as Narcotics Anonymous (N.A.) and Alcoholics Anonymous (A.A.) will be in high demand. Group therapy as well as behavior modification techniques combined with cognitive short-term therapy will be the standard. Because many of our consumers are addicted to tobacco, and the cost of 1 pack of cigarettes will probably be well over $5.00 a pack, the emphasis will be on prevention as well as the importance of not smoking in public places due to the hazards of secondary smoke. As a former smoker myself I recognize how difficult it is to quit smoking, it was the hardest addiction to overcome. However, for many clients caffeine and nicotine are the only pleasure they have in life.

We will be watching and waiting for continued client recipient rights as well as policies related to the Americans with Disabilities Act. We must become our own lobbyists and take responsibility for informing legislatures of our needs. It is a myth that consumers are not capable of being lobbyists. We have been doing this at NEDO and have actually been written back by President Clinton and Governor Engler, as well as several other elected officials. There is however an element of stigmatization that prevents many clients from "coming out of the closet." We will need more mentors, such as MSEP provides, to be peer counselors.

The family stresses related to being a caregiver, guardian and/or payee have to be addressed. Mental illness can destroy a family. Usually there is a trust broken in the relationship and anger inhibits the relationship. Groups like MDDA and IAPSRS will be imperative to support the family. With the onset of HMO's, PPO's, and EAP's traditional treatment will not be available for family counseling.

Finally spirituality should be addressed. With the dawn of the new century ones faith is important. Scriptures state that we need faith, hope, and love. We must never discount a client's faith, no matter how delusional it may sound, it may be the only hope they have. This combined with genuine love will heal.

Chairman SHAW. Thank you, Mr. Gallagher. Mr. VanOoteghem.

STATEMENT OF WILLIAM R. VANOOTEGHEM, FATHER OF SOCIAL SECURITY BENEFICIARY, AND WENDY VANOOTEGHEM, SOCIAL SECURITY BENEFICIARY, ESSEXVILLE, MICHIGAN, ON BEHALF OF ARC OF THE UNITED STATES

Mr. VANOOTEGHEM. Good afternoon, Chairman Shaw and members of the Subcommittee. My name is William R. VanOoteghem and this is my daughter, Wendy. Before I get started, I would like to thank the Arc, and your Committee for the work that you did on the work incentives bill last year.

Wendy and I are here to talk to you about what will happen to Wendy if her work increases her wages over the SGA level of $700 per month—which, by the way, is just about the poverty level for an individual. We are here to talk to you about SGA and what it means to all people with disabilities across the country.

I have been able to observe people with disabilities for over 25 years. I have seen them grow over the years with the desire to have a better life, especially in this growing economy. Last summer, allowable monthly earnings went from the $500 level to $700 a month. People with disabilities have more opportunities now to get better paying jobs as the business community now recognizes that they can do the same jobs as persons without disabilities.

I have seen my daughter Wendy's life begin to take a real positive outlook as she did more productive work that paid her more money and made her look forward to every payday. The more work skills people with disabilities acquire, the more money they make, the more part of the community they become. They have more buying power and also pay taxes, therefore, they become an asset to their community.

Wendy has mental retardation, and limitations in physical movement. She functions at the third-grade level in reading, spelling and arithmetic. She enjoys work and is a dedicated worker on a production line.

I believe that working is important for Wendy and other people with disabilities, just as it is for people without disabilities. But we actually cause a hardship to many people with disabilities if they are penalized and have to lose basic supports as a result of work. Now Wendy and her co-workers have to worry about going over the $700 a month that the Social Security Administration sets for the SGA level per month. That means that if they make more than $700 per month, they will eventually give up all their cash benefits and will eventually lose Medicare health insurance and have to pay out of their own pocket to get insurance. If a person with a disability works 40 hours per week, at a minimum wage of $5.15 per hour, they will earn $824 per month. That is $124 above the current SGA level of $700 per month. This will cause the loss of benefits that they need to survive.

Under the work incentives available in the SSI program, Wendy would have been able to earn more, but because she receives Title II benefits as a disabled adult child since I retired, she is limited by the $700 a month amount.

For many like my daughter, their disabilities are lifelong and severe and they cannot afford to lose the basic safety net supports of Social Security and Medicare. That is why we are asking for the same financial advantage that a person who is blind gets at $1,170 per month, with annual indexing or COLAs. In doing this, we will never again hold people back from being productive in the years to come.

STATEMENT OF WENDY VANOOTEGHEM, SOCIAL SECURITY BENEFICIARY, ESSEXVILLE, MICHIGAN

Ms. VANOOTEGHEM. My name is Wendy VanOoteghem, I am 39 years old. I have been working at Do-All in Bay City, Michigan, for 13 years. Right now I am working 30 hours a week on a packaging line, packaging zip-loc bags and doing other specialty packaging. I believe I could make more than $700 a month, but I cannot afford to lose Social Security and Medicare. I have to make sure that I do not make more than $700 each month. It makes me angry. I want to be able to work more.

Mr. VANOOTEGHEM. My wife and I are in our 60s, like a lot of other families, and if something would happen to us, we want Wendy to be able to make it on her own. Yet she must depend on her Social Security and Medicare as a safety net, especially when we can no longer assist her.

What the SGA level amounts to is a wage ceiling for people with severe, lifelong disabilities, a ceiling that is created in federal policy. We need your help to bring the SGA level up to a reasonable amount and index it for inflation.

Thank you for giving us this opportunity to testify here today.

[The prepared statement follows:]

Statement of William VanOoteghem, Father of Social Security Beneficiary, and Wendy VanOoteghm, Social Security Beneficiary, on behalf of Arc of the United States

A Parent's Perspective on SGA

My name is William R. VanOoteghem and this is my daughter Wendy. We are here to talk to you about what will happen to Wendy if her work increases her wages over the SGA level of $700.00 per month (which, by the way, is just about the poverty level for an individual). We are here to talk to you about SGA and what it means to all people with disabilities across the country.

I have been able to observe people with disabilities like my daughter for over twenty-five years. I have seen them grow over the years with the desire to have a better life, especially in this growing economy. Last summer, allowable monthly earnings went from $500.00 to $700.00. People with disabilities have more opportunities now to get better paying jobs, as the business community now recognizes that they can do many of the same jobs as a person without disabilities. I have seen my daughter Wendy's life begin to take a real positive outlook, as she did more productive work that paid her more money and made her look forward to every payday. The more work skills people with disabilities acquire, the more money they make, the more part of the community they become. They have more buying power and also pay taxes, therefore, they become an asset to their community.

Wendy has Down syndrome, mental retardation, and limitations in physical movement. Her reading, spelling, and arithmetic are at the third grade level. She enjoys work and is a dedicated worker on a production line.

I believe that working is important for Wendy and other people with disabilities, just as it is for people without disabilities. But we actually cause a hardship to many people with disabilities if they are penalized and have to lose basic supports as a result of work. Now Wendy and her co-workers have to worry about going over the $700.00 a month that the Social Security Administration sets for the SGA level per month. That means that if they make more than $700.00 per month, they will eventually give up all their cash benefits and will eventually lose Medicare health insurance and have to pay out of their own pocket to get insurance. If a person with a disability works forty hours per week, at a minimum wage of $5.15 per hour, they will earn $824.00 per month. That is $124.00 above the current SGA level of $700.00 per month. This will cause the loss of benefits that they need to survive.

Under the work incentives available in the SSI program, Wendy would have been able to earn more; but because she receives Title II benefits as a "disabled adult child" since I retired, she is limited by the $700.00/month amount.

For many, like my daughter, their disabilities are lifelong and severe and they cannot afford to lose the basic safety net supports of Social Security and Medicare. That is why we are asking for the same financial advantage that a person who is blind gets at $1170.00 per month, with annual indexing or COLAs (cost of living adjustments) for all people with disabilities. In doing this, we will never again hold people back from being productive in the years to come.

Wendy's Perspective on SGA

My name is Wendy VanOoteghem; I am thirty-nine years old. I have been working at Do-All in Bay City, Michigan, for thirteen years. Right now, I am working about thirty hours a week on a packaging line, packaging zip-loc bags and doing other specialty packaging. I believe I could make more that $700.00 a month, but I cannot afford to lose Social Security and Medicare. I have to make sure that I do not make more than $700.00 each month. It makes me angry. I want to be able to work more.

Preparing for the Future

My wife and I are in our sixties, like a lot of other families, and if something would happen to us, we want Wendy to be able to make it on her own. Yet she must depend on her Social Security and Medicare as a safety net, especially when we can no longer assist her.

What the SGA level amounts to is a wage ceiling for people with severe, lifelong disabilities -a ceiling that is created in federal policy. We need your help to bring the SGA level up to a reasonable amount and index it for inflation.

Thank you for giving us this opportunity to testify here today.

The Arc of the United States is a membership organization made up of people with mental retardation, their families, friends, interested citizens, and professionals in the disability field. Together they form approximately 1,000 state and local chapters of The Arc and the largest voluntary organization in the United States devoted solely to working on behalf of people with mental retardation and their families. The Arc works through education, research, and advocacy to improve the quality of life for children and adults with mental retardation and their families and works to prevent both the causes and effects of mental retardation.

Chairman. SHAW. Thank you, sir. Dr. Hanes.

STATEMENT OF PAMELA HANES, PH.D., ASSOCIATE DIRECTOR FOR RESEARCH, OREGON HEALTH POLICY INSTITUTE, DEPARTMENT OF PUBLIC HEALTH AND PREVENTIVE MEDICINE, OREGON HEALTH SCIENCES UNIVERSITY

Ms. HANES. Mr. Chairman and Members of the Subcommittee, I want to thank you for the invitation to present testimony at your hearing today. I am Research Director at the Oregon Health Policy Institute, and in this capacity I am currently directing an evaluation, a three-year evaluation, of a three-state work incentive initiative demonstration project that is being conducted in Oregon, Vermont and Wisconsin, and is being funded by the Robert Wood Johnson Foundation. This research is attempting to better understand the perceived and real barriers to employment as experienced by Social Security beneficiaries who live with a severe disability, and to understand how these perceptions influence their return to work efforts.

We are confident that this research effort will illuminate the individual structural factors that contribute to the high rates of unemployment and under-employment among Social Security beneficiaries.

I am presenting to you today preliminary findings from our Employment Barriers Survey. This survey was first developed in 1993 and conducted with a group of severely physically disabled beneficiaries in Wisconsin, and has more recently been administered to Social Security beneficiaries not only in Oregon, Wisconsin and Vermont, but also the State of Alaska.

The survey data reports the collective experiences, beliefs, attitudes and fears about returning to work, pursuing gainful employment, and the potential impact of this pursuit on the preservation of their essential income and health insurance benefits. We have learned from our participants that SGA is a major basis for the fears that are experienced by beneficiaries.

To focus our attention on today's hearing, I would like to quickly summarize some of the findings from the Alaska survey, which has been more extensively analyzed than the three-state evaluation, and then I would like to summarize what the findings of these surveys are pointing to.

In Alaska, of 354 individuals who returned the survey, 59 percent reported that they would like to return to work if employment didn't jeopardize their eligibility for needed benefits.

What we are hoping to learn in the three-state work incentive evaluation is what happens to thwart these expectations about employment.

This is the primary finding that we hope to learn from the participants of the three-state study over the next two and a half years. When this study is complete, the Institute will have not only self-reported data from individuals that has been collected at three points in time, but we will be linking this information to earnings, public program participation, cost of disability-related benefits and services, and health care utilization. These data will be reported on approximately 600 program participants and a comparable group of nonparticipants.

I mention this to tell you that it is a very unique study in the country in terms of our ability to understand the impact of employment barriers on the personal lives of a cross-section of individuals who have severe disabilities.

Fifty-eight percent of the survey respondents in Alaska reported that they had been employed prior to receiving Disability benefits. Only 96 of these individuals were employed at any time after collecting Disability benefits. At the time the survey was administered, only 39 individuals of the full 354 people were working. Of these 96 individuals who reported working, we had some very interesting findings about what the supports were that allowed them to continue to work. Support from family and friends, as we just heard from the presenters right before me, was a very important factor in individuals with severe disabilities to get and keep a job. In addition to that support from family and friends, having convenient and accessible transportation, and most especially and somewhat surprising, is employer and co-workers' attitudes toward people with disability was reported to be a major support in the reason that people were able to remain at their job.

Finally, 70 percent of these few people who told us they had worked since their disability, told us that continuing to be able to get their SSI checks while working was a very important factor for getting and keeping a job.

Now, among the majority of people who didn't work, we had findings about what were the barriers to pursuing gainful employment, and I am sure this committee has heard these factors many times as we were hearing testimony for the Ticket to Work and Work Incentives Improvement Act.

Disability and health problems was the most important factor to keep people out of the labor market but, after the disability itself, not having affordable health insurance, not being able to earn enough money to make up for lost benefits, not being eligible for Medicare and Medicaid were top vote-getters in the reasons that people perceive it is not in their best interest to go back to work.

I would just like to say that it is very instructive when we looked at the information that came from people who had worked since collecting Disability benefits and those who had not, the differences in their perceptions of these barriers. Twice as many people were likely to report they couldn't work because of their disability, if they had never worked. Three times were more likely to say that their inability to get time off for disability-related benefits was a major reason for not working, and six times more people were more likely to report that not having control over the pace and scheduling of work was a major barrier to working.

I mention these barriers because we are learning from the research that we are doing that many of these are perceptual barriers that don't hold up once people have successes in the workplace. And this is a very powerful message, I think, to those of us who are interested in looking at policy and system level modifications that help get folks with severe disabilities back into the labor market.

And almost every employment barrier measure presented, individuals who were currently working did not express major concern about the effect of working public benefits. It is a powerful and instructive finding.

I would like to complete my comments by just suggesting one thing that is particularly relevant to the hearing here today, and that has to do with the challenge facing—the changing face of disability and the challenge of reshaping and modifying policy that is disability sensitive.

Individuals with differing types of disabilities have very differing needs in terms of getting back to work. Individuals with physical and sensory disabilities depend heavily on adaptive equipment and devices, durable medical equipment and personal support. There is no "one size fits all" accommodation to overcome the misfit between individuals' functional limitations and their work environment.

It is incumbent on all of us to acknowledge that employment barriers are equally disempowering for all individuals who live with a severe disability, whether it be physical, psychiatric, sensory, or developmental in nature.

Structural barriers to employment, therefore, must be resolved based on the unique needs and differences of the different types of disabilities that present in the Social Security beneficiary rolls. Thank you, and I would be happy to answer any questions about the data that are contained in my written testimony.

[The prepared statement follows:]

Statement of Pamela Hanes, Ph.D., Associate Director for Research, Oregon Health Policy Institute, Department of Public Health and Preventive Medicine, Oregon Health Sciences University

Chairman E. Clay Shaw, Honorable Robert Matsui, and distinguished subcommittee members, thank you for the invitation to present testimony at today's hearing. My name is Dr. Pamela Hanes. I am the Associate Director for Research at the Oregon Health Policy Institute (OHPI) in the Department of Public Health and Preventive Medicine at the Oregon Health Sciences University. I am here today to discuss early findings from an important research project currently underway at the Institute. This research is attempting to better understand the barriers to employment experienced by a population of SSA beneficiaries who live with severe disabilities. Further, the research will help us learn the extent to which mitigation of these barriers will lead to increased rates of gainful employment among severely disabled workers.

I come today with findings from an *Employment Barriers Survey* that has been administered to SSA beneficiaries in four states. These findings are unique in several ways. The data are derived directly from individuals who live with a severe disabling condition and represent their collective experiences, beliefs, attitudes and fears about returning to work, pursuing gainful employment, and the potential impact of this pursuit on the preservation of their essential income and health insurance safety net. This survey was conducted with SSA beneficiaries who live in Oregon, Vermont and Wisconsin and are participating in the 3-State Work Incentive Initiative currently underway in these three states. In addition to the self-reported experiences of individuals participating in the 3-State Initiative, comparable data are presented from a representative sample of 1000 low-income SSDI and SSI beneficiaries on Medicaid in Alaska who were mailed in an earlier version of the *Employment Barriers Survey* in 1998.

These data are unique because they represent a true cross section of a severely disabled population in terms of geography and the types of disabilities experienced. The data include a representative sample of SSDI and SSI beneficiaries living with psychiatric, physical, sensory, and developmental disabilities. This information gives voice to over 1000 SSA beneficiaries in these four states.

When this 3-state study is completed in 2002, we will have individually reported attitudinal data that is linked to the earnings, public program participation, and health care utilization data of approximately 600 program participants and a comparable group of non-participants. This uniquely linked data set will provide a comprehensive picture of the relationship between living with a severe physical, psychiatric or developmental impairment and the structural factors in the policy and physical environment that both thwart and facilitate gainful employment. I look forward to a future date when I can report these very important research findings to the Social Security Subcommittee of Ways and Means.

The field of disability policy research has been slowly and steadily building a body of evidence to support policy and systems change at the state and federal levels. These changes can be seen in both the re-structuring of SSA benefits and work incentives as well as in the new options and protections available in the Medicare and Medicaid programs. AK, OR, VT, and WI, along with several other states, have taken a strong leadership role in these reform efforts. The Robert Wood Johnson Foundation has provided generous support to the 3-State Work Incentive Initiative (OR, VT, and WI) currently being evaluated by OHPI. Additionally, Vermont and Wisconsin are among ten other states that have cooperative agreements with the Social Security Administration to further support the individual states' work incentive efforts.

The Ticket to Work and Work Incentives Improvement (TWWIIA) Act of 1999 is another vitally important foundation to facilitate these knowledge-building and policy reform processes. My research team at OHPI will be closely monitoring the early impact of TWWIIA on the 3-State Work Incentive Demonstration programs in Oregon, Vermont, and Wisconsin.

The initial "pictures" we have taken of individuals participating in the 3-State Work Incentive Initiative and those taken in Alaska have produced somewhat differing images of living with a severe disability. A primary reason for these differences can be explained by certain characteristics of the underlying populations sampled. In Alaska, a randomly selected sample of SSA beneficiaries who receive Medicaid was drawn from the state Medicaid files. Therefore, this sampled population represented a particularly low-income group of individuals. Although likewise SSA beneficiaries in OR, VT, and WI, the survey respondents also are current or past clients of their states' vocational rehabilitation agencies. Thus, this group represents a population of beneficiaries that has demonstrated some vocational readiness to enter or re-enter the labor market.

To set the context for the reported attitudes, beliefs and fears associated with being gainfully employed, I have provided a brief description of educational and employment history characteristics of the population surveyed in AK and also those found among participants in the 3-State Work Incentive Initiative.

Alaska Profile

- Almost 30% of Alaskan respondents had less than a high school education;
- 96% reported an annual income of less than $15,000;
- In spite of full Medicaid coverage among survey respondents, 46% reported having out-of-pocket medical expenses; of these, ⅔ reported spending between $50–100/month on medical and health-related expenses;
- 35% of all respondents had been on disability benefits for over 10 years;
- 63% of all respondents reported having more than one diagnosed disability; the group least likely to have a second disability was those with a primary sensory disability;
- 58% of all survey respondents reported being employed prior to receiving disability benefits. Of those with an employment history, the majority held non-professional positions and had substantial work histories (53% worked over 5 years and 32% of these over 10 years);
- Wages from prior employment were low, in most cases near the poverty level;
- Of the 29% of respondents who reported being employed at any time since collecting disability benefits (n=96), 41% were working at the time of the survey.

To summarize this respondent profile, survey responders in Alaska were an extremely disadvantaged group as noted in their pre-disability as well as post-disability demographic profiles. Because the sample was stratified to capture the voices of rural as well as urban dwellers, a disproportionately high response from the frontier areas of the state (49%) is reflected in the prior occupation of beneficiaries, with almost one-third of formers workers in the manual laborer category prior to becoming a SSA beneficiary.

Of the individuals who reported having worked since becoming eligible for SSA benefits:

- 69% said that having support from family and friends was an important factor in getting or keeping a job;

- 71% reported having convenient and accessible transportation was important;
- 76% reported that positive employer attitudes about people with disabilities was important; likewise 74% said co-workers attitudes were important; and
- 70% said that continuing to get SSI checks while working was important to getting or keeping a job.

When the group of respondents who never worked since collecting SSA benefits was asked about the major barriers that keep them from working:

- 77% said their disability was a major barrier to work;
- 51% reported not having affordable health insurance was a major barrier;
- 57% reported not being able to earn enough money to make up for lost benefits as a major barrier to work;
- 65% reported not being eligible for Medicare or Medicaid as a major barrier to work;
- 61% said losing eligibility for Medicare or Medicaid as a major barrier to work;
- 56% reported that employment would affect their ability to keep disability-related benefits as a major barrier to work; and
- 52% reported employment making it harder to get disability-related benefits in the future as a major barrier to work.

To summarize the major barriers to work reported by a representative sample SSA beneficiaries on Medicaid in Alaska, it is instructive to note the differences in perception of what constitutes a barrier to work between respondents who had worked at some time since collecting benefits and the majority of respondents who had not returned to work. Respondents who hadn't worked since collecting disability benefits were:

- Twice as likely to report they couldn't work because of their disability;
- Three times more likely to say that their inability to get time off disability-related reasons was a major barrier to work;
- Three times more likely to say that lack of convenient transportation was a major barrier to work; and
- Almost six times more likely to report that not having control over the pace and scheduling of work was a major barrier to working.

Even more dramatic are the differences in perceptions of barriers between those who were currently working at the time of the survey and those who had not worked since collecting SSA benefits. Current workers were:

- Six times LESS likely to report that employment affecting their benefits in the future was a major barrier to working;
- Six times LESS likely to report that employment affecting their ability to keep disability-related benefits was a major barrier to working;
- Six times LESS likely to report that not having the ability to receive Medicare and Medicaid was a major barrier to working; and
- Three times LESS likely to report that not being able to earn enough money to make up for lost benefits was a major barrier to working.
- Current workers reported no major concern about negative employer or co-worker attitudes as a major barrier to working.

On almost every employment barrier measure presented, individuals who were currently working did not express a significant level of fear about the effect of working on public benefits compared to those who had not worked since collecting benefits. This is a powerful and instructive finding about the support that is needed and the positive impact of successful employment on dispelling the fear of loss of benefits. This support will come, in part, through education about the informed use of existing and the new work incentive programs that are embodied in TWWIIA. It also will come when beneficiaries have reason to believe and trust in a solid safety net that exists should their disability or health worsen while attempting or engaging in gainful employment.

Oregon, Vermont, Wisconsin Profiles

The data reported today from the 3-State Work Incentive Initiative is preliminary. We are currently in the process of tabulating information from the baseline Employment Barriers Survey that was administered to all individuals who are participating in the three states' programs and a cohort of non-participants who are being tracked in the same way as program participants. The full population of program participants has not been enrolled in the three states' programs. Enrollment will continue through the end of April 2000.

A modified version of this survey will be re-administered two more times during a three-year study period. I am reporting preliminary baseline data today. The data have been presented by type of disability to reinforce the fact that type of disability DOES make a difference in how individuals relate to their physical environment, therefore impacting their ability to work, and subsequently affecting their belief in their ability to work.

Individuals with sensory disabilities have been included the “physical disability” category. We estimate that approximately 10% of the individuals in this group have a self-reported primary or secondary sensory disability. In terms of the preliminary data: 44% of participants reported a physical disability, 28% a psychiatric disability, 11% a developmental disability, and 13% reported more than one primary disability.

% Of participants reporting ever being employed before collecting SSA benefits:

- 84% Physical
- 89% Psychiatric
- 42% Developmental
- 76% More Than One Primary Disability

% Of participants reporting working full-time prior to collecting SSA benefits:

- 81% Physical
- 67% Psychiatric
- 41% Developmental
- 74% More Than One Primary Disability

% Of participants reporting working more than 10 years prior to collecting SSA benefits:

- 59% Physical
- 40% Psychiatric
- 17% Developmental
- 53% More Than One Primary Disability

% Of participants reporting being currently employed at the time of the survey:

- 58% Physical
- 50% Psychiatric
- 35% Developmental
- 57% More Than One Primary Disability

% Of participants reporting working full-time at the most recent job lasting 30 days or more:

- 36% Physical
- 23% Psychiatric
- 8% Developmental
- 27% More Than One Primary Disability

% Of participants reporting their ability to work is limited because of their disability:

- 59% Physical
- 46%% Psychiatric
- 41% Developmental
- 63% More Than One Primary Disability

% Of participants reporting strong concern that working will affect their ability to keep their SSA cash benefits:

- 52% Physical
- 54% Psychiatric
- 41% Developmental
- 46% More Than One Primary Disability

% Of participants reporting that unless a job offers prescription drug coverage they can’t afford to work:

- 34% Physical
- 45% Psychiatric
- 13% Developmental
- 42% More Than One Primary Disability

% Of participants reporting that it would be hard to earn enough money to make up for lost SSA benefits:

- 45% Physical
- 51% Psychiatric
- 34% Developmental
- 40% More Than One Primary Disability

% Of participants reporting a major concern about not being eligible for Medicare and Medicaid if they return to work:

- 19% Physical
- 29% Psychiatric
- 16% Developmental
- 30% More Than One Primary Disability

From these preliminary data we can see that earnings from return to work does pose a significant threat to beneficiaries in terms of their fear of loss of essential safety net benefits. Tracking these beliefs and fears over time, and being able to link them to participants’ back to work efforts will provide a critical body of information that is currently missing from our knowledge base. We do know that in Vermont when policy analysts looked at the successful closures of their SSA beneficiary clients in 1995 there was a strong tendency to "park" earnings right under $500/month which, at the time, was the level of Substantial Gainful Activity (SGA). This parking behavior was in stark contrast to their successful closures of non-SSA beneficiaries—the non-SSA clients demonstrated a steady upward trend in earnings out to 18 months after closure.

The *take away* messages I would like to leave with subcommittee members today are based on ten years of policy research in this area.

First, the problem of un-and underemployment among SSA beneficiaries living with a severe disability represents a complex web of personal, policy, and environmental factors, and as such, any potential policy or systems reform solutions must both recognize and appropriately deal with this complexity.

Second, the severity of an individual's disability, that is, the degree of functional limitation one experiences in pursuing normal activities of daily living is ultimately a function of an individual's fit with his or her physical environment. Disability describes a *misfit* between an individual and his physical environment. As such, much of what we call disability can be ameliorated through accommodation, modification of the built and policy environment, and changing societal attitudes from those that use the label of disability to those that put the focus on individuals with differing abilities.

Third, the face of work disability has changed dramatically since the disability insurance (DI) amendments were added to the Social Security Act in 1958. In the late 1950s, a DI beneficiary characteristically would be described as a 50-something "worn out worker" -a male with a life expectancy of 60 (+/−a few years), laboring in a production-oriented, heavy industrial position who exits the labor force with a physical disability. In the 1990s a younger worker in his 30s or 40s who is increasingly exiting from an information-based, high technology or service-based labor market with a severe mental disorder is more characteristic of a DI beneficiary. The profile of the 1990s beneficiary is supplementing, if not replacing, the earlier profiled disabled worker, this is especially true in the northern tier states of the U.S. The largest single category of disability in the DI and SSI population is mental disorders followed by muscular-skeletal disorders. In the past 10 years alone, the number of disabled beneficiaries under age 30 has more than doubled from 116,000 to 275,000. With this growth in the younger disabled population is a projected lifetime stay on SSI disability benefits of 25 years for recipients between the ages of 0–17 and 16 years for those between the ages of 18–34. The primary reasons individuals leave the SSDI rolls are death (55%), followed by reaching retirement age (34%), disability cessation (8%) and Other (2%). The "other" category includes return to work. These sobering statistics require a re-thinking and subsequent re-engineering of the disability safety net.

Fourth, with the changing face of disability comes the challenge of re-shaping and modifying policy that is disability-sensitive. Work patterns, earnings, and employment barriers differ on the basis of the underlying disabling condition. Individuals with psychiatric disabilities are the most vulnerable to starts and stops in employment because disability management is so heavily dependent on professional involvement and strict adherence to drug regimens that often outlive their usefulness. On the other hand, individuals with physical and sensory disabilities depend heavily on adaptive equipment and devices, durable medical equipment, and personal support services. There is no one-size-fits-all accommodation to overcome the misfit between an individual's functional limitations and his or her work environment. Each individual's experience of functional impairment is unique and yet we know that what facilitates employment for individuals with spinal cord injuries or blindness will not necessarily lead to gainful work activity for individuals with bipolar disorder or schizophrenia.

It is incumbent on all of us to acknowledge that employment barriers are equally disempowering for all individuals who live with a severe disability, whether it be physical, psychiatric, sensory, or developmental in nature. Structural barriers to employment for individuals with severe disabilities are no respecter of person based on their particular type of disability. Policy solutions that promote access to the world of work therefore must be equally and equitably available to all SSA beneficiaries regardless of their underlying disability. Only when this happens will the full legislative intent of the ADA become realized and the potential for fuller employment of individuals with severe disabilities embodied in the TWWIA be fully utilized.

Chairman SHAW. Thank you, Dr. Hanes. Mr. Young.

STATEMENT OF TONY YOUNG, DIRECTOR OF GOVERNMENT ACTIVITIES, NISH, VIENNA, VIRGINIA, AND CO-CHAIR, SOCIAL SECURITY TASK FORCE, AND VICE CHAIR, CONSORTIUM FOR CITIZENS WITH DISABILITIES

Mr. YOUNG. Thank you. Good afternoon. I would like to start this afternoon by thanking the Subcommittee and the staff for the time and energy that went into passing the Ticket to Work and Work Incentives Improvement Act. The leadership of this Subcommittee was crucial to ensuring this legislation became law.

As you well know, the Social Security Disability Insurance was established to protect workers against the loss of income due to a disability that prevented them from working. When SSDI was established 50 years ago, it was reasonable to expect that people with the most severe disabilities would almost certainly never work. The technologies, services, supports, and medications that exist today would seem like science fiction to those who wrote the original SSDI law.

Let me put this in some perspective. A popular comic of the 1950s portrayed a character whose car had a telephone in it. Another had a car that could display maps on a television in the dashboard. Today, this is no longer science fiction, this is reality.

The reality for people with disabilities has changed also. Work, a job, a career, things that were not possible 50 years ago today can be an expectation for people with even the most severe disabilities. These expectations can be a reality when we have access to new technologies, new services, supports, and medications, yet we struggle to work under SSA rules that were created when things were quite different. The automobile industry has kept up with the times, and so, too, should disability policy.

On many occasions CCD has testified about the difficulties posed by the SSDI earnings limit. The earnings limit, also know as the "cash cliff", creates an all-or-nothing situation that forces beneficiaries to forego all cash benefits after only a meager level of earnings. This earnings limit is now $700 per month, $8400 per years. Earning just one dollar over this limit can cause an SSDA beneficiary to be determined no longer eligible for cash benefits. Oftentimes, the benefit amount lost is nearly equal to the earnings limit, subjecting the beneficiary to a whopping 50 percent drop in net income.

Further, all individuals with severe disabilities incur substantial costs in attempting to work. In my case, I pay over $10,000 a year just for personal assistance services. The wheelchair that I use to get around and go everyplace and go to work, cost $20,000. I spent another $20,000 buying a van to transport me and my wheelchair, and then had to spend another $15,000 to make it accessible. Assistive technology, hearing aids, animal companions, medical equipment and supplies, deductibles and co-payments, communications devices and the maintenance of all this equipment all increase costs faced by individuals with severe disabilities who work.

As a result, far fewer beneficiaries attempt work than would under a more rational policy. Many never work above the earnings limit, even if they can. This policy creates financial costs for the government because beneficiaries who could work and pay taxes aren't. It costs the government because people fear they can't jump the cash cliff to achieve a level of earnings that allow them to live above poverty, so they remain on full benefits.

It took ten years for SSA to raise the earnings limit to $700 from $500. It took just as long to go to $500 from $300. And those increases weren't even enough to keep up with the low rate of inflation our economy experienced during that time.

For more than 20 years, the disability community has advocated for changes in the SSDI program, particularly about the SSDI cash cliff. Legislative addressing the earnings limit could take many forms. However, certain key principles should form the foundation for any congressional action addressing the earnings limit. These principles are: (1) Do No Harm. Changes made by Congress to earning limit, or to the Social Security Disability programs as a whole, should ensure that no disability group is negatively affected. Whatever Congress does, it must not enact policy detrimental to any category of DI beneficiaries; (2) Equity. Should Congress take favorable action on legislation that addresses earnings limits, Congress must ensure equity among all DI beneficiaries.

There are a variety of options available to Congress that would eliminate the cash cliff. We would welcome the opportunity to work with you and your Subcommittee staff in developing a proposal that eliminates the cash cliff.

We urge Congress to finish the work begun with the enactment of the Ticket to Work and Work Incentives Improvement Act by removing the cash cliff barrier to work.

Again, I thank the Subcommittee for this opportunity. I will be glad to answer any questions you might have.

[The prepared statement follows:]

Statement of Tony Young, Director of Government Activities, NISH, Vienna, Virginia, and Co-Chair, Social Security Task Force, and Vice Chair, Consortium for Citizens with Disabilities

Thank you Chairman Shaw, Mr. Matsui and members of the subcommittee, for the opportunity to testify today on the SSDI earnings limit. I am Tony Young, the Director of Government Activities for NISH and Vice Chair of the Consortium for Citizens with Disabilities. CCD is a coalition of nearly 100 national organizations advocating on behalf of people with all types of physical and mental disabilities. I am testifying today in my role as a Co-Chair of the CCD Task Force on Social Security.

Mr. Chairman, I want to begin this morning by thanking you and Mr. Matsui, the subcommittee, and your staff, for the hard work and commitment that went into passing the Ticket-to-Work and Work Incentives Improvement Act. Your leadership and that of the subcommittee were crucial to ensuring that legislation became law. We especially appreciate your decision to hold this hearing so quickly after the recent approval of H.R. 5, legislation that completely eliminates the earnings test for people over age 65.

As you know, the Social Security Disability Insurance Program was established to protect workers against the loss of income due to a disability that prevented them from working. When SSDI was established some fifty years ago, it was reasonable to expect that people with the most severe disabilities would almost certainly never work. The technologies, services, and medications that exist today would seem like science fiction to those who wrote the SSDI law in the 1950s. Let me explain by putting this in some perspective. A popular comic of the 1950's portrayed a main character whose car had a phone in it, and a wristband that had a television screen. Another had a car that could produce maps on a television in the dashboard.

Today, this is not science fiction, it's reality. We have cell phones that can call anywhere in the world, and cars can be equipped with a map system that uses satellites to find your location and give you directions. You can even watch your favorite 1950's cartoon show via satellite broadcast to the on-board television.

The reality for people with disabilities has changed too. Work, a job, a career, things that were not possible fifty years ago are today an expectation for people with even the most severe disabilities. New technologies, new services, evolving employment supports, and better medications have made those expectations a reality. Yet we struggle to work under rules created when things were quite different. The automobile industry has kept up with the times, and so too, should disability policy.

On many occasions in the past CCD has testified about the difficulties posed by the SSDI earnings limit on the ability of people with disabilities to achieve meaningful employment before losing all cash benefits. The earnings limit, known as the "cash cliff" creates an all-or-nothing situation that causes people with disabilities to forgo all cash benefits after only a meager amount of earnings are achieved. Currently, the earnings limit is at $700 per month, or $8,400 per year. **This amount is at just about the federal poverty level for a single individual.** Earning just one dollar over this amount, can cause an SSDI beneficiary to be determined no longer eligible for cash benefits. Often times, the benefit amount lost is nearly equal to the earnings limit, thus subjecting the beneficiary to a whopping 50% marginal tax.

Further, workers with disabilities incur substantial expenses in attempting to work. The cost of personal assistance, of a wheelchair, an accessible van or hand controlled car; assistive technology, hearing aids, animal companions, computers, communications devices and the repair and maintenance costs of the equipment all increase the costs faced by individuals with severe disabilities who want to work.

As a result, far fewer beneficiaries attempt work than would under a more reasonable, rationale policy. Many never work above the earnings limit, even if they could. This policy is just plain wrong. Worse, this policy creates financial costs for the government, and the SSDI program. It costs the government because people who could be working and paying taxes aren't, and people who are working might be working more, but aren't. It costs the SSDI program because people fear they can't jump the cash cliff to achieve a level of earnings that allow them to live above poverty, so they remain on full benefits.

Further, although the earnings limit was recently raised to seven hundred dollars from five hundred dollars, it took ten years for the Social Security Administration to act on that increase. And it took just as long to raise the earnings limit to five hundred dollars from three hundred dollars in the mid–1980's. These increases weren't even enough to keep up with the low rate of inflation our economy has experienced these past 15 years.

For more than twenty years, the disability community has advocated for changes in the SSDI program, and particularly about the SSDI earnings cliff. Legislative advocacy concerning the earnings limit has often taken many forms. However, certain key principles should form the foundation for any congressional action addressing the earnings limit. Those principles are:

1) Do No Harm—Changes made by Congress to earning limit, or to the Social Security disability programs as a whole, should ensure that no disability group is negatively affected. Whatever Congress does, it must not enact policy detrimental to any particular category of DI beneficiaries.

2) Equity—Should Congress take favorable action on legislation that addresses earnings limits, Congress must ensure equity among all DI beneficiaries.

There are a variety of options available to Congress that would deal with the "earnings cliff" that beneficiaries face if they try to work. We would welcome the opportunity work with you, and subcommittee staff in developing a proposal that eliminates the earnings cliff.

In this time of profound fiscal growth and economic prosperity, Congress should "fix" the SSDI earnings limit to allow all people with disabilities the opportunity to contribute to this unprecedented economic expansion. We urge Congress to finish the work substantially started with the enactment of the Ticket-to-Work and Work Incentives Improvement Act by removing the "earnings cliff" barrier to work.

Finally, while not directly on point regarding SGA, several issues have come to the attention of the CCD Social Security Task Force that we believe merit further attention. It is our understanding that, for a "disabled adult child," leaving the Title II program as a result of earning above SGA after the EPE has expired means the loss of "disabled adult child" status for life. Many people do not understand that the benefits that the parent has earned for the disabled adult child (severely disabled since childhood) are permanently lost, and there is no re-entry under SSA's current interpretation. We believe that this must be fixed; otherwise, the purpose of the Ticket-to-Work & Work Incentives Improvement Act will be thwarted for those who qualify as disabled adult children. We believe that the TTWWIIA clearly contemplated the ability of disabled adult children to move on and off the program to the same extent that other people with disabilities will be allowed to do so. The statutory language establishing the eligibility category for disabled adult children was clearly cited in every case that eligibility for the SSDI program was cited.

In addition, we understand that SSA's interpretation regarding the value to be placed on a worker's work effort (regarding whether it exceeds SGA or not) is different for people in supported employment depending upon whether the individual is supported directly by an employer or whether the individual is supported by services from an outside source, such as a state-funded supported employment agency. Due to this distinction, an individual's work effort could be found to exceed SGA when the support is from a third party while that same work effort could be found not to exceed SGA when the support is from the employer. From the perspective of the individual, this is an arbitrary distinction. Further, there may be additional complications in that the nature and scope of the support provided to the individual may be misunderstood when making the valuation of work effort. For instance, while the individual may be performing the actual task (bagging groceries, assembling a package, etc.), it may be that the individual would be unable to perform the task without the help of the job coach in ensuring that the individual arrives at work on time properly attired, that he/she interacts appropriately with customers and co-workers, and that he/she remains focused on the assigned job tasks, among other things. We believe that this is an area that also needs further examination if work incentives are to work as intended by TTWWIIA.

Again, I thank the subcommittee for this opportunity to testify. I will be glad to answer any questions you may have.

TONY YOUNG
NISH
Director of Governmental Activities

Chairman SHAW. Thank you. Mr. Matsui

Mr. MATSUI. Thank you, Mr. Chairman. I want to thank all five of the panelists for their testimony today. I just have one series of questions of Dr. Hanes.

Dr. Hanes, it is my understanding that in your written testimony you talk about the profile of a disabled individual when the program was first established, and then you have a profile today of that same disabled individual. The original profile was somebody who was in the workforce for years and became disabled perhaps at the age of 50 or thereabouts, and then received some benefits. Today's disabled individual is somebody that perhaps has mental problems, emotional problems, is much younger. Is that a correct representation of your findings?

Dr. HANES. Yes. I would like to just clarify that. If you look at the prevalence of disability across the country, there is a very interesting difference between the prevalence of mental disorders as the primary disabling condition in both the SSI and the DI beneficiary population. It appears to be much more linked to the kind of industrial base that workers are coming from.

We still see a lot of the musculoskeletal, the bodies that are breaking down under manual labor in the southern areas of the country, and it is very interesting, and it is an area that I think merits further research. But I do think it is correct to say that the face of disability has changed since the Disability Insurance program was first enacted, and the most single prevalent category of disability is mental impairment, mental condition.

Mr. MATSUI. And I guess the conclusion I am reaching from your findings there is that the earnings limit years ago is probably in need of significant adjustment for the nonblind disabled today because they are younger and they still have a lot of work years left, perhaps unlike those that were defined as disabled 30 years ago, is that correct?

Dr. HANES. I think that is an appropriate conclusion to make, and some of the data that have actually been analyzed by Social Security Office of Statistics and Evaluation have projected the lifetime of benefits for this younger disabled population, and it is very true that the younger—obviously, the younger someone goes on the Disability rolls, the longer the projection is that individual will be on the rolls.

The other piece of my testimony that is written, that I would like to reinforce with you, is the primary reason for leaving Disability Insurance is death. Fifty-five percent of the people exit the program because of death. The next largest category, I believe around 35 percent, is retiring or moving from Disability Insurance to retirement benefits. And I think there is fairly persuasive evidence that less than 1 percent of people leave the Disability rolls permanently because of employment, and the impact of a younger disabled population it doesn't take heavy mathematics to understand the impact on the trust fund, in particular, of having people on the Disability rolls for much longer periods of time.

Mr. MATSUI. Well, I want to thank you and the other four panelists as well for their testimony. Thank you.

Chairman SHAW. Mr. McCrery.

Mr. MCCRERY. I am sorry I missed the first two witnesses' testimony. Mr. VanOoteghem, could you expound a little on the work-related expenses associated with your daughter's work?

Mr. VANOOTEGHEM. Right now, she rides the bus to work, they supply it, and she pays for the fare which is $2.87 per trip. She doesn't really have any other expenses. We don't claim any other expenses for her.

Mr. MCCRERY. How about Mr. Young?

Mr. YOUNG. Yes, I would be happy to talk about my expenses.

Mr. MCCRERY. Well, the work-related expenses that would be deductible from your income for purposes of staying under the limit.

Mr. YOUNG. Under impairment-related work expenses for nonblind people, it has to be an expense that is incurred at work. The majority of the expenses aren't incurred at work, it is getting ready for work and getting to and from work. The personal assistance that I use to get dressed in the morning, people that need cuing and supervision to get ready, the transportation to and from. If you have an employer, especially one of the nonprofit employers, that provides transportation for you, it is not a problem. If you don't, then you are stuck with a huge bill every month trying just to get to and from work.

Under the ADA, the employer can provide reasonable accommodations that takes care of some of the work expenses, and the other things are deductible. But by that time, you have already incurred 75 percent of the work-related expenses that you are going to get to in a situation.

Mr. MCCRERY. But those expenses you cannot deduct from—

Mr. YOUNG. Those we cannot deduct, not from earnings to bring it down below $700, nor are they available for deduction on Schedule A of the 1040 Form.

Mr. MCCRERY. If you were here earlier today when we had other panels, there was a lot of discussion about the difference in the earnings limit for the blind disabled and the nonblind disabled. Would any of you like to comment on that? Do you agree or disagree that there is a rationale for the disparity?

Mr. YOUNG. I would certainly like to say that there is no rationale that I can think of for treating one disability group differently from another disability group int he types of expenses that we incur. The level of expense is much more related to the severity of disability and, frankly, the geographic location in which one lives than it is to whether you are of one type of disability or another. I can cite any number of examples of people with various kinds of disabilities that are going to have huge costs—a person with very high technological needs, no matter what type of disability, is going to have huge costs. A person on DI who is going to be much more severely disabled is going to have higher costs than a person not on DI, whether they are served by the VR program or not. Persons who are not on DI are not going to be that disabled and are not going to have the kind of work-related costs that somebody who is on DI who, by definition, is more severely disabled will have.

Mr. MCCRERY. Anybody else? Yes?

Mr. VANOOTEGHEM. We watched in 1977 when people who are blind received the retiree's earning limits. We didn't say much then and there was no change until 1990 when the SGA level was raised to $500 per month. I know our folks had to fight to make this happen. In 1999, SGA went to $700, but with the raises in minimum wage within the next three years, that is going to out of our league again. We need some help, and we need indexing for future increases in the SGA level. Even if it is not retroactive, we need to be brought up to what people who are blind have for their SGA level.

Dr. HANES. I would like to comment just for a moment on that.

Mr. MCCRERY. If you don't mind, comment on that, and also comment on the cliff situation, would it be more helpful for us to smooth out the cliff, or more helpful to just raise the earnings limit and still have a cliff.

Dr. HANES. Well, I wanted to comment on the cost because some of the previous testimony talked about the cost in the Vocational Rehabilitation Program, for example, and I think it is very important that we consider the total cost of living with a severe disability. And when we think about the total cost and the costs that are incurred to the individual, and also the costs that are incurred in the Medicaid program—for example, I can speak with some knowledge about people with psychiatric disabilities are incurring tremendous costs through prescription drugs and intensive case management and psychotherapy.

When you look at costs across type of disability, I think it is very easy to make a persuasive argument how all people with severe disabilities incur a tremendous amount of cost, both personal and to the system, in order to be able to be job ready.

And so, although I would not make a statement that one type of disability is more deserving than the other, I think that it is incumbent on all of us to factor in the total cost of living with a disability.

And in terms of the cliff, I think anything to mitigate the cliff is going to get people back to work. In my own research—and now I have heard from probably 1700 people across the country—the fear factor that someone spoke about earlier is so strong that until you can deal with that fear in ways that people trust, that they know there is a safety net there that they can trust, I don't think we are going to see large numbers of people going back to work no matter how you deal with SGA.

Mr. MCCRERY. Thank you. Anybody else?

Mr. GALLAGHER. I was director of a program for five years, earning over $35,000 a year with full Blue Cross, and when I had my last esposode due to neuroleptic malignant syndrome, I had a ventricular drillout, which means I had a blood clot, I had to change my medications to Closeral and Depokote. These medications, while the technology is new, are very expensive. It is close to $1,000 a month, which I don't have the insurance to pay for. Blood is drawn when you first start out, you get your blood drawn every day, then it is every week, and after three years now I have been taking it, it is every two weeks. The cost factor of the medications alone, the factors of going back to seeing the psychiatrist, your medical doctor, and all the medical problems that come because of the medications, it is keeping me on Disability. It makes no sense at all. I am capable of working. I do want to work. It is just it is very frustrating. Right now, I owe the Social Security Administration I don't know how many thousand dollars. My dad is my payee. I am 42 years old, and I have a Master's Degree. I have been successful over the last ten years. I don't know. I don't have the answers, that is why I am here today, because I am looking for you all to help find the answer. I don't know what the answer is. I do know that I am sure you will figure it out.

Mr. YOUNG. If I might, just briefly, obviously, I think we need to take care of this earnings cash cliff because it is a huge barrier. But the SGA level, because it is the first determiner of disability, work disability, if you don't index it to wage inflation, every year the wages go up, the definition of disability changes for the worse for people. It is like nonlegislative clamping down on the definition because it just keeps crashing down on people. And if it goes ten years, then you have got a substantial change in the definition.

So, I would very much urge you guys to look at the possibility of indexing that SGA.

Chairman SHAW. Mr. Gallagher, I am interested. You said that you earned more. How far over the limit does the Social Security Administration claim you went?

Mr. GALLAGHER. I don't know. This is back when I was the direct care staff. I was three years on Disability back in the 1980s, and I was earning over $560 a month at the time. My dad has been taking care of my finances, and my dad and I are not on the the best of relationship we have a business relationship, we don't have a very emotional relationship. I do not know the financial parameters. I do know that he is paying back out of my Social Security check $100 a month back to SSA because of the overpayment. I do know that much.

Chairman SHAW. As I understand the law you may have just stepped over the line slightly and now are incurring a huge debt.

Mr. GALLAGHER. That was back in the 1980s, I believe it was. Correct.

Chairman SHAW. Who is your congressman?

Mr. GALLAGHER. I am from Detroit, Michigan area.

Chairman SHAW. That could be any number of people. You might want to contact their office and ask them to take a look at it for you. If you don't know the figures, you are certainly entitled to know them.

Mr. GALLAGHER. The problem is, my dad is so private about things. He is paranoid that I am going to lose all my benefits, so he doesn't disclose anything to me about my finances. I live in his house. I pay him $400 rent. It is a $150,000 house. I could not live there without the support you know, it is just very frustrating. I don't have the answers. I am estranged with my father. He is my payee, but I do work part-time currently.

Chairman SHAW. Well, this hearing is held for a definite purpose, it is not just to allow people to vent their anger. I know Wendy told us that she was very angry, and I think that certainly adds to the intensity of the testimony that we have gotten today, and I think it has been very open and forthright, and I think all the witnesses have been great.

We are taking a look at the figures and what we can do, and we recognize the problem. I think the abruptness of the cutoff is very troublesome to me. Mr. Matsui and I—you wonder sometimes, when we start whispering to each other up here, what we are talking about—we weren't talking about the ballgame, we were talking about the subject at hand and what we might be able to do.

Mr. McCrery has talked about putting up some type of gradual tapering of benefits after you reach the limit. I am very troubled by your situation, Mr. Gallagher, where you stepped over the line and now you have got all hell to pay for it. That is a big problem, and the law should not be that way and we need to take a close look at it. On the other hand, we also have to be careful that these programs don't get out of hand and that we are concerned about the solvency of the system, and that is something we have to constantly work on. And we are not going to stop with this hearing, we are going to continue to work and see what we can do to change things.

I want to thank this panel and all the panels and the people who stayed with us all afternoon. Thank you very much for being here, and this hearing is adjourned.

[Questions submitted by Chairman Shaw to Mr. Gallagher, Dr. Hanes, Mr. VanOoteghem, and Mr. Young, and their respective answers, follow:]

Mr. David Gallagher
c/o Paul Seifert
International Association of Psychosocial
Rehabilitation Services
10025 Governor Warfield Parkway, #301
Columbia, MD. 21044–3357

Dear Mr. Gallagher:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following questions:

1. Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600 -below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?
2. Does working help your medical condition? Would you work more if you weren't afraid of losing your disability benefits?

I thank you for taking the time to answer these questions for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 19, 2000

The Honorable Clay Shaw
Chairman, House Social Security Subcommittee
B–316 Rayburn House Office Bldg.
Washington, DC 20515

Attn: Kim Hildred, Staff Director

Dear Mr. Chairman,

Thank you for the opportunity to address questions regarding Impairment Related Work Expenses (IRWEs) and other work-related issues. First, I want to thank you for holding the March 23rd hearing on the Substantial Gainful Activity level in the Social Security Disability program. For too long beneficiaries have struggled against the unfair SGA limit placed on their ability earn. I hope that the hearing, and these answers, will help the Subcommittee develop a response to the concerns expressed on March 23rd.

I am aware of the IRWE provision but have never used it. Further, although I have been on and off benefits I have never been informed by Social Security about how the provision could benefit me. I hope that the Work Incentive Planners that are a part of the Ticket-to-Work & Work Incentives Improvement Act will change this all beneficiaries.

Also, as you know I have a Master's of Social Work and conduct group self-help counseling sessions for mental health consumers at my program in Michigan. All the people in my groups have severe mental illnesses, and many work, yet none had heard of the IRWE benefit. Further, no other consumers I have talked with seem to be aware of this benefit. I should qualify this statement by saying that many beneficiaries do not fully grasp the complicated work incentives in SSDI and SSI. So the fact that everyone I talked with didn't know what an Impairment Related Work Expense deduction was or if they used it does not mean that a case manager or other counselor didn't utilize the deduction on their behalf.

The IRWE could benefit some SSDI beneficiaries, but overall it is a limited answer to a bigger problem, namely the SSDI SGA earnings limit/cash cliff. The IWRE is limited in several ways. First, the beneficiary has to incur the expense in the first place, and pay for it out of pocket. Second, to be effective the amount of the IRWE has to equal or surpass the amount of income above SGA. If not, then the IRWE doesn't protect you. Third, once you use an IRWE, you have to keep it to remain on benefits. For example, if the costs of medications are paid for out of pocket then they can be used as an IRWE. (The amount spent on medications, which incidentally might be more than the benefit, can't be used for other necessities). If a person changes jobs and the employer's health plan pays for part of the medications, they might lose enough of the IWRE to lose benefits without earning enough to cover the non-reimbursed cost of the medications.

Here's how loss of an IWRE could affect a beneficiary:

If the beneficiary's DI check is $500 and they earn $1,300, they need over $600 in IRWEs to keep $500 of benefits. (i.e. $500 in benefits and $700 in earnings after the IRWE ($1,300 -$600) for a total income of $1,200). Now that works out better than losing one's benefit AND having to pay for the medications. However, if the employer's health plan picks up $300 of the medication cost, the beneficiary loses $500 in benefits and still must pay the $300 co-pay for the medications (MH parity notwithstanding, 50% co-pays are NOT unusual for mental illness), plus the other costs of the plan. The beneficiary earns $1,300 but loses all the DI benefit because the IRWE is too low ($300). They also pay the $300 in co-pay for the medications, and now has only $1,000. Now, I suppose the person could refuse the healthcare, but how wise is that?

Also, not every one with a disability has impairment related work expenses or has enough expenses to keep from losing all their benefits. Because of this, the IRWE program is at best a selective solution to the cash cliff problem. I believe that the IRWE program working in conjunction with sliding-scale cash offset in the SSDI program would better address the cash cliff and more fairly benefit ALL working SSDI benefits rather than just a lucky few.

Finally, in response to the second set of questions, there is much research that proves that work does help a person cope better with their mental illness. Work can't be called "treatment" nor does it have a direct medical impact on mental illness in terms "curing" the medical condition (at least not that any research has proved). However, by adding a strong sense of self-worth and providing an opportunity at independence and self-reliance, work does improve the lives, outlook, and overall psychosocial/life condition of people with mental illness. In this respect, work can be extremely beneficial for consumers and it has been for me.

As for working more, if the SSDI program was geared to encouraging more work I could work more. The cash cliff is tremendously discouraging and consumers are acutely aware of it and avoid it at any cost. Almost every consumer I talked to about IRWEs mentioned the cash cliff as being a problem. Even if earnings don't approach the cliff people fear that some unforeseen circumstance, like an increase in the minimum wage or a bonus, might push them over the cliff. This keeps people from doing the best they can.

In closing, I urge you Mr. Chairman and the Congress to eliminate the cash cliff. Again, thank you for the opportunity to testify and to respond further to your questions.

Sincerely,

DAVID GALLAGHER, MSW
Eastpointe, MI 48021

April 26, 2000

Pamela P. Hanes, Ph.D.
Oregon Health Sciences University
3181 Southwest Sam Jackson Park Road
Portland, OR 97201

Dear Dr. Hanes:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries New Roman. In order to complete our hearing record, I would appreciate your answering the following questions:

1. Your testimony indicates that the face of disability has changed dramatically since 1958. The largest single category of disability in the DI and SSI population is mental disorders followed by muscular-skeletal disorders. Each individual's experience of functional impairment is unique and what may facilitate gainful work activity for individuals with one disability may not necessarily lead to gainful work activity for an individual with another disability. You indicate that we should re-

think and subsequently re-engineer the disability safety net. In addition, you refer to employment and structural barriers that need to be overcome. To accomplish what you suggest, what factors should we be focusing on?

2. Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600—below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?

3. In your research about barriers to work, did you find that barriers to work differ considerably depending on the type of impairment an individual has? Did you find that individuals who are blind faced greater barriers than those who are not blind?

I thank you for taking the time to answer these questions for the record and would appreciate your response by no later than May 19, 2000. New Roman In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. New Roman If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 16, 2000

E. Clay Shaw, Jr.
Chairman
Subcommittee on Social Security
Committee on Ways and Means
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Shaw:

Thank you for allowing me to present further information on work incentives and disincentives for blind and disabled beneficiaries for your hearing record. As I stated during my oral testimony, the Oregon Health Policy Institute is currently engaged in a very unique research project that will, when completed, provide a comprehensive picture of the dynamic relationship between disability, health, public benefits, employment, and overall quality of life. Part of the uniqueness of this research effort is that the detailed picture presented in our evaluation findings will focus on the social and economic experience of living with a disability based on whether an individual's primary disabling condition is physical, developmental, sensory, or psychiatric.

At this time I will respond to each of the three questions you presented in your April 26, 2000 letter.

1. What factors should the subcommittee focus on in re-thinking and subsequently re-engineering the disability safety net?

I suggest that a primary focus should be on understanding the differing experience of disability that derives from whether an individual lives with a physical, cognitive, mental, or multiple impairments. For too long disability policy has assumed a homogeneous population, that is, that all functional limitation on a continuum from major to minor, and regardless of the underlying condition, produces the same outcome -disability. Disability research has suffered from the same myopic view, we study the health status of people with disabilities or the employment status of people with disabilities and have engaged in very few, if any, disability studies of employment behavior that control for type of disability and its effect on individuals' employment patterns and earnings histories.

Although our current understanding of cross disability employment dynamics is still quite limited, we can learn from what is known about the employment patterns, health status, and employment-related support needs within particular disability groups.

I suggest that a major disability-specific focus to be considered in re-engineering the safety net ought to concern the issues surrounding reasonable accommodation, assistive technology and devices, and the supportive services necessary to return to work or increase earnings to a level of economic self-sufficiency.

To illustrate this point, there have been significant advances in the development of assistive technology and devices that allow individuals with quadriplegia to drive their own vehicles, manage computer websites, become professional artists and craftspeople—in each case, a technological breakthrough or device has been so designed as to overcome historic misfits between person and environment. For individuals with sensory impairments the technological advances are different but equally impressive, for example the growing availability and uses of service dogs, large print books and publications, advances in telecommunications and electronic media access, and the increasing numbers of individuals trained in American Sign Language, these technologies and adaptive devices have served to mitigate many of the barriers that previously prevented individuals with sensory impairments from full integration into community affairs and the world of work.

Among the most challenging and intractable problem areas in terms of accommodation and assistance are those faced by individuals with severe psychiatric disabilities. The primary work and community integration support available to these individuals comes in the form of pharmacological assistance. Because mental disabilities are largely invisible when the symptoms are controlled, the true costs associated with drug therapies at the personal and societal level are not widely known or understood. Just as the gentleman who testified at your hearing reported, the drugs that are necessary to stabilize acute psychiatric symptoms are often toxic to the user, producing potentially life-threatening side effects that exacerbate rather than ameliorate the misfit between individual and environment. Another important component of the support needed by individuals with psychiatric disabilities is on-going and intensive clinical case management that relies on professional assistance as opposed to technological devices or equipment.

It is important to recognize that costs incurred in getting individuals with severe disabilities into competitive employment are borne throughout a large number of federal, state, and private agencies and organizations and therefore cost comparisons between disabilities groups must be made with extreme caution. For example, a large portion of the costs associated with supporting individuals with psychiatric disabilities in their return to work efforts is borne through the Medicaid program. Vocational rehabilitation services have historically underserved individuals with psychiatric disabilities so a cost comparison across disability types in this program is not appropriate; particularly when the underlying assumption is that costs associated with vocational rehabilitation service agencies are the sole input in the vocational rehabilitation process.

Another critical dimension of a disability-specific focus is sensitivity to the impact that the underlying disabling condition has on overall work effort, particularly from a longitudinal perspective. For many individuals with physical disabilities once the needed technology has been employed, there is a high likelihood of stability in the work environment. The caveat to this statement is of course the effect that the underlying disabling condition can have on compromising the health status of individuals with physical disabilities. Many physical disabilities derive from a chronic health condition that manifests itself in progressive loss of function, acute medical episodes, chronic pain, and physical deterioration. Individuals with multiple sclerosis, HIV/AIDS, Parkinson's Disease, all will experience setbacks in their work effort that are directly related to their disabling condition. The same is true among individuals with severe psychiatric disorders whose medications cease to be effect or worse yet, become toxic.

The primary point I want to make about a disability-sensitive focus is to encourage subcommittee members to look beyond the label 'disability' and instead to focus on the personal dynamics of living with a severe disability, recognizing that these dynamics manifest themselves differently based on the type of disabling condition and the anticipated course of the disease or chronic condition.

Reengineering the disability safety net requires an acknowledgement of the predictable nature of disability -disability does not go away over time, nor does it disappear because of earnings in excess of some fixed, albeit, arbitrary dollar figure. It is important to remember that without accommodations, technological advances, and changing societal attitudes, competitive employment among individuals with severe disabilities would be an unrealistic and unattainable policy goal.

I suggest that the policy goal of the disability safety net should be to maximize the number and types of opportunities available to individuals with severe disabilities who want to work and to allow them to pursue competitive employment at whatever level is reasonably possible in terms of hours worked and monthly earnings. We know from a growing body of survey research conducted at the Oregon Health Policy Institute that the vast majority of individuals with significant disabilities want to be employed, want to have meaningful life rolls, and strongly believe that work is a primary way to give something important back to their community. The fear that gets played out in high rates of unemployment in this population is quite understandable when the choice is between living entirely on poverty level or near poverty cash assistance with health insurance or the possible permanent loss of a cash assistance and health care safety net when the possibility of failure in the workplace looms largely.

2. Are you familiar with existing Social Security work incentives and how widely are they being used?

Yes, I am familiar with the impairment-related work incentive (IRWE) program as well as the 1619 (a) and (b) Work Incentive provisions and the Plan to Achieve Self-Sufficiency (PASS) program. The best source for tracking the impact of these work incentive programs on the work efforts of Social Security beneficiaries is the *Quarterly Report on SSI Disabled Workers and Work Incentive Provisions* issued by the Social Security Administration and available on their website. The short answer to your question is that, with the exception of 1619, these work incentive programs are largely unutilized. A snapshot from the March 1999 report reveals:

- Only 6% of the total SSI caseload were working during the first quarter of 1999
- 72% of SSI disabled workers had earned income below $500/month; 30% earned $65 or less
- In general, the percentage of SSI disabled workers was higher in the Northern states than in the Southern states
- The greatest use of a work incentive provision was 1619 −30% of disabled workers used this provision
- 3% of SSI disabled workers used the IRWE provision
- 1% of blind disabled workers used the Blind Work Expense (BWE)
- .3% of disabled workers used the PASS program

My opinion about these work incentive programs is largely shaped by the professionals and advocates in the field who work on a daily basis with individuals with severe disabilities who want to return to work, are returning to work, or are choosing not to return to work because they fear the loss of disability status, health benefits, and a cash assistance safety net. The overwhelming sentiment expressed is that existing work incentive programs are too complicated, result in overpayments, lack real protection against set backs in the workplace, and are subject to interpretation based on who one talks to at which agency. More importantly, there has been a lack of trust in the past in the individuals who administer these programs. I have come to appreciate the elegance of the strategies employed by Wisconsin and Vermont in their work incentive demonstration projects which are designed, simply stated, to make return-to-work incentives as simple and straightforward as possible for the consumer.

Work incentives that *support* individuals on the path to economic self-sufficiency, that allow them to *gradually work off benefits,* that recognize the *extraordinary expenses associated with accommodating functional impairments* in the workplace and community, and that *function as a true safety net,* not a way of life, should be the goals of an efficient, user friendly disability safety system.

8. In my research did we find that barriers to work differed depending on type of impairment? Did we find that blind individuals face greater barriers than others?

Our preliminary baseline data suggest that significant differences exist in perceived employment barriers faced by individuals based on type of impairment, particularly striking differences appear to exist between individuals with physical as contrasted with mental impairments. The total number of individuals who are blind and participating in the 3-state work incentive initiatives is too small to segregate their responses from other types of physical disabilities.

I am happy to share with you and your staff the baseline frequencies related to work attitudes and motivation, attitudes and beliefs about work and benefits, and issues of self-esteem among individuals participating in the Wisconsin Pathways to Independence program. These data represent 187 program participants as of 4/00. Because of the preliminary nature of these data, I respectfully request that these data not be made a part of the public record and that they are not duplicated or disseminated until such time that our research team does so.

These data provide an as yet incomplete picture of the individuals who are participating in the 3-state work incentive projects, what they do illustrate is a range of beliefs and perceptions about the value of work, fears about working, and the profound impact that living with a disability has on the self-esteem of individuals. When our study is completed in December, 2001 we will have linked these perceptual data with the actual work experiences and earnings of participants and be able to discuss more fully the impact that type of impairment has on the work efforts of a group of severely disabled Social Security beneficiaries.

Please feel free to contact me for further information as needed. I am happy to be able to add our research findings and policy experience to this important public policy discussion.

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Work Attitudes and Motivation

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8a-Work will provide me with opportunities for increasing my knowledge and skills	Somewhat Disagree	1.0%	2.1%	4.8%		1.7%
	Not Sure	2.0%	8.3%	19.0%	10.0%	6.2%
	Somewhat Agree	32.7%	29.2%	9.5%	20.0%	28.2%
	Strongly Agree	64.3%	60.4%	66.7%	70.0%	63.8%
PTI Total	N =	98	48	21	10	177
	Mean	4.60	4.48	4.38	4.60	4.54
	Std Deviation	.59	.74	.97	.70	.69

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8b-The jobs I could get do not pay enough	Strongly Disagree	8.2%	8.3%	4.8%	10.0%	7.9%
	Somewhat Disagree	12.2%	14.6%	14.3%	10.0%	13.0%
	Not Sure	30.6%	20.8%	28.6%	10.0%	26.6%
	Somewhat Agree	23.5%	39.6%	23.8%	10.0%	27.1%
	Strongly Agree	25.5%	16.7%	28.6%	60.0%	25.4%
PTI Total	N =	98	48	21	10	177
	Mean	3.46	3.42	3.57	4.00	3.49
	Std Deviation	1.23	1.18	1.21	1.49	1.23

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/ DD	1+indicated	
Q8c-I want others to find out how good I really can be at work.	Strongly Disagree	2.0%	4.3%			2.3%
	Somewhat Disagree	2.0%	4.3%	9.5%		3.4%
	Not Sure	6.1%	8.5%		20.0%	6.8%
	Somewhat Agree	34.7%	34.0%	14.3%	10.0%	30.7%
	Strongly Agree	55.1%	48.9%	76.2%	70.0%	56.8%
PTI Total	N =	98	47	21	10	176
	Mean	4.39	4.19	4.57	4.50	4.36
	Std Deviation	.86	1.06	.93	.85	.92

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/ DD	1+indicated	
Q8d-Work increases dignity and self-respect	Somewhat Disagree			4.8%		.6%
	Not Sure	1.0%	6.3%			2.3%
	Somewhat Agree	19.4%	14.6%	23.8%	20.0%	18.6%
	Strongly Agree	79.6%	79.2%	71.4%	80.0%	78.5%
PTI Total	N =	98	48	21	10	177
	Mean	4.79	4.73	4.62	4.80	4.75
	Std Deviation	.44	.57	.74	.42	.52

Work Attitudes and Motivation

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8e-I should work because it is expected of me and not because I really want to	Strongly Disagree	41.2%	34.0%	52.4%	40.0%	40.6%
	Somewhat Disagree	24.7%	8.5%	23.8%	10.0%	19.4%
	Not Sure	9.3%	12.8%	4.8%	10.0%	9.7%
	Somewhat Agree	20.6%	27.7%	4.8%	20.0%	20.6%
	Strongly Agree	4.1%	17.0%	14.3%	20.0%	9.7%
PTI Total	N =	97	47	21	10	175
	Mean	2.22	2.85	2.05	2.70	2.39
	Std Deviation	1.29	1.56	1.47	1.70	1.43

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8f-I have a career plan for myself	Strongly Disagree	2.0%	8.3%	4.8%		4.0%
	Somewhat Disagree	4.1%	14.6%	9.5%		7.3%
	Not Sure	26.5%	27.1%	23.8%	30.0%	26.6%
	Somewhat Agree	30.6%	18.8%	19.0%	40.0%	26.6%
	Strongly Agree	36.7%	31.3%	42.9%	30.0%	35.6%
PTI Total	N =	98	48	21	10	177
	Mean	3.96	3.50	3.86	4.00	3.82
	Std Deviation	.99	1.30	1.24	.82	1.12

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8g-I worry that jobs I can get will be disappointing	Strongly Disagree	16.3%	16.7%	23.8%	10.0%	16.9%
	Somewhat Disagree	19.4%	4.2%	28.6%		15.3%
	Not Sure	14.3%	18.8%	19.0%	30.0%	16.9%
	Somewhat Agree	38.8%	33.3%	19.0%	30.0%	34.5%
	Strongly Agree	11.2%	27.1%	9.5%	30.0%	16.4%
PTI Total	N =	98	48	21	10	177
	Mean	3.09	3.50	2.62	3.70	3.18
	Std Deviation	1.30	1.38	1.32	1.25	1.34

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8h-I feel that most jobs are pretty boring and routine	Strongly Disagree	27.6%	23.4%	28.6%	10.0%	25.6%
	Somewhat Disagree	36.7%	21.3%	19.0%	20.0%	29.5%
	Not Sure	17.3%	19.1%	14.3%	20.0%	17.6%
	Somewhat Agree	15.3%	21.3%	19.0%	40.0%	18.8%
	Strongly Agree	3.1%	14.9%	19.0%	10.0%	8.5%
PTI Total	N =	98	47	21	10	176
	Mean	2.30	2.83	2.81	3.20	2.55
	Std Deviation	1.12	1.40	1.54	1.23	1.29

Work Attitudes and Motivation

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8i-I worry I will have to do same kind of work for the rest of my life	Strongly Disagree	37.1%	31.9%	42.9%		34.3%
	Somewhat Disagree	24.7%	17.0%	19.0%	10.0%	21.1%
	Not Sure	13.4%	12.8%	4.8%	30.0%	13.1%
	Somewhat Agree	16.5%	25.5%	14.3%	40.0%	20.0%
	Strongly Agree	8.2%	12.8%	19.0%	20.0%	11.4%
PTI Total	N =	97	47	21	10	175
	Mean	2.34	2.70	2.48	3.70	2.53
	Std Deviation	1.35	1.47	1.63	.95	1.43

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8j-Work can make me feel good about myself	Strongly Disagree		2.1%			.6%
	Somewhat Disagree	1.0%		4.8%		1.1%
	Not Sure	1.0%	6.4%			2.3%
	Somewhat Agree	21.4%	14.9%	19.0%	30.0%	19.9%
	Strongly Agree	76.5%	76.6%	76.2%	70.0%	76.1%
PTI Total	N =	98	47	21	10	176
	Mean	4.73	4.64	4.67	4.70	4.70
	Std Deviation	.53	.79	.73	.48	.63

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8k-There are many career options available to me	Strongly Disagree	14.3%	4.2%	14.3%	10.0%	11.3%
	Somewhat Disagree	13.3%	20.8%	14.3%	40.0%	16.9%
	Not Sure	14.3%	20.8%	19.0%	30.0%	17.5%
	Somewhat Agree	28.6%	25.0%	19.0%	10.0%	25.4%
	Strongly Agree	29.6%	29.2%	33.3%	10.0%	28.8%
PTI Total	N =	98	48	21	10	177
	Mean	3.46	3.54	3.43	2.70	3.44
	Std Deviation	1.41	1.24	1.47	1.16	1.36

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q8l-A job can give me the opportunity to do work I think is important	Strongly Disagree			4.8%		.6%
	Somewhat Disagree	2.0%	4.2%	4.8%		2.8%
	Not Sure	8.2%	12.5%	9.5%	10.0%	9.6%
	Somewhat Agree	30.6%	27.1%	19.0%	40.0%	28.8%
	Strongly Agree	59.2%	56.3%	61.9%	50.0%	58.2%
PTI Total	N =	98	48	21	10	177
	Mean	4.47	4.35	4.29	4.40	4.41
	Std Deviation	.74	.86	1.15	.70	.82

Work Attitudes and Motivation

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8m-Work can give me the opportunity to gain more responsibility	Somewhat Disagree	3.1%	2.1%	9.5%		3.4%
	Not Sure	8.3%	4.3%			5.7%
	Somewhat Agree	25.0%	31.9%	23.8%	50.0%	28.2%
	Strongly Agree	63.5%	61.7%	66.7%	50.0%	62.6%
PTI Total	N =	96	47	21	10	174
	Mean	4.49	4.53	4.48	4.50	4.50
	Std Deviation	.78	.69	.93	.53	.76

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8n-Work can give me the opportunity to interact with other people	Strongly Disagree		2.1%			.6%
	Not Sure	2.0%	2.1%	4.8%		2.3%
	Somewhat Agree	21.4%	27.1%	4.8%	40.0%	22.0%
	Strongly Agree	76.5%	68.8%	90.5%	60.0%	75.1%
PTI Total	N =	98	48	21	10	177
	Mean	4.74	4.60	4.86	4.60	4.71
	Std Deviation	.48	.74	.48	.52	.57

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8o-Work can give me the opportunity to give something back to the community	Strongly Disagree		2.1%			.6%
	Somewhat Disagree	1.0%	4.3%	9.5%		2.8%
	Not Sure	4.1%	10.6%		20.0%	6.3%
	Somewhat Agree	27.6%	21.3%	14.3%	50.0%	25.6%
	Strongly Agree	67.3%	61.7%	76.2%	30.0%	64.8%
PTI Total	N =	98	47	21	10	176
	Mean	4.61	4.36	4.57	4.10	4.51
	Std Deviation	.62	.99	.93	.74	.79

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q8p-Working will increase my income	Somewhat Disagree		2.1%			.6%
	Not Sure	5.1%	6.4%	19.0%	20.0%	8.0%
	Somewhat Agree	15.3%	27.7%	4.8%	10.0%	17.0%
	Strongly Agree	79.6%	63.8%	76.2%	70.0%	74.4%
PTI Total	N =	98	47	21	10	176
	Mean	4.74	4.53	4.57	4.50	4.65
	Std Deviation	.54	.72	.81	.85	.65

Employment History before SS Disability Status

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q9-Ever been refused a job interview because of disability	No	69.1%	75.0%	71.4%	90.0%	72.2%
	Yes	30.9%	25.0%	28.6%	10.0%	27.8%
Total		99	49	21	11	180

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q10-Ever been refused a job because disability or health problems	No	57.9%	66.7%	85.7%	90.0%	65.5%
	Yes	42.1%	33.3%	14.3%	10.0%	34.5%
Total		99	49	21	11	180

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q11-Ever employed before started collecting SS disability benefits	No	14.3%	12.5%	66.7%	18.2%	20.2%
	Yes	85.7%	87.5%	33.3%	81.8%	79.8%
Total		99	49	21	11	180

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q13-Last job before disability	Executive, administrative, managerial	14.1%	7.1%		14.3%	11.1%
	Professional	16.7%	11.9%		14.3%	14.1%
	Secretarial, clerical	3.8%	11.9%	12.5%	14.3%	7.4%
	Technical, paraprofessional	3.8%			28.6%	3.7%
	Skilled craft	25.6%	14.3%		14.3%	20.0%
	Service, maintenance	19.2%	28.6%	37.5%		22.2%
	Other	15.4%	23.8%	50.0%	14.3%	20.0%
	More than 1 marked	1.3%	2.4%			1.5%
PTI Total		78	42	8	7	135

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q14-Work hrs/wk at last job before disability	< 20 hrs/week	3.5%	25.6%	37.5%	10.0%	12.2%
	20-29 hrs/week	12.8%	16.3%	12.5%		12.9%
	30+ hrs/week	80.2%	51.2%	37.5%	90.0%	70.1%
	Did not have paying job	3.5%	7.0%	12.5%		4.8%
PTI Total		86	43	8	10	147

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q15-Satisfaction with pre-disability work	Very dissatisfied	9.5%	27.5%		10.0%	14.1%
	Somewhat dissatisfied	8.3%	10.0%	25.0%	30.0%	11.3%
	Neither satisfied nor dissatisfied	14.3%	15.0%	12.5%		13.4%
	Somewhat satisfied	32.1%	27.5%	12.5%	30.0%	29.6%
	Very satisfied	35.7%	20.0%	50.0%	30.0%	31.7%
PTI Total	N =	84	40	8	10	142
	Mean	3.76	3.03	3.88	3.40	3.54

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q16-Years worked before SSI/SSDI	Less than 1 year		2.4%	28.6%	10.0%	2.8%
	1 up to 2 years	5.9%	7.1%	14.3%	10.0%	6.9%
	2 up to 4 years	7.1%	26.2%	14.3%		12.5%
	4 up to 6 years	3.5%	14.3%		10.0%	6.9%
	6 up to 8 years	10.6%	14.3%	14.3%	10.0%	11.8%
	8 up to 10 years	8.2%	4.8%	14.3%	10.0%	7.6%
	10 years or more	64.7%	31.0%	14.3%	50.0%	51.4%
PTI Total	N =	85	42	7	10	144

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q17-Years since last worked for pay	I am currently working	22.1%	46.5%	75.0%	40.0%	33.3%
	Less than 1 year	14.0%	16.3%		10.0%	13.6%
	1 up to 2 years	14.0%	14.0%		20.0%	13.6%
	2 up to 4 years	18.6%	14.0%	12.5%		15.6%
	4 up to 6 years	10.5%	2.3%		10.0%	7.5%
	6 up to 8 years	7.0%		12.5%		4.8%
	8 up to 10 years	5.8%	2.3%			4.1%
	10 years or more	8.1%	4.7%		20.0%	7.5%
PTI Total	N =	86	43	8	10	147

Employment After SS Disability Status

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q18-Currently employed	No	69.7%	51.0%	33.3%	36.4%	58.3%
	Yes	30.3%	49.0%	66.7%	63.6%	41.7%
PTI Total	N =	99	49	21	11	180

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q42k-Ability for time off for health-related reasons	Not important at all		4.3%			1.1%
	Somewhat unimportant	1.0%	2.2%	4.8%		1.7%
	Neither	1.0%	4.3%			1.7%
	Somewhat important	21.2%	26.1%	23.8%	18.2%	22.6%
	Very important	76.8%	60.9%	71.4%	81.8%	72.3%
	Does not apply		2.2%			.6%
PTI Total	N =	99	46	21	11	177

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q42l-Life insurance, paid time off, retirement plan	Not important at all			4.8%		.6%
	Somewhat unimportant		8.7%			2.3%
	Neither		15.2%		9.1%	4.5%
	Somewhat important	19.2%	17.4%	19.0%	9.1%	18.1%
	Very important	77.8%	54.3%	76.2%	81.8%	71.8%
	Does not apply	3.0%	4.3%			2.8%
PTI Total	N =	99	46	21	11	177

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q42m-Supportive employer attitudes	Somewhat unimportant	1.0%		4.8%		1.1%
	Neither	1.0%	6.4%			2.2%
	Somewhat important	9.1%	23.4%	9.5%	18.2%	13.5%
	Very important	88.9%	70.2%	85.7%	72.7%	82.6%
	Does not apply				9.1%	.6%
PTI Total	N =	99	47	21	11	178

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q42n-Supportive coworker attitudes	Not important at all		2.1%			.6%
	Somewhat unimportant	1.0%				.6%
	Neither	1.0%	6.4%	4.8%		2.8%
	Somewhat important	18.2%	29.8%	9.5%	27.3%	20.8%
	Very important	78.8%	59.6%	85.7%	63.6%	73.6%
	Does not apply	1.0%	2.1%		9.1%	1.7%
PTI Total	N =	99	47	21	11	178

Attitudes and Beliefs about Work and SS Disability

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43a-Limited ability to work because of disability	Strongly disagree	5.1%	18.4%	15.0%		9.5%
	Somewhat disagree	6.1%	14.3%			7.3%
	Not Sure	6.1%	10.2%	10.0%	18.2%	8.4%
	Somewhat agree	27.3%	26.5%	40.0%	27.3%	28.5%
	Strongly agree	55.6%	30.6%	35.0%	54.5%	46.4%
PTI Total	N =	99	49	20	11	179
	Mean	4.22	3.37	3.80	4.36	3.95

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43b-Working will affect ability to keep SS cash benefits	Strongly disagree	3.1%	10.4%	5.0%	9.1%	5.6%
	Somewhat disagree	5.1%	6.3%	10.0%		5.6%
	Not Sure	16.3%	16.7%	20.0%	9.1%	16.4%
	Somewhat agree	22.4%	14.6%	25.0%	27.3%	20.9%
	Strongly agree	53.1%	52.1%	40.0%	54.5%	51.4%
PTI Total	N =	98	48	20	11	177
	Mean	4.17	3.92	3.85	4.18	4.07

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43c-Unless a job offers prescription coverage, I cant take it	Strongly disagree	16.5%	26.1%	20.0%	9.1%	19.0%
	Somewhat disagree	16.5%	23.9%	10.0%		16.7%
	Not Sure	20.6%	8.7%	15.0%	18.2%	16.7%
	Somewhat agree	15.5%	10.9%	20.0%		13.8%
	Strongly agree	30.9%	30.4%	35.0%	72.7%	33.9%
PTI Total	N =	97	46	20	11	174
	Mean	3.28	2.96	3.40	4.27	3.27

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43d-It will be hard to earn enough money to make up for lost SS benefits	Strongly disagree	5.1%	14.3%	5.0%		7.3%
	Somewhat disagree	9.1%	12.2%			8.4%
	Not Sure	20.2%	20.4%	35.0%	18.2%	21.8%
	Somewhat agree	22.2%	8.2%	25.0%	18.2%	18.4%
	Strongly agree	43.4%	44.9%	35.0%	63.6%	44.1%
PTI Total	N =	99	49	20	11	179
	Mean	3.90	3.57	3.85	4.45	3.84

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43e-It is difficult to get the voc rehab services I need	Strongly disagree	35.7%	36.7%	35.0%	9.1%	34.3%
	Somewhat disagree	21.4%	28.6%	10.0%	9.1%	21.3%
	Not Sure	17.3%	16.3%	25.0%	18.2%	18.0%
	Somewhat agree	14.3%	12.2%	10.0%	27.3%	14.0%
	Strongly agree	11.2%	6.1%	20.0%	36.4%	12.4%
PTI Total	N =	98	49	20	11	178
	Mean	2.44	2.22	2.70	3.73	2.49

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43f-I cant get health ins at a job because of my disability	Strongly disagree	10.2%	18.8%	20.0%		13.0%
	Somewhat disagree	13.3%	14.6%			11.3%
	Not Sure	41.8%	41.7%	35.0%	36.4%	40.7%
	Somewhat agree	14.3%	14.6%	15.0%	18.2%	14.7%
	Strongly agree	20.4%	10.4%	30.0%	45.5%	20.3%
PTI Total	N =	98	48	20	11	177
	Mean	3.21	2.83	3.35	4.09	3.18

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43g-Will not be eligible for Medicare or Medicaid if I work	Strongly disagree	9.1%	25.0%	15.0%		13.5%
	Somewhat disagree	10.1%	8.3%	5.0%	9.1%	9.0%
	Not Sure	40.4%	37.5%	45.0%	27.3%	39.3%
	Somewhat agree	13.1%	8.3%	10.0%		10.7%
	Strongly agree	27.3%	20.8%	25.0%	63.6%	27.5%
PTI Total	N =	99	48	20	11	178
	Mean	3.39	2.92	3.25	4.18	3.30

		Primary Disability Category-Self-Report				
		Physical	Mental	Cognitive/DD	1+indicated	PTI Total
Q43h-I dont have adequate skills or training to work	Strongly disagree	36.4%	34.7%	40.0%	18.2%	35.2%
	Somewhat disagree	27.3%	22.4%	5.0%	9.1%	22.3%
	Not Sure	17.2%	22.4%	20.0%	18.2%	19.0%
	Somewhat agree	11.1%	16.3%	15.0%	27.3%	14.0%
	Strongly agree	8.1%	4.1%	20.0%	27.3%	9.5%
PTI Total	N =	99	49	20	11	179
	Mean	2.27	2.33	2.70	3.36	2.40

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q43i-It will be difficult to re-qualify for SS benefits if I work	Strongly disagree	8.1%	12.5%	10.0%		9.0%
	Somewhat disagree	12.1%	6.3%	5.0%	10.0%	9.6%
	Not Sure	36.4%	22.9%	35.0%	30.0%	32.2%
	Somewhat agree	17.2%	14.6%	5.0%		14.1%
	Strongly agree	26.3%	43.8%	45.0%	60.0%	35.0%
PTI Total	N =	99	48	20	10	177
	Mean	3.41	3.71	3.70	4.10	3.56

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q43j-Unless a job offers mental health coverage, I cant take it	Strongly disagree	48.5%	22.9%	25.0%		36.0%
	Somewhat disagree	13.1%	25.0%	20.0%		16.3%
	Not Sure	21.2%	16.7%	20.0%	36.4%	20.8%
	Somewhat agree	7.1%	14.6%			7.9%
	Strongly agree	10.1%	20.8%	35.0%	63.6%	19.1%
PTI Total	N =	99	48	20	11	178
	Mean	2.17	2.85	3.00	4.27	2.58

Self-Esteem, Locus of Control and Quality of Life

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44a-Little control over things that happen to me	Strongly disagree	31.3%	35.4%	35.0%	9.1%	31.5%
	Somewhat disagree	25.3%	25.0%	10.0%	9.1%	22.5%
	Not sure	3.0%	14.6%	20.0%	9.1%	8.4%
	Somewhat agree	31.3%	16.7%	20.0%	54.5%	27.5%
	Strongly agree	9.1%	8.3%	15.0%	18.2%	10.1%
PTI Total	N =	99	48	20	11	178
	Mean	2.62	2.38	2.70	3.64	2.62

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44b-No way I can solve problems I have	Strongly disagree	27.3%	35.4%	35.0%		28.7%
	Somewhat disagree	23.2%	20.8%	10.0%	9.1%	20.2%
	Not sure	7.1%	14.6%	15.0%	9.1%	10.1%
	Somewhat agree	26.3%	20.8%	20.0%	45.5%	25.3%
	Strongly agree	16.2%	8.3%	20.0%	36.4%	15.7%
PTI Total	N =	99	48	20	11	178
	Mean	2.81	2.46	2.80	4.09	2.79

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44c-Little I can do to change important things in my life	Strongly disagree	35.4%	34.7%	30.0%	27.3%	34.1%
	Somewhat disagree	28.3%	20.4%	20.0%		23.5%
	Not sure	9.1%	14.3%	15.0%	9.1%	11.2%
	Somewhat agree	21.2%	20.4%	10.0%	27.3%	20.1%
	Strongly agree	6.1%	10.2%	25.0%	36.4%	11.2%
PTI Total	N =	99	49	20	11	179
	Mean	2.34	2.51	2.80	3.45	2.51

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44d-I feel helpless in dealing with the problems of life	Strongly disagree	32.3%	37.5%	20.0%	18.2%	31.5%
	Somewhat disagree	19.2%	18.8%	25.0%		18.5%
	Not sure	7.1%	8.3%	20.0%	27.3%	10.1%
	Somewhat agree	33.3%	25.0%	10.0%	9.1%	27.0%
	Strongly agree	8.1%	10.4%	25.0%	45.5%	12.9%
PTI Total	N =	99	48	20	11	178
	Mean	2.66	2.52	2.95	3.64	2.71

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44e-I feel like Im being pushed around in life	Strongly disagree	34.3%	25.0%	20.0%	27.3%	29.8%
	Somewhat disagree	19.2%	22.9%	10.0%		18.0%
	Not sure	8.1%	6.3%	10.0%	9.1%	7.9%
	Somewhat agree	30.3%	35.4%	35.0%	36.4%	32.6%
	Strongly agree	8.1%	10.4%	25.0%	27.3%	11.8%
PTI Total	N =	99	48	20	11	178
	Mean	2.59	2.83	3.35	3.36	2.79

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44f-What happens in future depends on me	Strongly disagree	4.0%	4.3%			3.4%
	Somewhat disagree	6.1%	2.1%		9.1%	4.5%
	Not sure	4.0%	17.0%	10.0%	9.1%	8.5%
	Somewhat agree	34.3%	29.8%	10.0%	36.4%	30.5%
	Strongly agree	51.5%	46.8%	80.0%	45.5%	53.1%
PTI Total	N =	99	47	20	11	177
	Mean	4.23	4.13	4.70	4.18	4.25

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44g-I can do anything I set my mind to	Strongly disagree	4.1%	4.2%	5.0%		4.0%
	Somewhat disagree	7.1%	10.4%		27.3%	8.5%
	Not sure	5.1%	10.4%	5.0%	9.1%	6.8%
	Somewhat agree	33.7%	41.7%	25.0%	36.4%	35.0%
	Strongly agree	50.0%	33.3%	65.0%	27.3%	45.8%
PTI Total	N =	98	48	20	11	177
	Mean	4.18	3.90	4.45	3.64	4.10

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44h-Overall, I have a good relationship w/my family	Strongly disagree	2.0%	12.2%		18.2%	5.6%
	Somewhat disagree	9.1%	6.1%		18.2%	7.8%
	Not sure	4.0%	4.1%	5.0%	9.1%	4.5%
	Somewhat agree	22.2%	22.4%	25.0%	36.4%	23.5%
	Strongly agree	62.6%	55.1%	70.0%	18.2%	58.7%
PTI Total	N =	99	49	20	11	179
	Mean	4.34	4.02	4.65	3.18	4.22

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44i-If given the opportunity to work I could work	Strongly disagree		2.1%			.6%
	Somewhat disagree	5.1%		5.0%		3.4%
	Not sure	10.1%	4.2%	5.0%	18.2%	8.4%
	Somewhat agree	18.2%	35.4%	15.0%	18.2%	22.5%
	Strongly agree	66.7%	58.3%	75.0%	63.6%	65.2%
PTI Total	N =	99	48	20	11	178
	Mean	4.46	4.48	4.60	4.45	4.48

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44j-I have an active social life	Strongly disagree	8.2%	10.6%		18.2%	8.6%
	Somewhat disagree	25.8%	8.5%	25.0%	9.1%	20.0%
	Not sure	5.2%	6.4%	5.0%	27.3%	6.9%
	Somewhat agree	30.9%	38.3%	25.0%	36.4%	32.6%
	Strongly agree	29.9%	36.2%	45.0%	9.1%	32.0%
PTI Total	N =	97	47	20	11	175
	Mean	3.48	3.81	3.90	3.09	3.59

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44k-I am happy with my living situation	Strongly disagree	6.1%	16.7%	15.0%	36.4%	11.8%
	Somewhat disagree	25.3%	14.6%	5.0%	9.1%	19.1%
	Not sure	7.1%	4.2%	5.0%	9.1%	6.2%
	Somewhat agree	28.3%	22.9%	20.0%	27.3%	25.8%
	Strongly agree	33.3%	41.7%	55.0%	18.2%	37.1%
PTI Total	N =	99	48	20	11	178
	Mean	3.58	3.58	3.95	2.82	3.57

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44l-I take a positive attitude toward myself	Strongly disagree	1.0%	6.4%		9.1%	2.9%
	Somewhat disagree	6.2%	12.8%		18.2%	8.0%
	Not sure	3.1%	4.3%	5.3%	18.2%	4.6%
	Somewhat agree	36.1%	31.9%	31.6%	9.1%	32.8%
	Strongly agree	53.6%	44.7%	63.2%	45.5%	51.7%
PTI Total	N =	97	47	19	11	174
	Mean	4.35	3.96	4.58	3.64	4.22

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44m-All in all, I am inclined to think I am a failure	Strongly disagree	63.6%	40.4%	60.0%	45.5%	55.9%
	Somewhat disagree	21.2%	25.5%	5.0%	9.1%	19.8%
	Not sure	5.1%	14.9%	10.0%	9.1%	8.5%
	Somewhat agree	7.1%	14.9%	15.0%	18.2%	10.7%
	Strongly agree	3.0%	4.3%	10.0%	18.2%	5.1%
PTI Total	N =	99	47	20	11	177
	Mean	1.65	2.17	2.10	2.55	1.89

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Qffn-I feel I am a person of worth, on an equal basis with others	Strongly disagree	1.0%				.6%
	Somewhat disagree	4.0%	10.4%	5.0%	9.1%	6.2%
	Not sure	5.1%	4.2%		18.2%	5.1%
	Somewhat agree	26.3%	37.5%	20.0%	45.5%	29.8%
	Strongly agree	63.6%	47.9%	75.0%	27.3%	58.4%
PTI Total	N =	99	48	20	11	178
	Mean	4.47	4.23	4.65	3.91	4.39

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44o-I feel like I have many good qualities	Strongly disagree	1.0%	2.0%			1.1%
	Somewhat disagree	1.0%	2.0%		9.1%	1.7%
	Not sure	1.0%	8.2%	15.0%		4.5%
	Somewhat agree	31.3%	36.7%	15.0%	27.3%	30.7%
	Strongly agree	65.7%	51.0%	70.0%	63.6%	62.0%
PTI Total	N =	99	49	20	11	179
	Mean	4.60	4.33	4.55	4.45	4.51

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44p-I am able to do things as well as others	Strongly disagree	4.0%	4.2%		9.1%	3.9%
	Somewhat disagree	12.1%	8.3%	5.0%	9.1%	10.1%
	Not sure	6.1%	10.4%	5.0%	27.3%	8.4%
	Somewhat agree	36.4%	35.4%	40.0%	36.4%	36.5%
	Strongly agree	41.4%	41.7%	50.0%	18.2%	41.0%
PTI Total	N =	99	48	20	11	178
	Mean	3.99	4.02	4.35	3.45	4.01

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44q-I feel confident about my abilities	Strongly disagree	1.0%			9.1%	1.1%
	Somewhat disagree	4.0%	12.8%		9.1%	6.2%
	Not sure	8.1%	17.0%	10.0%	9.1%	10.7%
	Somewhat agree	37.4%	36.2%	25.0%	36.4%	35.6%
	Strongly agree	49.5%	34.0%	65.0%	36.4%	46.3%
PTI Total	N =	99	47	20	11	177
	Mean	4.30	3.91	4.55	3.82	4.20

		Primary Disability Category-Self-Report				PTI Total
		Physical	Mental	Cognitive/DD	1+indicated	
Q44r-Overall, I am satisfied with myself	Strongly disagree	2.0%	6.3%		18.2%	3.9%
	Somewhat disagree	15.2%	16.7%	5.0%	9.1%	14.0%
	Not sure	12.1%	12.5%	10.0%	27.3%	12.9%
	Somewhat agree	28.3%	33.3%	20.0%	27.3%	28.7%
	Strongly agree	42.4%	31.3%	65.0%	18.2%	40.4%
PTI Total	N =	99	48	20	11	178
	Mean	3.94	3.67	4.45	3.18	3.88

Mr. William VanOoteghem
c/o Marty Ford
The ARC
1730 K Street, N.W.
Washington, DC 20006

Dear Mr. VanOoteghem:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following question:

Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600—below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?

I thank you for taking the time to answer this question for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

May 18, 2000

The Honorable E. Clay Shaw
Chairman
Subcommittee on Social Security
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Shaw:

This is in response to your letter of April 26 requesting additional information on work incentives for blind and disabled Social Security beneficiaries. Specifically, you asked:

Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600 -below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?

According to the Social Security Administration, about 9,500 people with disabilities take advantage of this provision. It can be effective in assisting an individual to show the net value of their work efforts, after all of the disability-related expenses of work are deducted. However, I believe that it is important to point out that a distinction is made between the expenses that an individual can deduct depending on whether they are blind or not. As I understand it, people who are blind can deduct any*work-related* expense, while all other people with disabilities who are not blind can deduct only *disability-related work expenses.*

In my daughter Wendy's case, she does not have many disability-related work expenses. Her transportation costs are minimal since her workcenter provides transportation. However, I do know that for many people with mental retardation who cannot drive, transportation costs to and from work can be very high in relation their earnings, particularly in rural areas or in cities without adequate public transportation systems. As I understand it, these transportation costs are excludable. This provision should be continued.

There are also many people with needs for services while they are working. One typical service is that of a "job coach" in a supported employment setting. While many other services are deductible from SGA, supported employment services are treated differently depending upon who provides such services. This is a problem for many people with mental retardation and is discussed in the statement for the record submitted by the Consortium for Citizens with Disabilities. I urge you to address that issue as well.

Thank you for this opportunity to provide additional information. Please let me or Marty Ford (202/785–3388) know if I can help you in any further way.

Sincerely,

WILLIAM VANOOTEGHEM

William VanOoteghem
c/o The Arc of the United States
1730 K Street, NW Suite 1212
Washington, DC 20006

April 26, 2000

Mr. Tony Young
NISH
2235 Cedar Lane
Vienna, VA 22182

Dear Mr. Young:

Thank you for testifying before our Subcommittee regarding work incentives for blind and disabled Social Security beneficiaries. In order to complete our hearing record, I would appreciate your answering the following question:

Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600—below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?

I thank you for taking the time to answer this question for the record and would appreciate your response by no later than May 19, 2000. In addition to a hard copy of your response, please submit your response on an IBM compatible 3.5-inch diskette in WordPerfect or Microsoft Word format. If you have any questions concerning this request, please feel free to contact Kim Hildred, Staff Director, Subcommittee on Social Security at (202) 225–9263.

Sincerely,

E. CLAY SHAW, JR.
Chairman

June 11, 2000

The Honorable E. Clay Shaw, Chairman
Subcommittee on Social Security
House of Representatives
Washington, DC 20515

Dear Chairman Shaw:

This is in response to your letter of April 26 requesting additional information on work incentives for blind and disabled Social Security beneficiaries. Specifically, you asked:

Individuals with disabilities can actually earn more than the SGA limits and stay eligible for benefits. The reason is they can subtract work expenses related to their disability in determining earnings subject to the limit. (For example, if an individual who is disabled earns $900 per month but has $300 in work expenses, their SGA is $600—below the $700 limit.) Are you familiar with the provision? Is it being used? How many individuals with disabilities take advantage of these deductions? Is it effective? Should it be changed?

I am familiar with this work incentive provision, although I did not personally make use of it when I was on SSDI. This provision is being used to a limited extent by beneficiaries. According to the Social Security Administration, about 9,500 people with disabilities take advantage of this provision.

In my view, Impairment-related work expenses could be effective in assisting an individual to show the net value of their work efforts, if certain improvements are made.

1. Currently, a distinction is made between the expenses that an individual can deduct depending on whether or not they are blind. Blind beneficiaries can deduct any *work-related* expense, while people with disabilities who are not blind can deduct only *disability-related work expenses.* Beneficiaries who have multiple significant disabilities have as many or more expenses related to work as do Blind beneficiaries. *All beneficiaries who work should be allowed to deduct all work-related expenses*
2. The Social Security Administration field office determines whether expenses may be deducted from earnings. The determinations are rarely done on a consistent

basis. These expenses are often disputed by SSA as to whether they are disability-related, and are excluded inconsistently. *SSA must issue better guidance to Field Office personnel and improve consistency in work incentives determinations.*

3. Beneficiaries need better decision making tools to determine how IRWE can work for them. *SSA should make available decision-support software, such as WorkWORLD, to beneficiaries and their families so that truly informed decisions can be made.*

While the IRWE could benefit some SSDI beneficiaries, overall it is a limited answer to a bigger problem, namely the SSDI SGA earnings limit/cash cliff. The IRWE is limited in several ways.

1. The beneficiary has to incur the expense in the first place, and pay for it out of pocket.
2. To be effective the amount of the IRWE has to equal or surpass the amount of income above SGA. If not, then the IRWE doesn't protect you.
3. Once you use an IRWE, you have to keep it to remain on benefits. For example, if the costs of personal assistance services are paid for out of pocket then they can be used as an IRWE. (The amount spent on PAS, which might be more than the benefit, can't be used for other necessities).

Also, not every one with a disability has impairment related work expenses or has enough expenses to keep from losing all their benefits. Because of this, the IRWE program is at best a selective solution to the cash cliff problem. I believe that the IRWE program working in conjunction with sliding-scale cash offset in the SSDI program would better address the cash cliff and more fairly benefit ALL working SSDI benefits rather than just a lucky few.

Thank you for this opportunity to provide additional information. Please call me at 703–425–8633 or e-mail at *tyyoung@bellatlantic.net* if I can help you in any way.

Sincerely,

TONY YOUNG, DIRECTOR
NISH Governmental Activities Office
Vice Chairperson
Consortium for Citizens with Disabilities

[Whereupon, at 1:50 p.m., the hearing was adjourned.]
[Submissions for the record follow:]

The Honorable E. Clay Shaw, Chair
House Committee on Ways and Means
Subcommittee on Social Security
B316 Rayburn House Office Building
Washington, DC 20515

March 27, 2000

American Council of the Blind

Dear Chairman Shaw and Members of the Subcommittee:

Please accept the appreciation of the membership of the American Council of the Blind for the serious consideration your subcommittee is exercising in reviewing the Social Security Administration's program of disability insurance that impacts upon our members throughout this land. We offer the following testimony to assist the subcommittee with this important albeit daunting task.

There is no question that the pace of our economy is outstripping the allowable income that a blind person can make before SSDI benefits are lost. The net effect of this phenomena is to discourage those receiving benefits from going to work in fear of losing the financial and medical security provided through SSDI. This situation is further complicated by the fact that blind persons must rely upon the cash value of benefits plus whatever limited earnings we can make to pay for service and equipment needs not available under other programs that currently address many similar needs of persons with other disabilities. These expenses include, but are not limited to readers, adaptive hardware and software, low vision magnification devices, dog guide medical costs, orientation and mobility equipment, and a high reliance upon taxi and other transportation costs.

If we are to arrive at a solution to the problems described above, while maintaining faith with the workforce paying into Social Security, then we simply must find a way to help beneficiaries locate employment that offsets or eliminates reliance on the SSDI program while contributing to the revenue base of Social Security. Here is how.

ACB suggests that the earnings limit for blind persons be either totally removed (See attached letter of personal testimony from a woman who is blind) or set to the earnings limits of what elders had before the passage of HR5. In the former case, all disincentives to work would be removed and increased revenues to the treasury would result. In the latter case, this would allow for an eventual $30,000 in earnings before benefit loss. ACB further proposes that the earnings limit be automatically raised based upon inflation in order to avoid recreating the current situation where the SSDI program has become counter-productive to its original intent. Moreover, ACB recommends eliminating the cliff effect of benefits lost at a certain income level by decreasing the SSDI benefit by one dollar for every three earned over the earnings limit. These approaches would resolve the cash benefit issues and ACB suggests that the medical issues could be resolved by allowing the previous cash beneficiary to purchase Medicare for his or her health needs.

ACB further believes that raising the SGA levels for other disability groups to that of the earnings limits for the blind would be appropriate if expanded Medicare coverage of blindness related services and equipment were to occur as a question of equity with other disabilities. Only in this fashion could a “do no harm” and fairness oriented approach to blind persons be accomplished.

These concepts represent a way to provide real incentives for recipients to work, greater revenue growth to the Social Security trust fund, equity in disability policy, and a new view of disabilities as participating in the national economy rather than being viewed as a cost to it.

Please feel free to communicate with me to further explore the options presented above, and I and ACB wish the subcommittee every success in your efforts.

Sincerely,

CHARLES H. CRAWFORD
Executive Director

JENINE STANLEY
March 22, 2000

House Ways & Means, Social Security Subcommittee

RE: Earnings Income Limits for Blind People

I am writing this letter in hopes that it will be shared by representatives of the American Council of the Blind with the House Ways & Means, Social Security Subcommittee. I would like the members of this committee to know, through my own personal story, why removing the earnings limits for blind people is so crucial to maintaining or even establishing independence.

I am a college graduate and have been employed in the not-for-profit sector since 1988. Since 1991 I have been receiving Social Security Disability Insurance due to my blindness. I have also attempted to work, within the limits imposed by the Social Security Administration. For me, the ability to work, to sustain gainful employment, is vital to my mental and physical well being.

In America, people are measured, rightly or wrongly, by the work they do. What one does for a living is often the first question asked in social conversation. For people with disabilities, especially blind people who have been the recipients of some of the most negative stereotyping in history; being able to state a profession or employer holds a very important place. It equalizes “us” with “them” and removes the stigma of “charity for the blind.”

The ability to be gainfully employed also removes those old stereotypes of blind people as simply musicians, chair caners or helpless wards of the state or their families. This ability to work, however, is often marred by the complex rules and regulations of the Social Security Administration.

Blind people are faced with significant lag time in processing any changes to their Social Security status, such as reporting of employment or benefits decisions because all applications noted as being from “blind” recipients must go through a special office in Baltimore. As a result, I and many other blind people who want to work, do so under the threat of having our benefits, income tax returns and even salaries garnished upon decision that are often up to four years in the making.

I have worked as a private contract employee for the State of Ohio in two different departments since 1996. In 1998 my income tax refund was garnished because I failed to appeal a decision of the Social Security Administration I knew nothing about. This decision involved me making an amount over and above the Substantial Gainful Activity limit. When I looked into the matter, I was told that there was nothing I could do. My debt to the SSA was paid and it was just too bad that I lost my tax return, but. . .

Now, I continue to work as a contract employee. I keep meticulous records and only work eight hours a week as I continue my education. At some point, I will want to work more. Logic says that I should be able to simply end my reliance on SSDI benefits and return to work, but things are not that simple.

Like many Americans, I live in an urban area that suffers from "urban sprawl." Many of the jobs I am qualified for are located far from public transportation. I do not drive. Due to the low unemployment rate in my city, Columbus Ohio, it is very difficult to secure dependable transportation, either by taxi or paratransit services. This is only one expense associated with my blindness that keeps me from employment at the level I desire. I must also purchase my own computer equipment and other adaptive devices if I expect to have tools to help me do my job. The consumer, the blind person, to assure a proper fit of technology, best purchases these devices. Although state rehabilitation services may cover some of the items I need, the time lag is too great for my employment prospects.

Just as people over sixty-three years of age want the freedom to continue to work while earning Social Security benefits, I, as a blind person, want and need the extra assistance provided by SSDI. I have paid into the system for over ten years now. I truly deserve its benefits, including the ability to work without the fear of having everything taken away.

This fear, this reluctance to seek employment that is equal to my potential, is specific to blindness in that our claims, our decisions and our appeals are significantly delayed by being sent to Baltimore rather than decided at the local SSA office as such situations are for people with other types of disabilities. I would think that the blind population is so small compared to the rest of the SSDI or SSI recipient population, that allowing no cap on Substantial Gainful Employment would not effect the budget any more significantly than doing so for seniors who have just received such benefits through House and Senate actions.

I urge you to please consider lifting the cap on earnings for blind people. Otherwise, we will continue to be under or unemployed and painful destructive stereotypes will continue both in the workplace and the public. I appreciate your attention to my opinions and sincerely hope that you will take them into consideration in your debate.

Sincerely,

JENINE STANLEY

Statement of the American Network of Community Options and Resources, Annadale, Virginia

The American Network of Community Options and Resources (ANCOR) commends the subcommittee for its work to remove work barriers for individuals with disabilities through passage last year of the Ticket to Work and Work Incentives Improvement Act of 1999 and for its continued work in examining remaining work disincentives in the Social Security Disability Insurance program (SSDI). ANCOR is concerned about the changes being considered to the Social Security earnings limit for SSDI beneficiaries, also known as the substantial gainful activity (SGA) level. If there are to be changes to the earnings limit for SSDI beneficiaries, ANCOR urges the Committee to make changes that will ensure equity among benefits for all people with disabilities who receive SSDI benefits, not just for individuals with one type of disability.

As the Committee members know, most SSDI beneficiaries must limit their earnings to $700 per month. At any amount over $700, beneficiaries lose all cash benefits. However, SSDI beneficiaries who are blind are allowed a greater monthly earnings limit—up to $1170—before they lose their cash benefits. While the loss of cash benefits to beneficiaries if they earn too much money is one of the major disincentives for SSDI beneficiaries to return to work, ANCOR has long advocated to end the disparity in the SGA for SSDI beneficiaries who are blind and those who are not blind.

When the Committee considers reforms to the earnings limit for SSDI beneficiaries, ANCOR believes such reforms should ensure that no individuals with disabilities—whether they are blind or non-blind—should be adversely affected by these reforms. ANCOR also believes that reforms to the Social Security earnings limit should ensure equity in earnings among all people with disabilities.

BAY CITY, MI 48708
March 29, 2000

Testimony on work incentives for Blind and Disabled Social Security Beneficiaries

Richard L. Davis (Father of a son that is disabled)

Congressman Shaw and other distinguished members of the Committee on Ways and Means. I am the father of a son 33 years of age that is disabled and is eligible to receive Social Security Benefits under title II of the Social Security Act.

I have elected to continue working and not collect benefits for the past year and one half so that my son would not suffer from the indignity of losing all benefits because he wants to work. This could soon change due to the bill that you have just passed that will enable me to receive the benefits of social security now. I think this is good legislation and I thank you for it. I hope that what you do on SGA legislation will enable David to continue working. As an advocate for people with a disability, I recognized many years ago that a person with mental retardation or other related disabilities could be a productive individual within their own community. I believe and it has been proven that these people can work side by side with their non-disabled counterparts. The unfortunate part of this is that these people usually only get jobs at minimum wage and without benefits.

My son David works on a packaging line with Wendy VanOoteghem whom you heard testimony from on March 23, 2000. David earns $5.43 per hour. If David would work 40 hours per week, he would earn $217. This would put him at $241 over the $700 SGA level. Because of this, David can work no more than twenty-nine hours per week. This penalizes both him and his employer. With the expected increase in minimum wage, which will be passed on through other wage levels, David will only be able to work twenty-seven hours a week. Two years from now with the second step of the minimum wage increase,David will only be able to work twenty-five hours per week. This is certainly a disincentive for David and for his employer to keep him. If this continues, why should David continue to work? He can receive his Social Security benefits and Medicare, after all he is totally and permanently disabled. Why should it matter that his parents have encouraged the work ethic within him to help him be a better person and citizen?

I have found that the work incentives that congress has passed this past year, when they are activated, will benefit people with disabilities to get and maintain jobs within their community. The raise, in minimum wage, will help people to make more to support themselves. This is good for people with a disability, but all of the good we may have done may cause a hardship to others. If a person works a 40-hour week at minimum wage of $5.15 per hour, they will earn $893 per month, which is $193 above the current SGA wage level of $700 per month. This will cause the loss of all of the benefits that they need to survive such as SSI, SSDI, RSDI, Medicaid and Medicare.

In 1999, the SGA level was increased from the $500 per month level set in 1990 to $700 per month. This will not keep all people with a disability working a full 40-hour workweek from loosing their benefits. I ask you to increase the SGA level for all people that are Blind or Disabled and make them equal. Additionally, SGA should be indexed or have a cost of living attached to it so that the inequities never occur again.

I ask that you do your job so that my son David can continue to do his.

Respectfully,

RICHARD L. DAVIS

March 23, 2000

The Honorable Clay Shaw
Subcommittee on Social Security
Committee on Ways and Means

Dear Chairman Shaw:

I would first like to commend you and the Social Security Subcommittee for holding a hearing to examine the work incentives in the Social Security Disability program for the blind and those with other disabilities. I share your commitment to ensure that disabled workers have the opportunity and incentive to remain in the workforce.

As you are aware, the Social Security Administration increased the monthly substantial gainful activity (SGA) level from $500 to $700 for non-blind disabled adults. I believe that this was an important first step in correcting a deterrent in the system which in effect pushes disabled adults out of the workforce.

I feel that a further increase is necessary and should be addressed this year. Time and time again, disabled citizens have proven their invaluable contributions to the U.S. workforce. These individuals, like our seniors and the blind disabled, should be encouraged to work when able to do so.

I am particularly pleased that *The Ticket To Work and Self-Sufficiency Act of 1999,* H.R. 1180, requiring the Social Security Administration to conduct a demonstration project providing for Social Security Disability Insurance (SSDI) reductions based on earnings. Currently, disabled workers who earn over the SGA levels face an “income cliff” -in effect they lose their benefits. The demonstration project would examine the effects of gradually reducing SSDI benefits $1 for every $2 in earnings over a level determined by the Commissioner. This is a serious problem for disabled workers and I look forward to the Commissioner’s findings.

Thank you again for holding a hearing on this important issue. I look forward to working with you in the future on this issue.

Sincerely,

PHIL ENGLISH
Member of Congress

Statement of Michael Freedman, Member, Board of Directors, National Alliance for the Mentally Ill, Arlington, Virginia

Chairman Shaw and Representative Matsui, on behalf of the more than 210,000 members of NAMI (The National Alliance for the Mentally Ill) and the 50 state organizations and over 1,240 local affiliates across the nation and in Puerto Rico, American Samoa, and Canada, I would like thank you for this opportunity to submit testimony on work incentives for disabled beneficiaries of the disabled and income security programs of the Social Security Administration.

NAMI is the nation’s leading grassroots organization dedicated solely to improving the lives of persons with severe mental illnesses such as schizophrenia, bipolar disorder (manic-depressive illness), major depression, obsessive-compulsive disorder, and anxiety disorders. NAMI’s efforts focus on support to persons with these serious brain disorders and to their families; advocacy for ending discrimination in federal income support and health insurance programs and education to eliminate the pervasive stigma surrounding severe mental illness. NAMI also endorses efforts to promote employment opportunities and greater independence through increased access to rehabilitation and job training programs and extended health care coverage to workers who need treatment in order enter and stay in the workforce.

I am Mike Freedman, member of the Board of Directors of NAMI, and a former president of the NAMI Consumer Council, the nation’s largest organization of consumers of mental health services. I was diagnosed with Clinical Major Depression, extreme Panic/Anxiety Disorder, and Post Traumatic Stress Disorder as a result of a genetic disposition that came to the surface in 1976 after experiencing both war and the suicide of my father, a decorated Air Force Pilot, and later a Federal Narcotics Officer. In addition, my spouse, a former mental health crisis counselor, became afflicted with Bi-Polar Disorder and was very suicidal until she was properly diagnosed and medicated. During this long period of stabilization, rehabilitation, and recovery, we did the best we could raising a child in deprivation and poverty caused by the existing rules governing state and federal policies that deal with assistance to the psychiatrically disabled on SSI and SSDI. I know first hand the struggles that consumers face in getting and keeping a job, and attempting to leave the Social Security disability programs for a productive and independent life. As a State Program Director with the New York Association of Psychosocial Programs, I encounter consumers every day who struggle with the confusing, unfair and complicated rules governing the SSDI program.

At the outset, I would like to express our deep appreciation to every member of the Subcommittee for the important role and leadership displayed in the passage of the Ticket to Work and Work Incentives Improvement Act late last year. This law takes important steps toward self-determination in the rehabilitative process for people with disabilities, including people with severe mental illnesses, and removes barriers for disability beneficiaries who wish to enter the workforce and lead independent lives. NAMI is extremely grateful for the bipartisan leadership that you and your colleagues exhibited in passing this long overdue reform.

Substantial Gainful Activity's (SGA's) Impact on Work

Individuals with disabilities, including people with severe mental illnesses, want to work, but are often discouraged by many barriers existing in the current public system. A recent Harris survey showed that 72% of unemployed people with disabilities, including people with severe mental illnesses, have a strong desire to have a job. Several recent surveys have found this rate to be even higher for adults with severe mental illnesses, as high as 80%. Yet 69% of those surveyed by Harris say that their need for benefits is a major impediment to seeking employment. Employment is an essential part of recovery for people with severe mental illnesses and recent advances in treatment services and medications have increased the capacity of people with severe mental illnesses to join the mainstream and live independently. NAMI has heard the frustration from countless members who would like to begin the road to recovery by gaining employment but cannot risk losing their benefits by exceeding the SGA.

Employment assistance is critical for people with severe mental illnesses to regain independence, dignity and purpose. People with severe mental illnesses are the fastest growing population within both the SSI and SSDI programs. More importantly, SSA data reveal that people with mental illnesses are joining the disability rolls at an earlier age. Given how difficult it is to get off the rolls through employment—less than 1% successfully do so—it becomes imperative to enact reforms that end the severe penalties for those who are willing to take the tremendous risks inherent in entering the workforce. Increasing the SGA level will certainly have a positive impact on individuals who would like to work but cannot afford to lose their eligibility for disability benefits.

The Current SGA Level is Outdated

Although NAMI strongly supported the increase of SGA to $700 a month in 1999 and acknowledged the intent of SSA to create an environment where more beneficiaries with disabilities can "enter the workforce and lead more productive self-sufficient lives," this figure does not reflect an adjustment based on the national average wage index since the inception of SGA in 1979. SGA was designed as an indicator to signal whether a beneficiary is capable of earning significant wages and provides an incentive to enter the workforce. However, the current earnings limit of $700 a month reflects an income of only $8,400 per year, which barely raises an individual who wants to become independent of public support to the federal poverty level. Once making it to this meager plateau, a demarcation point that usually signals a crisis in an unimpaired workers life, a person with a disability that makes one dollar more can lose their eligibility for cash benefits. This is referred to as the "cash cliff" and represents an all-or-nothing design that encourages people with disabilities to remain in poverty and dependent on the system. NAMI believes that a more equitable approach would be to increase SGA and index it to wage growth since the establishment of SGA.

Indexing SGA to Wage Growth

Since the establishment of SGA over twenty years ago, it has been increased only twice, in 1990 and just recently last July in 1999. Obviously, those modest increases have not kept up with inflation over that period. This is especially the case with respect to cost increases in treatment, medications and support services. As wages have increased over that same period, people with severe mental illnesses and other disabilities receiving SSA benefits have been forced to reduce the amount of hours they work in order to keep from exceeding SGA. Thus, SGA has become a very unreliable indicator of a beneficiary's ability to work. As you know, Social Security has stated that the past increase in SGA has resulted in substantial cost increases to both the SSI and SSDI programs. Likewise, any proposed increase is projected to increase the overall cost of Social Security's disability programs.

However, indexing SGA to wage growth, as is currently done for the SGA amount for the blind, would result in costs going gradually over time. Such a move would allow SGA to be a more reliable indicator of an individual's ability to earn wages and work. It would also more effectively incentivize work for all people with disabilities, including people with severe mental illnesses. This would mean that the federal government would not be hit by substantial periodic cost increases that are needed to correct an antiquated and unreliable SGA. Finally, such a move would also avoid placing an unfair burden on beneficiaries who are eager to attempt to work.

Equivalence to the SGA Level for Blind Beneficiaries

NAMI believes that SSI and SSDI beneficiaries with severe mental illnesses and other disabilities should have an SGA level equivalent to the level established for the blind, around $1,170 per month, which is about 67% greater than the SGA level for non-blind beneficiaries. Such an adjusted level should also be adjusted annually for the cost of living, as is done for blind beneficiaries. This figure currently allows a blind disabled beneficiary to earn minimum wage (or a little more) and work a 40 hour week, without a substantial loss of cash benefits.

Currently, people with disabilities (excluding blind beneficiaries), can work barely more than 30 hours a week at minimum wage before exceeding SGA and thus risk losing all, or part of their cash benefits. It is likely that increasing SGA for non-blind beneficiaries to that for the blind disabled would create an additional fiscal burden for Social Security's programs. However, this change would create greater equity and fairness in both the SSI and SSDI programs and would more effectively incentivize work for many beneficiaries.

The difference in SGA levels for people disabled by blindness, and for people disabled by severe mental illnesses or other disabilities, has been supported by a rationale that has not been proven by research. In fact, evidence shows that the very characteristics thought to distinguish blind from non-blind disabled beneficiaries accurately describe the fate of non-blind beneficiaries disabled by severe mental illnesses. As was reported to the Subcommittee in the GAO testimony given by Barbara D. Bovbjerg, associate director, Education, Workforce, and Income Security Issues, Health, Education, and Human Services Division, disadvantages thought to separate people disabled by blindness were greater employment discrimination and low rates of employment.

The GAO noted that likely job prospects were low-wage jobs, and higher costs for supportive services. However, research done by the National Institute of Disability and Rehabilitation Research shows that while people disabled by blindness are participating in the workforce at a rate of only 28.9%, they exceed the overall participation of rate of individuals disabled by severe mental illnesses (27.2%). In fact, NIDRR found that within the broad category of severe mental illness, the participation rate of persons with depressive disorders was only 25.4% and that the rate for individuals with schizophrenia was 11.9%, the lowest among any measured category.

The GAO testimony further compares evidence of cost differentials of supportive services associated with disabled blind beneficiaries and beneficiaries disabled by severe mental illnesses. A study conducted by the American Foundation for the Blind and Mississippi State University found that over 50% of legally blind individuals spent less than $500 for devices used to support work. In comparison, literature reviewed by GAO showed that on average, people with severe mental illness incur costs of $1,400 to $3,600 annually for supportive employment services and annual costs for mental health services range from $3,200 to $7,000.

If the presuppositions that led to the original segregation of beneficiaries with severe mental illnesses and other disabilities are not supported by research evidence, how can the disparities remain. If the evidence actually points to people disabled by severe mental illnesses having a greater disadvantage, how can the disparities remain?

NAMI does not seek to single out any group in determining fair and legitimate SGA levels or their complete removal for all groups of people with disabilities. On the contrary, NAMI wishes to advance fair and equitable treatment for all disability groups. NAMI endorses the goals cited by the Consortium of Citizens with Disabilities that congressional action regarding SGA should:

1) Do No Harm—Changes made by Congress to the earnings limit, or to the Social Security Disability programs as a whole, should ensure that no disability group os negatively affected. Whatever Congress does, it must not enact policy detrimental to any particular category of DI beneficiaries.

2) Establish Equity—Congress should take favorable action on legislation that addresses earnings limits and must ensure equity among all DI beneficiaries.

NAMI would like to thank the Subcommittee for taking this important look at long overdue steps toward greater fairness in the SSI and SSDI programs. NAMI is hopeful that congressional action will allow more beneficiaries with severe mental illnesses to reach their potential through employment. Thank you for the opportunity to comment on this important work disincentive in Social Security's disability programs.

Thank you, and with deep respect,

MICHAEL FREEDMAN

Statement of Hon. Jim Nussle, a Representative in Congress from the State of Iowa

I appreciate this opportunity to express my views to the Subcommittee on the issue of the Social Security Disability Insurance (SSDI) program's substantial gainful activity (SGA) level. I would like to acknowledge the Subcommittee's great work on securing the enactment of the Ticket to Work and Work Incentives Act of 1999 (H.R. 1180) last fall. This legislation promotes independence and will lead to greater employment for individuals with disabilities. If people with disabilities want to enter the working world or return to their career or workplace, we should do everything we can to make that happen. We currently have a system that not only discourages people from going to work but also encourages them to continue collecting public benefits. The enactment of the H.R. 1180 was the first step in providing disabled Americans with the means to add to the productivity of our nation's workforce.

We must now continue the efforts we made last fall by exploring ways to allow blind and non-blind disabled individuals to increase their earning potential while securing their SSDI benefits. As you are aware, during the Committee's consideration of the Senior Citizens' Freedom to Work Act (H.R. 5) on February 29, I was prepared to offer an amendment to re-establish the link between the SGA level for SSDI beneficiaries and the earnings limit for individuals receiving Social Security Retirement benefits. I believe the SSDI proves to be a disincentive to work. While Americans take pride in their strong work ethic, not all Americans are given to opportunity to work towards their full potential.

Throughout my career in Congress, I have heard from many Iowans who believe they are treated unfairly by the SGA levels. Iowans are dependable and honest Americans who work hard to support themselves and their families. However, many disabled Iowans are being held back because of the SGA limit. I would like to share with you a few stories of Iowans who are effected by the SGA limit.

Doug Elliott of Grinnell, Iowa, was serving his country in the Vietnam War when he lost his sight. After the war, Doug was able to not only to get his GED, but also graduate college and receive his masters degree. He is now a social worker in the state of Iowa. However, Doug had to make the tough decision that many other blind individuals in the country face to choose between being active in the workforce and losing his SSDI benefits, or remaining unemployed and retaining his full benefits. Doug had a wife and two children and wanted to work to support them. Doug is unlike other blind Iowans in the fact that he had a little security behind him. Because Doug is a veteran and was injured while in the service, he is able to retain his service-connected compensation. This is the only way Doug could remain economically stable.

Priscilla McKinney of St. Ansgar, Iowa, is currently a graduate student at the University of Iowa pursuing a maters degree in education. Priscilla is blind and also has a young son to look after. While Priscilla is currently receiving SSDI, she will have to soon make the unfortunate choice of pursuing a teaching job or remaining on SSDI. If Priscilla finds that the economic benefits of staying on SSDI and not entering the workforce far out weigh the benefits of leaving the SSDI rolls to pursue teaching, Iowa stands to lose a much needed qualified teacher.

Cathy Reinehart and Bruce Bivens, both of Clarksville, Iowa, have bipolar disorder. Cathy is a college graduate and a certified nurses aid. She currently works intermittently out of fear of exceeding the $700 SGA monthly threshold. Bruce is also a college graduate and is working in a meat locker in Clarkville. Bruce faces the similar obstacle of having to carefully regulate his working hours in order to remain below the SGA limit.

The federal government is contradicting the American work ethic by not allowing these individuals to expand their employment opportunities. Disabled Americans should not have to choose between government assistance or the opportunity to seek meaningful employment. For many disabled Americans, such as those with mental retardation, the only employment they currently are eligible for is low-paying jobs that do not offer health benefits or job security. If these individuals do have the opportunity of earning just slightly above the current minimum wage, they will lose their SSDI benefits, even though they have no health benefits or job security through their employment.

As the Subcommittee continues to explore this matter legislatively, I would like to express my support for a resolution in the most fair manner to all disabled Americans. I am currently aware of many proposals that address ways do so. Members of the blind and non-blind disabled communities would ultimately hope for complete re-linkage of the SGA level to the Social Security earnings limit. However, if we cannot achieve complete re-linkage, we'll have to look at alternatives to give some relief to blind and non-blind disabled people. I would like to offer my assistance to the Subcommittee in any way possible to seek the best legislative avenue.

Statement of Paralyzed Veterans of America

The Paralyzed Veterans of America commends the subcommittee for its interest in ongoing work disincentives in the Social Security Disability Insurance Program [SSDI]. We appreciate having the opportunity to share with you our thoughts on the substantial gainful activity [SGA] level as it affects the ability of SSDI beneficiaries to go to work.

Over half of PVA's members have spinal cord injuries that are not connected to their military service. As a result, they are not eligible for many of the benefits offered to service-connected disabled veterans through the Department of Veterans Affairs. Instead, they have turned to the SSDI program that has provided invaluable support and assistance to them and their families. In fact, a survey of our members found that over 60 percent were on SSDI and another 22 percent received supplemental security income or SSI.

Over the years, many of our members on SSDI have expressed frustration with the SGA because of its adverse impact on their ability to return to work. Consider PVA member Michael W. from Maryland. Michael is a fairly young man, in his mid–40s, who was injured in the early 1980s. He has been on SSDI since 1982. Several times he considered going back to work. However, he always rejected that course of action because even modest earnings above SGA would have meant both the loss of his cash benefits before he was able to support himself and his health care coverage through Medicare. He once determined that, if he went back to work, and lost his SSDI benefits, he would be working, after taxes, for $4000 a year. Not too long ago, he was approached for a part time job but had to ask his prospective employer if he could limit his work hours so that his pay would not exceed $700 a month [the current SGA level].

Last year, with significant assistance from the members of this committee, Congress passed the Ticket to Work and Work Incentives Improvement Act, Public Law 106–170. PL 106–170 was a major step forward in eliminating many of the barriers to employment that kept recipients of federal disability benefits out of the workforce. An important provision of that law was the extension for another four and a half years of premium free Part A Medicare. Beginning this October, someone like Michael W. could return to work with the assurance of that additional Medicare coverage.

However, SSDI recipients will still confront the "earnings cliff" should they attempt to enter the workforce. As you know, an SSDI recipient who is blind faces loss of cash benefits when his or her monthly income surpasses approximately $1170. As noted earlier, people like Michael W. and other SSDI beneficiaries with non-visual impairments lose their cash benefits once their earnings reach $700 a month.

Last year, Social Security raised the SGA for SSDI beneficiaries with non-visual impairments from $500 to $700 a month. PVA supported this action, particularly since the last such increase occurred on January 1, 1990. Even at $700, this SGA level is still lower than what the SGA level would have been had it been indexed to inflation.

Indeed, at $700, the SGA level is still below minimum wage. Someone working at the current minimum wage full time over a year would earn slightly over $10,000. An individual on SSDI whose average monthly earnings reached $700 for a full-time job over a full year would earn $8,400, at which time his or her cash benefits terminate. True, the rapid loss of Medicare coverage, which once served as an impediment to going to work, is no longer as much of a threat. However, the prospect of immediate elimination of cash benefits when yearly earnings reach $8400 can be intimidating to someone who may not have been in the workforce for many years or who may never have worked. What incentive is there for someone to take a low-paying entry-level job when it would jeopardize approximately half of his or her income [assuming he or she receives the average SSDI benefit of roughly $700 per month]?

PVA has long believed that the approach used for SSI recipients, in which benefits are gradually reduced as earned income rises, should be applied to SSDI. We know that Public Law 106–170 directed SSA to examine ways to phase out SSDI benefits as earned income increases to alleviate the "income cliff" now faced by SSDI beneficiaries who go to work. However, today's fiscal climate is such that immediate action by Congress may be more advisable than waiting for a study to be completed. Congress has signaled its willingness to reconsider earnings limits with the passage of HR 5, lifting the earnings cap for retired Social Security beneficiaries. With the robust economy and positive budget numbers we are now enjoying, this may be a once in many decades opportunity to address the problems in the current SGA for people with disabilities.

PVA has always objected to the bifurcation of the substantial gainful activity level for persons with visual impairments and all other people with disabilities on SSDI and SSI. Individuals on SSDI who are blind can, at least, earn minimum wage with an SGA level set at $1,170 per month and that is adjusted for inflation. The General Accounting Office has found that the costs and rates of unemployment do not appear to be necessarily higher for the blind than those who have other disabilities. Indeed, a study sponsored by PVA found that someone with spinal cord injury faces initial hospital and medical costs of over $95,000. He or she will spend approximately $8000 on home modifications and will incur yearly average medical costs of over $14,000. Average lifetime costs associated with spinal cord injury range from $500,000 to $1,000,000 and include high medical expenses, costs of personal assistance services and the costs of special transportation. [M. Berkowitz, Ph.D., *The Economic Consequences of Traumatic Spinal Cord Injury (1992).]* PVA urges Congress to rectify the imbalance in treatment of those with spinal cord and other non-visual disabilities under SSDI earnings limits.

Another inequitable factor in SGA is the manner in which Social Security treats impairment related work expenses [IRWEs] that can be used to keep an SSDI recipient below the substantial gainful activity level. Blind SSDI recipients can claim far more costs as IRWEs than non-blind recipients can. For non-blind beneficiaries, IRWEs must be directly related to work, thus eliminating expenses associated with getting ready for and travelling to and from work.

Many people on SSDI would embrace the opportunities offered by our new economy if they did not feel they would be punished by Social Security policies for doing so. By addressing the disparities in the SGA level, this committee can complete the work begun by the Ticket to Work and Work Incentives Improvement Act.

In sum, PVA supports:

- An SGA level that is made consistent by raising the level for non-visually impaired recipients to, at least, the level for blind SSDI beneficiaries.
- Indexing all SGA levels to average wage growth to prevent its value as a work incentive from eroding over time.
- Changes in the impairment related work expenses policy for non-blind SSDI recipients to allow for costs associated with preparing for and getting to and from the workplace.
- Ongoing efforts to implement a sliding scale reduction in SSDI cash benefits when beneficiaries go to work.

PVA appreciates your attention to our comments. We look forward to working with your subcommittee in the future on improvements in Social Security policy to help people with disabilities return to work.

Statement of Protection & Advocacy, Inc., Los Angeles, California

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Protection & Advocacy, Inc. 3580 Wilshire Blvd., Suite 902, Los Angeles CA 90010–2512 Protection & Advocacy, Inc., of California appreciates the opportunity to comment on how Social Security applies its substantial gainful activity (SGA) rules to persons who work in supported work programs and particularly to persons who qualify for disability benefits based on the work history of a parent and who receive “disabled adult child” or DAC benefits under the parent’s Social Security number. One of your witnesses at the March 23 hearing—Wendy VanOoteghem—is someone who works in a sheltered or supported work program and who receives DAC benefits. Statistics gathered by the Rehabilitation Research and Training Center of the Virginia Commonwealth University indicate that nationally, two-thirds to three-quarters of the supported employment participants have mental retardation diagnoses. Of the balance, the majority have diagnoses of severe psychiatric disabilities.

Protection & Advocacy, Inc., is a nonprofit agency that works with Californians with disabilities to protect and advocate for their human, legal and service rights.

This statement is prompted by Protection & Advocacy’s work with persons with the most severe disabilities who receive DAC benefits based on their parent’s work history and who are working through a supported work program. It is also prompted by our representation of Fred Innerebner[1] who lost forever his DAC benefits[2] because of his earnings through supported work program.

How Social Security applies its SGA rules to this particularly vulnerable group—persons on DAC benefits and in supported work programs—frustrates a national policy of encouraging individuals with significant disabilities to participate in competitive employment. Social Security interprets its regulations in a way that penalizes persons in supported employment because their supports come from an outside publicly or charitably funded agency rather than from the employer itself. A private employer is asked to determine the amount of any subsidies including special conditions provided to an employee when determining the value to the employer of the employee’s work. 20 C.F.R. § 404.1574(a)(2).[3] Those calculations would necessarily include the cost of extra supervision, extra training, services to address behavior problems, etc. Initially Social Security took the position that it would not consider at all any subsidy including special conditions provided by a supported work program. Social Security has changed its position in that it will recognize to a limited degree subsidy provided by a supported work program[4] but not to the extent SSA

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[1] *See Innerebner v. Apfel,* 2000 WL 274185, Case No. C–99–00794–WHA (N.D. Cal. 3/3/00) involving a DAC beneficiary whose mental retardation met Social Security’s listing of impairments and who lost his DAC benefits because his gross earnings through a supported work program eventually averaged more than $500 a month, the then applicable SGA level.

[2] Section 202(d)(6)(B) of the Social Security Act, 42 U.S.C. § 402(d)(6)(B), provides that a DAC beneficiary whose benefits stopped before because he ceased to be under a disability, may be reinstated to benefits if he “is under a disability . . . which began before the close of the 84th month following the month in which his most recent entitlement to child’s insurance benefits terminated because he ceased to be under such disability.” See also 20 C.F.R. § 494.351(c). The legislative history indicates that this provision [added by § 108(d) of Pub.L. 92–603 in 1972] was intended to enable persons whose benefits ceased because of work to be reinstated. Social Security, however, has treated this provision as a nullity saying that performing SGA makes you ineligible for re-entitlement. Social Security has not identified anyone who could qualify for re-entitlement under this provision.

[3] “An employer may set a specific amount as a subsidy after figuring the reasonable value of the employee’s services.”

[4] Per the August 17, 1999, Program Memorandum from Ken McGill, Social Security will consider only a limited number of service hours provided by a supported employment program—hours when the supported work program is actually doing the employee’s job -and values those services at the employee’s rate of pay. Not covered are all the other tasks performed by the supported employment program which are necessary to maintain employment. Those services include providing extra supervision, training the supervisors on how to work with the employee in light of his disability, working with the employer to restructure the job to accommodate to the employee’s disability limitations, incorporating sequencing cues to the work site, developing positive and appropriate interactions with coworkers, working with employer and employee to address problem behaviors, etc.

will recognize subsidy provided directly by an employer -and not to the extent SSA will recognize subsidy provided by a third party to someone who is self-employed.[5]

About Supported Employment

Supported employment programs administered by state rehabilitation agencies were established by Congress "to serve individuals with severe disabilities for whom competitive employment has not traditionally occurred or has been interrupted or intermittent."[6] They target "those with the most severe disabilities who may have been thought to be too disabled to benefit from rehabilitation services to achieve successful employment outcomes."[7] They target those who have been traditionally served in segregated sheltered workshops and "day activity programs because they appear to lack the potential for unassisted employment."[8]

A person with a disability cannot qualify for supported employment unless he is someone who cannot keep a job in the competitive labor market without intensive and ongoing support services.[9] Because federally funded state rehabilitation programs serve persons in supported employment for only a limited initial period of not more than 18 months, eligibility also requires the availability of a state program to provide the ongoing support needed to maintain someone in a competitive sector job.[10]

The Role of SGA Determinations in the title II Disability Programs for Persons in Supported Employment

SSA's regulations defining what is and is not "substantial gainful activity" are all regulations adopted to define who does or does not meet the statutory definition of disability under the Social Security disability programs.[11] Thus the determination that a title II disability beneficiary performed substantial gainful activity based on earnings from one particular job is also a generalized determination of the person's ability to perform substantial gainful activity outside that one particular job.

For a person in supported employment, a finding that work constitutes substantial gainful activity based on earnings is a finding that the supported employment participant has demonstrated the general ability to perform work at the substantial gainful activity level. This is so even if there is no dispute that the person could not work at all outside the supported employment program[12] and even if there is no dispute that the cost of the supported employment program exceeded the gross earnings so that, if the employer were providing the supports, the person would be found not to be performing SGA.[13]

Conclusion & Request for Oversight

Supported employment provides a significant opportunity for those closed out of competitive employment because of their disabilities. Supported employment has in-

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[5] *See* the section on unincurred business expenses in Social Security Ruling (SSR) 83–34 about SGA determinations for self-employed persons. In that Section Social Security says it will deduct from earnings "any business expenses which were incurred and paid for by another agency" including expenses paid for by the State Rehabilitation Agency: "This policy is consistent with the principle that only income attributable to an individual's own productive work activity should be considered in determining SGA." *See, also,* 20 C.F.R. § 404.1575(c).

[6] House Report (Education and Labor Committee) No. 102–822 (August 10, 1992) to accompany H.R. 5492 that became Pub.L. 102–569, 1992 WL 202382, page 175.

[7] Id. at page 123.

[8] House Rep. No. 99–571 (Education and Labor Committee), May 5, 1986, accompanying H.R. 4021 that became Pub.L. 99–506, at page 31, reporting on testimony of Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services, U.S. Dept. of Education, 1986 U.S. Code Cong. & Adm. News 3471, 3501.

[9] See, e.g., 29 U.S.C. § 795j(2).

[10] 29 U.S.C. §§ 705(36)(C), 705(13), 722(b)(3)(F)(ii), 795i.

[11] The term 'disability' means—(A) inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months;" Section 223(d)(1)(A) of the Social Security Act, 42 U.S.C. § 423(d)(1)(A). "The Secretary shall be regulations prescribe the criteria for determining when services performed or earnings derived from services demonstrate an individual's ability to engage in substantial gainful activity." Section 223(d)(4) of the Social Security Act, 42 U.S.C. § 423(d)(4), emphasis added.

[12] In Fred Innerebner's case, for example, the Administrative Law Judge ruling against him also concluded that "the claimant would have been unable to perform the job without the support services he received from the various social service agencies."

[13] In Fred Innerebner's case, for example, there was no month in which his earnings came close to SGA if the cost of his supported employment services were deducted and many months where he was in minus territory or close to zero if the cost of supported employment services were deducted.

creasingly come to replace the more traditional sheltered workshop because it provides a more realistic opportunity for some to transition into self-support with little or no ongoing supports. Social Security's interpretation of its own regulations, however, frustrates the goals of supported employment programs. Because Social Security does not consider the actual subsidy represented by supported employment services, participants in supported employment cannot risk earning above the SGA level. They cannot risk getting to the point of where they have a chance of becoming self-supporting with little or no supports. If they do, they will suffer Fred Innerebner's fate: termination forever from DAC benefits even though they in fact have not demonstrated a general ability to perform SGA.

Protection & Advocacy respectfully requests that the Subcommittee on Social Security review how Social Security determines when the earnings of supported employment participants constitute SGA. That would include looking at how Social Security evaluates the support services provided by supported employment programs in that process and how the purposes of the Social Security Act and the Rehabilitation Act may be harmonized for Social Security title II disability beneficiaries participating in supported employment.

Protection & Advocacy respectfully requests that the Subcommittee on Social Security review how Social Security applies Section 202(d)(6)(B) and whether Social Security is correct in treating that provision as a nullity without force or effect.

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