



**TESTIMONY OF THE TASK FORCE ON SOCIAL SECURITY
OF THE
CONSORTIUM FOR CITIZENS WITH DISABILITIES**

**PRESENTED BY
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BEFORE THE HOUSE WAYS AND MEANS SUBCOMMITTEE ON SOCIAL SECURITY

B318 RAYBURN HOUSE OFFICE BUILDING

THURSDAY, JULY 13, 2000

ON BEHALF OF:

American Association on Mental Retardation
American Council of the Blind
American Network of Community Options and Resources
American Occupational Therapy Association
Association for Persons in Supported Employment
Brain Injury Association
Easter Seals
Epilepsy Foundation
International Association of Psychosocial Rehabilitation Services
InterNational Association of Business Industry Rehabilitation - INABIR
National Association of Developmental Disabilities Councils
National Association of Protection and Advocacy Systems

National Mental Health Association
National Multiple Sclerosis Society
National Organization of Social Security Claimants' Representatives
NISH - Creating Employment Opportunities for People with Severe Disabilities
Paralyzed Veterans Of America
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Chairman Shaw, Mr. Matsui and members of the subcommittee, thank you for the opportunity to testify today on the Future of SSA Disability Programs. I am Tony Young, 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.

INTRODUCTION

We appreciate having this opportunity to examine the needs of persons with disabilities who are on, or who will be participants in, the SSA disability programs – Social Security Disability Insurance [SSDI] and Supplemental Security Income [SSI]. SSDI began in 1956 as an early retirement program for injured workers who could not struggle through to the regular retirement age of 65. SSI, created in 1972, was a program intended to supply a minimum level of economic support to the elderly, blind or persons with disabilities whose work history was insufficient to qualify them for SSDI.

Since their inception, these disability programs have evolved unevenly whereby individual problems in the programs were identified and partially solved, not always with a comprehensive view or purpose. Changes have come only when program parameters have been found to be grossly out of line with reality. For instance, the substantial gainful activity [SGA] level was finally raised in 1999 to \$700 per month after having been set at \$500 per month since 1990. Some program criteria, such as the SSI earned income disregard, has not been changed since the program began in the early 1970s.

Federal disability programs, as originally envisioned, were based on the assumption that people who became disabled would remain disabled throughout the rest their lives. This static view of disability meant that little thought was given to what might happen if people returned to work after becoming eligible for benefits. However, disability is not static. Disability is a dynamic condition. Medical advances, new technologies, improvements in rehabilitation services, and the expectations of people with disabilities have all conspired to change the meaning of disability, the very definition of disability. The consequences of this new disability dynamic have rippled through the federal disability system, revealing a system that has not adapted to meet the challenges ahead.

DEMOGRAPHICS, SOCIETY AND THE ROLE OF PEOPLE WITH DISABILITIES

The changing demographics of individuals who might benefit from the SSA disability programs -- the nature of their disabilities, the age of onset, the length of time in the programs, and related factors – has had and will have a most profound impact on SSDI and SSI. Some brief statistics provide a snapshot of Americans with disabilities and the circumstances in which they live.

In 1996, the Government Accounting Office [GAO]^{1[1]} reported that, during the period 1985 to 1994, the number of people with disabilities on SSI and SSDI increased from 4.2 million to 7.2 million. By 1994, 57% of people on SSI aged 18 to 64 were those with mental impairments. For those on SSDI the percentage was 31% of the DI population. The DI and SSI populations became somewhat younger during that time period: DI beneficiaries in "middle age" [30 to 49] increased from 30% in 1986 to 40% in 1994; for SSI beneficiaries the increase was from 36% in 1986 to 46% in 1994.

^{1[1]} GAO/HEHS-96-62, SSA Disability Program Redesign Necessary to Encourage Return to Work, April 1996

The majority of Americans with disabilities are of working age [57.6%]. Native Americans have the highest disability rate of all racial groups [17.6%]; Asians and Pacific Islanders have the lowest rate [7.2%]. For whites and African Americans, the rates are 15.3 and 15.9 percent respectively but Hispanics report a disability rate of only 10.5%. Disability rates are highest in rural areas [although most people with disabilities live in metropolitan areas (74.8%)]. Disability rates are 3 times higher among people who did not finish high school than among those with college degrees. People with disabilities, according to a 1992 National Health Interview Survey, include 4 million Americans with heart disease, 3.7 million with arthritis, 1.5 million with mental disorders, 1.4 million with mental retardation or learning disabilities. There are over half a million Americans with spinal cord injuries or dysfunction and 654,000 with hearing impairments.^{2[2]} Another 1.4 million individuals have visual impairments.^{3[3]}

Only 3 in 10 working-age adults with disabilities are employed full or part time, compared with 8 in 10 non-disabled adults. This low rate of employment has led to an income gap not reduced since 1986. One in 3 disabled adults, compared to 1 in 8 non-disabled adults, live in households with incomes below \$15,000.^{4[4]}

Any examination of federal disability programs must be viewed in light of the evolving societal factors surrounding people with disabilities – such as the Individuals with Disabilities Education Act [IDEA] and Americans with Disabilities Act [ADA] -- and the shifting expectations of the role that individuals with even the most severe disabilities can play in the lives of our communities and economy. Among the most exciting advances have been our expectations for individuals with the most significant support needs. For example, over the past twenty years we have moved from building institutions to creating individualized living arrangements in the community for individuals who have been labeled with a significant cognitive disability. Well over 200,000 individuals who once were never expected to spend their days beyond the protective walls of congregate settings such as sheltered workshops or adult day activity centers are now working in the community in real, competitively paid jobs through supported employment. They now do what the rest of us do: go to a wide array of jobs, collect their paychecks, and go home, many with supports, some with none.

The nation will celebrate the tenth anniversary of the Americans with Disabilities Act later this month. That Act recognized what the disability community has known for years, that “disability is a natural part of the human experience.” The protections afforded by the ADA have opened the windows on the disability experience and revealed a myriad of individual skills and capacities that very closely parallel those of people without disabilities. This exposure, along with an explosive growth of technology, research and training, best practice services and supports, individual awareness and self-determination have changed forever the way that we approach disability in this country from public policy to practice.

NEW TECHNOLOGIES, MEDICAL ADVANCES AND IMPROVEMENTS IN SUPPORTS AND SERVICES

Much of the changing attitudes toward people with disabilities and their capabilities have been driven by the transformation of the workplace and the environment through technology, breakthroughs in medical science, and innovations in supports and services used to enhance the independence of individuals with

^{2[2]} Disability Watch, Disability Rights Advocates, Volcano Press, Volcano, CA, 1997

^{3[3]} American Council of the Blind

^{4[4]} 1998 N.O.D./Harris Survey of Americans with Disabilities

disabilities. Four years ago, the GAO noted that, despite poor return-to-work outcomes under SSI and SSDI, “many technological and medical advances have created more opportunities for some individuals with disabilities to engage in work. Electronic communications and assistive technologies--such as scanners, synthetic voice systems, standing wheelchairs and modified autos and vans--have given greater independence to some people with disabilities, allowing them to tap their work potential. Advances in the management of disability--like medication to control mental illness or computer-aided prosthetic devices--have helped reduce the functional limitations associated with some disabilities. These advances may have opened new opportunities, particularly for some people with physical impairments, in the growing service sector of the economy.”⁵[5]

Finally, the development and replication of new supports and services has made it possible for many more people with disabilities to receive the rehabilitation and on-going supports they need to work. Psychosocial rehabilitation, occupational therapy, and job coaching are just some of the services now available to people with severe mental and physical disabilities. These services help people assume and maintain work and also include services to develop or enhance self-care skills so that the individual can function in society.

Many people with significant disabilities are surviving injuries at birth, disabling diseases, or traumatic accidents. Some of these survivors are living longer, more healthy lives. Some, however, are not. Some of these survivors have access to the latest technological aides that make them productive and independent. Many other survivors do not have access to this technology. Some individuals have access to the latest prescription medications, surgical techniques, intervention therapies, and other modern disability management procedures. Most people with severe disabilities do not. The future holds potential for remarkable advances in gene therapy and similar genetic treatments that some will have access to, but many still will not. This opportunity gap will widen the discrepancy in work opportunities for those who might qualify for SSA disability programs.

Different types of supports and expectations are needed and appropriate for people of different ages and with different types of disabilities. Disability is as individual as the person who experiences it. Each disability has its own personality, with strengths, weaknesses, and even quirks. Each must be treated appropriate to its own personality in order for the individual with the disability to be successful at whatever they might attempt to do.

Clearly, age and disability are interrelated when it comes to work aspirations. A young adult who has never worked will have greatly different aspirations than an individual in mid-work life with several years of work experience, and that individual will have different aspirations than an older individual who has many decades of work experience.

Their needs for income and supports will vary greatly as well. To treat everyone equally is to mistreat the majority of those on the program. Individualized assessments of needs and services are essential to successfully assisting people with disabilities to work. There must be incentives for people to encourage them to risk leaving the benefit program, and there must be an easy transition from benefit support to personal support. It is essential that all persons be allowed to seamlessly reenter the benefit program should they fail in the effort to work.

⁵[5] GAO/HEHS-96-147, Social Security: Disability Programs Lag in Promoting Return to Work

It is possible to identify common concerns for all as well as particular concerns of subgroups. Common concerns include: 1) an easy transition from benefits to personal support rather than a sudden cutoff of benefits; 2) easy reentry to benefits if work is not successful; 3) no total cutoff of benefits until one reaches a living wage with comparable health coverage; and 4) a flexible benefit for individuals who can only work episodically, such as those with mental illness.

WEAKNESSES OF FEDERAL DISABILITY POLICY

Definition of Disability – In a 1996 report, the GAO identified at least "fourteen different definitions of disability used by federal programs alone, and many of these definitions provided considerable agency and state discretion in eligibility determination...For example, programs administered through the Department of Education, such as VR, defined eligibility in terms of physical or mental impairments, whereas the programs administered through SSA defined disability in terms of the inability to work."6[6]

One of the most serious problems with current disability program design and policy derives from the fact that Social Security's definition of disability continues to focus on near-complete inability to work. Furthermore, the measure for ability to work is set at a level of income that does not provide even a base of support necessary for most people to live. Many of the policies that penalized people with disabilities for working have been addressed through last year's Ticket to Work and Work Incentives Improvement Act. Yet, the retention of the unrealistically low substantial gainful activity [SGA] level continues to punish rather than reward people who attempt to leave entitlement programs through work. We recognize that considerable debate has already occurred on this subject. However, we reiterate once again our firm belief that federal disability programs must respond to modern reality rather than remain mired in the mind-set of the last century.

In the past, CCD has recommended changes in the definition of disability that would: retain the criterion of mental or physical impairment [or combination of both] verifiable by accepted clinical methods; replace the concept of SGA with an assessment of functional limitations in all areas of life activities; and consider vocational, medical and other factors in an overall assessment of an individual's functioning in areas of major life activity. Furthermore, attention must be paid to how temporary, recurring/intermittent, or partial disability is addressed by federal disability programs.

Whatever future steps Congress may take in this regard, CCD urges you to proceed with caution. Any proposals to revise the definition of disability, whether through statute or regulation, should be subjected to careful analysis of the effects on people with disabilities and a realistic assessment of the true meaning of disability, including for those who are able to work with necessary, on-going supports.

Multiplicity of Federal Disability Programs -- In 1996, the GAO found that federal assistance to millions of people with disabilities was provided through 130 programs in 19 federal agencies.7[7] Very often, service delivery is performed through numerous public and private agencies at the state and local level. In the fiscal year studied [1994], GAO revealed that the federal government spent over \$60 billion on 69

6[6] GAO/HEHS-96-126, *People with Disabilities: Federal Programs Could Work Together More Efficiently to Promote Employment*, September 1996

7[7] *Ibid.*

programs targeted exclusively to people with disabilities. In addition, people with disabilities benefited from between \$81 billion and \$184 billion in spending through 61 partially targeted programs. This list of programs did NOT include AFDC, the forerunner of Temporary Assistance to Needy Families [TANF] -- as GAO eliminated programs not specifically intended to address disability. How well these programs coordinate with one another and how well they serve the people they were created to help are questions worth considering.

Interaction with Other Governmental Programs – As noted above, SSA disability programs do not exist in a vacuum. There are over 100 federal programs that affect people with disabilities. It is imperative to examine how the SSA disability programs interact with other poverty programs, e.g., job training, Food Stamps, housing subsidies, transportation supports, long-term supports, and similar programs. A major issue for individuals with severe disabilities concerns the need to stitch together a patchwork quilt of income, and in-kind supports in order to live. Too often, taking a job unravels this quilt in ways that undermine the work effort and trap them in poverty and government cash assistance.

For example, Medicaid policy allows some states to have stricter Medicaid income levels, asset levels, income disregards and even medical disability definitions than SSI. This means that incentives for SSI recipients to return to work are seriously undermined because the Medicaid needed to support work attempts is not always available if Medicaid rules are not the same as those of SSI. In addition, continuing disability reviews [CDRs] that find people "no longer disabled" not only deprive them of cash benefits but they cost such persons continued Medicaid and Medicare which, under current law, are supposed to be available to those who leave the SSI and SSDI rolls to work. Furthermore, the Medicaid formula for determining medical expenses used for individualized computations of earnings thresholds in determining continued eligibility under Section 1619(b) now only recognizes publicly-provided attendant care costs and fee-for-service per capita Medicaid expenditures on behalf of that particular patient. Accounting for the true costs of supports becomes an issue when states' Medicaid reimbursements are only recorded as capitations to managed care contractors---and do not, therefore, fully recognize the high costs of services actually rendered to particular disabled individuals.

HUD housing programs do not have earnings disregards. Local public housing authorities do have authority to institute earnings disregards for public housing units---but NOT for Section 8, vouchers, Section 212, Section 811 or the special subsidies for people with disabilities established by Congress in the late 1990s. And even this limited authority has so far been largely directed at helping TANF mothers in public units return to work.

A growing body of research indicates that a large proportion of parents receiving TANF [or who have left TANF] have disabilities or health conditions that may affect their ability to succeed in the workforce if they are not provided with the appropriate supports and services to help them succeed. 8[8] In addition, many families who are eligible for Medicaid or other publicly funded health insurance coverage are not enrolled in those programs, due to the de-linking which has occurred.

These are but a few of the complexities of the social security disability programs' interactions with other government programs.

8[8] Center for Budget and Policy Priorities, Feb. 2000, "Recent Studies Indicate that Many Parents who are current or former welfare recipients have disabilities or other medical conditions"

Integrating SSI with work programs for older disabled children -- Children in the IDEA era have, generally speaking, been entitled to a free and appropriate public education and, theoretically, have had access to an array of services while in school. However, they lose these supports upon attaining a certain age and often fail to advance into the world of adult employment as a result. Children and their families need the services accorded by IDEA in order for them to perform at satisfactory levels to achieve their educational goals. These same or similar services may be required for them to then meet their vocational goals. In addition, there is the need to eliminate the penalties built into the current system for young people who need ongoing supports even while working.

Work Incentives -- The Ticket to Work and Work Incentives Improvement Act, in reality a major achievement in addressing certain deficiencies in federal disability programs, is placed here to draw attention to remaining hurdles confronting people on SSI and SSDI. Furthermore, because PL 106-170 has yet to be implemented, we cannot predict how successful it will be in eradicating barriers it was created to remove.

A major problem with the SSDI program has been its eligibility determination system that forces applicants to assert that they have no residual work capacity in order to qualify for benefits. Then, if someone attempted to work, the system abruptly withdrew all supports that individual needed to survive. The Ticket to Work and Work Incentives Improvement Act took significant steps toward eliminating this bias through its provisions assuring extended Medicare coverage for workers with disabilities and the easier return to benefits should a work attempt fail. However, SSDI retains the assumption that work beyond a very modest, less-than-minimum wage level of earnings means that a person is no longer "disabled".

The concept of appropriate supports means the elimination of all financial and psychological disincentives to work. In the past, applicants for SSDI had to undergo months of review in which they had to assert no capacity for work. They waited months for benefits, often after months of appeals, and waited again to qualify for Medicare coverage. Only recently, did they have the presumptive eligibility for entrance into the vocational rehabilitation system and, even if they did receive VR services, they were warned not to earn too much, lest they lose all of their benefits.

If implemented properly, the Ticket to Work and Work Incentives Improvement Act could address many of these disincentives. The extension of Medicare will assure continued health care coverage for SSDI recipients. Depending on how and whether they are adopted by states, the Medicaid buy-in provisions have the potential to provide more complete health care supports to beneficiaries going to work. Again, depending on how SSA implements the Ticket to Work program, beneficiaries should have greater choice in provider and type of vocational rehabilitation services. And, the benefits outreach, counseling and assistance, if done properly, can offer beneficiaries clearer road maps to navigate the consequences of going to work. For those with a recently acquired disability, early intervention of the type envisioned through the counseling and assistance planners may mean the difference between returning to work and languishing on the disability rolls for years. Finally, the expedited reentry provisions offer some measure of reassurance that benefits will not be difficult to obtain should a work attempt fail.

However, while the system manages to make initial disability determinations, it is totally inadequate at tracking income and earnings as people take advantage of the aforementioned services. This inadequacy will become more apparent as people take advantage of the recently enacted work incentives legislation. For example, while overpayments to beneficiaries who work have always been problematic, they promise to become catastrophic if left unchecked. Beneficiaries will more deeply mistrust the program, providers won't get paid under the Ticket if the benefits continue unnecessarily, the fiscal strain on the program will continue, and other parts of the disability program will suffer as SSA struggles to correct the problem

without adequate resources. Congress must address the need for systems improvement and modernization.

CHALLENGE OF THE BABY BOOM

It is no secret that during the next twenty years, there will be a large increase in the number of people who reach both retirement and early retirement ages. Strategies must be explored to help individuals reaching early retirement age, who lose their ability to perform their existing jobs, to remain in the workforce for as long as possible. Currently, the SSA disability programs only respond once someone's disability has reached the acute stage in which an individual is driven out of the workforce entirely.

The sheer number of baby boomers will have an enormous impact on SSA's operations. According to SSA's Office of the Actuary, by 2010, SSDI applications will increase by 54% and SSI disability applications by more than 10%.^{9[9]} Over the same period, the increase in the normal retirement age also will affect the number of disability applications.

In addition, SSA has been faced with more complex and changing work challenges. The disability determination process is complicated and lengthy. The SSA customer population has changing expectations about technology. More claimants are non-English speaking or limited-English speaking, leading to a need for more bilingual staff. Recent legislation requires SSA to provide increased rehabilitation and employment services for people with disabilities, to maintain a schedule of continuing disability reviews and other eligibility reviews, and to implement new approaches to prevent fraud and abuse.

The problem is aggravated by the fact that SSA's workforce also is aging and will begin to lose significant numbers of experienced staff, including senior management and leadership personnel. More than one-half of SSA's 63,000 employees will be eligible to retire by 2009 or leave government service after twenty years with pension rights.^{10[10]} Between 2007 and 2009, about 3,000 employees are expected to retire per year. The service delivery problems have been exacerbated by SSA's prolonged period of downsizing – since 1982, SSA's workforce has declined by 27%. At Subcommittee hearings earlier this year, the Social Security Advisory Board, the Commissioner of Social Security, and the General Accounting Office raised the issue of how SSA should plan to retain experienced staff and train new managers to meet these needs.

The CCD Social Security Task Force has voiced concern for some time over the continued long-term downsizing of the SSA workforce and believes that failure to conduct appropriate and timely CDRs and other eligibility reviews could lead to decreased trust in the integrity of the Social Security and SSI programs. In addition, the new efforts to assist people with disabilities to go to work, through the Ticket to Work and Work Incentives Improvement Act of 1999, will require new and expanded approaches for SSA interaction with beneficiaries. Adequate staffing levels are critical for these and other efforts to be successful, especially given the coming disability and retirement years of baby boomers.

^{9[9]} Testimony of Cynthia Fagnoni, Director, Education, Workforce and Income Security Issues, General Accounting Office, to the Ways and Means Social Security and Human Resources Subcommittees, Hearing on Social Security's Readiness for the Impending Wave of Baby Boom Beneficiaries, Feb. 10, 2000

^{10[10]} Ibid.

The independent, bipartisan Social Security Advisory Board has unanimously urged that SSA's "administrative budget, like its program budget, be explicitly excluded from the statutory cap that imposes an arbitrary limit on the amount of discretionary government spending." 11[11]

We believe that the entire Limitation on Administrative Expenses [LAE] should be removed from under the domestic discretionary spending caps so that SSA's administrative functions can continue to operate smoothly for beneficiaries. [For background, see CCD statement for the record, March 16, 2000]

ISSUES FOR THE FUTURE

No single hearing can capture the entire range of questions that need to be asked about the future of federal disability programs. The CCD Social Security task force recognizes that this is just the beginning of an exploration of ways to modernize SSDI and SSI. We also recognize that some of these questions fall under other committees' jurisdictions. That, however, may indicate a need for greater coordination among Congressional bodies responsible for programs affecting people with disabilities. Based on our testimony, we would like to offer several issues that the committee should examine as it continues its investigations.

- Does the definition of disability under social security adequately capture the spectrum and continuum of disability today? Does it reflect the interaction of vocational, environmental, medical and other factors that can affect the ability of someone on SSI or SSDI to attain a level of independence?
- Do current SSA program policies foster or hinder acquisition of technology that will lead to greater independence? Are these technologies covered under impairment related work expenses? Would someone acquiring necessary supports to go to work encounter problems with asset and resource limits imposed under federal disability programs. Should tax credits or other incentives be provided for people to obtain these supports to go to work?
- How competent is SSA at communicating with its SSI and SSDI beneficiaries with visual impairments? Frequent failure of SSA to produce notices and documents in accessible formats lead to penalties imposed on such beneficiaries and increased administrative expenses in dealing with the consequences.
- Should CDRs be reevaluated for those covered under Medicaid Section 1619(b) or individuals still relying on Medicare to prevent denial of the very health care coverage offered to encourage people to work?
- Can the stricter income, asset levels allowed under Medicaid's 209[b] provisions undermine promotion of Medicaid buy-ins and other initiatives designed to assure continued health care coverage for individuals on SSI and SSDI going to work?

11[11] Testimony of the Honorable Stanford Ross, Chair, Social Security Advisory Board, before the House Subcommittee on Social Security, Committee on Ways and Means, February 10, 2000

- Are changes needed in the current Medicaid 1619[b] formula for individualized determinations to allow for other medical costs of working disabled persons met by other programs? [e.g. Medicare, state pharmacy assistance, AIDS Drug Assistance Programs, WIC, public maternal and child health programs, cash medical purchases and private health insurance.]
- Why are earnings disregards recognized for SSI, SSDI, Medicaid and Medicare purposes not so honored by housing subsidy programs as well? Income and assets excluded by the PASS program are excluded under the housing statutes. The HUD programs should similarly recognize other disability-related disregards.
- How well do veterans' programs interact with and serve veterans with disabilities who rely on SSDI and/or SSI?
- Can steps be taken to replicate the earnings disregards and work incentives of the SSI and SSDI programs in Medicaid and the AIDS Drug Assistance Programs? This is important for individuals dependent for drugs on non-SSI-based Medicaid (e.g., TANF-related cases) and the AIDS Drug Assistance Programs rely for essential pharmacy coverage on programs which currently have NO meaningful earnings disregards or other work incentives.
- Should state standards for exemption from welfare time limits and work/training requirements make allowances for families in which either a primary or secondary parent cares for a child with a disability? Studies suggest that at least 20% of TANF cases have disabled primary caretakers, children or second parents (since many states can and do now include two parent families).

Again, these are but a few questions that arise when considering the array of federal programs affecting Social Security beneficiaries with disabilities. We appreciate the subcommittee's attention to these issues and look forward to continuing to work with the members in examining the future of the disability programs.