Disability Income Policy in 2001 – Excerpts from *Balancing Security and Opportunity: The Challenge of Disability Income*

In 1996, the Academy's Disability Policy Panel released a landmark study of disability income policy, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*. Below are key excerpts from the report that are useful to the current policy debate.

Stories from people receiving disability benefits.

How does disability income policy fit into the broader disability picture?

Does the Social Security Definition of work disability fit the program's purpose?

How are disability claims decided?

Why do the rolls grow and shrink?

Are DI benefits a deterrent to work?

Does the Social Security Administration have adequate funding to administer the program with fairness and integrity?

What is the Academy's Disability Policy Panel?

Living with a Work Disability: Stories from People Receiving Disability Benefits

Introduction and Methods

To get beneficiaries' perspectives on their disabilities, benefits and prospects for work, the Academy's Disability Policy Project conducted focus group and telephone interviews with over 40 people ages 25-61 who were receiving either Social Security disability insurance (DI) benefits or Supplemental Security Income (SSI) disability benefits. A pilot focus group was held in Virginia in August 1994. Other focus groups were conducted in three sites -- Iowa, New York and Oregon -- in October 1994. The Academy collaborated with the U.S. General Accounting Office to obtain from the Social Security Administration lists of beneficiaries' names. They were contacted by phone and invited to participate in the focus groups. All of the beneficiaries contacted had filed for disability benefits within the prior five years. Beneficiaries gave permission for the information to be used for the research project. Interviews were conducted by LaScola Qualitative Research and covered the beneficiaries' perspectives on their quality of life, their experience with disability and work, their prospects for returning to work and their experience with the Social Security Administration.

Focus group participants were selected to include a mix by gender, ethnicity and three broad categories of impairments: musculoskeletal; mental; and cardiovascular, respiratory and other impairments. Excerpts from their stories are presented in three categories:

- Beneficiaries with cardiac, respiratory or other impairments
- Beneficiaries with musculoskeletal conditions
- Beneficiaries with mental impairments

Of the 4.9 million disabled workers receiving DI at the end of 1999, mental disorders were the primary diagnosis for 32 percent (5 percent had mental retardation and 27 percent had other mental disorders). Musculoskeletal conditions were the primary diagnosis for 23 percent, while "other" conditions accounted for the remaining 45 percent. Common diagnoses in the "other" category were diseases of the circulatory system (11 percent), of the nervous system and sense organs (10 percent), of the blood and blood-forming organs (5 percent), the respiratory system (3 percent) and cancers (3 percent). Many beneficiaries have multiple impairments.

Beneficiaries with Cardiac, Respiratory and Other Impairments

These individuals often were very ill or had life-threatening health conditions. Many had remained on their jobs months or even years after the onset of their conditions, determined to "beat the odds" of their diagnoses. By the time they turned to Social Security, they had experienced the loss of their health, their livelihood and their hopes for ending their work lives with a comfortable retirement. Returning to work usually was not an option. Most had exhausted efforts to remain at work before turning to disability benefits. Their emphasis was on preserving their health, and often their lives, and finding meaning in activities without the psychological and monetary rewards of paid employment. Some were more serene about this than others, being grateful for their "good days" and finding meaning in family or other relationships. Many said that their claims were processed promptly by Social Security. They often had clearly diagnosed and documented medical conditions that probably met SSA's medical listings.

Accountant. Age 53, she is an accountant who worked her way up from being a bookkeeper. She has five sons and a daughter and now lives in Oregon near her daughter. She has chronic respiratory failure and wore oxygen during the focus group. Her condition was diagnosed in 1990 when she lived in Las Vegas. She applied and received Social Security without difficulty. She is very worried about paying for her medication.

> In 1990, I'd just arrived in Las Vegas. I was trying to apply for work, and I just didn't feel well. I kept going into emergency. I thought maybe it was the atmosphere there, and then the doctor said "Your lungs are gone. You should be on total disability." I had no health insurance in Las Vegas. I had worked in California, and had Kaiser insurance there. So I went back to San Diego and stayed with my son.
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> When I applied for Social Security, the paperwork went through and everything. I had no problem. I just couldn't believe that I was totally disabled. I still can't believe it. I'm getting more oxygen to my brain and I'm getting more aware. But I don't have the energy. Even walking a block, I'm out of breath -- and it isn't getting better.
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> I thought at this time of my life I'd be comfortable. Not wealthy or anything, but all right. But with the increases in drugs, you can't make it. It's going to get worse. It's not going to get better. The longer I live, the more medication I have to take. The bills just keep mounting. I don't want to worry about it, because it just makes it worse. I pay $81 a month for my insurance, and I have to pay 70 percent of my prescriptions. At this point, I've been charging my prescriptions, because they've been running over $100 a month. I applied for family services, senior disabled services. I should know today whether I'll get assistance or not. If I don't, he says to keep trying. I may be able to get them to pick up the prescriptions.

Management Secretary. In her 40s, she had been a management secretary in a hospital in Iowa. She has cancer and worked after her first surgery. After her second surgery she applied for Social Security and qualified quickly. She also receives a disability benefit from the hospital where she worked.

> I probably look pretty good, but I have a tumorous cancer that could not be removed by surgery. So I have gone the chemo/radiation route. It's in regression now.

> I had cancer before and was able to work through my first surgery. Then when it occurred again, I was working and I tried to go back to work after surgery, and could only maintain about two weeks and I couldn't because of the pain, and so forth.
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> The hospital gave me options to come back to work. But you have to look at it long term. They've seen you when you've been able to perform 100 percent. Now with your illness, maybe you can only perform 50 percent one day, maybe 30 the next. Maybe one day you just can't make it to work. So eventually, you're not going to have a job because you cannot fulfill that obligation.
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> My first disability benefit was through the hospital. Then I called the Social Security office. Mine went right through without any problem.
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> With cancer, they say a lot of times most of your therapy is your attitude. I don't plan to go back to work. I don't know how long I have. I haven't been told yet -- it could be any time. So I try to take a very positive attitude so I don't make myself worse than I am. There may be a chance maybe later on, to find something in therapy or medication to live longer. We take a day at a time.

Insurance and Financial Services Representative. In his 40s, he lives in Virginia. He was diagnosed with multiple sclerosis (MS) two and a half years ago. He worked 20 years for an insurance company selling financial services. He kept working until his vision declined to the point where he was no longer able to read or drive. His motor coordination is faltering. He was initially denied Social Security before being allowed on appeal.

> For me, a good life would be just being able to be mobile. To be able to walk more than 3 blocks without falling down. To be able to see so I can drive and get myself around.
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> I was originally diagnosed as having MS in August of '91. And I went through approximately two years with no major problems. Around June of '93 my vision got to the point I was having problems seeing street lights. Finally, my wife insisted I stop driving. I had to stop working in August '93.
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> I have a good relationship with the executives of my company. I've been working with them for 20 years. And they have been very fair and very nice to me. They have tried to come up with alternative things I could possibly do while I am on disability. But because of not being able to read properly, that has created problems. But one of the things we've talking about is my giving little speeches, motivational things, you know, for prospective agents.
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> I try to stay active. For example, my daughter's in college and my wife works, so I do the cooking. I can't see what I'm cooking, but I can still try to cook it. I do things around the house, so I feel like I still have some self-worth. Your body and

> your attitude can adjust. I mean, I fall down all the time now. So I just get up. I just keep getting up.

Private School Teacher. A widow in her 50s, she has lived in New York City all her life and had taught 12 years at a private girls school. She had heart surgery nine years ago and returned to her job after being out for six months on temporary disability. In January 1994, she again had heart surgery and found that her condition was more serious than she had expected.

> When I had surgery the first time nine years ago, it was great to get back to work. In January I went to have surgery again to get a new valve. I have a leaky aortic valve. But when they went in they found out I had a silent heart attack. So instead of doing the two operations -- they did it with the balloon. The doctor said, no, I should not go back to work this time. It would be too much.
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> I had 52 weeks of disability benefits from the school. After that I went on Social Security disability. I'm a widow, so I got more on my husband's than I did on mine.
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> I had no problems with Social Security. It went through the first time. The business office in the school helped me file. She filled out certain things and the doctor had the information. I waited the six months. But I had no problems. I get a pension from the school, too. They'd only started it maybe nine years ago. So I get something from them too. And then from my husband's job, too. Thank goodness.

Clerk, Nurse's Aide. In her 40s, she has been a file clerk, a singer and a nurse's aide. She lived in Detroit and Dallas before moving to Iowa. She stopped working 4-5 years ago because of severe headaches. She was diagnosed with brain tumors, one of which has been removed. Two were inoperable.

> I stopped working because I was having real bad headaches. My cousin told me to go get my head checked out. When they cut my brain -- opened me up -- they saw three tumors in my brain. The doctor said he's going to remove one, but he couldn't touch the other two. They were right in the middle of my brain. I could have died or lost my speech forever. I didn't used to talk this way. But the doctor told me, he said, "Baby, you're getting up fast!" I said, "Yes, I want to get on." And three days later I had another stroke. I couldn't talk. I couldn't walk. I couldn't do anything. That's why I thank God for every day that he gives me.
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> The state of Iowa told me to go on disability. They put me on Social Security straight out of the hospital. They just automatically put me on. I did not know it then.
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> A good life? A good life would be if I could quit hurting. Every morning I take Phenobarbital, aspirin, I take a nerve pill. I take them all. And if I really want to do something, I do it. I just put my mind to it. There's a higher power in me to feel

> better. Every day when I wake up, I sit up and look at the sky and say, "Thank you, Jesus, for another day."

Switchboard Operator. Age 41, he had been a switchboard operator at a hotel for years. While hospitalized with pneumonia, he was diagnosed with emphysema. After his health insurance with the hotel ran out, he went on welfare and received Medicaid. The welfare office referred him to Social Security.

> A good life? Being able to create something, like write a book or make a movie, just doing something positive. Leaving a mark that you did something with your life, or being able to help someone else. I like to go shopping with my roommate, to help her carry the packages. Even though it takes a lot out of me, it feels like I'm accomplishing something. It helps my peace of mind.
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> I had a lung operation in 1991 because I had a complication with pneumonia. I have severe emphysema. For a while I didn't know I could collect disability. I was on welfare. They told me to go to Social Security.
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> I was on Medicaid. Before that I was on the hotel's insurance. But, they only give you a certain amount of time after you're out of work, then they don't pay your health benefits.
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> Just getting to a job would be hard. I could only work two hours at a time. Maybe being able to rest would help, but that wouldn't be very productive. Who would put up with that? My doctor said I shouldn't.

Day Care Center Worker. In her 50s, she had worked in a day care center. Both she and her partner were diagnosed with HIV. He has since died. She was referred to Social Security by public assistance and had no problem qualifying for SSI. Her illness came as a great shock. She is determined to keep a positive attitude to fight her illness.

> About five and a half years ago I was starting to feel kind of sick. At that time, I was living with this guy, and he started getting sick. I wanted him to go and have himself checked because there was a lot of things going wrong with him. I felt that I didn't need to for the simple reason that I was never into drugs, I was not running around. Before that I was a housewife with my children and my husband. It turned out that he had the HIV virus. I was hysterical. I went into a depression. It was hard for me to deal with the idea that he had HIV.
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> I went to have myself checked. And it turned out that I came down with HIV myself. So I started crying, "What do I do now?" I never thought of myself as being in that situation. I loved to work in the day care with the children. I could never go back. That was my first reaction, "I can never be around anybody now." I felt like I was contagious. But anyway, about four and a half years ago is when I did find out, and I went to Social Security and they started giving me SSI.

> I was on public assistance at the time. Public assistance sent me down to Social Security. They approved the SSI, and I've been on SSI right now for four and a half years. But it's a struggle. Living from one month to the other. Food, rent, and everything. All I get is $10 of food stamps. I go to the store once and they are gone. That's it.
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> Lately, I've been very sick. I try to keep my attitude positive -- going to church. And I have gone to groups with people with HIV. It's the only thing that keeps me going. The guy that I was with, he passed away last year. It has been some rough times. But I am a survivor. I won't let it get me down.

Nurse Manager. Age 50, she has lived in the Portland area for 25 years. She had been a nurse manager in charge of eight departments in a hospital. She was diagnosed with lupus in 1986. Despite her doctor's prognosis, she kept working for 18 months after her diagnosis. But she ultimately had to leave her job and claim disability benefits from the hospital and Social Security.

> A good life? Just to be able to do the things that I had thought I would be able to do when I reached this point in my life.
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> I have lupus, and I've had it most of my life. In 1986, I thought I had a heart attack. And they found out it was an infection around my heart. There are very few reasons why it should happen, and one of them is lupus. And we went back over all my records and did more tests. When I was first diagnosed, my physician said, "You won't be able to work any longer." And I laughed at him, because I wanted to prove him wrong.
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> I didn't want anybody to know that I was not well, and finally it became evident that I could no longer function. It took me a half hour to walk half a block from my car into the hospital, and when I got there I had to rest for an hour. I just didn't have the energy to get upstairs to my office. My staff members carried a lot of my load for me. When I found that in an eight hour day, I was spending four and five hours just trying to gear up the energy to do something -- it was time to leave. After 18 months, I decided on my own that I needed to leave, because I couldn't carry on any longer.
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> All my medical records were documented for about five years. And there was never any question about whether I would get Social Security. I turned it in and I got it. I got a letter in about two months, saying your disability will start -- once they settled it with the disability insurance from the hospital.

Beneficiaries with Musculoskeletal Conditions

Beneficiaries with musculoskeletal impairments included many who had back injuries and chronic pain. They reported difficulty with a broad range of physical functions -- walking, standing, stooping, lifting, sitting, even sleeping -- and some had difficulty with concentration due to the pain or their medications to ease it. They shared a common experience that employers, insurers and doctors often were not sympathetic to their conditions, particularly when workers' compensation was involved. Perhaps because pain is difficult to diagnose, measure and treat, many felt accused of malingering, often being told, "You should be better by now" or "There's nothing wrong with you." They had typically remained on their jobs for a time after the onset of their injuries. Some had aggressively sought other work and were still looking. Some found that both their age and medical history reduced their appeal to prospective employers. They typically qualified for Social Security disability benefits only after lengthy appeals. The long hiatus between earnings and benefits had often wiped out their savings. While they expressed frustrations with the Social Security claims process, their feelings about workers' compensation were even more negative.

Custodian. Age 53, she lives in Oregon and is a mother and grandmother. She has worked as a hairdresser, a sales person in cosmetics, and most recently as a custodian, where she has worked for six years before she was injured on the job about five years ago. She uses a scooter.

She is very angry about her experience with workers' compensation. In Oregon, workers' compensation is administered by the State Accident Insurance Fund (SAIF). After receiving compensation for about four years, she had a heart attack. When her workers' compensation ended, Social Security determined she was disabled. But she had lost her insured status for DI and qualified only for SSI. Social Security, apparently, set the onset of her disability after her heart attack, rather than at the time of her back injury.

> I was injured on the job and that was a disaster. I feel that somebody should do an investigation of the SAIF. I went through hell.
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> Well, I weighed 110 pounds. I was strong as a horse. I could outwork anybody. I was a custodian. I fell down the stairs and injured by back, sacroiliac and my hips some. I just couldn't work any more. I was in pain. They kept telling me there wasn't anything they could do to stop the pain.
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> I went through four years of misery with the state workers' compensation. They were giving me my money -- but they wouldn't train me. They kept saying, "You apply for Social Security." I applied for my Social Security. Social Security said, "You can't apply for Social Security when you're on workers' compensation." We went through this for four years.
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> The doctor said I couldn't do the work I was doing. I tried to find other work. I went back to the drug store. I thought maybe I could at least clerk for a while. No way. They wouldn't hire me. Number one, they said my age. Number two, they said I'd been on disability for a year. I was now a risk.
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> I begged the insurance company to help me get other work. My doctor said, "She can't do that physical labor anymore. Train her." I went through a year of aptitude

> testing. They got me all set to go into a program. It was a medical records certification course. I really was excited about doing that. It was two years and you're certified. That would have been fantastic. At the last minute they said, "Sorry, we can't send you to a two-year program. That's too long. You'll have to find something else. We're going to send you to Goodwill." I keep trying to think of the straw that broke my back. That was a big one.
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> I think that's why my health deteriorated. If you're fighting all the time just to survive -- with an insurance company that you've paid for -- then the rest of your health goes. That happened to me. I had a stroke. I had a heart attack. Then Social Security finally says, "Yes, you're disabled all right!"
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> SAIF then dropped me and I was in the middle of fighting them. The thing that hurts is, after five years of this misery and my health goes down, and Social Security finally accepted me as disabled, they told me, "Well, you can't get Social Security because you don't have the earnings credits." I didn't have enough credits because I didn't work for the last four years. So because of that job injury and that insurance company, I lost all my Social Security income. So then they put me on SSI, which in the long run turns out to be better for me. Because now I'm on Medicaid. My medical costs are like $1,200 a month. But, it's still not right. I'm just so angry.
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> I've been downing everything, Let me say one good thing. It if wasn't for Medicaid from the State of Oregon, I would be decayed in the ground because I had no other insurance. I have $1,200 a month worth of pills and medicines and treatment. And if they hadn't helped me, I'd be dead. And maybe it would have been just as well. I've certainly felt that way. But my children and grandchildren don't. So, I want to say that I do appreciate Medicaid.
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> Nobody wants to be disabled. Nobody wants to live off the state. I'd love the play with my grandkids and start hiking and bowling again. It's a great loss.

Contractor and Carpenter. In his 40s, he has been a carpenter and contractor for a number of years. He moved to Iowa from Illinois, where he had been injured on the job. He had back surgery, and after the surgery, developed deep venous thrombosis in his lower left leg, which he described as 2 1/2 inches bigger than the other due to the thrombosis. He walks with a cane. He received no cash benefits from the company where he was injured. He qualified for Social Security without difficulty. In Illinois, workers' compensation is administered by private insurers or self-insured employers. It is a state where employees have a choice of their doctor. He has worked with a professional job locator and put out over 300 job applications, but has not yet succeeded in finding other work he can do with his disability.

> I was hurt on the job. They had a fire, and this man turned the fire hose on and it blew him off a four foot platform. I tried to catch him. The fire hose hit me and he landed on me and knocked me down. Immediately, I was suffering a lot of pain.

So they sent me to the doctor, and he confirmed I had something wrong. Then they brought me back to work. I never missed a day of work. The doctor put me on light duty. They put me on a stool that was three foot off the ground, and they had me bending over pulling trays of nuts and bolts out of the bottom to separate them. And I just couldn't do it. I told them I'd get on my knees and do it and they said, "Well, you should be getting better by now." It was just intimidation on their part.

I went 10 months at my company after the injury and did not receive a dime in benefits. Never have received any money. I was hurt there. I was automatically alienated from any benefits. I never received them, and to this date have never received them.

When I applied for Social Security, I went to a Social Security doctor, and he said, "You're really messed up." He wrote a letter and they just took me right through and it was all said and done.

I had a professional job locator I worked with for quite a few months. I put in over 300 applications. I didn't even get a call. That's pretty discouraging. I made phone calls. I did everything I could. It's like me and her starting out. She's 18 years old and I'm over 40. I've got some serious problems going on, and this kid here is right out of high school. They are going to hire her. They wouldn't even look at me. They haven't looked at me.

Technically, they are not allowed to ask if you have a disability. But they have asked me how come there's a lapse between this time and that time on my resume. I said, you know by law you're not allowed to ask. He said, "Well, if you want a job, I've got to ask you."

I can understand how people don't understand pain. I know what I used to think. I had an uncle that was built like a gorilla, a muscle man. He had a back that was absolutely shot. To look at that guy, his chest and arms, you'd think, "He could lift a tank!" But the poor guy could hardly walk. If I didn't know him, I'd think -- what's your problem?

I'm six two, and I weigh over 200 pounds. People are looking at me like, "Look at this big strong guy. What's the problem?" I was the second highest on medication in St. Anthony's Hospital. I've never been a drug addict. I've got a real high tolerance to medication. I do not take medication now. Because I'd have to take it by the handfuls -- and I'm not going to do it. I'm in pain right now. You learn to live with it.

In the time before my benefits went through, we went through all our savings. I own my house. That was fortunate. I didn't have to pay rent. We went almost a year between my last pay and when Social Security came in. So we were down to our last $500. It just wiped us out.

Hospital Transcriber. In her 40s, she worked at a hospital doing surgical transcriptions. She had also been a school teacher and a church organist. Before college she sold encyclopedias, waited tables and tended bar. She has multiple back problems and is very bitter about her experience with workers' compensation. In Iowa, workers compensation is administered through private insurers or self-insured employers. Iowa is one of the states where insurance carriers select the physicians that treat injured workers.

> I've had a four level fusion which was not successful, and a rhizotomy which also was not successful. I have a cervical spine problem that I am reluctant to have surgery for because the other surgery has not been successful.
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> I was working in a hospital when I was injured. The big shock for me was that other people did not have any grasp of what was happening to me physically. They do not understand pain. It's always a surprise to tell somebody you worked side by side with, that you're in tremendous pain and that you can't do something.
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> When you're injured in a work comp setting, you find that people change their attitudes toward you. There was a little indictment. You can see yourself losing respect in their eyes, because you've been injured on comp. So you try to not show the injury. In physical therapy, I can look back on doctor's reports and see a difference. I think they think we are malingering. Faking it. Even though you're not, there's a judgment. "Well, you should be better by now."
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> I think people who are injured on comp are discouraged from connecting with other people. I used to go to chronic pain support group meetings at Mercy Hospital. About 50 of us showed up. And it was the most reinforcing, affirming thing I'd experienced. But I think what happened, too many of the comp people were expressing their true feelings about the way they've been treated, and for some strange reason the group was disbanded. It was not for lack of participants.
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> I went to the insurance company doctor to see if he could help me. He said, "Did your attorney send you here, or did the insurance company send you here?" And I said "The insurance company." He closed my file and said "Well, I don't think anything else can be done for you." And I said "What am I supposed to do?" And he said "Go into business for yourself." I said, "If I can't work for somebody else, how am I going to go into business for myself?" And he said that maybe I should go on disability. That's when I applied for Social Security.

Meat Packer. In his 40s, he lives in Iowa. Married with two teenage children, he has been a laborer all his life. He sustained a back injury on his last job at a meat packing company. He has had back surgery twice and lives with chronic pain. He apparently received no workers' compensation income, although he did attend a workers' compensation seminar. It took three years for his Social Security to be approved on appeal, during which time his family depleted their savings and turned to relatives for help.

> You asked, "What is a good day?" A good day for me is to wake up once without pain. To go one hour without pain. It doesn't happen.
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> When it (back pain) first happened to me, I was told I had a muscle spasm. They sent me back to work. I pulled between 75 and 100 pounds of meat every two and a half seconds. I did not miss a day of work. They told me I was faking the pain.
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> My co-workers told me you have to pull your number, so I did. When you work in a packing house on a line, there's four of you. You might be number one, two, three or four. One coming up, that's your number to pull off the line. They were telling me I couldn't pull my number. I was determined to prove that I could still do it. I'd trained them. I knew this job. But it took half an hour for me to get on the line, find a comfortable position to pull my load. It went on for a month, month and a half. And it got to the place where I couldn't do it. But then they said I was goldbricking.
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> When I went to the company doctor, he told me there was nothing wrong with me. They said, "Here, go into the back room and they'll give you a treatment with infrared. You can be back to work in no time."
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> I went to a seminar probably two years ago. They call it "Workforce." It was through the workman's comp. And I was told by them repeatedly there is nothing wrong with you. We want you to go out and get a job. I put out applications and didn't get a call back.
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> At home, my wife got tired of me laying in bed crying because my back hurt. You can't lay down. You can't sit down. You can't stand up. You can't do anything.
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> It took me three years to get Social Security. And I had to go to court to get it. I went to court on a Friday, and I had surgery on the Tuesday. The judge says, "When did you have your last surgery?" I said, "Three days ago." He said, "This case is closed." Because when I was there I told him that I could not sit down -- and I couldn't. I was there merely five minutes.
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> In the three years before I got any kind of disability money, we used our savings, which are long gone. In the last year and a half, my family helped us out.
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> I'm a laborer. I've been a laborer all my life. I worked in factories. And I would rather go back to the job that I got hurt on. Because that, to me, is the hardest job I ever had in my life -- but to me it was the best job. But I don't think it is possible for me to pull 50 pounds of meat off the line every couple of seconds. And there's nothing they can do. There's no such thing as light duty in a packing house.

Salesperson. Age 57, he lives in Oregon. He sustained back and leg injuries in an automobile accident 2 1/2 years ago. He worked in sales and sales management and had been a coach in the past. He believes that he should have qualified for the company's disability benefits, but did not learn about them until after he was laid off because he was no longer meeting his sales quota. It took him two years to be allowed Social Security on appeal. While waiting for his Social Security, they relied on his wife's earnings until she had a heart attack. Her Social Security disability claim is now on appeal.

> I was injured in this car accident. I was rear ended. But it wasn't during work, so it wasn't covered by comp.
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> I tried to continue working for about three months after the injury, because I'd just started with this company. But during this time I was spending most of my time at the doctor's office or getting therapy. I was in outside sales. And my numbers were going down. My supervisors were constantly on me to produce. But the people I was working with couldn't understand how I was up and around. It finally got to the point where I was asked to leave. I couldn't maintain a quota. They couldn't afford to keep me on.
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> Little did I know at the time that I should have gone on the company's disability. I could have drawn benefits -- 70 percent of my salary until I got better -- if I got better. I found out about that after they let me go. Then I read the policy. But it was too late to go back and say, "Wait a minute!"
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> When I was out of work, people were saying "Well, there must be some kind of work that you can find." I can't stand for long periods of time, I'm not supposed to sit for long periods of time, I'm constantly up and down. The only position I'm comfortable in is laying down. I'm on pain medication, I take it every three hours. So I finally gave up. I tried, but I couldn't do it.
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> Then it was fighting the Social Security system. It's about a two-year scenario. They tell you right there in the Social Security office. You get denied, then you ask for a reconsideration, and then you appeal.
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> My wife was working and we had a small amount of income from her -- but my income went from about $2,000 a month down to zero. We squeaked by with her income, and fell further and further in debt. My Social Security was finally approved in June of this year, and it went back to August of the year that I had the accident. However, I lost the first six months. And I paid $4,000 out of my back benefits for the lawyer.
>
> In December of last year, my wife had a heart attack. All the doctors she has seen have told her she cannot go back to work, now or ever. She filed for Social Security and has been denied. Here she is with all these medical records. What do you have to be, in a body bag? I mean, mine wasn't as definite as hers, because mine was pain and suffering, and tissue problems in my lower back and legs. Hers, it's right there, heart attack, insulin dependent diabetic, asthma and high blood pressure. Yet she's denied and has to appeal.

> Until my wife gets her Social Security, we're not going to make it. I always thought when I was younger, growing up and working, that when I reached a certain age and level, retirement time, things would start being a little easier. Well, it's turning around the other way. It's getting harder and worse, and there's just nowhere to turn, no help available.

Restaurant Manager. In his late 40s, he has a history of back problems that goes back 20 years. He has had five back surgeries and reported he has two steel plates and six screws in his spine. He lived in Michigan, where he had managed a restaurant, before moving to Omaha, where he had his most recent back surgery. He recently moved to Iowa. Before he was a restaurant manager he had been a personnel manager in retail sales. Having been in management, he understood employers' concerns about employing and paying benefits for high-risk employees.

Because of his chronic back problems, he has had experience with medical care financed by workers' compensation. He was covered by private long-term disability insurance on his last job. The insurer helped him appeal his denial of Social Security benefits and offered to help him find other work. He is still looking.

> A good life? To live without pain. If we rate pain on a scale of one to ten, a five is a good day. Eight or nine is a bad day. So, you learn to live with what you've got left and go from there.
>
> All the comp carriers I have dealt with have certain doctors they send you to. The doctor in Michigan, all he wanted to do was give me pills. He had me on so many pills I hardly knew day from night. They want to push you back into the work force. In my type of business, there is no light duty. Everyone has to carry their own weight. I was in management, but don't let that fool you. I used to go out there and load trucks when that had to be done.
>
> To get the medical treatment you need, you have to keep pushing until you get somebody that could possibly help you. When they finally sent me to the orthopedic surgeon, who was not a comp doctor, you get the feeling that because you're on comp, you're some kind of a drag on the earth. Comp, you know, pays doctors less than they get from private insurance. After a period of time, the comp carriers were not paying the medical bills on time. Then the doctor wants you to settle up. You've got enough to worry about making a living and making ends meet without having to worry about making comp pay your doctor bills.
>
> My back history goes back about 20 years. I've learned to work through pain. And I've had some good years, too. The restaurant that I worked for took a chance on me, quite frankly, by hiring me knowing my history of back problems. That has to be on their minds because the employer pays the premiums for workers' comp claims. I can appreciate what they go through. I was a personnel manager in retail for about 5 years, and then being in the restaurant business -- I know what they

> feel. I have to have this person in this position 38 hours a week, and get this much production out of them -- or I don't need them.
>
> It got to the place where my back just finally gave all the way out. The long-term disability carrier is willing to train you to go back into another position. My problem is I can't stand for a long period of time. I can't sit for a long period of time. And I can't be on my feet, as far as walking, for a long period of time. Driving is the same way. So I'm trying to find something else. I've been thinking about real estate. If there's something out there, I'm going to find it. It's just that right now the pain is too debilitating. And I have another minor surgery scheduled in November.
>
> After I was rejected for Social Security in Michigan, the long-term disability carrier said they would pay the legal cost for an attorney. So, in the Iowa branch of Social Security, it went right through. When I got on Social Security, my LTDI went down. They pay the balance up to your "reasonable wage." But they don't count your bonus pay. That's where you really get killed, when you work on bonus programs. I'm drawing one-third to one-quarter of what I was drawing in management.
>
> We're all nervous about whether you can handle another job or not. Can you do it? Or will we go back through this whole thing over again -- surgeries, rehabilitation. It's scary. We can laugh on the exterior, but you cry on the inside. You don't know what tomorrow will bring. Yesterday it brought pain.

Information Analyst. In her 50s, she was an information analyst at a New York hospital for 29 years, where she dealt with third-party insurance claims. She also was a violinist and did volunteer advocacy work assisting elderly nursing home patients. She has arthritis, sciatica and spinal stenosis that was exacerbated by a fall at the hospital where she worked. She has dealt with bouts of depression in the past. Her mental health declined after her injury. Her Social Security disability benefit is reduced by the amount of workers' compensation payments she is entitled to but is not receiving.

> I have worked with my health problems for 30 years. Stenosis, arthritis and sciatica. I was happy, my work kept me going. But then I had an awful fall, and with stenosis, it's all you need, for things to break. I had a serious problem with my spine, lower and upper, and I went into such a depression.
>
> After the first fall, I was off for a while. When I went back to work, I was severely depressed. And they knew, unfortunately. The hospital had to pay for my psychiatrist. Before my fall, I felt as an analyst I was never second-guessed. But now I was, and by people I had trained and promoted.
>
> There is a terrible misconception of depression and being able to perform. I have worked with depression for many years. I was able to go along with it. But when they know that there's something wrong, then they kind of belittle you. That's how

> I felt. I tried desperately to work. I had my second fall. It's been an incredible nightmare. It does not even allow me to play the violin, which I love, or clean my house, or do anything.
>
> When I fell I was sent to the workmen's compensation doctor. He would not even give me an x-ray. I had to sue workmen's compensation in order to get an x-ray. That's how bad it was. And I worked in the hospital.
>
> Comp is the most humiliating thing that you can deal with. My problem is not with Social Security. But I was assigned a very small amount of Social Security based upon what workmen's compensation should give me on full disability. But the insurance company who carries workmen's comp refuses to pay me. I'm going to court with the insurance company. In the meantime, social security is just sending me a very small amount -- thinking that I'm getting the payment from workmen's compensation. So I have to cash my IRA and cut my expenses in order to survive. I was making a decent salary. It's so frustrating.
>
> When I found myself on Social Security, struggling for myself this time, I could not believe that it was I who was asking. I was very upset because I felt I'm supposed to be doing this for others. For years I've helped other people get the benefits they are entitled to. Here I am myself. When you're sick, it is hard to be your own advocate.

Beneficiaries with Mental Impairments

Focus group participants who had mental disorders were also a diverse group. Many were taking concrete steps to get treatment and improve their situations. Some were working, others looked forward to returning to work, although with some trepidation. Like those with back injuries, they felt a stigma attached to their impairments. Having an advocate -- whether a son, mother, therapist or community mental health clinic -- was a key link in getting connected with supports in their communities.

Those with mental illness were generally being treated with costly prescription medications, often financed by Medicaid. Medicare does not cover out-patient medications. If they were able to earn enough to leave the benefit rolls, continued coverage of their medication would be essential.

Musician. In his 40s, he is a musician. During the years when his schizophrenia was in remission he taught piano. A Virginia resident, when his mental illness returned he enrolled in a research program at the National Institute of Mental Health (NIMH) to test a new drug to treat schizophrenia. It has helped him. It is very expensive and he is grateful that Medicaid covers it. He hopes to work again.

> A good life? I'm sure that every one of us would answer that question by saying, "If I didn't have my disability..." In my case, my good life would be totally free of mental illness.

> I had been schizophrenic, but I had achieved 15 golden years of remission, during which time I was teaching piano. I'm a musician, even a composer in the past, and a pianist. So during those years I was doing great. I was in remission. And then the voices came back. I got sick again. I got so that I couldn't put a sentence together. And I was totally out of it. Schizophrenic, you know. I just couldn't work any more.
>
> My mother heard about the NIMH program, because she's always looking around for new things for me. Basically, the reason I went to NIMH is to try Clozapine, which is a new drug. It worked on me. After I entered the NIMH research project, I was able to get Medicaid and Medicare. Before that, Blue Cross wouldn't pay my bills because they didn't cover mental illness. My family's paid most of my expenses, the shrink and whatnot. But when I went to NIMH, I guess that cinched the fact that I was schizophrenic, or I wouldn't have been there, right? As a result, I think, that's how I got Medicaid and Medicare. They take care of most of my expenses. Medicaid and Medicare really does help a lot with Clozapine. I pay $1 a week for my medicine. That's really a bargain. I wish everyone could have that.
>
> The people that I like to hang around with are the people that are caring and concerned about you and you can do the same thing for them. My family for instance. I found that when I was diagnosed with my mental disorder, all of a sudden I was a loony. I was crazy. People didn't have anything to do with me. So being in recovery as I am, I've got friends now. People who I can call and talk to.
>
> As a recovering mental patient -- I'm pretty close to being recovered now -- they have a great thing, a social rehab center. And I go every morning and that helps me, too. It's a structured environment, sort of a mixture of work and play. In the afternoons, I work on my music.

Sheltered Employment Worker. Age 57, she has three grown children and has lived in Portland for 22 years. She has chronic depression, and had been receiving SSI until she recently began receiving Social Security benefits on her deceased husband's record as a disabled widow. She has worked as a microfilm reader. Currently she works part-time in a vocational rehabilitation program where she is paid $1.86 per hour.

> Well, I'm in good health physically, and I feel very grateful to God for giving me good physical health, but I've been going through depression for about 30 years, pretty severe depression.
>
> I worked at a credit union as a microfilmer for about six years, working about eight hours day. If I hadn't had my religion, I don't think I could have kept working on that job, because I was in a room all by myself working on this computer. And it wasn't working half the time. The work wasn't coming out right. I don't know how I stuck it out.

> I've had depression most of my life. I'm still depressed, but I'm doing better now due to the fact that they've got me on the right medicines now. I very grateful for that. But it has taken years of trying to find the right one that would at least ease the depression. Maybe not completely take it away, but at least ease it some. But through the help of my friends and family I have been able to keep going.
>
> I was getting regular SSI before. Now I'm getting the widow's disability pension from Social Security. They are two separate payments. My son helped me. I don't know how he managed to do that -- but he made inquiries after my husband died. Now I'm getting quite a bit more than what I was receiving before. I get my medicines through the spend-down program from adult and family services.
>
> Now I'm working part-time. It's with vocational rehab at the Network. I heard about it through the mental health clinic where I go as a patient. They do bulk mailing. They do it part-time and I've been there going on six years. You only get paid $1.86 an hour. But I realized even though I wasn't getting paid much for what I was doing, it's the sociability. Just being with others and knowing you're extending yourself toward others.

Home Shopping Club Worker. In her 30s, she has lived in Iowa three years. She has severe diabetes and major depression. In the past she worked at the Home Shopping Club. She was turned down for Social Security six years ago. When she reapplied three years ago, her application went right through. She now receives DI and Medicare.

> A good life? I think waking up in the morning and feeling good about things. I take 30 pills a day. Depression gets hold of me pretty easily. I'd like to just be able to get up and say, "Gee, it's a new day." But it doesn't work like that.
>
> My problem is everything overwhelms me. The simplest thing, like doing the dishes or making the bed. It just overwhelms me and I can't handle it. So I just try to figure out why I can't do these things any more.
>
> Mine started when I was really young. I was sexually abused by four members of my family. For years I just didn't think about it, until it got to the point you just can't not... People don't understand mental problems. They don't understand at all. It's, "Well, you should be able to just put that behind you and go on." Even my in-laws are like that. "Just forget it and go on." Well, how do you just forget it and go on? People treat you like you've got the plague or something. They think if you've got major depression, you're crazy.
>
> I applied to Social Security six years ago and they turned me down. I applied the last time three years ago and it went right through. Before that I'd had 17 jobs in three months.
>
> I'm going to start school here. The newspaper sponsors a 16-week course in computers and they try to get you into a job you can handle. I learned about it

> through my therapist. I'm nervous about the training. Whether I can do it or not. The last time I held a job I had a nervous breakdown.
>
> I'm kind of in a mess right now because Medicare doesn't cover any of your prescriptions. And my prescriptions run $800 to $3,000 a month.

Graphics Illustrator. Age 52, she lives in Oregon. She has held numerous jobs in the past including one as a graphics illustrator. She describes herself as slow. She has difficulty keeping jobs and finds that employers expect more from her than she is able to perform. She has tried to find other types of work, but has been unsuccessful.

> I've been disabled all my life with dyslexia and learning disabilities. I never realized I was disabled, I just thought I was a slow person. I held jobs where speed wasn't important for about 20 of my years in the advertising business. Leaning over the drawing board started bothering my back.
>
> I started other types of work, and found out speed was more important than quality. I didn't have trouble getting a job, but I had a hard time keeping a job, because they expected my speed to improve after the probationary period, but it never did. So I've had 33 jobs in my life. The state job service had difficulty finding the right niche for me. They recommended that I go to vocational rehabilitation. They were the ones that advised me to go to Social Security.

How Does Disability Income Fit Into the Broader Disability Policy Picture?

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996) p. 1.]

The Panel's findings and recommendations derive from its fundamental belief that the primary goal of national disability policy should be the integration of people with disabilities into American society.

The Panel drew clear distinctions between *impairments,* such as heart disease, spinal cord injury, major depression or hearing loss, and *work disability*. Work disability occurs when an impairment reduces functional capacity and, in conjunction with the person's other abilities, the demands of work and the broader environment, makes the person unable to perform the tasks of work.

Disability policies can improve work outcomes by addressing any of the factors that together produce work disability. Potential remedies include: health care to prevent or ameliorate the disabling consequences of an impairment or chronic health condition; vocational rehabilitation, education and training to develop new work skills; job accommodations to change the tasks of work; and environmental changes to reduce other barriers to employment. These potential remedies typically are organized and financed locally, by employers, insurers, and local and state governments. (See figure below.)

Income support ameliorates one of the consequences of work disability, loss of income from earnings. Earnings replacement benefits may be paid while remedies are tried or when they are not successful. Social Security disability insurance (DI) and Supplemental Security Income (SSI) are parts of a broader system of earnings replacement benefits for work disability that are financed largely by employers either through insurance they purchase or through self-insurance. These include workers' compensation for workers injured on the job, private short-term sickness and disability benefits, and private long-term disability benefits.

Remedies for Addressing the Causes of Work Disability:

Element of Work Disability	**Potential remedies**
Impairment	Health care may prevent or remedy the disabling consequences of an impairment Personal assistance services can compensate for the consequences of some impairments
Aptitude, skills, knowledge, abilities and age	Education, training, vocational rehabilitation
Tasks of work	Job accommodations, job restructuring, assistive equipment
Broader environment	Safety, public access, transportation, telecommunications, nondiscrimination, Americans with Disabilities Act (ADA), availability of jobs and demands of the jobs, limitations on access to non-work income

Does the Social Security Definition of Work Disability Fit the Program's Purpose?

Impairments vs. Work Disability

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*, Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996) p. 1]

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* * *

Do We Need a Single Definition of Disability?

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*, Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp. 75-76]

A single, broad definition of disability, as illustrated by the conceptual model of disability adopted by the Panel, is useful in drawing meaningful distinctions among such disability-related concepts as *medical condition*, *impairment*, *functional limitation* and *work disability*. The conceptual definition of *work disability* is useful in clarifying its four elements -- impairments, skills and abilities, tasks of work, and the broader environment -- and therefore in considering various possible remedies for work disability.

But a single legal definition of disability for purposes of defining eligibility for benefits and services is neither necessary nor desirable. A one-size-fits-all definition would be ill-suited to the diverse needs of persons with impairments or work disabilities. Rather, eligibility criteria should and do relate directly to the service or benefit being offered:

- A definition of disability based on need for assistance with activities of daily living (ADLs) is appropriate for determining eligibility for publicly-financed services that assist with ADLs.

- A definition of disability based on need for and likely benefit from vocational services is appropriate for determining eligibility for publicly-financed vocational rehabilitation (VR) services.

- A definition of disability that encompasses all who are at risk of discrimination in employment or public access is appropriate for determining who is covered by civil rights protection.

- A definition based on loss of earning capacity is appropriate for determining who is eligible for public or private cash benefits to replace part of lost earnings.

A mismatch between eligibility criteria and benefits that are offered creates inappropriate incentives and gaps in coverage for people seeking to gain access to the services they need. For example:

- Basing eligibility for personal assistance with ADLs on a definition of disability related to work incapacity fails to cover individuals who need such assistance whether or not they are working.

- Basing eligibility for health care on a definition of disability related to work incapacity is appropriate if, and only if, people who work are ensured access to health care through their jobs. If they cannot get health care coverage when they work, then basing eligibility for health care coverage on work disability leaves uncovered those who can and do work.

Consistency in disability policy is found instead in its overarching goals. The Panel believes the primary goal of a national disability policy should be the integration of people with disabilities into American society. That includes equality of opportunity, full participation, independent living and economic self-sufficiency. These goals are pursued through a broad landscape of systems that finance health care and education for the general population and various programs that provide disability-related goods and services, legal protections and earnings replacement benefits. Legal definitions of disability that are used as eligibility criteria for these various services, legal protections and cash benefits rightly differ because they target particular remedies to a specific need among the varied needs that people with disabilities have.

* * *

Alternative Definitions of Disability for Social Security

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp. 81-84]

Because the Social Security test of disability is very strict, it is often criticized for requiring that applicants be unable to do "any substantial gainful activity" in order to qualify for benefits. That is, of course, true. The Panel considered various less strict tests of work disability for Social Security. The appeal of such alternatives is that they would make Social Security more "work friendly" by paying benefits to more persons who can and do work. The drawback of such proposals is that they would increase the number of people who would qualify for Social Security disability benefits and, therefore, would increase the cost of the DI program.

Occupational Test of Disability

The occupational test of disability -- inability to perform one's own occupation -- that is used in many private long-term disability insurance plans is less strict than the Social Security test. This test would allow benefits to be paid to workers who are no longer able to do their usual occupation, but nonetheless are quite capable of doing other work, including work at relatively high pay.

The Panel reviewed a comprehensive reform proposal that involved an occupational test of disability for DI that would allow benefits if the applicant were unable to do his or her usual occupation.[1] This occupational test was estimated to increase the cost of the DI program by about $20 billion per year (in 1994 dollars) after 10 years, or by roughly 50 percent.[2]

Partial Disability

Some European social insurance programs pay partial disability benefits. In the Netherlands, for example, if workers have a loss of 15 to 80 percent of their working capacity, they may receive a partial disability pension. If such workers are employed, they are eligible for a fraction of the full disability pension. In Sweden, partial disability pensions may be paid at 25 percent, 50 percent or 75 percent of a full disability pension for either the universal disability pension or the earnings-related pension.[3]

Both the Netherlands and Sweden spend significantly more on disability benefits than does the United States. The United States in 1991 spent 0.7 percent of its gross domestic product (GDP) on Social Security and SSI disability benefits. In contrast, the Netherlands and Sweden spent 4.6 and 3.3 percent of their GDP, respectively for their disability benefit systems that include partial disability benefits.[4]

In the United States, permanent partial disability benefits also are provided by state workers' compensation programs. Compensation for permanent partial disability is one of the most complicated and contentious aspects of workers' compensation. Broadly speaking, three different bases are used for determining compensation for permanent partial disability:

- Impairment-based methods provide compensation based on physical or mental loss of use of bodily function. This method pays a specified amount for such factors as loss of motion, loss of strength or loss of a part of the body.

- Wage-loss methods base the benefit on the actual partial loss of earnings as a result of the permanent partial impairment. The amount of the benefit is based on demonstrated loss of past earning capacity.

- Earnings-capacity-loss methods take into account the impact of the worker's age, education and work experience in combination with the permanent partial impairment to estimate the consequences of the injury for the worker's future stream of earnings.

A blue ribbon panel on workers' compensation concluded that each of these methods has certain advantages as well as significant flaws. *Impairment-based valuations* of loss can be measured with ease, but the benefit is not related to the economic consequences of the loss for the individual worker. *Wage-loss systems* come the closest to the traditional purpose of workers' compensation, but they provide disincentives for workers to return to full employment if the amount of the benefit is related to the demonstrated partial wage loss. In addition, it is difficult to determine whether the wage loss experienced long after the injury is due to the injury or to other factors, such as economic conditions. Finally, assessment of *earnings-capacity loss* takes account of both the impairment and its future economic consequences, but the assessment is highly subjective and often involves dispute and litigation about the valuation of future earnings lost due to the injury.[5]

In brief, experience in other countries and with workers' compensation in the United States suggests that partial disability benefits tend to be costly as well as difficult and contentious to implement. The Panel believes that the disabled worker tax credit it is recommending as a wage subsidy for low-income workers with disabilities (modeled on the existing earned income credit) is a far preferable way to provide partial support to low-income workers whose capacity to earn is reduced, but not eliminated, by a disabling impairment.

Veterans' Compensation Impairment Test

The veterans' compensation (VC) system in the United States uses a wholly different concept for paying cash compensation. It pays monthly benefits to veterans whose impairments resulted from injury or disease incurred or aggravated while in active military service. The amount of compensation depends solely on the degree of impairment, rated as a percentage of normal function that is lost. One appeal of this approach is that receipt of benefits is not based on work incapacity. Veterans with service-connected impairments receive benefits for life, regardless of their future success in the labor market. Monthly payments range from $98 for an impairment with a 10-percent rating to $2,036 for a 100-percent impairment rating in 2000. Applying this concept to Social Security for all Americans is problematic for at least two reasons:

Cost versus Benefit Adequacy. The VC impairment test for paying compensation is much more expansive that the Social Security test based on "inability to engage in any substantial gainful activity." Of the 1.3 million people under age 65 receiving veterans' compensation in 1992, only about 9 percent are classified as "unemployable," a concept similar to the Social Security definition of work disability. About 22 percent have impairment ratings of 50 percent or more.[6] The rest have lesser impairments. If the distribution of impairments in the general population is comparable to that among veterans receiving compensation, then;

- To compensate all Americans who have an impairment equal to the VC rating scale from 10 to 100 percent would cover about 10 times the number of people who meet the Social Security test of work disability.

- To compensate only those Americans who had an impairment rating of 50 percent or more on the VC scale would cover a population more than twice the size of the Social Security beneficiary population.

To pay this much larger group would require either a tremendous increase in Social Security benefit outlays, or a significant reduction in the current level of support for those who are found unable to work, or both.

Problem of Rationale. Veterans' compensation is based on a unique employer-employee relationship where the federal government is the employer. It has the authority to draft people into military service and subject them to extremely hazardous duty. While the draft has not been used since 1974, the government has the authority to reinstate it when needed. Even with an all-volunteer military, there is a special responsibility of the federal government to compensate people in the armed forces and their family members for lives lost or impairments sustained in order to attract a volunteer force that is subject to the rigors and dangers of military service.

This compensation concept is not based on the veteran's need for income support. Rather, it is based on the government's liability, as employer, to compensate the veteran for the harm sustained while in the government's employ. The amount of compensation is related to the degree of harm as determined by the veteran's impairment rating. It is not directly related to veterans' need for support either because of their lost earnings capacity or because of the cost of particular impairment-related services or supports they have to buy. In fact, the federal government generally pays for those other services for injured veterans -- such as medical care, attendant allowances, prostheses, equipment and rehabilitation -- in addition to cash compensation for their impairments.

In short, the rationale for the federal government to compensate veterans or their survivors for harm sustained or lives lost while on active duty in the armed forces does not apply to income support for all members of society.

On the other hand, the idea of compensating for some of the impediments or financial costs people face because of their impairments is an important element of U.S. disability policy. It is not based on government liability, but rather on the social value of leveling the playing field between people with and without impairments. Examples include: eliminating environmental barriers and providing job accommodations as called for in the ADA, providing publicly-financed rehabilitation services and compensating for some of the added costs that people face because of their impairments. This "leveling of the playing field" concept of compensation underlies the Panel's recommendation for a federal income tax credit for expenditures for personal assistance by working taxpayers with disabilities.

Such policies that compensate for impairments by leveling the playing field promote employment and full participation for people who have various kinds of impairments. But they are not a substitute for income support to replace earnings while workers are unable to work because of illness or disability.

* * *

Are Programs with Different Definitions and Purposes in Conflict with Each Other?

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*, Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp. 84-85]

Some observers are troubled by the multiplicity of program definitions of disability and are concerned that the programs involved have conflicting goals and work at cross-purposes. The Panel, however, finds that programs are not in conflict simply because they are designed to meet different needs of various subsets of the population who have impairments or work disabilities. Nor are they in conflict because they use different definitions of disability to target the different services, legal protections or earnings-replacement benefits that they offer.

Rehabilitation and Social Security

Cash benefits to replace earnings are not in conflict with vocational rehabilitation aimed at improving an individual's skills and abilities to perform the tasks of work. They complement each other: cash benefits can provide income to meet daily living expenses while rehabilitation and a job search take place. At the same time, not everyone who receives cash benefits is a good candidate for vocational rehabilitation. Some who receive Social Security disability benefits are too ill to work. In focus group interviews, many beneficiaries indicated they had exhausted other options for rehabilitation or return to work before they applied for Social Security benefits. DI beneficiaries tend to be older than rehabilitation clients. While about half those who enter the DI rolls are over the age of 50, about half those successfully rehabilitated by state VR agencies are younger than age 35.[7] Nonetheless, a subset of Social Security beneficiaries may be good candidates for rehabilitation and return-to-work services. Linking beneficiaries with return-to-work services and providing income support while return to work is tried are complementary elements of disability policy. The Panel's proposal for issuing return-to-work tickets to Social Security beneficiaries is designed to improve that linkage and to expand the supply of service providers who can be paid to assist beneficiaries to return to work. [Note: This recommendation of the Panel was enacted into law as P.L. 106-170, the Ticket to Work and Work Incentives Improvement Act of 1999.]

The Panel also recognizes that VR services can be beneficial to persons who are not Social Security beneficiaries. The large majority of persons that state VR agencies successfully place in competitive employment (85 percent) are not recipients of DI or SSI benefits.[8]

In brief, both Social Security and VR are important elements of disability policy. In many cases they serve different subsets of the population. In other cases, individuals with severe work disabilities receive earnings-replacement benefits from Social Security while they engage in vocational training to return to work.

Social Security and the Americans with Disabilities Act

The income support provided through the Social Security Act and the civil rights protection of the Americans with Disabilities Act (ADA) are both essential pillars of disability policy, but one is not a substitute for the other. Some work disabilities are amenable to the solutions offered by the ADA. Others are not. The ADA provides legal remedies to workers who face discrimination in employment. Social Security provides income support to those who have lost their capacity to work. The two laws typically target different needs of the very diverse population of persons who have impairments or disabilities.

The ADA bans discrimination against workers who have impairments but who are nonetheless able to perform the essential functions of the jobs they seek to hold or retain. It requires employers to make "reasonable accommodations" for those workers. Whether an accommodation is "reasonable" or whether it poses "an undue hardship" on employers is evaluated on a case-by-case basis that depends on the circumstances of the individual, the employer and the employer's ability to bear the cost. Accommodations that are not considered "reasonable" for a particular employer under a particular set of conditions may be "reasonable" for another employer or when circumstances change.

Research has shown that job accommodations, such as those now required by the ADA, have delayed the point at which ill or injured workers leave the work force and turn to Social Security.[9] The focus group interviews conducted by the Panel indicate that beneficiaries often had received accommodations before they turned to DI benefits. They left their jobs when they could no longer perform them even with accommodations.

In general, Social Security is for workers whose impairments, in conjunction with their other abilities and the demands of work, are not usually amenable to reasonable accommodation by their current employers. It provides benefits that partially replace earnings when people are out of work and it is reasonable to conclude that the severity of their impairment is the cause. It is meant to do so in a way that enables workers to retain their dignity and self-respect while they cope with the human and financial losses associated with lost capacity to earn. Without Social Security, those who receive it often would be destitute or dependent on relatives or public assistance for support. By providing wage-replacement income, Social Security promotes individual empowerment and community integration. By basing entitlement to benefits on prior contributions and scaling benefit amounts to the worker's former purchasing power from earnings while working, Social Security promotes economic self-sufficiency.

While Social Security is paid only to those who meet a very strict test of work disability, it is not necessarily paid for life. Some people medically recover and others may gain new skills and abilities that enable them to return to work and leave the benefit rolls. In some cases, persons who legitimately qualify for DI may, with appropriate accommodations in a new setting, be able to return to work. The extent to which society is willing and able to invest in accommodations, jobs and the human capital of workers with significant impairments will affect the numbers who turn to Social Security and the number who return to work and leave the benefit rolls.

At any given time, different people need the civil rights protections of the ADA or earnings-replacement benefits from Social Security. And any particular individual may need both at different stages of his or her life or under different environmental circumstances.

* * *

Cash Benefits and Rehabilitation: Distinguishing Assessments

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), p. 88]

Many concerns the Panel has heard about the Social Security assessment of disability appear to reflect the view that it should be more like the kind of assessment that is used for determining rehabilitation potential or service needs.

The Social Security assessment is necessarily different from an assessment of rehabilitation potential. Its purpose is not to determine who should be offered services or what services they should be offered. Rather, its purpose is to determine which applicants for benefits meet the definition of work disability used to award wage-replacement benefits.

Private disability insurance distinguishes between assessing work disability for purposes of wage-replacement insurance and assessing rehabilitation potential. Employees covered by private long-term disability insurance have a contractual entitlement to cash benefits if they meet the eligibility criteria in the insurance contract. It usually requires a medical diagnosis, an evaluation of medical prognosis and a finding that the employee is currently unable to work. The insurer may then arrange for a second kind of assessment to evaluate the employee's rehabilitation potential. In this case, the decision to offer and pay for rehabilitation services takes into account the insurer's future benefit liability as well as the employee's return to work prospects. Favorable indicators for the insurer to invest in rehabilitation services, on a case-by-case basis, include the employee's prospects for medical stability and his or her youth, aptitude, motivation and need for vocational services in order to return to work.

The Panel is recommending ways to increase access to rehabilitation and return-to-work services for Social Security beneficiaries. Because the Social Security Administration does not have the expertise or resources to assess rehabilitation potential, the Panel's proposal draws on the expertise of service providers to make that assessment and offer services (the Panel’s recommendation for "return-to-work tickets" is contained in chapter 6 of its report).

Endnotes:

1. A.I. Batavia and S.B. Parker, "From Disability Rolls to Payrolls: A Proposal for Social Security Program Reform," *Journal of Disability Policy Studies*, Vol. 6, No. 1, 1995.

2. Social Security Administration, Office of the Actuary, memorandum, "Estimated Increase in OASDI Benefit Payments Under the 'Batavia-Parker' Proposal To Modify the DI Program," September 10, 1993.

3. Social Security Administration, *Social Security Programs Throughout the World -- 1995* (Washington, DC: U.S. Government Printing Office, July 1995), pp. 316-17.

4. L.J.M. Aarts and P.R. de Jong, "European Experiences with Disability Policy," *Disability, Work and Cash Benefits*, J.L. Mashaw, et al., (eds.) (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, 1996), pp. 129-166. (The figure for the Netherlands includes the cost of work-injury benefits.)

5. Blue Ribbon Panel on Workers' Compensation, *Policy Statement on Permanent Partial Disability* (Denver, CO: National Conference of State Legislatures, 1992).

6. Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context*, Interim Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), table 2-3.

7. U.S. Department of Education, Rehabilitation Services Administration.

8. U.S. Department of Education, Rehabilitation Services Administration.

9. R.V. Burkhauser, et al., "The Importance of Employer Accommodation on the Job Duration of Workers with Disabilities: A Hazard Model Approach," *Labor Economics*, June 1995, pp. 1-22; and K.K. Charles, "Employer Accommodation and the Early Post-Onset Separation of Disabled Workers," unpublished paper, Cornell University, June 1995.

How are Disability Claims Decided?

The process for deciding and appealing disability claims has many layers. First, applications for disability benefits are filed at local Social Security district offices, which collect available evidence and determine whether DI applicants meet insured status requirements. Case files are then sent to the state disability determination service (DDS) agencies, which gather additional medical evidence, if necessary, and assess the evidence to determine whether applicants meet the disability criteria for benefit entitlement. If the claim is denied, the applicant can request a reconsideration, which is done in the DDS by personnel other than those who made the initial denial. If the claim is again denied, the applicant can request a hearing before an administrative law judge (ALJ). If the ALJ denies the claim, the applicant can request a review of that decision by the Social Security Appeals Council. If the Appeals Council affirms the denial, the applicant can begin civil action in the U.S. district court. At each step in the process, individuals are informed of their right to appeal the decision to the next level. They are also told how to seek the help of an attorney or other representative.

Sequential Disability Determination Process

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp. 90-92]

A five-step sequential process is used to determine whether an applicant for Social Security disability benefits meets the definition of work disability in the law. The sequential process is spelled out in regulations and is illustrated in Figure 1. Each step in the sequence poses a different question about the nature of the disability. At each step a decision is made either to allow or deny the application or to move on to the next step.

- **Step 1** asks, "Is the applicant is engaging in SGA?" If so, the application is denied. (SGA is “substantial gainful activity,” which is part of the statutory definition of disability. It is defined in regulations as having earnings of more than $740 per month in 2001.)

- **Step 2** asks, "Does the applicant have a severe impairment?" If not, the application is denied.

- **Step 3** asks, "Does the applicant have a medically determinable impairment that meets or equals the medical listings?" It refers to listings in regulations of over 100 medical conditions that are considered to be of such severity that the condition can be presumed to constitute work disability.[1] At this step, SSA draws on medical evidence from treating sources or a consultative exam (by a physician paid by SSA) to document the existence, severity, duration and prognosis of the person's impairment. If the applicant's condition meets or equals a listed condition, benefits are allowed. If benefits are not allowed at Step 3, the sequential process calls for an assessment of the person's residual functional capacity (RFC) to do various kinds of work activities.

- **Step 4** asks "Does the impairment(s) prevent doing past work?" The applicant's RFC is compared with functional capacities required to do his or her past work. RFC is classified mainly in terms of the exertional demands of jobs. The current RFC assessment produces a finding that the person is capable of sedentary, light, medium or heavy work. That capacity is then compared with the person's prior work experience to determine whether he or she can do work at the exertional levels required by past work. If the person can do past work, the application is denied. If the person is unable to do past work, the assessment goes to Step 5.

- **Step 5** asks "Does the impairment prevent doing any other work?" Applicants' RFCs are considered in conjunction with their age, education, and work experience to determine whether they can do any other work that exists in significant numbers in the national economy. Their age, education and transferable job skills are taken into account to determine whether they have the residual capacity to do kinds of work they have not done before.

For persons with solely exertional impairments, the assessment of ability to do other work is aided by the "vocational grid," which was codified in 1979 regulations and has not been updated. The grid dictates a decision about work disability (and eligibility for benefits) based on the person's age, education and transferable skills, in conjunction with his or her RFC to do sedentary, light, medium or heavy work. If the person is found able to do other work, the application is denied. If not, the application is allowed.

For persons with impairments other than exertional ones -- such as cognitive, emotional, sensory, postural (stooping, crouching, kneeling) or environmental (inability to tolerate fumes, dust, noise) impairments -- the grid does not apply. It is to be used, however, as a "framework" for evaluating the person's ability to do other work. If the grid does not apply, opinions of vocational specialists[2] or vocational experts[3] can be used as evidence that there are, or are not, jobs the particular individual can do.

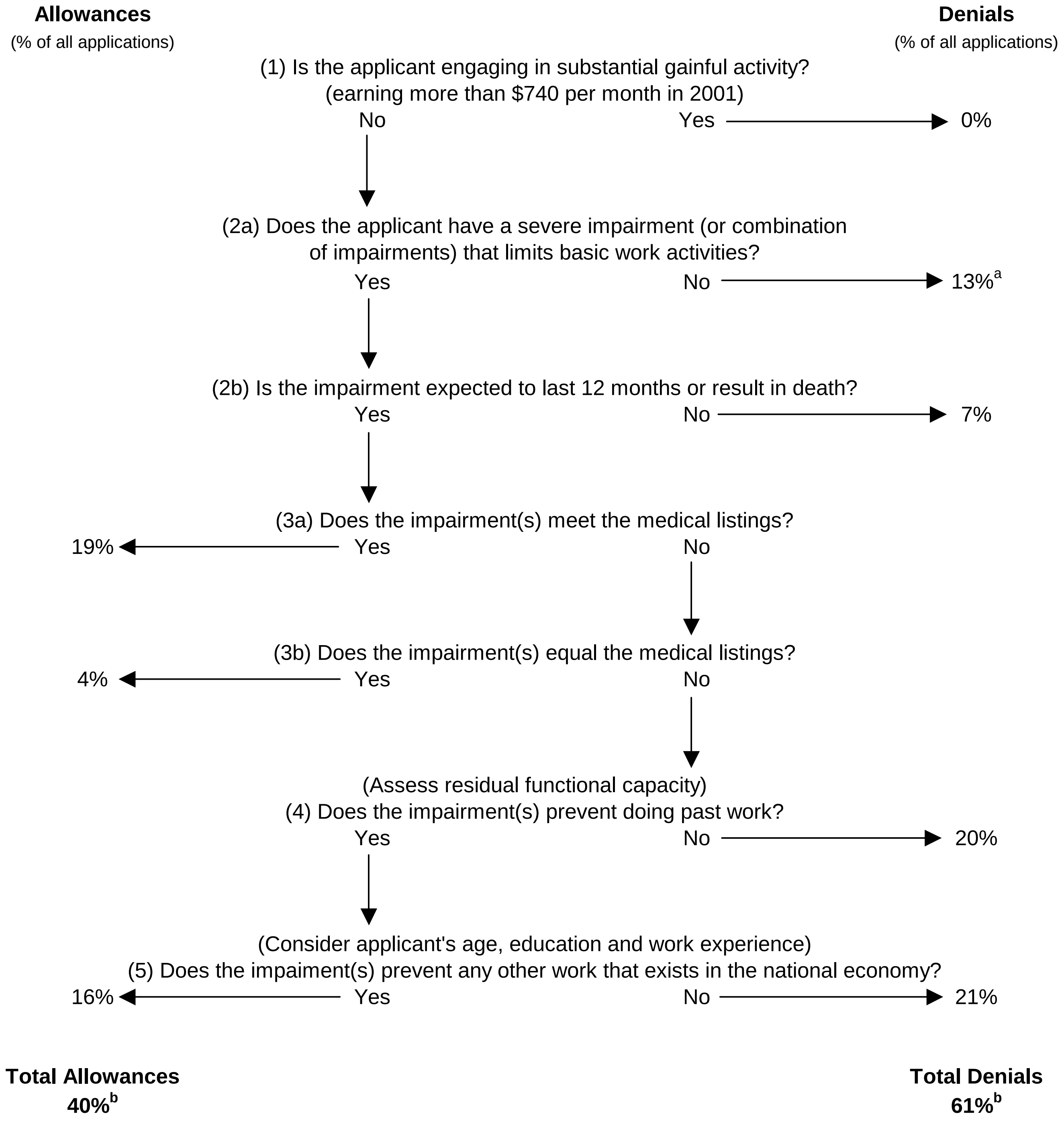
Endnotes:

1. The other evidence that supports this presumption is discussed in chapter five of the Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) (National Academy of Social Insurance, 1996).

2. Used by state agencies in initial decisions.

3. Used by administrative law judges at hearings on appeals of denied applications.

Figure 1. Social Security Disability Determinations: Sequential Decisionmaking Process and Outcomes of Decisions on Initial Disability Insurance Applications, Fiscal Year 2000



a. This response includes 5 percent of claims that were denied because the applicant failed to cooperate in obtaining evidence needed for the claim. The other 7 percent were denied for "impairment not severe." Totals do not add due to rounding.

b. Totals do not add due to rounding.

Source: Social Security Administration, Office of Disability

Why Do the Rolls Grow and Shrink?

Summary

Are the rolls growing now?

While the number of people newly awarded Social Security disabled-worker benefits each year has been fairly stable since the mid-1990s, the total number of people receiving benefits continues to grow because more people are entering the rolls than are leaving. Death and shifting to retirement benefits at normal retirement age are the main reasons people leave the rolls.

Has the number of people receiving disability benefits steadily increased over time?

No. The number of people receiving benefits has fluctuated in response to the economy and changes in law and administrative policies.

The Economy. During economic recessions, more people apply for disability benefits. When jobs are plentiful and employers are actively seeking new workers, more people with disabilities find jobs where they can be accommodated. When firms are downsizing and jobs are scarce, workers with disabilities who lose their jobs have fewer prospects for finding new jobs. Rising benefit claims and allowances during economic recessions are common in private disability insurance, workers' compensation and foreign disability systems as well as in the U.S. Social Security disability program.

Policy Changes. The DI program has gone through periods of rapid growth (in the early 1970s, and the early 1990s), a period of increasingly strict retrenchment (in the late 1970s and early 1980s), a period of reaction to that retrenchment (in the mid-1980s), and well as some periods of relative stability (in the late 1980s and the mid 1990s).

What lessons can be learned from the policy history of disability benefit programs?

The Academy's Disability Policy Panel recounted lessons learned from the tumultuous history of Social Security disability programs. Steps taken to strengthen eligibility criteria in the late 1970s escalated in the early 1980s to radical retrenchment policies that denied or terminated benefits on a large scale. The sharp cutbacks in eligibility brought widespread hardship and were challenged in the courts. States ultimately refused to implement the harsh policies because they were left to support vulnerable people who were denied federal benefits. Those federal policies were ultimately reversed in the mid-1980s.

The Disability Policy Panel concluded that (a) statutory and administrative changes need to be undertaken very carefully to avoid over correction in either allowing or denying benefits and (b) adequate administrative resources are essential to balance adequate support for vulnerable populations with proper stewardship of the public fisc.

* * *

Disability Policy Panel Report Excerpts

Lessons from History of the Disability Benefit Program

[Excerpt from: Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) (National Academy of Social Insurance, 1996), pp 82-83.]

Several lessons emerge from the tumult of the past 30 years in the DI and SSI disability programs. First, stable administration of these programs is critical to the economic security of people with severe disabilities who rely on these benefits, as well as to the fiscal integrity of the programs.

Second, cutbacks in administrative resources during the 1980s were accompanied by growing concern that vulnerable populations were not being well-served. Problems were identified in such needed individualized services as: appropriate assignment and monitoring of representative payees, clear and accurate answers to individuals' questions about their benefits, post-entitlement benefit updates to avoid underpayment or overpayment problems and outreach to those eligible for, but not receiving, benefits. Individuals with disabilities must be able to count on receiving the individualized attention and accurate information they need in order to understand their rights and responsibilities with regard to cash benefits.

Third, adequate staff and other resources to administer the programs are essential. The investment of resources in making correct initial disability decisions, and documenting those decisions fully, should shorten delays in getting correct benefits to applicants, reduce appeals and avoid the cost of paying any incorrect allowances. If the required medical improvement standard for conducting continuing disability reviews is to be implemented effectively, allowances must be sufficiently documented to support an assessment of whether there has been a change in the beneficiary's condition between the allowance and the review. To be fair to the beneficiary, there must be adequate staff to assure that the record is fully developed at the time of the review. For program integrity and public confidence in the programs, resources must be adequate both to decide and document initial claims promptly and correctly, and to conduct appropriate quality reviews and continuing disability reviews.

Fourth, changes in regulations that were called for in legislation and court decisions in the 1980s require greater emphasis than in the past on assessing claimants' functional capacity in conjunction with medical evidence. These changes in adjudicative requirements were based on expert medical judgment about disability assessment. If properly conducted, these functional assessments are likely to be more time consuming than determinations based solely on medical evidence. This shift toward more labor intensive adjudicative requirements needs to be taken into account in resource allocations.

Fifth, it is reasonable to expect some volatility in disability claims with cyclical changes in the economy. Disability claims have risen during every economic recession since the late 1960s--with the one exception of the early 1980s, when harsh retrenchment policies offset those effects. Persons with disabilities have much better prospects for finding work, despite severe impairments, when jobs are plentiful. When they lose their jobs during recessions and exhaust other sources of support, it is reasonable to expect they will apply for disability benefits. Flexibility in administrative resources is needed to accommodate cyclical changes in disability claims.

Finally, research is needed to better understand the size and attributes of the underlying population of persons with disabilities who could meet the program definition of disability if they were not working. Such research is needed in order to anticipate the consequences of cyclical changes in the economy, of outreach efforts to enroll eligible persons, or other changes such as routine updates in the medical and other criteria for making disability determinations. Such research would also provide information about the circumstances that distinguish persons with disabilities who are successfully integrated into the work force from those who become unable to work because of their impairments. That information could help develop ways to expand opportunities for successful integration of beneficiaries into the world of work.

Understanding Recent Program Growth

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp 6-7.]

After a period of stability in the last half of the 1980s, the DI and SSI programs grew rapidly in the early 1990s. The rapid rate of growth in new benefit awards appears to have been a temporary phenomenon tied to the economic recession of 1990-91. The DI incidence rate (new benefit awards as a percent of the eligible population) declined and flattened out after 1992. The benefit rolls continue to grow, however, because fewer people are leaving than are entering. Death and shifting to retirement benefits at age 65 are the main reasons why people leave the DI rolls. The proportion who medically recover or return to work has always been relatively small.

Trends in the broader environment have contributed to the growth in the rolls. They include:

- The eligible population is larger. The working-age population is growing and the baby boom is entering the 40-60 age range where the risk of work disability rises. In addition, more women have enough work experience to be insured for benefits. Consequently, when they become severely disabled, they qualify for DI benefits.

- The eligible population is younger. While the baby boom makes a bulge in the disability rolls in the 40-60 age range, the birth dearth that occurred during the Great Depression and World War II between 1935 and 1945 means relatively fewer disability beneficiaries are entering their 60s. Consequently, fewer people are leaving the DI rolls because of retirement. Although the DI population is younger, their death rate remains high. The proportion who have life-threatening conditions has not declined.

- The economic recession of 1990-91 caused a rapid, but temporary, increase in benefit applications and awards. When jobs are scarce and firms are downsizing, workers with disabilities who lose their jobs, particularly at older ages, have few prospects for regaining employment or shifting to new careers.

- Cutbacks in state general assistance programs and active referral of former recipients to the SSI program contributed to growth in applications. While most did not meet the strict test of disability, some did.

- Increased recognition and diagnosis of disabling conditions may be a factor. Depression, a common form of disabling mental illness, has increasingly been recognized and diagnosed following a public information campaign by the National Institute of Mental Health to improve its diagnosis and treatment.

- Structural changes in the labor market affect the kinds of impairments that result in work disability. The value placed on intellect, advanced education and adaptability means fewer employment prospects for people with the double disadvantages of impairments combined with limited education and skills. Further, individuals whose social and adaptive functioning is impaired by mental disorders are particularly disadvantaged in a highly competitive job market.

Explicit changes in Social Security policy also contributed to growth in applications and awards. New medical and functional criteria to decide claims based on mental impairments were required by Congress in 1984 after retrenchment policies adopted in the early 1980s were challenged in the courts and lost public support.

Policy History of Disability Benefit Programs

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp 68-71. This history is presented in greater detail in *The Environment of Disability Income Policy: Programs, People, History and Context,* Interim Report, J.L. Mashaw and V.P. Reno (eds.) (National Academy of Social Insurance, 1996), pp 77-106.]

Over the last 30 years, Social Security policy changes, juxtaposed with cyclical changes in the economy, help account for the wide fluctuations in new benefit awards.

1970-75: Economic Recession, Outreach, Rising Benefits. Rapid growth in DI incidence rates in the early 1970s coincided with economic recessions in 1969-70 and 1973-75, legislated benefit increases, outreach to enroll eligible persons in the SSI program and restrictions in staffing for disability-related activities.

The SSI program was enacted in 1972 and implemented in 1974 with a national outreach effort to notify and enroll eligible aged and disabled persons. Some who applied also qualified for DI. In addition, during this period Social Security benefit levels and replacement rates rose as a result of legislative increases, and Medicare was extended to DI beneficiaries who had been on the rolls for 24 months. At the same time, SSA staffing was reduced in the early 1970s as part of a government-wide effort to reduce the number of federal employees. To handle the rising workload, personnel were diverted from reviewing the accuracy of disability decisions and conducting CDRs (Continuing Disability Reviews) to processing new claims.

1975-80: Tightening Rules, Lowering Benefits. Declining DI incidence rates in the last half of the 1970s accompanied administrative initiatives to tighten disability adjudication and legislative changes that lowered replacement rates for new disabled-worker beneficiaries.

Legislation in 1977 lowered replacement rates for new disabled-worker beneficiaries, as well as other Social Security beneficiaries. In 1980, new limits on family benefits for disabled workers were adopted. The higher benefit levels that had been in place were viewed as posing too great an incentive to claim benefits for some subsets of disabled workers.

In response to congressional concerns about growth in the rolls, SSA instituted administrative measures to tighten adjudication of DI and SSI initial disability claims and CDRs; it also stepped up the number of CDRs being done.

Initial claims. In 1979, after more than a decade of work, SSA published in regulations the "vocational grid," which was designed to introduce more objectivity and uniformity in assessment of applicants' residual functional capacity in relation to their vocational factors (age, education and work experience) in determining their ability to work. The grid was based largely on physical requirements of jobs -- strength and endurance -- and was not well suited to assessing ability to work for persons with mental impairments.

Terminations without medical improvement. Between 1969 and 1975 SSA had followed a policy of terminating benefits only when the beneficiary did not meet the current disability criteria and medical improvement was indicated. In 1976, the policy was changed to no longer require evidence of improvement before benefits were terminated. With the new policy in place benefit termination rates increased in the late 1970s and escalated in the early 1980s.

In some cases, benefits were terminated that had been allowed by an administrative law judge (ALJ), after being denied earlier. On close calls, beneficiaries found themselves buffeted between the ALJ decision, which had allowed benefits, and reviews by state disability determination agencies, which terminated them, without apparent change in the beneficiary's condition. As adjudication criteria were tightened at all levels, beneficiaries were subject to having their benefits terminated unexpectedly and without indication of a change in their condition.

In 1980, Congress set in law requirements for SSA to review initial allowances before benefits could be paid (called "pre-effectuation reviews"), and legislated a timetable for CDRs for those on the rolls.

1981-84: Retrenchment and Reaction. With the congressional mandate for pre-effectuation reviews and CDRs in place, the new Reagan administration sought to fulfill its promise to significantly reduce the size and cost of government by applying an increasingly restrictive interpretation to disability eligibility criteria. The administration aggressively reviewed the continuing disability of those on the rolls and terminated benefits for many. During this period -- and in spite of the severe recession in 1980-82 -- the disability incidence rate reached an all-time low and benefit terminations reached an all-time high (see figure 2). [For a printer-friendly version of the chart, click here.]

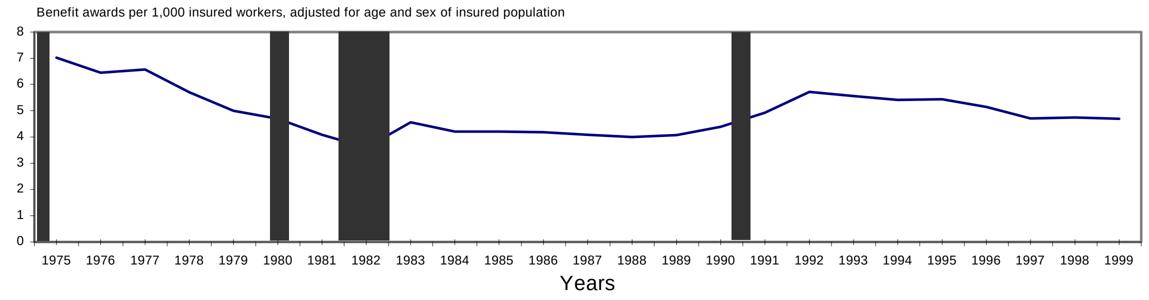


Figure 2: Social Security Disability Insurance Incidence Rates, 1975-1999
(shaded areas are economic recessions)

Note: The incidence rate is benefit awards per 1,000 insured workers, excluding the population already receiving benefits; and adjusted to the age and sex distribution of insured workers (calender year 1998 standard population). See Actuarial Study No. 114 for additional details.

Source: DI incidence rates: Actuarial Study No. 114, Table 4, Office of the Chief Actuary, Social Security Administration; recessions: Congressional Budget Office.

Public support for the sharp retrenchment eroded as its consequences became known. The policies were challenged in the courts and some states refused to implement them. Ultimately, the administration stopped doing CDRs and denying mental impairment claims until new guidelines were developed. In 1984, Congress enacted legislation to preclude the kinds of policies that had been adopted, challenged, and halted in the early 1980s.

New mental impairment criteria. Many of those whose benefits were denied or terminated during the retrenchment of the late 1970s and early 1980s were persons with mental impairments, and there was widespread agreement that SSA's practices with respect to mental impairment claims had become overly restrictive.[1] SSA's practices for deciding claims of persons with mental impairments were challenged in the courts and were criticized by Congress and congressional agencies for such deficiencies as: inadequate consideration of the functional consequences of mental impairments; inadequate consideration of claimants' residual functional capacity and vocational factors; inadequate use of existing medical evidence from treating sources and over-reliance on medical examinations purchased by SSA; and inadequate use of psychiatrists or psychologists in assessing disabling mental impairments.[2]

In 1983 the administration placed a moratorium on denial or termination of benefits for claimants with mental impairments and began work in collaboration with the professional mental health community to develop new regulations. In 1984 Congress mandated that new regulations be developed that focused on evaluating the person's ability "to engage in substantial gainful work in a competitive work place environment."[3] The new mental impairment criteria were published in the summer of 1985.

Medical improvement standard for CDRs. The policy of aggressively reviewing the rolls and terminating benefits without evidence of an improvement in the beneficiary's condition was also challenged by the courts and ultimately met resistance from states, as they experienced increased claims for state assistance from people whose disability benefits had been terminated. In April 1984, the administration placed a temporary moratorium on CDRs. At the time, nine states were operating under court-ordered medical improvement standards, and nine others had suspended reviews pending a court-ordered medical improvement standard or pending action by the circuit court.

Legislation passed in 1984 required SSA to establish and publish in regulations a medical improvement standard to use when evaluating the continuing disability of those on the rolls.

1985-89: Economic Expansion, Agency Downsizing. In the mid-1980s, disability incidence rates rose slightly from the all-time low in 1982 and then stabilized in the last half of the decade as the nation enjoyed a sustained period of economic growth and the policies to undo the sharp retrenchment of the early 1980s took effect. The main Social Security initiative during this period was to downsize agency staffing and streamline operations. Fewer administrative resources were available to perform tasks that required individualized attention such as implementing work incentives, assisting those who could not independently file an application for benefits, or assigning and monitoring representative payees for beneficiaries who were not capable of managing their benefits.

1989-92: Outreach, Economic Recession. In the early 1990s, DI incidence rates again rose as an economic recession coincided with renewed interest in outreach activities and administrative resources were sharply constrained.

Beginning in 1989, Congress appropriated earmarked funds over five years for outreach efforts to enroll eligible persons in SSI. With the new funding, SSI outreach became an SSA priority. Outreach activities were cited by SSA field office managers as a cause of growth in disability applications in the early 1990s.[4] Some who applied for SSI were found to have enough covered work experience to qualify for DI concurrently with SSI.

Also during this period, new criteria were issued to adjudicate childhood disability claims. These changes were required by the Supreme Court decision in *Sullivan v. Zebley*. National outreach to enroll eligible children, as required by Congress and the Court, contributed to SSA's new claims workload in the early 1990s and to increased disability awards in the SSI childhood disability program.[5]

The recession of the early 1990s contributed to the rapid increase in benefit applications. Coming on the heels of a 25-percent reduction in staff, SSA was not able to process the huge workload of new claims. As in similar circumstances in the past, pressure to adjudicate claims quickly, without adequate resources, coincided with higher levels of awards.

1993-95: Incidence Rates Flatten, Rolls Continue to Grow. The DI incidence rate declined slightly and flattened out after 1992. Thus, the rapid rate of growth in benefit awards appears to have been a temporary phenomenon due, in part, to the economic recession in 1990-91.[6] The number of people receiving benefits continues to grow, however, because fewer people are leaving the benefit rolls than are entering.

Endnotes:

1. H. Goldman and A. Gattozzi, "Balance of Powers: Social Security and the Mentally Disabled," *Milbank Quarterly*, Number 66, 1988, pp. 531-551.

2. U.S. Senate, Special Committee on Aging, *Social Security Reviews of the Mentally Disabled*, Hearing 98-170 (Washington, DC: U.S. Government Printing Office, 1983).

3. Public Law 98-460, Section 5(e).

4. L.S. Muller and P.M. Wheeler, "Disability Program Growth: Results from Social Security's Survey of Field Office Managers," unpublished paper presented at a conference sponsored by SSA and DHHS/ASPE, Washington, DC, July 20-21, 1995.

5. Committee on Childhood Disability, *Restructuring the SSI Disability Program for Children and Adolescents* , J.L. Mashaw, J.M. Perrin and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, March 1996).

6. D.C. Stapleton, et al., "Lessons from Case Studies of Recent Program Growth in Five States," unpublished paper presented at a conference sponsored by the Social Security Administration (SSA) and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE), Washington, DC, July 20-21, 1995, p. 18; and Lewin-VHI, Inc., "Labor Market Conditions, Socioeconomic Factors, and the Growth of Applications and Awards for SSDI and SSI Disability Benefits," prepared for SSA and DHHS/ASPE, May 23, 1995, chapter 4.

Are Disability Insurance Benefits a Deterrent to Work?

[In its request to the Academy for a study of disability income policy, the Committee on Ways and Means of the House of Representatives posed the following question: *Is it correct that Americans with disabilities now confront strong incentives to emphasize their impairments as a means of securing and maintaining disability benefits?* (Click here for an overview of the Academy's Disability Income Project.)]

[The following response to this question is excerpted from the Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*, Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp 12-15.]

Any income support system presents some level of work disincentive. The challenge is to design benefit policies that cost-effectively target reasonably adequate support to those who are unable to work, while minimizing work disincentives.

The Panel's basic finding is that the Social Security and SSI disability benefit programs do not pose strong incentives for Americans with disabilities to seek benefits in lieu of working. Rather, the strict and frugal design of these programs makes remaining at work preferable to benefits for those who are able to work.

Social Security Disability Insurance

The purpose of DI is to protect workers and their families against the severe financial hardship that would otherwise occur when workers sustain severe illnesses or disabling conditions that interrupt their capacity to work. DI is part of the nation's Social Security -- or old-age, survivors and disability insurance -- system.

DI shares with every other insurance system the requirement that applicants for benefits must show that the insured event has occurred before benefits are paid. In the case of DI, the insured event is long-term work incapacity. Although DI is sometimes criticized for making people "prove their disability," a requirement that work disability be shown is unavoidable and is thoroughly consistent with the fundamental purpose of insurance -- which is to cushion the financial loss when the insured event occurs. Any insurance system also builds in safeguards to discourage unwarranted claims and to protect the insurance system against paying them. In this regard, Social Security disability insurance includes a number of provisions that, taken together, make remaining at work preferable to claiming benefits for those who have the capacity to do so. As such, the following features could be characterized either as incentives to remain at work or as deterrents to leaving work to claim disability benefits.

First, only those who have a record of fairly steady and recent work are insured for DI benefits.[1] Second, the medical and vocational test of disability for DI benefits is very stringent. Under the law, benefits are paid only if one has a medically determinable impairment of such severity that given one's age, education and work experience, one cannot perform substantial gainful activity in any job that exists in significant numbers in the national economy, regardless of whether or not the claimant would be hired for such a job. Benefits are payable only if that impairment is expected to last at least 12 months or result in prior death.

Third, there is a five-month waiting period after the onset of disability before DI benefits are paid. And, health care coverage through Medicare begins only after an additional 24-month waiting period after benefits begin. Both of these waiting periods provide incentives for persons to remain at work, if possible.

Finally, the level of DI benefits is modest in relation to a worker's prior earnings from work. The average monthly benefit for disabled-worker beneficiaries was $786 in December 2000.[2] In December 1999, those receiving as much as $1,200 a month accounted for 11 percent of beneficiaries, while 35 percent received less than $600 a month.[3] Hence, remaining at one's job is more financially rewarding than receiving benefits. DI benefits replace a worker's prior earnings under a sliding scale that provides higher levels of earnings replacement for low earners than for higher earners. This recognizes that low earners have a smaller margin for reducing their consumption. It also recognizes that higher earners have better prospects for having private insurance or pensions to supplement Social Security benefits. DI also pays supplemental benefits to dependent children or spouses of disabled-worker beneficiaries.

For workers whose earnings are average or above, DI replacement rates range from 43 percent for a person earning $30,000 per year to about 28 percent for a person earning $76,000. At lower earnings levels, when benefits amount to as much as half of prior earnings, they provide a level of living that is below the poverty threshold, which is estimated to be $747 a month for a working-age person living alone in 2000.[4]

The replacement rates for DI are considerably less than what would be needed to match the worker's standard of living while working. Studies generally find that replacement rates of between 70 and 80 percent are needed to match the worker's prior level of living. These studies take account of the difference in tax treatment of various sources of income and the absence of work-related expenses. The studies that have been done, however, generally presume that the Social Security beneficiary is a relatively healthy retiree.[5] These studies do not take account of the additional costs of disabled workers, which include the need to support themselves without earnings during a five-month waiting period, and other disability-related expenses, including health care during the first 29 months after the onset of disability.

In brief, disability insurance from Social Security helps to avert financial disaster when workers sustain periods of long-term work incapacity. But the benefits are designed to make remaining at work a more rational and economically rewarding choice for those who are able to do so.

Supplemental Security Income

The purpose of the needs-based SSI program is different from that of Social Security disability insurance. SSI is intended to provide a basic minimum income below which no American should have to live if he or she is elderly or has a severe work disability. Although SSI, unlike DI, does not require prior covered employment that is the hallmark of social insurance, it has a number of features that make work preferable to claiming benefits for those who have the capacity to work.

SSI provisions that discourage benefit claims among those who have the capacity to work include: very modest benefits; a strict test of means that takes account of other income and financial resources; and a strict test of disability that is essentially the same as that for DI.

The SSI federal benefit rate ($530 a month for an individual in 2001) is modest, amounting to about 70 percent of the official poverty threshold for an individual under age 65. When SSI was originally being developed, Congress intended that it would keep elderly and severely disabled individuals out of poverty.[6] Financing fell short of that goal. While some states supplement federal SSI benefits, the federal benefit rate remains well below the poverty threshold.

The SSI means test reduces SSI benefits dollar for dollar for all other countable income. To build in incentives to work, a portion of the recipient's earnings from work is excluded from countable income. The SSI resource test renders an individual ineligible for benefits if he or she has financial resources in excess of $2,000.

Finally, the SSI program uses the same strict test of medical and vocational work disability used in the DI program. For individuals to choose SSI over work at reasonably remunerative employment would often mean choosing a level of living below the poverty threshold. Thus, the SSI benefits, themselves, are not a powerful incentive for individuals to emphasize their impairments rather than their capacities to work if they are able to earn a living wage.

Notwithstanding these basic findings, the Panel believes that there are reasonable concerns about potential work disincentives that need to be addressed. The first involves gaps in health care coverage that limit employment options for persons with disabilities. The second involves concerns about recent growth in federal disability benefit programs.

[A version of the Panel’s recommendations for expanding access to health care coverage through Medicare and Medicaid was enacted into law in the Ticket to Work and Work Incentives Improvement Act of 1999, P.L. 106-170.]

[To read the Panel's findings on growth in the disability programs, click here. The Panel also recommended that its proposals to promote work be adopted (the majority of which have since been enacted through the Ticket to Work and Work Incentives Improvement Act of 1999); that adequate resources be provided for SSA to administer the disability programs with fairness and integrity; and that the medical and vocational criteria used in determining disability be kept up to date.]

Endnotes:

1. To qualify for disabled-worker benefits, an individual must have worked in employment subject to Social Security contributions for about one-fourth of the time elapsing after age 21 and up to the year of disability. In addition, he or she must have recent covered work -- equivalent to five of the preceding 10 years (or, if between ages 24 and 31, half the time since age 21, or if under age 24, half of the preceding three years).

2. Social Security Administration, Office of Research, Evaluation and Statistics, *Highlights of Social Security Data, December 2000.*

3. Social Security Administration, *Annual Statistical Supplement to the Social Security Bulletin, 2000* (Washington, D.C.: U.S. Government Printing Office), table 5E.2, p. 197.

4. U.S. Census Bureau.

5. B.A. Palmer, "Retirement Income Replacement Ratios: An Update," *Benefits Quarterly*, Second Quarter, 1994, pp. 59-75.

6. U.S. Senate, *Social Security Amendments of 1972, Report of the Committee on Finance, U.S. Senate to Accompany H.R.1*, S. Rpt. No. 92-1230 (Washington, DC: U.S. Government Printing Office, Sept. 26, 1972), p. 384.

Does SSA have Adequate Administrative Resources to Administer the Program with Fairness and Integrity?

[Excerpt from: Disability Policy Panel, *Balancing Security and Opportunity: The Challenge of Disability Income Policy*, Final Report, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), pp. 20-21. Figures have been updated to most recent available.]

Adequate Administrative Resources Are Essential. A review of the last 25 years finds a common theme in the three periods that produced major concern about the disability programs: the two periods of rapid growth, in the mid-1970s and in the early 1990s, and the period of sharp retrenchment in the early 1980s. All three periods coincided with economic recessions, which place increased demands on disability benefit systems. In each case, new administrative demands were placed on the system without commensurate investment in administrative resources. In all three cases, the under-investment in administrative resources was followed by concerns that the program was out of control.

In the mid-1970s, SSA was called upon to implement the new Supplemental Security Income (SSI) program and was not provided sufficient additional resources to do it. In the early 1990s, after agency staffing had been "downsized" by nearly 25 percent, SSA did not have the resources to respond to the growth in new claims that accompanied an economic recession. When backlogs grow and claims are not decided promptly, Congress responds to constituent concerns by urging the agency to speed up its disability decisions.

Pressure to speed up decisions in spite of inadequate administrative resources can contribute to growth in the rolls in a number of subtle and interrelated ways.[1]

- New instructions may be issued to ease standards for documenting claims that are allowed.
- Personnel involved in quality review of disability decisions are likely to be reassigned to help process claims. Fewer allowed claims then are reviewed for accuracy.
- Greater reliance may be placed on third parties to assemble and submit claims for disability benefits. While SSA does not pay third parties, some have a financial interest in benefits being allowed.
- Personnel responsible for CDRs (continuing disability reviews) of those on the rolls are shifted to processing new claims.
- Personnel and systems supports for so-called "post-entitlement actions" that are essential to support beneficiaries' attempts to work get low priority.

In the retrenchment period of the early 1980s, new policies were initiated to vigorously review the disability rolls and terminate benefits to anyone not found to meet a very restrictive interpretation of the eligibility criteria. This was done without adequate staffing or training in the new review procedures. The 1980 legislation that had required stepped up review of those on the rolls had estimated modest savings from this initiative, recognizing that investment in administrative resources in the early years would outweigh any early benefit savings. The reviews were vigorously launched, however, without the investment in staff and training. They were abandoned after they lost public support, were successfully challenged in the courts and some states refused to implement them.[2]

Given this history, the Panel repeats the concern expressed in our interim report that attempts to administer a complex and expensive benefit program without adequate administrative resources ill serves both beneficiaries and the public fisc. In relation to the importance and size of the disability benefit program, investment in administrative resources is very modest, at 2.9 percent of DI program outgo in 2000. In particular:

Administrative resources including technology must be set at a level that ensures stable, effective management of the disability programs. Resources must be adequate to provide: (1) fair, accurate and prompt decisions on disability claims, (2) individualized service to beneficiaries that is contemplated under the law, including accurate information and prompt action to implement benefit adjustments when beneficiaries work, and (3) timely and predictable review of the continuing eligibility of those receiving disability benefits.

Endnotes:

1. Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context*, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), see chapter 5.

2. Disability Policy Panel, *The Environment of Disability Income Policy: Programs, People, History and Context*, J.L. Mashaw and V.P. Reno (eds.) (Washington, DC: National Academy of Social Insurance, 1996), see chapter 5.

What is the Academy’s Disability Policy Panel?

In response to a request from the Chairman of the Committee on Ways and Means of the U.S. House of Representatives and the Chairman of its Subcommittee on Social Security, the National Academy of Social Insurance in March 1993 convened a Disability Policy Panel of national experts to conduct a comprehensive review of the nation's Social Security disability benefit programs. The Academy secured funding for the Panel's work from The Pew Charitable Trusts, The Robert Wood Johnson Foundation and corporate members of the Health Insurance Association of America that offer long-term disability insurance.

The Panel was charged with determining whether the design of the programs strongly encouraged Americans with disabilities to emphasize their impairments as a means to securing and maintaining disability benefits; what changes could be made to encourage persons with disabilities to use their residual work capacity; and how rehabilitation could be incorporated into the benefit programs without greatly expanding costs or weakening the right to benefits for those who cannot work.

The Panel's findings and recommendations derive from its fundamental belief that the primary goal of national disability policy should be the integration of people with disabilities into American society.

The Panel as a whole met for 31 days from March 1993 to January 1996, in addition to subcommittee meetings and countless conference calls. The Panel issued two reports: its final report and recommendations, *Balancing Security and Opportunity: The Challenge of Disability Income Policy* (1996), and its interim report, *The Environment of Disability Income Policy: Programs, People, History and Context* (initially released in 1994; republished in 1996). In addition, the Panel’s Committee on Childhood Disability released *Restructuring the SSI Childhood Disability Program for Children and Adolescents* (1995).

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