

# Pathways to Disability Income among Persons with Severe, Persistent Psychiatric Disorders

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**H**ARSH SKEPTICISM PERVADES CURRENT PUBLIC debate about who deserves public support and on what basis, particularly regarding the claims of individuals with disabling illness and injury. Heretofore, these claims were accepted, even if reservedly, and the needs of such individuals were considered to be legitimate even when they were monitored closely (e.g., Satel 1995; Shaner et al. 1995). The Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs and their recipients have been among the most visible and vulnerable targets of increased scrutiny and shrinking public beneficence. In 1997, congressional legislation redefined SSI eligibility for children, sparked largely by concerns that children have been deployed to engage in a type of public begging by “acting crazy” in order to secure benefits for their families. “Maladaptive behaviors” was removed from the mental disorder listings, and the Social Security Administration (SSA) estimates that 135,000 children will lose their benefits after review. In March 1996, Congress eliminated SSI, SSDI, Medicare, and Medicaid benefits for persons whose drug addic-

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tion or alcoholism is a prominent cause of disability, and as a result 141,000 recipients have been terminated. The SSA also was ordered to begin another sweeping review of all recipients of disability income. SSA officials reportedly expect this process to produce a termination rate of 14 percent, resulting in an estimated 196,000 additional individuals who would cease to receive SSI and SSDI (*Los Angeles Times* 1996).

Persons with psychiatric disorders represent the largest diagnostic group of recipients of both SSDI and SSI programs. More than half of disabled SSI recipients and 25 percent of SSDI recipients have some form of mental disorder (Ferron 1995; Kocchar and Scott 1995). Since 1986, the largest growth in benefit allowances for persons with psychiatric impairments has been in the SSI program, but the SSDI program has also seen increases. Whereas allowances have been steady for persons with a diagnosis of schizophrenia and other functional psychotic disorders, there has been a substantial increase in allowances for SSI, SSDI, and concurrent SSI and SSDI receipt among persons with affective disorders (Rupp and Stapleton 1995; Rupp and Scott 1996).

People with psychiatric disabilities are arguably doubly marginal—unwelcome in both the nondisabled and the disabled communities. They were included only grudgingly under provisions of the Americans with Disabilities Act (Bell 1997). Recent Equal Employment Opportunities Commission rulings requiring workplace accommodation for people with psychiatric conditions have evoked an unsympathetic response, which was epitomized by a *New York Times* story that ran under the headline, “Just What the Government Ordered: Breaks for Mental Illness,” with a subhead that declared, “Employers are Terrified.”

In this atmosphere, and in view of the mixed meanings and consequences of receiving disability income, it is especially important to lend empirical findings to the debate about why and how people with disabling conditions apply for and receive disability income. We report the main results of a prospective cohort study designed to describe how individuals with serious mental illness come to apply for and receive SSI and SSDI. The research addressed the question, Among a group of people at risk for applying and receiving disability income, what factors influence their becoming recipients? Our goal was to sort out and understand the force of social, clinical, and service system contributions to this potentially critical juncture in the life and illness course of study participants. We compare applicants and recipients in the cohort with those eligible persons who did not apply or become recipients of dis-

ability income. By following this cohort prospectively over 32 months, we observed, described, and analyzed the processes that shaped the trajectories study participants took to their formal designation as recipients of disability income. We used narrative analysis of extensive interview material to inform the findings, and we employed event history analysis to model the factors that contributed to application and receipt among study participants.

### Emerging and Persisting Dilemmas of Disability Income for People with Serious Mental Illness

SSI and SSDI have become major, often sole, sources of support for people with serious, enduring psychiatric disorders. Both programs rely on the same determination process and eligibility criteria in terms of impairment and disablement, but they differ in significant ways. Because SSDI is intended as a social insurance program for disabled workers, it requires a set amount of prior labor force participation. SSI was designed to supplement the incomes of people who had little or no labor force participation, and it is means or income tested by household. The concentration of people with serious mental illness in the SSI program reflects their multiple disadvantages in employment and lack of other resources.

The most recent estimates are that approximately 1,154,754 persons with severe, persistent mental illnesses receive SSI and SSDI (Kennedy and Manderscheid 1992), or about half of the projected 2.4 million people in this population. The 1997 average monthly payment of \$704 for disabled SSDI recipients and \$484 for SSI recipients with no other earnings places beneficiaries well below the poverty level. At the same time, receiving benefits from these programs creates a jumble of bureaucratic and financial obstacles to obtaining or earning more income and often poses distressing personal and familial dilemmas (Reno, Mashaw, and Gradison 1997).

Although providing partial relief from financial and life strains, receipt of disability income may also signal or hasten the end of efforts to engage actively in rehabilitation (Lindsey and Ozawa 1979; Dykacz and Hennessey 1989). As one study participant related:

She [sister] kept doing it [paying bills], and kept doing it, then month after month I didn't work, and she kept paying me, and so I got used to it. So I sort of never accepted it, I guess I sort of got passive about the whole thing. So, it kind of contributed to me not working. I mean it's sort of like a crutch, you know.

Massel et al. (1990, 39) conclude, "While work incapacity may lead to disability, the status and role of a disabled person may also reinforce work incapacity." This observation is echoed by another study participant:

I told him [counselor] that I felt bad about going on disability because I felt like it was giving up. And I didn't like the idea, so I told him that I wanted to try to work. . . . I've had 2 jobs this year that didn't work out, for different reasons. I still don't like the idea of having to be on disability, but at this point, I have no other way to go.

As compelling are the sense of shame and stigma that for some accompanies the receipt of disability income:

- "You know, if they turn me down, I won't be surprised if they turn me down, you know. I might feel relieved morally."
- "At first it [SSDI] was like a real turn off. . . . [A]t the time I didn't have a very good understanding about social security. And so I really didn't want to get social security 'cause I always felt like, well, I don't want nobody giving me money like that. Money that I felt like I could always go out and work for. I always wanted to, you know, work for anything that I've got. I always done it that way."

Finally, but perhaps most alarmingly, as managed care becomes the predominant mode of organizing, financing, and delivering public mental health services, Medicaid and Medicare coverage, which almost always accompanies both SSI and SSDI, is vital for access to care for people with disabilities (National Advisory Mental Health Council 1993; Iglehart 1996). Public mental health services nationwide are creating various managed care arrangements that rely heavily on Medicaid and Medicare. As a result, individual access to services is even more tied to Medicaid and Medicare (via SSI and SSDI) than in the past for people with persistent and severe mental illness. Yet overarching questions about how to provide for the growing number of people with no health insurance and for aging baby boomers cast a shadow on the future

availability of adequate resources for people with disabilities (Vladeck et al. 1997).

### Conceptual Model

Our investigation was informed by a conceptual model of pathways that we refer to as “impairment,” “labeling,” and “needs/resources” (Estroff et al. 1997). Figure 1 illustrates each pathway and specifies the processes that we expected to be most influential. We hypothesized that individuals with the following characteristics and circumstances would be more likely to apply for and receive disability income:

- Their clinical impairments would be more severe, which would affect their overall functioning.
- They would have undergone longer and more frequent hospitalizations.
- They would have had more interactions with mental health service systems.

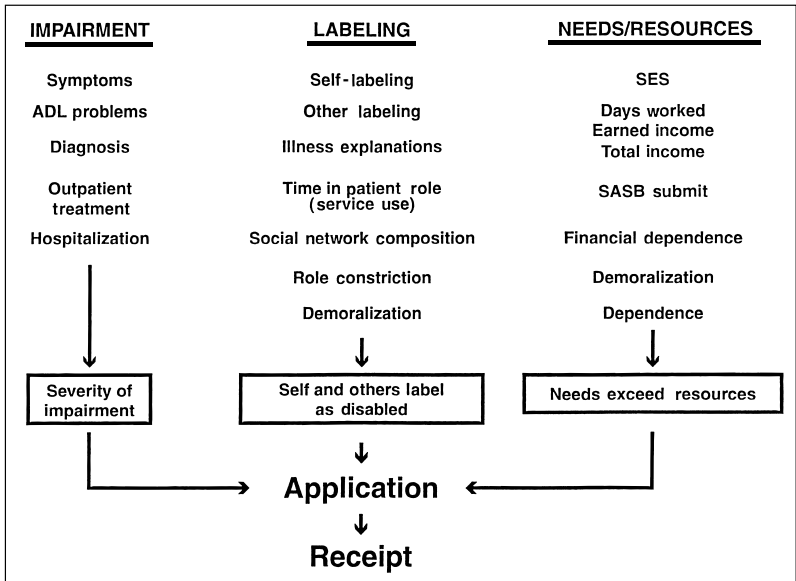


FIG. 1. Conceptual model of SSI and SSDI application and receipt.

- They would have less earned income and fewer days of employment.
- They would view themselves as mentally ill, disabled, or primarily as psychiatric patients.
- Their most significant others would concur with that view.
- They would experience more instrumental and affective dependence on relatives and significant others.
- They would have fewer financial resources and limited social support.

Each pathway in the conceptual model differentially favors one component among the multiple forces of the disablement and income-support-seeking process. We separated these to examine the significance of each pathway to application and receipt among the study cohort.

The impairment model posits that severity and duration of psychiatric symptoms, duration and frequency of hospitalization as a result of severe impairment, and the resulting widespread and substantial deficits in functioning will lead to application for SSI and SSDI. This formulation articulates what might be called a medical or clinical conceptualization of the disablement process (Mechanic 1995).

The labeling formulation emphasizes that the persons' view of themselves as mentally ill and disabled, the views of relatives and significant others about their illness and prognosis, the amount of time they spend as patients in treatment, and their lack of other roles and identities (i.e., not being a spouse, employee, or student) will influence an application for disability income. Progressive social and interpersonal role constriction accompanies severe, persistent mental illness. The individual loses, fails to attain, or blemishes positively valued and multiple roles like spouse, friend, and employee. Over time, identity narrows and solidifies around the axis of patienthood and disability (Erikson 1957; Estroff 1985). Application and receipt of SSI and SSDI may formally, even permanently, label the person as disabled, decrease role obligations, especially in the area of work, and permit sustained withdrawal from social relationships (Link 1982, 1987; Caras 1994). Social roles may constrict in number and decrease in value, and identity may become engulfed by the disability process (Estroff 1989; Zola 1992).

Taking a needs/resources approach, we reasoned that the larger the gap between individuals' needs and their ability to provide for them, and the more dependent they were on others for instrumental and af-

fective support, the more likely they would be to apply for SSI and SSDI. This formulation calls for a political economy of the disablement process. In this view, disablement is produced within and by the macropolitical economy of the labor force and the micropolitical economies of families and individuals (Stone 1979, 1984; Yelin 1986, 1992; Yelin and Cisternas 1996; Mashaw 1997). The interaction of various dependencies in relation to available resources, and the confluence of needs within the context of available opportunities, drives this process.

In an earlier publication (Estroff et al. 1997), we reported findings from the analysis of application for disability income among this cohort. A combination of social and clinical dysfunction, despair and demoralization, and instrumental and psychological dependence accounted for SSI and SSDI applications. The significant predictors and their effects on the odds of application were demoralization (2.1,  $p < .05$ ); days in hospital during the study (1.1,  $p < .10$ ); doing worse than others financially (3.9,  $p < .01$ ); one or more difficulties with activities of daily living (ADLs) (2.96,  $p < .05$ ); financial dependence on family (2.4,  $p < .10$ ); and psychological submission and dependence on a significant other (2.4,  $p < .05$ ). Each of the three pathways was supported to some extent by the findings, but none proved to be determinate. In light of these findings, we focus here on the analysis of receipt of disability income. Although our investigation derives from a relatively small cohort residing in the southeastern United States with a specific set of disabling conditions, the analysis provides a multidimensional view of processes, characteristics, and circumstances that led some individuals to disability income and permitted others to live without this support.

### Sarah

The narrative of one study participant illustrates the multiple pathways to disability income application and receipt among persons with psychiatric disorders. When she entered the study, Sarah was 26 years old and a college graduate. She had been in outpatient psychiatric treatment for approximately seven years and had spent 160 days in psychiatric hospitals. She was diagnosed with atypical psychosis and multiple personality disorder. Sarah labeled herself as mentally ill, and her explanation for her problems was based on an emotional model (see Estroff et al. 1991). During the course of the study, she applied for and received

SSDI. After less than a year of being a recipient, she went back to work full time. Soon after, she took an overdose of acetaminophen and was treated in the intensive care unit of a nearby university hospital. Below, she describes her reasons for applying for disability income, her experience of the process, and her sentiments about being a recipient.

*Sarah:* I worry a lot about, you know, asking my mom for so much support, because she does have limited resources. And for that I thought it was acceptable to take some sort of help, because otherwise it was going to come out of her pocket. And you know, it's such an ordeal to get approved for stuff like that. You have to basically say, "I'm incompetent to be a person." You know, I mean, you really have to declare yourself a complete basket case, and that's very upsetting, you know. Nobody likes to say, you know, "I can't cope and I won't be able to cope for a while." I don't like thinking of myself as a disabled person. On the other hand, had my parents not taken me in, I literally would have been homeless. I didn't have a home anymore. I didn't have anybody else to take care of me. . . . It's kind of ridiculous to be a 28 year old, and to be in the position of needing somebody to take care of you, but I did need somebody to take care of me.

God, you know, if there were any alternative, if there were any way to have handled a job, I definitely would have gone for that instead. I don't think anybody gets on disability because they're too lazy, because it's too much of a job to get the disability. . . . Well, for one thing, they make you feel like you're a, you're trying to cheat somebody out of something when you're applying. You know, it's like they want verification in so many ways of so many different things that you might be hiding something from them, you know. And then you have—you're obligated to tell them if anyone gives you a present.

*Interviewer:* And when you got the disability, did you feel better or worse?

*Sarah:* In some ways, it was a relief; for one thing then I didn't always have to ask for everything. I could just go out and buy my medicine instead of saying, "Can I have some money to buy my medicine?" And I was able to, I gave all the back payment to my psychiatrist. So I was able to give him something of what I owed him. . . . but I don't know, I mean there's a lot of guilt in receiving it too. You know, you're not supposed to get something for nothing. . . . I didn't feel like I deserved it, I just felt like I needed it you know, there's a difference. I guess the only way I'll ever be able to stop feeling bad about it, really, is if I can make enough money to somehow pay it back. I would like to do that. . . . I feel like I'm one of those people that society took care of for a while. I should pay it back.



Sarah went on to explain that she would not have known to apply for disability income and Medicaid if the billing department at the university hospital had not intervened.

The billing department called here, he called my social worker. . . . And he [the billing department rep] called me up, and he told me that I had to call her [the social worker] back. . . . And you know, they were very aggressive. I mean they need their money, you know. . . . It [applying] was not my idea. I wouldn't even have known to apply if it hadn't been for them.

Sarah's narrative contains elements from all three pathways to disability income: impairment; needs/resources; and resistance to labeling. It reveals her financial dependence on her family; pressures from providers to pay medical bills; an inability to tolerate the stresses of full-time employment; a sense of obligation to family; and a desire to be self-supporting. She also conveys in unusually rich detail the humiliation of applying, her sense of dis-ease at needing and receiving public assistance, and a strong desire to repay this social benevolence.

As Sarah's experience illustrates, incentives abound for treatment staffs, relatives, and clients themselves to seek SSI and SSDI (Cain 1993). Hospitals, community agencies, and clinicians require reimbursement for extensive services to patients, who are often indigent (Gronfein 1985). Relatives desire financial security for their loved ones, health insurance from Medicaid and Medicare, and a lessening of the potentially ruinous financial burden of a long-term psychiatric disorder (Lefley 1987; Hatfield and Lefley 1987; Carpentier et al. 1992). Individuals with severe and persistent mental illness may seek needed relief from repeated failures at employment, may lack family resources, and may feel entitled to public financial assistance.

Like Sarah, other study participants held pragmatic views of disability income:

- "Like I said, it's just money, just another check coming in, and income and stuff like that. Makes me feel like I'm pulling my own weight, paying my own way in some ways. Besides that, nothing else didn't do it."
- "Well, I feel good about it because I know I'm just simply disabled. That's all it amounts to. And, uh, there's a fund set aside for people who have worked a set number of years and are qualified."

## Previous Research

The bulk of what is known about disability income applicants and recipients derives from research that can be characterized as descriptive, lacking both specificity to persons with severe, persistent psychiatric disorders and qualitative data or multivariate analyses that model or predict application or receipt. No previous studies address directly pathways to disability income among persons with enduring impairments who have recently become patients. However, a prospective study conducted among low-income adults who received income maintenance indicated that, among the lowest-income groups, psychological distress *increased* after receipt of income maintenance and that receipt of a stable income was associated with negative and stressful life events (Thoits and Hannan 1979).

Findings from recent research about disability income beneficiaries suggest that severity of psychiatric symptoms alone is not a reliable predictor of SSI or SSDI receipt, that receipt has some effects on the capacity and willingness of beneficiaries to work, and that receipt is associated with a mixed picture of functioning in other life domains.

Segal and Choi (1991) examined SSI receipt and tenure in a ten-year follow-up of sheltered care residents with psychiatric diagnoses, and they constructed a model to predict which residents were recipients at follow-up. SSI recipients and nonrecipients were comparable in terms of diagnosis, demographics, amount of mental health service use, percentage who were employed, and severity of symptoms. Compared to nonrecipients, the current SSI recipients had spent significantly less time in psychiatric hospitals since baseline, were more likely to be seeing a private counselor or psychiatrist, were much more likely to live in sheltered care, and had less informal social support from friends and family.

In a study of work capacity among persons with severe, persistent psychiatric disorders, Massel et al. (1990) also found no differences in symptom severity between disability income recipients and nonrecipients, and they discovered unexpected similarities in some areas of tested work capacity between the two groups. Work tolerance, performance, and grooming were significantly worse in the recipient group. Jacobs et al. (1992) found that their vocational rehabilitation program for people with psychiatric impairments was less effective with SSI recipients than with SSDI recipients and nonrecipients. They attribute this result to the poorer work histories, earlier age of illness onset, and higher number of hospitalizations among SSI recipients. In both of these studies, disabil-

ity income recipients were demonstrably more impaired vocationally than nonrecipients. Perl and Kahn (1983) compared fully financially compensated psychiatrically impaired veterans with those who were partially compensated or receiving no Veteran's Administration compensation. The only significant differences between the groups, on measures of psychopathology, use of services, locus of control, and self-esteem were the following:

1. The fully compensated were more hostile.
2. Their time in the hospital decreased during the year following receipt of full compensation.
3. The partially compensated had higher self-esteem.

A recent investigation (Calsyn, Kohfeld, and Roades 1993) of 288 people who were homeless focused on recipients of public benefits, examining the public assistance records of a subsample of 100 respondents. Having a prior psychiatric hospitalization significantly *lessened* the odds of being a public benefit recipient for women and had no effect on receipt among men. Psychiatric symptomatology did not affect public assistance receipt for men or women, but the number of agencies the person contacted did. The more agencies contacted, the more likely men and women were to receive benefits. Apparently, the psychiatric hospital did not function like a social service agency in engineering SSI or SSDI applications for these individuals.

While suggestive, these studies were not prospective and thus cannot reveal how disability income application and receipt either interact with the ebb and flow of psychiatric symptoms or influence the long-term course of illness; nor do they demonstrate either how receipt influences opportunities or capacities for employment or what other conditions brought the individual to become a recipient. It is apparent, nonetheless, that there are no simple causal relations among symptom severity, psychiatric hospitalization, employment capacity, the texture and quality of daily life, and disability income application and receipt.

## Methods

The study included 169 individuals who were at an early stage of a major psychiatric disorder and who had never applied for or received SSI or SSDI. Because of missing data for some persons on some variables, the baseline sample size for the analyses ranges from 110 to 146.

### *Sample Criteria and Recruitment*

Study participants were recruited from four psychiatric hospitals (two state, one university, and one community) and from two public outpatient mental health programs in a five-county area surrounding Chapel Hill, North Carolina, during the years 1986 through 1988. We recruited individuals who were “early and eligible”: early in their experiences with major psychiatric disorders and ostensibly eligible for SSI/SSDI because of a poor work history, earned income below \$300 per month (the SSA substantial gainful activity level at the time), and severe symptoms within the last 12 months. Over 3,100 hospital charts were screened in order to assemble the sample of 169 people. Each study participant was followed for 32 months in six waves of interviews at six-month intervals and was paid for each interview. Overall, 73 percent of the original sample completed three or more interviews, and 92 people completed five interviews.

### *Interviews*

Five of the six interviews were face to face; the last was by telephone. The baseline interview took place in the hospital in almost every case, and the follow-ups occurred in whatever setting was most convenient for the participants, usually their homes. Two of the interviews were primarily semistructured, in-depth sessions that were taped, transcribed, and content coded. Hospital charts and mental health center records were reviewed repeatedly to verify diagnoses and service use. We also interviewed each subject’s self-identified, most significant other (SO), usually a parent, once during the study if we were able to gain consent from the respondent and his or her designated SO, resulting in 64 SO interviews.

### *Instruments and Measurement of Variables*

Table 1 presents univariate statistics for all variables during the six months prior to the baseline interview for all subjects and for applicants and recipients for the six-month period in which application and receipt took place. (See Estroff et al. [1997] for additional details about variable definition and measurement.) The variables are organized by conceptual domains derived from each of the three pathways to disability income:

TABLE 1  
Descriptive Statistics for Study Variables

	Baseline	Applicants	Recipients
<i>Application and receipt variables</i>			
Number	146	55	43
Applicants (%)	37.7	100.0	100.0
Recipients (%)	—	78.2	100.0
SSI	—	—	48.8
SSDI	—	—	37.2
Dual	—	—	14.0
<i>Demographic variables</i>			
Number	146	55	43
% African American	30.8	29.1	34.9
% SES1	13.7	10.9	11.6
% SES2	19.2	21.8	20.9
% SES3	17.1	12.7	9.3
% SES4	30.8	32.7	34.9
% SES5	19.2	21.9	44.2
% female	50.0	47.3	44.2
Mean age (years)	28.4	29.2	29.2
% married	10.3	3.6	2.3
<i>Impairment variables</i>			
Number	143	51	39
% schizophrenias	41.3	51.0	53.8
% affective disorders	33.6	27.5	30.8
% personality disorders	16.8	11.8	5.1
% other disorders	8.4	9.7	10.3
Mean score			
BPRS	12.7	13.6	14.1
PERI AH	1.3	1.3	1.3
PERI DM	1.9	2.0	2.1
PERI SP	2.2	2.2	2.2
PERI PH	1.7	1.8	1.7
PERI SI	0.8	0.9	0.9
PERI CT	2.0	2.0	2.2
PERI FBP	1.1	1.2	1.2
PERI M	1.2	1.1	1.0
% newly hospitalized	91.6	78.4	51.3
Median years since first hospitalization	2.0	2.0	3.0
Median days in hospital—last six months	20.0	20.0	29.0
Median days in hospital—over lifetime	86.0	112.0	156.0
Median days in hospital—during the study	20.0	24.0	81.0

(continued)

TABLE 1 continued

	Baseline	Applicants	Recipients
<i>Needs/resources variables</i>			
Income variables			
Number	110	48	37
% with needs taken care of			
Poorly	30.9	45.8	43.2
Adequately	26.4	20.8	21.6
Fairly well	27.3	20.8	18.9
Very well	15.5	12.6	17.3
% doing worse financially than others	57.3	75.0	67.6
% doing about the same financially			
as others	33.6	18.7	24.3
% doing better financially than others	9.1	6.3	8.1
Median earned income per six months (\$)	1,120	718	280
Work variables			
Number	144	51	40
% with no job	19.4	23.6	27.5
% working mostly part-time	29.2	23.5	37.5
% working mostly full-time	51.4	52.9	35.0
% attending school	16.7	5.9	5.0
Median number of days worked			
during last six months	53.5	40	12
Service system use variables			
Number	145	53	40
% nonusers	40.0	35.8	25.0
% episodic users	19.3	15.1	15.0
% regular users	40.7	49.1	60.0
% county mental health center users	31.0	50.9	62.5
% private therapist users	29.0	17.0	20.0
Median number of outpatient visits			
during last six months	2	4	9.5
Median number of days as outpatient			
during last six months	30	87	123
Social network, social support, and dependence variables			
Number	119	51	38
% with one or more difficulties with ADL	73.1	80.4	76.3
% with one or more helpers with ADL	55.5	54.9	55.3
% listing one or more MHPs in social network	66.4	70.6	78.9

(continued)

TABLE 1 continued

	Baseline	Applicants	Recipients
<i>Needs/resources variables (continued)</i>			
% listing one or more MHPs on grid	24.4	33.3	42.1
% living alone	17.6	27.5	23.7
% with parent in the household	42.0	39.2	42.1
% with spouse in the household	9.2	3.9	2.6
% with adult child in the household	2.5	2.0	2.6
% financially dependent on family	28.6	41.2	44.7
Mean SASB submit coefficient	0.12	0.21	0.22
Mean SASB control coefficient	0.40	0.31	0.29
Mean symmetry score	0.69	0.54	0.42
Mean network size	11.8	11.6	11.6
Network composition			
Median % relatives	64.3	66.7	64.1
Median % friends	25.0	25.0	25.2
Median % MHPs	8.3	9.1	10.8
<i>Labeling variables</i>			
Illness behavior variables			
Number	146	54	39
Self-labeling			
% no	43.8	42.6	38.5
% yes	48.6	44.4	53.8
% don't know	7.5	13.0	7.7
Illness explanation			
% no explanation	11.6	14.7	12.8
% medical model	35.6	38.9	46.2
% emotional model	24.0	16.7	28.2
% medical/emotional model	8.2	9.3	5.1
% other model	20.5	20.4	7.7

*Abbreviations:* ADL, activity of daily living; BPRS, Brief Psychiatric Rating Scale; MHP, mental health professional; PERI, Psychiatric Epidemiology Research Interview (see text for components); SASB, Structural Analysis of Social Behavior; SES, socioeconomic status; SSI, Supplemental Security Insurance; SSDI, Social Security Disability Insurance.

*demographic; impairment; needs/resources* (income, work, mental health service system use, social network, social support, and dependence); and *labeling* (illness behaviors). Receipt of SSI and SSDI is the outcome variable, and application is a mediating variable.

*Application.* Information about application was primarily derived from self-reports, elicited at each interview via questions about the

sources and amount of respondents' income. We also learned of applications for SSI/SSDI from interviews with mental health staff and respondents' SOs, but we always confirmed these reports with the respondents before considering a person to be an applicant. Among the 146 respondents in the multivariate analyses, 37.7 percent applied for SSI/SSDI and 29.5 percent became recipients. Figure 2 illustrates the timing of application and receipt and, as is apparent, most of the applications (36, or 65.5 percent) occurred between the baseline and second interviews, declining over the study period. Receipt peaked in the middle study periods, declining gradually to the last interview. We coded the six-month time periods before each interview as dummy variables for the event history analysis, with the pre-baseline period as the reference category.

*Receipt.* Receipt of SSI and SSDI was primarily self-reported by study participants. At each interview after baseline, SSI and SSDI were included in the checklist of income sources. If a person did not mention SSI or SSDI during this portion of the interview, we again queried at the end of the session whether they had applied or become a recipient. Then we asked open-ended questions about the person's views of applying and becoming a recipient. Information about receipt of SSI and SSDI was

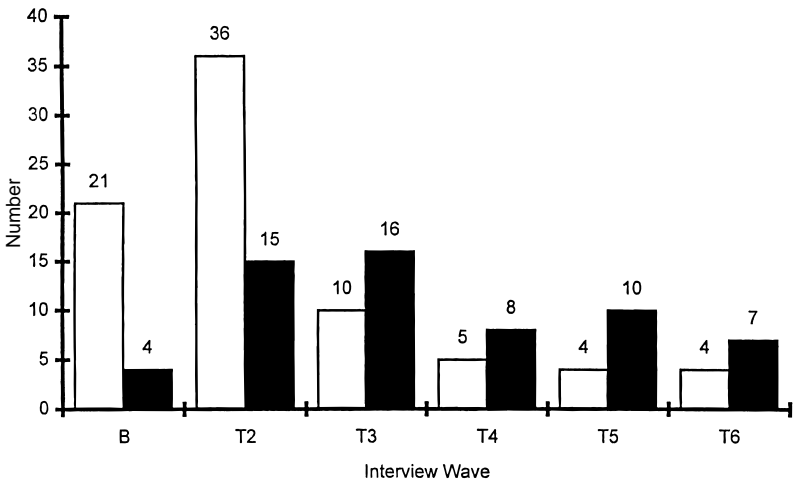


FIG. 2. Number of applicants and recipients by interview wave (N = 169). □, apply; ■, receive.



also gathered during interviews with SOs. A very high proportion of those who applied, 78.2 percent, became recipients.

*Demographic Variables.* Almost 31 percent of the baseline respondents were African American, slightly higher than their 25 percent representation in the census of the recruitment counties. African-American subjects are overrepresented among recipients at about 35 percent, given their initial percentage at baseline. Socioeconomic status (SES) was derived by using the Hollingshead and Redlich (1958) four-factor (education, age, marital status, and occupation) method for the respondent if he or she had an occupation; if not, it was applied to the respondent's parents when the respondent lived in the parental home. Respondents fell into five groups, with SES 1 being the highest group and SES 5, the lowest. Most respondents were ranked in SES 4 (30.8 percent), with the others fairly evenly spread across the other four groups. Although respondents in SES 5 were no more likely to apply for SSI/SSDI, a higher proportion became recipients. There were nearly equal numbers of men and women, but women were less than half of the recipients. The average age of respondents was 28.4 years, reflecting our attempt to sample individuals early in their experiences with psychiatric illnesses. Only 10.3 percent of the baseline respondents were married; one married subject received SSI/SSDI.

*Impairment Variables.* We summed eight symptom constructs from the BPRS checklist (Luckoff, Liberman, and Neuchterlein 1986; Overall and Gorham 1962) to provide an interviewer assessment of clinical impairment. These were conceptual disorganization, excitement, motor retardation, blunted affect, tension, mannerisms and posturing, uncooperativeness, and emotional withdrawal. At the end of each interview, the interviewer rated the respondent on these dimensions. The mean BPRS score for the sample is 12.7, and as expected, recipients had a higher mean score, indicating greater symptom severity.

The second method of symptom assessment consisted of combining eight PERI subscales that measured primary psychiatric symptoms: antisocial history (AH); demoralization (DM); schizoid personality (SP); perception of hostility (PH); suicidality (SI); confused thinking (CT); false beliefs and perceptions (FBP); and mania (M). The PERI (Dohrenwend et al. 1980, 1983a,b) is a self-report symptom scale with a one-year referent time frame. In general, recipients had somewhat higher symptom scores than the remainder of the sample.

Diagnosis was based on repeated review of clinical records with reference to the most recent *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed., rev.). People with a diagnosis of schizophrenia were more likely to apply for and receive SSI/SSDI than individuals in all other diagnostic groups; however, this difference is not statistically significant.

Because they were recruited primarily in hospitals, most of the sample participants, 91.6 percent, were hospitalized in the six months prior to the first interview. The number of years since the first hospitalization ranged from zero to 24 years, with a median of two years. Recipients had a median duration since first admission one year longer than others in the study. Only 10 percent of the sample had been first hospitalized eight or more years ago. We collected data on the number of days spent in the hospital via self-report and repeated review of hospital charts. For each of the three measures of days spent in the hospital, recipients had more hospital days.

*Income Variables.* Income was measured at each interview wave except baseline because we determined in pilot interviews that finances were a topic too personal to broach at this initial meeting. In the subsequent interviews, income and finances were discussed extensively. Most respondents felt their needs were taken care of poorly (30.9 percent), and a majority of respondents (57.3 percent) saw themselves as worse off than their peers. Applicants for disability income generally viewed themselves as worse off financially than either nonapplicants or recipients; however, recipients had median earned income well below that of all others in the study.

*Work Variables.* We asked respondents about their work activity repeatedly and intensively. Only 19.4 percent had no job during the six months prior to the first interview, 29.2 percent worked mostly part time, and 51.4 percent worked mostly full time. There were no significant differences in receipt by work pattern, but recipients worked substantially fewer days than others in the study.

*Mental Health Service System Use Variables.* Use of mental health center services and private therapists was self-reported. The frequency and pattern of mental health center use were collected from billing records provided by the centers (see George 1989).

*Social Network, Social Support, and Dependence Variables.* Social network/social support data covering a wide range of topics were gathered at each interview. There was no limit to the number of network members a

respondent could list when determining network size. A large portion of the sample had difficulties with ADLs like cooking, doing laundry, and transportation (73.1 percent). However, only 55.5 percent named one or more people who helped them with their daily lives. Mental health professionals (MHPs) were often named as part of the respondents' networks, and recipients were more likely than others to name an MHP as one of their five most important network members.

Few of the respondents lived alone (17.6 percent). Many lived with their parents (42.0 percent), and a few lived with a spouse (9.2 percent) or with their own adult child (2.5 percent). Again, only one recipient lived with a spouse. Financial dependence on the family is a variable constructed by comparing earned income with monetary and in-kind contributions from others. When monetary and in-kind resource contributions exceeded earned income, the person was considered financially dependent. More than a quarter of the sample was financially dependent on their family (28.6 percent), and both applicants and recipients were far more likely to be in such a position.

The Structural Analysis of Social Behavior (SASB) scale (Benjamin 1974, 1979) requires the respondent to choose another person with whom they rate their own behavior and the other's behavior in relation to themselves. Most respondents selected their mother as the person with whom they rated themselves. The submit and control coefficients measure dependency and enmeshment within this identified relationship. A person describes him- or herself as submissive and compliant in relation to the authority or control of an identified other. The coefficients range from  $-1$  (least controlling or submissive) to  $1$  (most controlling or submissive). Recipients describe themselves as more submissively dependent on their most significant others than the original sample.

Recipients had fewer give-and-take relationships than the subjects at baseline, as indicated by the symmetry scores. Social network size ranged from 1 to 30 members, with an average of about 12 people. These networks consisted predominantly of relatives (64 percent on average of respondents' networks). A quarter of these networks consisted of friends, and 8.3 percent were MHPs.

*Illness Behavior Variables.* The respondents' self-labeling position and explanation of the nature and workings of their problems were discussed during each interview. Verbatim responses to a series of structured questions were entered into a text base and coded. A respondent could label

him- or herself as mentally ill ( at baseline, 48.6 percent of the sample), decline to so label (43.8 percent), or indicate that they did not know whether they were mentally ill (7.5 percent) (see Appendix). Although individuals who labeled themselves as mentally ill were more likely to receive disability income than those who did not self-label, a significant group of people who did not consider themselves mentally ill also applied for SSI/SSDI.

Five types of illness explanations were identified: no explanation; a medical/clinical model; an emotional/developmental model; a social model; and, in the opinion of some respondents, no problem to explain. At baseline, over one-third of the respondents, 35.6 percent, had a medical model, 24.0 percent had an emotional model, and 8.2 percent combined a medical and emotional explanation of their illness. Among recipients, the predominant explanation was a medical one.

There are statistically significant bivariate relations between receipt and at least one variable from each domain. Nearly all of these were in the expected direction, anticipated by the impairment, needs/resources, and labeling models.

## Analysis Techniques

We used text analysis and other qualitative methods along with multivariate statistical techniques to analyze the data. The goal with both types of analysis was to look at the explanatory contributions of the three models—impairment, needs/resources, and labeling—to the process of becoming a recipient. To analyze survey data on application and receipt, we used discrete event history analysis (Allison 1982,1984). We used logistic regression to estimate separately the effects of the explanatory variables on the odds of receiving of SSI and SSDI.

## Results

Among the original study cohort of 169 people, 80 (47 percent) applied for disability income during the 32 months. Sixty people, or 35.5 percent of the cohort, became recipients. There were 28 SSI recipients, 24 SSDI recipients, and eight concurrent recipients. Eight people applied

twice and, among these, six became recipients. The remainder became recipients after one application. In the analyses that follow, the number of recipients is 37 because event history analysis requires complete data for each subject. The overall sample size and the number of recipients are small, making this analysis suggestive. Coupling the qualitative and this quantitative analysis gives us greater confidence in our findings.

### *Modeling Receipt*

First, we analyzed variable domains derived from the conceptual model one at a time in relation to receipt. Then we put all of the variables that were significant in the domain analyses into a final model. The coefficients in table 2 are effects on the odds of receipt that were significant when in a model with variables from the same conceptual domain. The time period variables (pretime 2 to pretime 5) refer to the six-month study periods from baseline until the time subjects became recipients of SSI/SSDI. The predicted probability of application is included to control for the self-selective nature of the application process that must precede receipt of SSI/SSDI (Berk 1983). Only applicants are at risk of receipt; therefore all nonapplicants were deleted from the sample before the analysis. The probability of application variable controls for this selection into the sample and allows us to separate effects of variables on application from those on receipt.

The strongest predictors of receipt derive from the demographic, impairment, and needs/resources pathways. In particular, confused thinking, submissive dependence in a primary relationship, and being African American greatly increase the odds of becoming a recipient, whereas living with a spouse and having a larger social network lower the likelihood. Additional significant contributions to receipt are made by interviewer-rated impairment (BPRS score) and financial dependence on family. However, none of the illness behaviors in the labeling pathway had a significant influence on receipt. The picture that emerges of recipients is one of individuals who are instrumentally and affectively dependent, impaired by psychiatric symptoms, and whose social networks reflect isolation and the absence of age-appropriate primary relations, such as, for example, with spouses.

TABLE 2  
Effects of Significant Domain Variables Taken Together  
on the Odds of Receipt<sup>a</sup>

Explanatory variables	
Time periods	
Pretime 2	1.913
Pretime 3	0.697
Pretime 4	10.705*
Pretime 5	27.053**
Predicted probability of application	23.424
Demographic variables	
African American	7.041**
Impairment variables	
BPRS score	1.361***
PERI SI score	0.520
PERI CT score	20.729***
Needs/resources variables	
Income variables	
Financially eligible	0.305
Social network, social support, and dependence variables	
Spouse in household	0.004***
Financially dependent on family	5.238*
SASB submit coefficient	7.693**
Social network size	0.852**
Model chi-square	64.77***/14df
Recipients	37

<sup>a</sup>N = 91.

\* $p < .10$ ; \*\* $p < .05$ ; \*\*\* $p < .01$ .

Abbreviations: See table 1.

## Discussion

In our earlier work, we found that dysfunction, demoralization, and dependence led to application for disability income. We expected that the factors influencing receipt would differ somewhat because application reflects the needs and actions of individuals with impairments, their families, and providers, whereas receipt reflects the procedures,

criteria, and actions of SSA and Disability Determination Services (DDS) officials (see Appendix). Impairment and needs/resources drive the disability income application and receipt process among this cohort. Confused thinking, a hallmark symptom of psychosis and schizophrenia, and the more global BPRS rating substantially increase the likelihood of receipt. Psychological dependence and submissiveness in relation to the most significant other, represented by the SASB submit coefficient, make another significant contribution, as does financial dependence on family. In addition to dysfunction and dependence, demographic characteristics, such as being African American, emerge as highly influential in this analysis.

Most study participants became involved in the disability income application process reluctantly, after repeated efforts to work and support themselves by other means, and with the substantial involvement of their families and mental health professionals. Seldom, if ever, were these decisions made primarily by the study participants alone, and equally rarely were the respondents the sole beneficiaries of receipt. We view the process as entangled with and reflective of the needs of service providers and members of the respondents' social network, and in relation to the limited opportunities available to them.

It is important to note that particular kinds of dependence on particular others is associated with receipt: financial and psychological dependence on family members, primarily parents, is critical, whereas dependence on spouses and other social network members is not. We take this to mean that those persons who were socially isolated from peers and partners, and reliant primarily on kin—perhaps as a result of their symptoms and stigmatization by others—became recipients. The combination of impairment and impoverished resources suggests that these recipients are precisely those for whom disability income was intended. In this sense, the findings should counter concerns that SSI and SSDI are being sought and received by persons with mental illness who are not seriously impaired or desperately in need of financial support (Yelin 1986).

We did not anticipate finding that race would exert such a strong effect on receipt. There are several possible explanations. It seems likely that major mental illness has a worsening effect on preexisting social and functional disadvantage among African Americans, largely attributable to discrimination and lack of opportunity. These complex socio-

economic and class-based stresses constitute the context within which African Americans experience schizophrenia and other major mental disorders (Neighbors 1987). The disadvantages faced by African Americans in the labor force, in housing, and in opportunities for upward mobility contribute to the diminution of social network resources, which may be overwhelmed by the tremendous demands of caring for a relative with a serious psychiatric disorder. The well-documented underutilization and lack of access to outpatient mental health services among African Americans represents another crucial lack of resources for coping with major psychiatric disorder (Lawson 1986; Brown et al. 1995). In this sense, our results illustrate the double, if not triple, jeopardy of being African American and having a serious psychiatric disorder.

A recent study by Lindsey, Paul, and Mariotto (1989) found that, compared with whites, the African Americans who presented for involuntary psychiatric admission had more “deficiencies in adaptive functioning” in areas like interpersonal interactions, self-maintenance, and instrumental activity, according to ratings by interviewers and clinicians. The repertoire of instrumental functioning of African Americans was more limited than that of whites, resulting in a composite rating of African Americans as having a greater level of disability than whites. These findings lend some empirical support to the notion that being African American and having a major psychiatric disorder results in measurable disadvantages, stemming from accumulated deprivations and obstacles—including lack of appropriate, accessible outpatient mental health services—that may have an important influence on their need and eligibility for disability income.

It is not surprising that these conditions would enhance the eligibility and need for SSI receipt among the African Americans in the study, particularly because SSI is household- and income-tested but requires no prior contribution to Social Security via earned income. A recent study by the General Accounting Office (1992) supports this view, noting that a lower proportion of African Americans than whites are insured by Social Security and thus eligible for SSDI. In contrast, a higher proportion of African Americans are eligible by income alone for SSI, largely because of their substantial disadvantage in labor force participation. Our findings starkly illustrate this pattern. Among the 16 African American recipients, 80 percent received SSI, in contrast to white recipients, among whom only 32.1 percent were SSI recipients. Almost half, 46.4 percent, of white recipients got SSDI, whereas only three African Amer-



icans, 20 percent of recipients, were awarded SSDI. All of the concurrent recipients were white.

It is important to note that there were no significant differences in application for disability income by race in our study. Arguably, if the African Americans in the sample were disproportionately eligible, they should have applied at a higher rate than whites. They did not. In virtually all national surveys, African Americans report higher rates of inability to work based on disability (General Accounting Office 1992). We might then argue that, in view of need and eligibility, African Americans in the cohort were *underutilizing* or *underapplying* for disability income.

The same study conducted by the General Accounting Office (1992) investigated racial differences in allowances for disability income. Overall, at the initial decision level, 29 percent of African-American applicants and 36 percent of white applicants were allowed SSI and SSDI benefits in 1988, the sample year for the study (General Accounting Office 1992, 31). The GAO found that African Americans were allowed at comparable rates to whites in the SSI and SSDI programs, except in the 18- to 24-year-old age group. In this age range in both programs, African-American applicants had allowance rates for benefits about three times lower than whites (General Accounting Office 1992, 29). The mean age of the study participants was 28 years, so we would not expect that they would be subject to these lower allowance rates. However, in the two categories of most relevance to our findings, African Americans with schizophrenia and “other” mental impairments were less likely than whites to be awarded benefits (see Appendix). This would seem to be at some variance with our findings. The overall allowance rate for our sample is 67.5 percent; for respondents in this analysis, it is 72 percent for whites and 94 percent for African Americans. The national allowance rate for all applicants in 1988 was 32.5 percent. The difference in our findings and those of the GAO may be explained in large part by the nature of our study cohort—a sample of persons in treatment for major psychiatric disorders who had poor work histories. In effect, we selected people for the study who we thought already were, or soon would be, eligible for disability income. The GAO sample was of all those who applied for SSI and SSDI benefits in 1988. The GAO study did not report allowance by impairment type by region. Since the South was the region reporting the smallest African-American–white allowance differential, it is possible that the experience of this North Carolina cohort

is not so different from other applicants with major psychiatric disorders in the South.

Finally, our findings regarding race and receipt illustrate well-recognized difficulties in the use of race as a single variable in multivariate analysis (Osborne and Feit 1992; Dressler 1993; Adebimpe 1994). We deliberately included measures of social class, social network composition and size, illness behaviors, material resources, work experience, use of mental health services, health status, and a host of other factors we expected to reflect differences in African-American and white study participants. Yet race retains an independent and significant effect on receipt of disability income. Thus, while we report our findings with confidence, we acknowledge the explanatory limitations of race as a single variable. As Link and Phelan (1995) and others argue, the confluence of structural, experiential, and socioeconomic factors that are glossed when we refer to race is difficult to operationalize and perhaps impossible to separate or sort out. Our findings confirm that the disadvantages of being African American in present-day U.S. society are cumulative and pervasive. The additional devastation of schizophrenia and other major psychiatric disorders understandably enhances the need for public resources via disability income. The good news is that those in such substantial need in this cohort were able to obtain the financial assistance provided by SSI and SSDI.

### Enabling and Disabling Income

Despite the lack of statistical significance of illness behavior variables in the event history analysis, the extensive qualitative data gathered during the study make a strong case for continued consideration both of labeling dynamics and trajectories and of the study participants' experiences with symptoms, treatment, work, and primary relationships in processes of disablement and rehabilitation. Many respondents were engaged in ongoing turmoil over their present and future well-being, the losses associated with having a major mental illness, their inability to live on their own, and the necessity of asking for help from public sources.

In our view, SSI and SSDI application and receipt represent two of the most influential events in a course of chronicity and the experience of severe mental illness. For the current generation of persons with severe,

persistent psychiatric disorders, becoming formally designated as *disabled* through SSI and SSDI receipt has replaced long-term hospitalization as a crucial social factor shaping the course and direction of disablement. Getting disability income can be viewed as the intervention of longest duration and most potential impact for current generations of persons with severe, persistent mental illness. Hennessey and Dykacz (1989) report that people with psychiatric impairments have the longest mean tenure (15.6 years) of any diagnostic group in the SSDI program.

Like the hospital, disability income is both nurturing and confining; it may relieve survival stresses and strains but may also spawn despair. In a fashion similar to the prolonged hospitalization, disability income helps family members and others who provide care and resources to those unable to find and retain work. Like long-term hospitalization, being on disability puts the individual in an indelible sociomedical and personal category. A new form of labeling may also be supplanting psychiatric diagnosis: that of disability recipient or “disabled” person. What so vexes policies and the various parties to the debate is that, for many persons with serious mental illness, SSI and SSDI represent a necessary buffer against the stresses of employment and community life (Lamb and Ragowski 1978).

The unintended consequences of receipt may countervail or undermine the supportive and therapeutic goals of the SSI and SSDI programs (Walls, Dowler, and Fullmer 1990). Several initiatives like 1619a and 1619b and the Plan for Achieving Self Support (PASS; see Appendix), have been developed in recent years by the SSA to counteract the most obvious disincentives to attempt work and rehabilitation. None of these initiatives has resulted in a significant departure by the target population from the rolls because of medical improvement or return to work. As of September 1992, slightly more than 5,000 of the 5.5 million SSI recipients were participating in the PASS program and, of these, only 1.1 percent had earned income—that is, a job (Prero 1993). It is even more significant that the “recovery” rate, or the rate of persons who leave the rolls because of self-reported or clinician-assessed medical improvement and/or a return to gainful employment, is at an all-time low of about 0.5 percent (National Academy of Social Insurance 1994, 82).

Fear of losing SSI and SSDI is a significant and realistic obstacle to risk-taking in vocational rehabilitation or employment by disabled recipients, and it may influence both the stance taken by their most

significant others (relatives) toward their attempts to work and the way recipients are viewed and treated by providers (Jensen 1990). This concern is articulated by one person in the study:

I'm always afraid—I'm still getting disability. I'm always afraid they're gonna write me a letter and say, "This has been a mistake. We want you to pay back \$1200 bucks now." You know? I'm always scared they're going to say give this money back that I just don't have.

The rules and criteria for SSA work initiatives are poorly understood by clients, their families, and mental health providers.

*Client:* I've got some medical bills that I've got to pay off [with the SSI money].

*Interviewer:* Is that going to have any effect on what you do for work?

*Client:* Well, I can't work on disability. I don't know what the rules and regulations are, cause I got the money, I got the check Saturday, but I didn't get a letter . . . . I don't know what the rules are."

Receipt of disability income may have profoundly mixed meanings, a view expressed in numerous ways by many study participants (Caras 1994). There may be conflict between patient and staff, or patient and family, about whether or when to apply. Depending upon who makes such a suggestion or decision, the individual's responses may move through despair, relief, anger, and resignation. The timing and process by which such significant choices are made are critical and may either solidify or injure a nurturing or explicitly therapeutic relationship.

Thus, disability income may play multiple roles in confirming an individual's devalued, disabled patient status, in facilitating withdrawal from the opportunity to interact with others, like work associates, thereby leading to and sustaining an isolated, stigmatized existence well below the poverty line (Cohen 1993).

- "Well, it's just—it's day by day. There's not enough money, but there's more money than it was before. At least I can pay my rent and power, you know. I mean, it's still a struggle. It's depressing kind of, you know, to know that I can't get out and do the things I did just a few years ago."

- “It’s not nothing to live off of . . . you know if I get in my career I can go on by myself, but I, I still have to settle down for that disability, but that’ll give me more money. . . . Nobody ain’t goin’ turn down money they just give to me, but just to help me out. But it’s not enough to support yourself. It’s not enough. You can’t just sit back on life cause everything goes on, just wait on that once a month thing. . . . I’d still want to work because you get bored just sitting around the house waiting on a check.”

Charmaz (1983) describes eloquently how “chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones.” We consider here that SSI and SSDI may play conflicting roles, abetting the crumbling away while easing suffering and stresses. The overwhelming problem is, however, that so few benign alternative means of financial support are available for persons so affected that gainful employment is not feasible.

## Policy Considerations and Conclusions

The main findings of this investigation are that impairment and absence of adequate financial and social resources drive the disability income receipt process. In this cohort, people with more severe limitations arising from psychiatric disorders who cannot, even with repeated effort, support themselves, applied for and received disability income. The results do not support the view that disability income is being received by people who *choose* not to work or by people who have mild impairments and seek to supplement already sufficient material sustenance. Despite widespread concerns about the unintended consequences of disability income receipt—reservations that we clearly share—we take the view that unless there are sufficient alternate resources in place and in the hands of people with disabilities, SSI, SSDI, Medicare, and Medicaid are bare necessities. Because persons with psychiatric impairments are the largest group of SSI and SSDI recipients, we anticipate that many will be terminated from disability income receipt as a result of the current SSA continuing disability reviews. In view of our findings and in the absence of alternative means of support, the potential damage done to these individuals and their families could be substantial (see

U.S. Senate 1983; General Accounting Office 1989). The confluence of these reviews and terminations with widespread cessation of public assistance benefits is particularly unfortunate. How will persons with disabilities fare in a labor market increasingly crowded with participants in numerous state and local welfare/workfare programs? The attention and resources being directed toward work training and placement for welfare recipients could easily result in even fewer opportunities for persons with disabilities in the workplace.

Most of the ironies and paradoxes of disability income described here are not new and have proved resistant to many a promising policy initiative (Reno, Mashaw, and Gradison 1997). Universal health insurance and a shift from illness testing of benefits to needs testing would uncouple disablement from dollars but is probably politically infeasible at present. The dichotomous conditions of being either on or off the benefit rolls, with no feasible or understandable middle ground, is a widely recognized and significant obstacle to a more reasonable policy (National Academy of Social Insurance 1994). Presumptive eligibility for SSI and SSDI, along with Medicaid and Medicare, for three to five years regardless of employment status and earned income might help some recipients attain or retain jobs with less fear of loss of any source of income.

Work incentives are another important challenge. However, SSA regulations regarding earned income by recipients are complicated and seldom understood, with the result that few beneficiaries believe they can retain SSI or SSDI when working even though technically they can. In this regard, one of the most striking findings of our study is the amount of work activity among the cohort, both before and after application for, and receipt of, SSI and SSDI. Nearly two-thirds of the sample reported at least some paid employment during each study period, and nearly half of recipients reported work days after receipt. What drove the respondents to disability income were their meager earnings and financial dependence on their families, not a lack of interest in working or an absence of attempts to work.

SSA policies regarding work incentives need to be informed by experiments that test various means of influencing employers and vocational rehabilitation services, not just recipients themselves. The newly proposed SSA "Ticket to Independence" demonstration program (see Berkowitz 1997) is intended to create beneficiary and rehabilitation provider incentives for finding and sustaining more work opportunities (Social Security Administration 1997, 5). The program allows benefi-

ciaries to work with providers other than state vocational rehabilitation agencies and rewards the provider with a portion of the beneficiaries' SSI or SSDI payments when these cease owing to work-derived earnings, that is, if the recipient is successfully, gainfully employed. Medicaid and Medicare coverage are extended into the employment period. Whether the program is enacted, and with what results, remains to be seen.

Some additional policy implications arise from our analysis that do not require further data. Receipt of SSI and SSDI among persons with psychiatric disorders is increasingly used as an indicator of chronicity and severity of disability by state and local mental health authorities for purposes of service system resource allocation and public mental health policy formulation. Although we consider SSI and SSDI application and receipt to be crucial components of the political economy of disability, we have reservations about the potential unintended consequences of relying on receipt as the primary indicator of need for services or level of dysfunction at the individual level and for systems-level planning, needs assessment, and financing of services.

There is a danger of developing a mentality or policy that if a person were "really disabled" he or she would be receiving SSI or SSDI; thus nonrecipients could be considered to be less in need or deserving of services. In fact, the opposite may be the case, and nonrecipients may have fewer resources, and thus greater service needs than recipients. All the data reported and reviewed here indicate that at best about half of individuals with enduring, serious psychiatric disorders receive SSI and SSDI. SSI and SSDI receipt should be used only as one of multiple indicators of extent of disablement among a population when needs assessments and resource allocation decisions are made. If services and resources are accessible primarily to those with the Section 8 federal housing subsidy and Medicaid or Medicare coverage, often available only to SSI and SSDI recipients, this would doubly disadvantage people with disabilities who are arguably most in need: those who are eligible for benefits but too impaired, stigmatized, or uninformed to become recipients, or those who are working for minimum wages on the margins of eligibility, whose productivity and well-being would be prolonged, if not enhanced, by income supports.

Providing societal support to those made vulnerable by their impairment, their disability, and their lack of opportunities is a major challenge to public will and ingenuity. Few participants in this study settled easily into the roles of disability income applicant and recipient. Many

grieved as much over their need for public resources as over the discomforts of their illnesses. In our view, social policy should augment individual and family resources that are insufficient to meet undesired and unexpected needs in the quest for meaningful and valued lives in the presence of severe mental illness. The safety net of the future should be strong and flexible enough to support and protect those who need it and to assist those who can and will find ways to meet some or all of their needs.

## References

- Adebimpe, V.A. 1994. Race, Racism, and Epidemiological Surveys. *Hospital and Community Psychiatry* 45(1):27–31.
- Allison, P.D. 1982. Discrete-Time Methods for the Analysis of Event Histories. In *Sociological Methodology*, ed. S. Leinhardt, 61–98. San Francisco: Jossey–Bass.
- . 1984. *Event History Analysis: Regression for Longitudinal Event Data*. Beverly Hills, Calif.: Sage.
- Bell, C. 1997. The Americans with Disabilities Act, Mental Disability, and Work. In *Mental Disorder, Work Disability, and the Law*, eds. R. Bonnie and J. Monahan, 55–104. Chicago: University of Chicago Press.
- Benjamin, L.S. 1974. Structural Analysis of Social Behavior. *Psychological Review* 81:392–425.
- . 1979. Structural Analysis of Differentiation Failure. *Psychiatry* 42:1–23.
- Berk, R.A. 1983. An Introduction to Sample Selection Bias in Sociological Data. *American Sociological Review* 48:386–98.
- Berkowitz, M. 1997. Linking Beneficiaries with Return-to-Work Services. In *Disability*, eds. V. Reno et al., 41–6, Washington, D.C.: National Academy of Social Insurance.
- Brown, D.R., F. Ahmed, L.E. Gary, and N.G. Milburn. 1995. Major Depression in a Community Sample of African Americans. *American Journal of Psychiatry* 152:373–8.
- Cain, L.P. 1993. Obtaining Social Welfare Benefits for Persons with Serious Mental Illness. *Hospital and Community Psychiatry* 44:977–80.
- Calsyn, R.J., C.W. Kohfeld, and L.A. Roades. 1993. Urban Homeless People and Welfare: Who Receives Benefits? *American Journal of Community Psychology* 21(1):95–112.



- Caras, S. 1994. Disabled: One More Label. *Hospital and Community Psychiatry* 45:323-4.
- Carpentier, N., A. Lesage, J. Goulet, P. Lalonde, and M. Renaud. 1992. Burden of Care of Families Not Living with Schizophrenic Relatives. *Hospital and Community Psychiatry* 43:38-43.
- Charmaz, K. 1983. Loss of Self: A Fundamental Form of Suffering in the Chronically Ill. *Sociology of Health and Illness* 5(2):168-95.
- Cohen, C.I. 1993. Poverty and the Course of Schizophrenia. *Hospital and Community Psychiatry* 44:951-7.
- Dohrenwend, B.P., P.E. Shrout, G. Egri, and F. Mendelsohn. 1980. Nonspecific Psychological Distress and Other Dimensions of Psychopathology. *Archives of General Psychiatry* 37:1229-36.
- Dohrenwend, B.P., I. Levav, and P.E. Shrout. 1983a. Screening Scales from the Psychiatric Epidemiology Research Interview (PERI). In *Community Surveys*, eds. J. Myers, M. Weissman, and C. Ross. Rutgers, N.J.: Rutgers University Press.
- Dohrenwend, B.S., B. P. Dohrenwend, B. Link, and I. Levav. 1983b. Social Functioning of Psychiatric Patients in Contrast with Community Cases in the General Population. *Archives of General Psychiatry* 40:1174-82.
- Dressler, W. 1993. Health in the African American Community: Accounting for Health Inequalities. *Medical Anthropology Quarterly* 7(4):325-45.
- Dykacz, J.M., and J.C. Hennessey. 1989. Postrecovery Experience of Disabled-Worker Beneficiaries. *Social Security Bulletin* 52(9):42-60.
- Erikson, K.T. 1957. Patient Role and Social Uncertainty: A Dilemma of the Mentally Ill. *Psychiatry* 20:263-72.
- Estroff, S.E. 1985. *Making It Crazy*. Berkeley: University of California Press.
- . 1989. Self, Identity, and Schizophrenia: In Search of the Subject. *Schizophrenia Bulletin* 15(2):189-96.
- Estroff, S.E., W.S. Lachicotte, L. Illingworth, A. Johnston, and B. Ruth. 1991. Everybody's Got a Little Mental Illness: Accounts of Illness and Self Among Persons with Severe, Persistent Mental Illness. *Medical Anthropology Quarterly* 5(4):331-69.
- Estroff, S.E., C.R. Zimmer, W.S. Lachicotte, J. Benoit, and D.L. Patrick. 1997. "No Other Way to Go." Pathways to Disability Income Application among Persons with Severe, Persistent Mental Illness. In *Mental Disorder, Work Disability, and the Law*, eds. R. Bonnie and J. Monahan, 55-104. Chicago: University of Chicago Press.
- Ferron, D.T. 1995. Diagnostic Trends of Disabled Social Security Beneficiaries, 1986-93. *Social Security Bulletin* 58(3):15-48.

- General Accounting Office. 1989. *Social Security Disability: Denied Applicants' Health and Financial Status Compared with Beneficiaries*. Report no. HRD-B-229289. Washington, D.C.
- . 1992. *Social Security: Racial Differences in Disability Decisions Warrants Further Investigation*. Report no. HRD-92-56. Washington, D.C.
- George, L.K. 1989. Definition, Classification, and Measurement of Mental Health Services. In *The Future of Mental Health Services Research*, eds. C. Taube, D. Mechanic, and A. Hohmann, 303–19. DHHS pub. no. (ADM)89-1600. Washington, D.C.
- Goldman, H., and A. Gattozzi. 1988. Balance of Powers: Social Security and the Mentally Disabled, 1980–1985. *Milbank Quarterly* 66:531–51.
- Gronfein, W. 1985. Incentives and Disincentives in Mental Health Policy: A Comparison of the Medicaid and Community Health Programs. *Journal of Health Social Behavior* 26(Sept.):192–206.
- Hatfield, A., and H. Lefley. Eds. 1987. *Families of the Mentally Ill*. New York: Guilford.
- Hennessey, J.C., and J.M. Dykacz. 1989. Projected Outcomes and Length of Time in the Disability Insurance Program. *Social Security Bulletin* 52(9):2–38.
- Hollingshead, A.B., and F. Redlich. 1958. *Social Class and Mental Illness*. New York: Wiley.
- Iglehart, J.K. 1996. Managed Care and Mental Health. *New England Journal of Medicine* 334(2):131–5.
- Jacobs, H.E., D. Wissusik, R. Collier, D. Stackman, and D. Burkeman. 1992. Correlations between Psychiatric Disabilities and Vocational Outcome. *Hospital and Community Psychiatry* 43:365–9.
- Jensen, A. 1990. Consumers' Experiences with Work Incentive Policies in the SSI and SSDI Programs. Elmhurst, Ill.: National Foundation for People with Disabilities.
- Kennedy, C., and R.W. Manderscheid. 1992. SSDI and SSI Disability Beneficiaries with Mental Disorders. In *Mental Health, United States, 1992*. Washington, D.C.: Department of Health and Human Services.
- Kocchar, S., and C.G. Scott. 1995. Disability Patterns Among SSI Recipients. *Social Security Bulletin* 58(1):3–14.
- Lamb, H.R., and A.S. Ragowski. 1978. Supplemental Security Income and the Sick Role. *American Journal of Psychiatry* 135:1121–4.
- Lawson, W.B. 1986. Chronic Mental Illness and the Black Family. *American Journal of Social Psychiatry* 6 (winter):67–71.
- Lefley, H. 1987. Aging Parents as Caregivers of Mentally Ill Adult Children: An Emerging Social Problem. *Hospital and Community Psychiatry* 38:1063–70.

- Lindsey, D., and M. Ozawa. 1979. Schizophrenia and SSI. *Social Work* (March):120–6.
- Lindsey, K.P., G.L. Paul, and M.J. Mariotto. 1989. Urban Psychiatric Commitments: Disability and Dangerous Behavior of Black and White Recent Admissions. *Hospital and Community Psychiatry* 40: 286–94.
- Link, B.G. 1982. Mental Patient Status, Work, and Income: An Examination of the Effects of a Psychiatric Label. *American Sociological Review* 47:202–15.
- . 1987. Understanding Labeling Effects in the Area of Mental Disorders: An Assessment of the Effects of Expectations of Rejection. *American Sociological Review* 52:96–112.
- Link, B.G., and J. Phelan. 1995. Social Conditions as Fundamental Causes of Disease. *Journal of Health and Social Behavior* (suppl.):80–94.
- Los Angeles Times*. 1996. Social Security Plans Eligibility Review (March 17).
- Luckoff, D., R.P. Liberman, and K.H. Neuchterlein. 1986. Symptom Monitoring in the Rehabilitation of Schizophrenic Patients. *Schizophrenia Bulletin* 12:578–602.
- Mashaw, J.L. 1997. The Unfinished Business of Disability Policy. In *Disability*, eds. V. Reno et al., 189–94. Washington, D.C.: National Academy of Social Insurance.
- Massel, H.K., R.P. Liberman, J. Mintz, et al. 1990. Evaluating the Capacity to Work of the Mentally Ill. *Psychiatry* 53:31–43.
- Mechanic, D. 1995. Sociological Dimensions of Illness Behavior. *Social Science and Medicine* 41:1207–16.
- National Academy of Social Insurance. 1994. Rethinking Disability Policy: Preliminary Status Report of the Disability Policy Panel. Washington, D.C. (Unpublished.)
- National Advisory Mental Health Council. 1993. Health Care Reform for Americans with Severe Mental Illness. *American Journal of Psychiatry* 150:1447–65.
- Neighbors, H.W. 1987. Improving the Mental Health of Black Americans: Lessons from the Community Mental Health Movement. *Milbank Quarterly* 65 (suppl. 2):348–80.
- Osborne, N.G., and M. Feit. 1992. The Use of Race in Medical Research. *Journal of the American Medical Association* 267:275–9.
- Overall, J., and D. Gorham. 1962. The Brief Psychiatric Rating Scale. *Psychological Reports* 10:799–812.
- Perl, J.L., and M.W. Kahn. 1983. The Effects of Compensation on Psychiatric Disability. *Social Science and Medicine* 17:439–43.
- Prero, A.J. 1993. Shifting the Cost of Self-Pay for SSI Workers in Supported Employment. *Social Security Bulletin* 56(2):44–51.

- Reno, V.P., J.L. Mashaw, and B. Gradison. Eds. 1997. *Disability*. Washington, D.C.: National Academy of Social Insurance.
- Rupp, K., and C.G. Scott. 1996. Trends in the Characteristics of DI and SSI Disability Awardees and Duration of Program Participation. *Social Security Bulletin* 59(1):3–21.
- Rupp, K., and D. Stapleton. 1995. Determinants of the Growth in SSA's Disability Programs—An Overview. *Social Security Bulletin* 58(4): 43–70.
- Satel, S. 1995. When Disability Benefits Make Patients Sicker. *New England Journal of Medicine* 333:794–6.
- Segal, S.P., and N. Choi. 1991. Factors Affecting SSI Support for Sheltered Care Residents with Serious Mental Illness. *Hospital and Community Psychiatry* 42:1132–37.
- Shaner, A., T.A. Eckman, L.J. Roberts, et al. 1995. Disability Income, Cocaine Use, and Repeated Hospitalization among Schizophrenic Cocaine Abusers. *New England Journal of Medicine* 333:777–83.
- Social Security Administration. 1997. Social Security Disability Notes Number 17. (March):5–6.
- Stolberg, S.G. 1997. Breaks for Mental Illness: Just What the Government Ordered. *New York Times* (May 4).
- Stone, D.A. 1979. Illness and the Dole: The Function of Illness in American Distributive Politics. *Journal of Health Politics, Policy, and Law* 4:507–21.
- . 1984. *The Disabled State*. Philadelphia: Temple University Press.
- Thoits, P.A., and M. Hannan. 1979. Income and Psychological Distress: The Impact of an Income-Maintenance Experiment. *Journal of Health and Social Behavior* 20(June):120–38.
- U.S. Senate. 1983. Social Security Reviews of the Mentally Disabled. S.HRG 98-170. Washington, D.C.: Special Committee on Aging, 95th Congress.
- Vladeck, B., E. O'Brien, T. Hoyer, and S. Clauser. 1997. Confronting the Ambivalence of Disability Policy: Has Push Come to Shove? In *Disability*, eds. V. Reno et al., 83–100. Washington, D.C.: National Academy of Social Insurance.
- Walls, Richard T., D.L. Dowler, and S.L. Fullmer. 1990. Incentives and Disincentives to Supported Employment. In *Supported Employment*, ed. F.K. Rusch, 251–70. Sycamore, Ill.: Sycamore.
- Yelin, E. 1986. The Myth of Malingering: Why Individuals Withdraw from Work in the Presence of Illness. *Milbank Quarterly* 6:622–49.
- . 1992. *Disability and the Displaced Worker*. New Brunswick, N.J.: Rutgers University Press.
- Yelin, E., and M.G. Cisternas. 1996. Employment Patterns among Persons with and without Mental Conditions. In *Mental Disorder, Work*

*Disability, and the Law*, eds. R. Bonnie and J. Monahan, 25–52. Chicago: University of Chicago Press.

Zola, I.K. 1992. Self, Identity, and the Naming Question: Reflections on the Language of Disability. *Social Science and Medicine* 36(2):167–73.

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## Appendix

*Disability determination process.* First it is determined that an applicant has an earned income below the substantial gainful activity (SGA) level, or \$300 per month, at the time the study participants were applying. After meeting this criterion, the application is forwarded from a Social Security field office to a DDS office, and a reviewer determines if the person's impairment is severe and meets the duration test of at least 12 months. Then the person's impairment is tested against the SSA list of medical impairments. After surviving these tests, steps 4 and 5 of the allowance process assess the vocational limitations and potential to work of an applicant, respectively. DDS examiners consult with physicians and review supporting material provided by the applicant's physician or other treatment providers. Residual functional capacity, or whether a person could perform work done in the past in view of current impairments, is an area in which the criteria for mental impairments have been changed substantially in the past decade at the urging of advocates for persons with psychiatric disorders (Goldman and Gattozzi 1988). The final determination focuses on the ability of a person who cannot perform the work he or she once did in the past to perform other work that is sufficiently available in the national economy. (See General Accounting Office [1992, 50–51] for a more detailed discussion.)

*Labeling.* Respondents were considered to be labeling themselves as mentally ill if they used a clinical psychiatric designation like manic depression or schizophrenia to describe themselves, if they called themselves mentally "sick," "crazy," or used similar popular terms, or if they indicated in other words that they viewed themselves as mentally or emotionally ill. Self-labeling designations for this analysis derive from questions posed during all six interviews. The labeling position taken most often is used here. See Estroff et al. (1991) for a more complete discussion of self-labeling. As one reviewer points out, it is possible that study participants had incentives not to label themselves as mentally ill in the research interviews, but when they were applying for disability income, the motives for applying this label to themselves were present.

*"Other" mental impairments.* These include affective disorders, alcohol and drug dependence, personality disorders, and neuroses. The GAO report notes that a higher proportion of African Americans than whites in the "other" category claimed as their impairment alcohol and drug dependence, which has the lowest allowance rate for mental impairments in general and now is not even considered an eligible impairment by SSA (General Accounting Office 1992, 32).

*Plan for Achieving Self-Support (PASS).* This is an SSA program intended to "provide the incentive and the means for SSI recipients to become employed, more self-sufficient, and ultimately, less dependent on SSI" (Prero 1993, 45). PASS allows SSI recipients to conserve or exclude assets that might exceed the usual SSA allowable limits, if these assets are being used to pursue specific self-support goals. Unearned income can also be excluded, or kept, under a PASS plan. With an approved PASS plan, the individual pays for expenses incurred in rehabilitation and employment, such as job-coaching services, case management, or training with the funds they are allowed to keep. In essence, the SSA holds harmless individuals who have and want to use their own resources to pursue a self-supporting status. The PASS plan is a written document, spelling out how the individual intends to accomplish employment goals and identifying the expenditures, like tuition, needed to pursue those goals. The initial plan covers an 18-month period and can be extended for three years. A fourth year is allowed if an educational program is involved.