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Social Security as Part of an Integrated National Disability Policy

Is the Social Security Definition Out of Sync?

by
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In its October 2003 report, the Social Security Advisory Board raised a number of questions about whether the definition of disability in the Social Security Act is at odds with the concept of disability reflected in the Americans with Disabilities Act of 1990. Are there contradictions created by the Social Security definition of disability, and if so, what should be done about it?

My assignment is to make the case that the Social Security definition of disability is not out of sync with sound disability policy. Moreover, the disability income programs – Social Security disability insurance (DI) and Supplemental Security Income (SSI) benefits -- serve very important functions that are an essential part of national disability policy.

Most of my observations are based on work conducted by and for the Disability Policy Panel of the National Academy of Social Insurance. The panel was asked by the Chairmen of the Ways and Means Committee and its Social Security Subcommittee to conduct a comprehensive review of the Social Security disability programs and to recommend ways to strengthen beneficiaries' link with rehabilitation and return to work. The Panel issued its findings in the 1996 report, *Balancing Security and Opportunity: The Challenge of Disability Income Policy.* It stands the test of time remarkably well. In going back over the report, I am struck by how timely and relevant the Panel's findings remain today. Many of the recommendations have been enacted. They include the return-to-work ticket, extensions of health care coverage to former beneficiaries who return to work, updating and indexing the substantial gainful activity level that is part of the definition of disability, and improving implementation of work incentives. Much more could be done to strengthen the disability income programs. The Panel's

recommendations were modest because it was asked to come up with proposals that would not significantly increase the programs' cost.

The Panel, chaired by Jerry L. Mashaw of Yale Law School, met over the course of three years for a total of 31 days. It also commissioned special studies and convened focus groups of recent entrants to the disability benefit rolls. The focus groups provided an important reality check for the Panel's work. Excerpts from those interviews are in the report's appendix and are appended to this paper. The interviews are recommended reading for all of us as we consider the employment prospects of DI beneficiaries and the likelihood that our economy will produce jobs that they can do.

I will organize my remarks around several themes:

First, is the definition of disability in the Social Security Act out of sync with the a 21st century view of disability? I will argue that it is not. Rather, the definition is consistent with the purpose of the program and that purpose remains essential today.

Second, are benefits a strong deterrent to work? I will make a case that they are not.

Third, if benefits are not a strong deterrent to work, how do we answer the claim that the DI program caused a decline in employment in the 1990s? I will explain why I find that claim unconvincing and will suggest other factors that may be at work.

Fourth, why did the disability rolls grow in the 1990s? I will suggest some hypotheses that have not been given much attention in current discussions.

Fifth, is experience with return to work from the DI program better than we think? I will suggest measures that could provide better insights into how we monitor recovery and return to work from the DI rolls.

I. Is the Social Security Definition of Disability Out of Sync?

The definition of disability in the Social Security Act is based on the concept of work disability. That definition is aligned with the purpose of the program – that is, to provide wage-replacement income to workers who have lost their capacity to earn a living due to a severe, long-lasting work disability. That purpose remains valid and critically important today. These benefits are a lifeline of basic income security for the people who receive them.

Wage Replacement Remains Important

The need for a program that fulfills this purpose does not go away because we have the Americans with Disabilities Act (ADA). Nor is this purpose made obsolete by advances in medicine, changes in the demands of jobs, new assistive technology, or widespread use of environmental accommodations. These developments may reduce claims from some categories of individuals with disabilities. For example, the ADA expands opportunity for people who have highly valued skills and whose main impediments to work were based on discrimination, architectural barriers, or other reasonable accommodations. But other disabled individuals may face increasing impediments to work as the work environment and demands of work change. For example, in an increasingly competitive world of work, emphasis on versatility and speed may reduce job prospects for people with mental impairments. The phenomenon of work disability will remain with us. And wage replacement programs will remain essential.

All of us can agree that the primary goal of national disability policy is the integration of people with disabilities into American society. That includes equal opportunity, full participation, independent living, and economic self-sufficiency. These goals are pursued through a broad landscape of systems that pay for health care, education, vocational rehabilitation, other disability-related goods and services, legal protections, and earnings replacement benefits. The Social Security programs are not in conflict with the overarching goals of the national disability policy.

Eligibility Definitions Should Match Particular Program Purposes

Disability definitions that are used as eligibility criteria for various programs should differ, because they target particular remedies to particular subsets of the large and diverse population of people with disabilities. A single legal definition of disability for defining eligibility for benefits and services is neither necessary nor desirable. In fact, a one-size-fits-all definition would not suit the varied needs of the highly diverse population of people with disabilities. Below, we compare four definitions of disability that are used as eligibility criteria for different remedies – civil rights, vocational rehabilitation, personal assistance services, and wage replacement income.

Civil rights protections. The ADA defines disability for the purpose of providing legal remedies to people at risk of discrimination in employment or public access. For this purpose, the definition of people with disabilities is very broad. *"Disability" means . . . a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment."* With regard to employment, the law prohibits discrimination against a "qualified individual with a disability with regard to job application, hiring, promotion or firing, pay, job training, or any other terms of employment." A "qualified individual" is a person who, with or without reasonable accommodation, can perform the essential functions of the job he or she desires or holds.

Vocational rehabilitation. The Vocational Rehabilitation Act defines eligibility for VR services as: *"an individual who (i) has a physical or mental disability that constitutes or results in a substantial impediment to employment and (ii) can benefit in terms of an employment outcome from vocational rehabilitation services provided*." In brief, people are eligible for VR services if they need them and can benefit from them.

Personal assistance services or long-term care services. Programs that provide long-term care or personal assistance services are often part of Medicaid. While not uniformly available across the United States, these programs generally base eligibility for

services on need for assistance with activities of daily living, such as bathing, eating, toileting, getting around inside the home and getting in or out of bed.

Earnings-replacement insurance. Cash benefits programs that are designed to replace earnings from work all use a definition of disability based on loss of ability to work. That is true of private long-term disability insurance, short-term disability insurance, sick leave, disability provisions of federal employee pensions and the railroad retirement system, and disability provisions of private defined-benefit pensions.

It is important to recognize that these wage-replacement systems have a different purpose than those of others disability programs. The benefits are not designed to pay for the added expenses associated with disability – such as personal assistance or vocational rehabilitation. Those, too, may be needed. But wage replacement benefits are designed to help pay everyday living expenses – rent, utilities, food bills, etc. -- when wages are lost.

The Social Security Definition Is Very Strict

Among the various wage-replacement programs Social Security is unique in several ways. It has one of the strictest definitions of disability. That is, *inability to engage in any substantial gainful activity by reason of any medically determinable impairment which can be expected to last for a continuous period of at least 12 months or result in prior death. ... An individual will be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.*

Not only is the test very strict, it covers a very broad population – almost everyone who earns income from work. And unlike the other disability programs, the

benefits are not tied to a specific employer. Most people apply for Social Security disability benefits only after they have lost their jobs and been out of work for some time.

Programs that cover temporary disability – such as sick leave or short-term disability insurance – use a less strict test of disability, usually inability to do one's own particular job. Moreover those programs have no waiting period. Benefits begin immediately, or within a few days after onset of the illness or impairment. Introducing a universal temporary disability benefit program would mean paying benefits much earlier in the disability process and paying benefits to people whose injury or illness is expected to be of short duration. Many more people would qualify for temporary disability benefits than are eligible for disability insurance. The Academy's Disability Policy Panel considered recommending a short-term disability system, but did not, in large part because it was inconsistent with the Panel's charge to seek low-cost proposals.

Social Security Is Not the Ideal Stage for Early Intervention

Because applicants wait five months for DI benefits and have usually lost their connection to a former employer, the Social Security determination process is not the ideal place for early intervention. Is early intervention occurring elsewhere? When the Academy conducted its study in the mid-1990s, we found that most people served by state vocational rehabilitation (VR) agencies were not Social Security or SSI beneficiaries. In fact, of the roughly 150,000 people VR agencies' successfully placed each year in competitive jobs, the large majority (85 percent) had not been on DI or SSI. While some people may view VR agencies' limited service to beneficiaries as a failure, it could be just the opposite. It is possible that those individuals were getting their remedies in the right order. That is they went directly to VR agencies – getting rehabilitation first – as suggested in the early intervention model.

In some cases, early intervention may be occurring on the job. There is evidence that some people who ultimately receive DI benefits have received accommodations that delayed the point at which they turned to DI benefits. And we hear that employers and private insurers use various early intervention techniques to facilitate return to work in some cases.

The most promising place to intervene early in the disability process is probably not the Social Security program. Rather, it would be in schools, VR agencies, employers, and state employment services. Nonetheless, SSA is to be commended for trying out an early intervention approach. It will be interesting to track the experience of the SSA's new early intervention demonstration project and we look forward to hearing about that from Monroe Berkowitz later today.

To recap, the definition of disability in the Social Security Act, while very strict, is consistent with the purpose of the program, which is to partially replace wages for people who have lost their capacity to work. That function remains essential.

II. Is Social Security Disability Insurance a Strong Deterrent to Work?

I will make the case for why Social Security disability benefits are not a strong deterrent to work. First, it is important to recognize that any wage-replacement program can be characterized as a disincentive to work to some degree. That is the nature of wage replacement. But that does not mean the concept is flawed. The vast majority of Americans rely on their wages for income to pay for the necessities of life for themselves and their families. If people can't work, they lose their livelihood. After the onset of a career-ending disability, wage replacement benefits are a key aspect of social integration, independent living, and economic self-sufficiency.

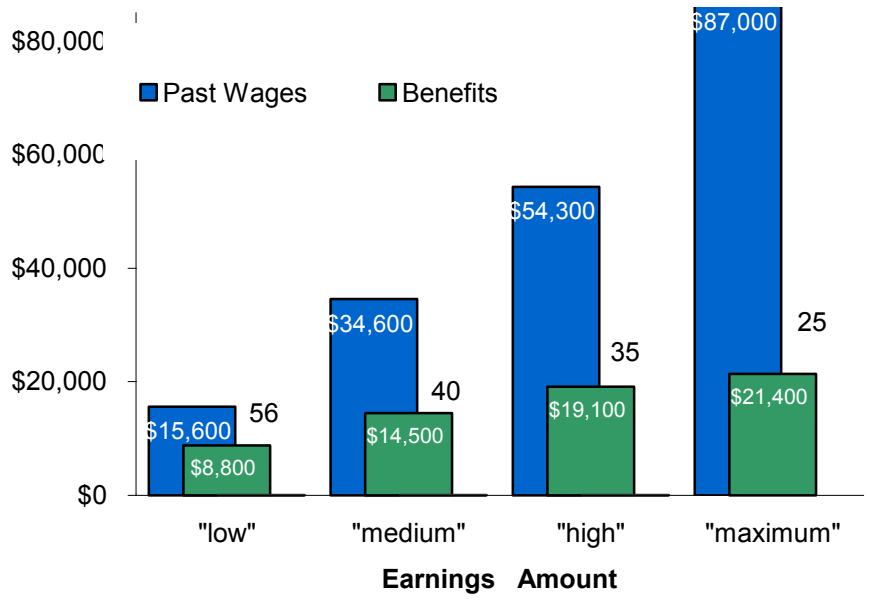
The case for why benefits are not a strong deterrent to work rests on several observations. First, benefits and replacement rates are relatively modest. Second, by international standards, U.S. spending on disability benefits is relatively low. Third, focus groups offer anecdotal evidence that people turn to disability benefits only as a last resort. Empirical studies find that people often remain on the jobs after the onset of disability and many change jobs or continue looking for work before applying for benefits.

Benefits and Replacement Rates Are Modest

As shown in Figure 1, benefits and replacement rates under the DI program are modest. For a low earner, making about $15,600 a year, benefits will replace just over half of prior earnings in 2004. That benefit income of about $8,800 is below the 2004 poverty guidelines, which are about $9,300 for an individual and $12,500 for a two-person household. At higher earnings levels, benefits are somewhat higher, but represent a declining share of prior earnings. For a medium earner making about $34,600, disability benefits would replace about 40 percent of prior earnings. The replacement rate declines to about one-third, or one-fourth of prior earnings at higher wage levels.

A specific issue has been raised about replacement rates during the 1990s for men at the bottom of the wage distribution. I will come back to that point.

Figure 1. Social Security Disability Benefits and Past Earnings, 2004



Source: Office of the Actuary, OASDI Trustees Report 2004.

U.S. Disability Spending Is Low By International Standards

By international standards, U.S. spending on disability benefits is relatively modest (Figure 2). As a share of gross domestic spending, public disability benefits in 1999 were 0.71 percent in the United States, compared to 1.01 percent in Germany, 1.27 percent in the United Kingdom, 2.05 percent in Sweden and 2.65 percent in the Netherlands. When the spending includes work injury benefits and short-term sickness benefits (which are provided through public or mandated social insurance systems in many countries), the differences are greater. In brief, as a share of the economy, the United States spends less than most other OECD countries on disability-related benefits.

Figure 2. Spending for Disability and Unemployment Benefits as a Percent of Gross Domestic Product, Selected Countries, 1990 and 1999

Country	1990		1999		
	Public disability benefits	Broad disability benefits (including work injury)	Public disability benefits	Broad disability benefits (including work injury)	Unemployment compensation
Program spending as a percent of GDP					
Germany	1.05	3.22	1.01	2.90	2.10
Netherlands	3.42	5.54	2.65	4.14	2.60
Sweden	2.03	5.21	2.05	4.02	1.60
United Kingdom	0.88	1.39	1.27	1.52	0.57
United States	0.56	1.48	0.71	1.37	0.25

Public disability benefits = contributory (earnings-related) and non-contributory disability benefits
Broad disability benefits = public disability benefits, sickness cash benefits, and work injury benefits.
Source: *Transforming Disability into Ability: Policies to Promote Work and Income Security for Disabled People*, OECD, 2003.

The low level of spending on disability benefits in the United States is more striking when we recognize that almost all our European counterparts have universal health care coverage. They also have social assistance or general assistance to aid the poor, regardless of disability or family status. And they have more comprehensive unemployment insurance. Both general assistance and unemployment insurance can provide a safety net for individuals with disabilities as well as non-disabled individuals

who are out of work. Unlike our European counterparts, the United States has no generalized assistance program for people who are down on their luck and unable to make ends meet. And unemployment insurance is much more limited in the United States than in many European countries. Other things being equal, one would expect somewhat greater pressure on disability benefit systems if alternative temporary support systems are lacking.

People Usually Turn to Disability Benefits As a Last Resort

The focus group interviews strengthen the finding that people turn to Social Security disability benefits only as a last resort. Beneficiaries' stories indicate they usually stayed on their jobs as long as they could after the onset of their impairments or illness and they often had sought other work before turning to disabled benefits. Excerpts from focus groups are attached as an appendix.

III. A Response to the Idea that DI Reduced Employment in the 1990s

How do we reconcile these observations with the claim that the DI program caused a decline in employment amount people with disabilities in the 1990s (Stapleton and Burkhauser, 2003)? That claim begins with the following observations:

(A) Employment declined during the 1990s among people who say they are limited in their ability to work. People with work limitations include two groups. Employment rose among those who report they are limited, but still able to work. (Good news.) But more people said they are unable to work and were not working. (Disappointing news.)

(B) More people received DI benefits over the 1990s.

It is argued that liberalized eligibility criteria and rising DI replacement rates caused people to leave the labor force and turn to DI. I believe there is another side to each story.

Eligibility Criteria Did Not Expand in the 1990s.

I do not know of any significant expansions of DI eligibility criteria in the 1990s. In contrast, some restrictions in SSI eligibility were enacted in 1996.[1] What, then, are the so-called "expansions" in eligibility criteria? They appeared to be the 1984 legislation, which was enacted to remedy the overly zealous administrative retrenchment that occurred in 1979-83. The 1984 law sought to restore the disability determination processes to a responsible center. It can be construed as an "expansion" only if one views the extraordinarily restrictive policies of the prior few years as the baseline. That does not hold up on close examination.[2] The notion that the 1984 changes caused a decline in employment during the 1990s is not convincing to me.

Whose Replacement Rates Rose and Why?

A study by Autor and Duggan (2002) estimates that replacement rates rose during the 1980s and 1990s for older men who are at the bottom of the wage distribution. This is plausible. To the extent this occurred, it is not a flaw in the DI benefit formula. Rather, it is the result of an aberration in the wage structure of our economy.

The authors creatively estimated wage histories for men, assuming they remained at, say, the bottom 10th percentile of the wage distribution of their age peers throughout their lives.[3] Those simulated wage histories show that men who reached their 50s in the 1990s were not only low earners, they were experiencing falling wages relative to prevailing earnings in the economy. Hence, as they grew older, they fell further and further behind. That kind of wage pattern would cause benefits (based on lifetime earnings) to replace a larger share of recent earnings because recent earnings are low.

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[1] The main source cited for historical changes in eligibility criteria cited in Chapter 10 of Stapleton and Burkhauser (2003) is the NASI Panel report, *The Environment of Disability Income Policy: Programs, People, History and Context.* But it does not mention any liberalization in disability criteria in the 1990s.

[2] In state after state, governors first protested new guidelines for terminating benefits to disability beneficiaries and then, citing judicial opinion in support of their actions, announced they would no longer conduct the disability reviews (Mashaw and Reno, 1996b).

[3] It is assumed, for example, that the men earned at the 10th percentile of earnings for men in their 20s in the 1960s, then in the 10th percentile of men in their 30s in the 1970s, in their 40s in the 80s and in their 50s in the 1990s.

What do these wage trends mean? For one thing, they suggest that employers have very weak demand for the services of these aging, unskilled men. If the men should sustain a significant impairment, what "reasonable accommodations" should we expect employers to offer? The economic behavioral model of labor supply posits that these men would choose DI benefits over work because the benefits are so attractive. Another perspective is that, given a significant impairment, advanced age, limited skills, and a lifetime of low and declining wages, such men would have no real job prospects.

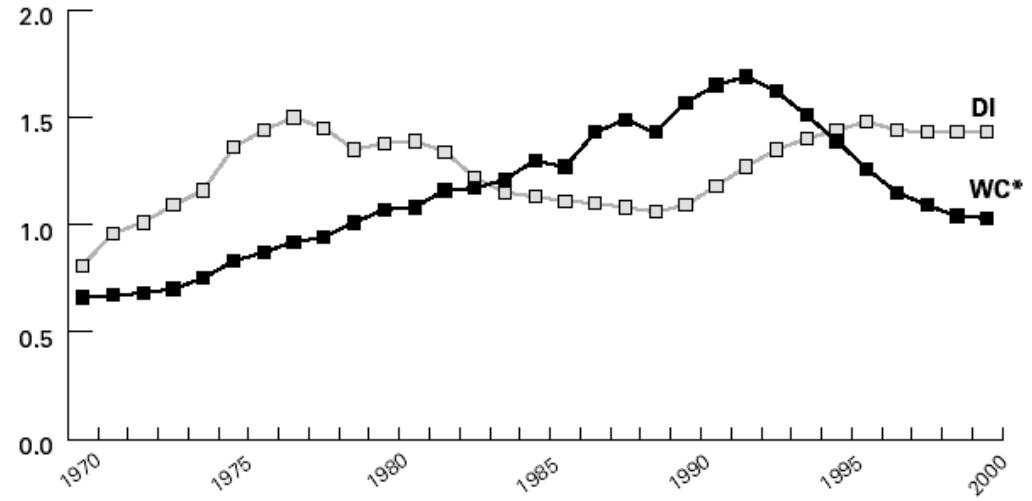
IV. Why Did the Disability Rolls Grow in the 1990s? Other Hypotheses

Instead of asking, did DI cause the decline in employment among a subset of people with disabilities, we can instead ask the more relevant question for this conference. Why did the DI rolls grow during the 1990s? I will point to three developments that may merit further study – although all may prove difficult to quantify. One hypothesis is that restrictions on other disability benefits are pushing people to Social Security disability insurance. A second hypothesis is related to global changes in the competitive workforce and what employer representatives have called an increasingly "unforgiving" workplace. A third hypothesis relates to how a decline in good early retirement options for workers in arduous jobs might increase the likelihood of reported work disability.

Are Other Disability Programs Sending People to DI?

We have indirect evidence of such a development with regard to workers' compensation, based on four kinds of clues. First, while spending on DI benefits rose during the 1990s, spending on workers' compensation actually declined, first in absolute dollars and then continued to decline as a share of payroll covered by the program. (See Figure 3).

Figure 3. Social Security Disability Insurance and Workers' Compensation Benefits as a Percent of Payroll, 1970-2000.



Source: National Academy of Social Insurance and the Office of the Actuary, Social Security Administration.
*Starting in 1989, a new estimation method was used for workers' compensation benefits as a percent of payroll which accounts for the decrease in that year. For more information, see NASI, 1997.

Second, during the 1990s states adopted a number of changes designed to limit the number and types of claims that are paid by workers' compensation. Two key areas of restriction are psychological impairments (mental illness) and cumulative trauma disorders, also known as repetitive stress injuries that affect the musculoskeletal system (Burton and Spieler, 2001). These same two categories are a growing share of the DI program in the 1990s.

Third, focus groups conducted in the 1990s found – almost without exception – that people with musculoskeletal impairments who ended up on disability insurance had previously been denied by workers' compensation. This occurred even in some cases that clearly appeared to be work injuries. (See Appendix A.) Fourth and finally, service providers are in business to help employers and insurers get their long-term workers' compensation cases on Social Security disability insurance if they can. An increase in

this activity could lead to an increase in DI claims. In reverse offset states,[4] workers' compensation payments could be reduced if the worker qualified for DI. Similar services are provided to employers and insurers who pay long-term disability insurance that is offset against DI benefits.

While we don't know the size of any such effect, a push from other disability programs could contribute to growth in the DI rolls. This trend would not, however, explain an increase in reported work disability because people are likely to report they are work disabled whether they are receiving workers' compensation or private long-term disability insurance or Social Security disability insurance.

How Does an Increasingly Unforgiving Workplace Affect Work Disability?

At the Academy's disability conference in 1996, two speakers offered an employer's perspective on the question "Where are the Jobs for people with disabilities?" Van Doorn Ooms, then Senior Vice President of the Committee for Economic Development, characterized the increasingly "unforgiving" world of work. "Cost efficiency and productivity improvements are now imperative for most larger American companies. They are matters of survival for many firms, and the forces that produce them are continuing and relentless. …The new competitive environment has brought both good and bad news. … The bad news is that this more intense competition has brought a less forgiving world. … There are more opportunities, but also much higher risks. Many of those risks are now borne by workers in ways that they were not in the old economy where firms were more paternalistic. … Intensified competition is a double-edged sword. … As skills become more valuable, the costs of discriminating against skilled disabled workers might become higher. … Conversely, as less skilled workers become relatively less valuable, the incentives for accommodating their disabilities diminish. A careful distinction must be made between disabled workers who have skill deficits and disabled workers who do not when discussing these issues" (Ooms, 1996).

[4] States with reverse offset laws are California, Colorado, Florida, Hawaii, Illinois, Louisiana, Minnesota, Montana, Nevada, New Jersey, New York, North Dakota, Ohio, Oregon, Washington, and Wisconsin.

Leslie Scallet, director of the Mental Health Policy Resource Center brought her dual perspective as an employer in a small non-profit organization and as a lawyer and advocate for persons with mental illness. She explained that downsizing and streamlining mean that employees have to be highly flexible: instead of having two or three employees to do different activities, one employee might be expected to do all kinds of activities. Workers who have mental disabilities will have a harder time being flexible in this kind of environment. Second, the new emphasis on speed and productivity is particularly difficult for workers who have mental disabilities. Third, policies that reduced income support for families with children brought added competition for low-skill jobs that will make finding and keeping a job more difficult for some workers with disabilities. Finally, many people with mental illness who have found a niche in the work force have done so in a semi-sheltered environment of public or nonprofit agencies. Reduced funding and downsizing in these agencies jeopardize those successes (Scallet, 1996).

In brief, a less forgiving work place makes it harder for people with mental impairments to find a niche and weak demand for unskilled workers weakens employers' incentives to accommodate unskilled workers with physical or mental impairments.

Do Fewer Early Retirement Options Bring More Work Disability?

This final hypothesis is based on observing retirement and disability policies over the past nearly four decades. In the 1970s and 1980s, men in arduous jobs were more likely than today to have the benefits of collectively bargained early retirement pension and health benefits. These benefits were common in heavy industry – automobile and steel manufacturing, mining, and so forth. A social compact among workers and employers often buttressed the notion that 30 years in arduous work was enough. Early retirement was good for the retiree. It was also good for his co-workers because senior positions opened up for mid-career workers to move up the ranks. Employers also benefited because an ample supply of young baby boomers would fill jobs at lower wages than those paid to retirees.

In this environment, men in arduous jobs could retire on adequate incomes before the onset of a disabling health condition. And, if a chronic condition arose after he retired, chances are that the retiree would still consider himself "retired," rather than disabled because retirement was the reason he left the workforce.

As employment in durable-good manufacturing has declined – through automation and movement of plants beyond U.S. borders – more of the arduous jobs that remain for American workers tend to be in jobs that rarely provide early retirement pensions or health benefits. These jobs – in agriculture, construction, food production and food service, retail trade, and repair services – rarely offer pensions at all and many don't provide basic health coverage for active workers, let alone retirees. Pension plans cover just 33 percent of workers in construction, 24 percent in retail trade, and 27 percent in services (other than professional services) (Copeland, 2002). Lacking any kind of health insurance were 42 percent of agricultural employees, 33 percent of employees in construction and in personal services, and 24 percent of employees in retail trade and in business and repair services (McDonnell and Fronstin, 1999).

Without early retirement health and pension options, workers in today's more arduous jobs may have no choice but to keep working until they become eligible for Medicare and Social Security retirement benefits, or experience a career-ending disability, whichever comes first. Thus, a decline in early retirement benefits for workers in arduous jobs could indirectly contribute to an increase in both reported work disability and claims for Social Security disability benefits.

V. Recovery and Return to Work: It May Be Better than We Think

We often hear that only a fraction of one percent of DI beneficiaries ever leave the rolls because of recovery or return to work. This rate compares the number of people who return to work in a year with the number of people on the DI rolls that year.

In the mid-1990s the Academy's Disability Policy Panel received special tabulations from the Social Security Administration that tracked the experience of

beneficiaries over six years after they entered the DI rolls. This study shows a more promising picture as well as a cautionary tale about the experience of disabled workers (Figure 4). Six years after entering the DI rolls:

- Just over half (53 percent) of people were still on the disability benefit rolls;
- Fully a quarter (26 percent) had died;
- Nearly a fifth (18 percent) had shifted to retirement benefits; while
- About 3.5 percent had recovered or returned to work.

The 3.5 percent rate of recovery or return to work may not be as high as some would like, but it is ten times higher than the kinds of figures we usually hear. The key difference is that the study followed people over time. Recovery and return to work take time.

The success rate is somewhat higher if we focus only on those still alive and not on the retirement rolls. With the deceased and retired excluded, the rate of recovery or return to work is about 6.2 percent.

Recovery or return to work is particularly important for younger people because they have a longer potential work life ahead of them. Younger disabled workers who survived were more likely than their older counterparts to leave the rolls. As a share of those still alive after six years, disabled workers who recovered or returned to work were:

- About 1 in 8 (13 percent) of those in their 20s when they entered the rolls; and
  About 1 in 11 (9 percent) of those in their 30s at onset.

The 9 to 13 percent rate of leaving the rolls for recovery or return to work among beneficiaries in their 20s and 30s is much better news than we usually hear. A key question is how such figures might look today. These special tabulations were provided to us in 1995 and were published in our 1996 report (Mashaw and Reno, 1996a). The period covered by the study was 1988 through 1994. During part of that time, SSA had

cut back on doing continuing disability reviews in order to process a backlog of new claims, because it lacked the resources to do both. It would be useful to know whether results are different now. In fact, it would be useful to track this kind of experience from year to year to have a historical record of how changes in policy, administrative practices, and the broader economy affect recovery and return-to-work rates.

Adequate Administrative Resources Are Essential

In both its interim and final reports, the NASI Disability Policy Panel urged that the Social Security Administration be provided adequate administrative resources in order to obtain appropriate evidence and fairly, thoroughly, and promptly decide new claims and to conduct continuing disability reviews as called for in the law. Disability determinations are inherently difficult and some cases are time consuming and labor intensive. Failure to properly fund administrative activities ill serves both beneficiaries and taxpayers.

Figure 4. Recovery and Return to Work Experience of DI Beneficiaries Over a 5 to 6 Six Year Period
Benefit status in February 1994 of persons awarded benefits in 1988, by age in 1988

Status in February 1994	Age in 1988						
	Total	Under Age 40			40-49	50-59	60-64
		Total	Under 30	30-39			
Number of persons awarded DI in 1988 (in thousands)	409.1	99.8	36.7	62.9	78.5	146.9	84.1
Total percent	100	100	100	100	100	100	100
Still receiving DI benefits	53	72	74	71	69	60	0
Died	26	19	15	22	27	32	25
Shifted to retirement benefits	18	–	–	–	–	6	75
Recovered or returned to work							**0**
Percent of total	**4**	**9**	**11**	**7**	**4**	**2**	**0**
Percent of those alive and not retired	**6**	**11**	**13**	**9**	**5**	**3**	**0**

Source: *Balancing Security and Opportunity: The Challenge of Disability Income Policy,* Final report of the Disability Policy Panel, National Academy of Social Insurance, 1996, page 110. Special tabulations provided by the Office of Disability, Social Security Administration.

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Appendix

Profiles of Disability Beneficiaries

To get beneficiaries' perspectives on their disabilities, benefits and prospects for work, the Disability Policy Project conducted focus group and telephone interviews with over 60 Social Security disability insurance (DI) and Supplemental Security Income (SSI) beneficiaries or parents of young adult beneficiaries. A pilot focus group was held in Virginia in August 1994. Eight other focus groups were conducted in three sites — Iowa, New York and Oregon — in October 1994. The Project collaborated with the U.S. General Accounting Office to obtain from the Social Security Administration (SSA) lists of beneficiaries' names. Beneficiaries were contacted by phone and invited to participate in the focus groups. All of the beneficiaries contacted had filed for disability benefits within the last 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 groups consisted of three age groups of beneficiaries — those ages 50 to 61, 25 to 49 and 18 to 24 — and parents of beneficiaries ages 18 to 24. Participants within each age group were selected to include a mix by gender, ethnicity and three broad categories of impairments. The categories were musculoskeletal impairments, common among those ages 25 to 61; mental impairments, most common among young adult beneficiaries but present in all age groups; and cardiovascular, respiratory and other impairments, also common among those ages 25 to 61.

Excerpts from the focus groups convey both common themes and the diversity of beneficiaries' experiences. The first sections of this appendix present profiles of participants ages 25 to 49 and 50 to 61, grouped by the three general impairment categories by which they were selected. These age groups are combined because they reported common experiences. Those ages 25 to 49 included many beneficiaries in their mid to late 40s, as is the case with the beneficiary population in general. Many in the age 50 and older group were in their early 50s and had been in their late 40s at the onset of their conditions. The final section of the appendix profiles young adult beneficiaries and parents of young beneficiaries.

Cardiac, Respiratory and Other Impairments

These beneficiaries 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 diagnosis. 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.

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.

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 remission 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.

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.

My first disability benefit was through the hospital. Then I called the Social Security office. Mine went right through without any problem.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

Musculoskeletal Impairments

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.

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.

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.

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.

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.

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!"

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.

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.

Nobody wants to be disabled. Nobody wants to live off the state. I'd love to 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 feet 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.

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.

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."

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.

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.

Meatpacker. 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.

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.

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.

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."

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.

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.

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.

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.

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.

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.

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!"

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.

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.

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.

Mental Disorders

Participants in the focus groups 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 outpatient 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'm 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.