

# Employment Barriers for Persons With Psychiatric Disabilities: Update of a Report for the President's Commission

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A major public policy problem is the extremely low labor force participation of people with severe mental illness coupled with their overrepresentation on the public disability rolls. This situation is especially troubling given the existence of evidence-based practices designed to return them to the labor force. This article reviews research from the fields of disability, economics, health care, and labor studies to describe the nature of barriers to paid work and economic security for people with disabling mental disorders. These barriers include low educational attainment, unfavorable labor market dynamics, low productivity, lack of appropriate vocational and clinical services, labor force discrimination, failure of protective legislation, work disincentives caused by state and federal policies, poverty-level income, linkage of health care access to disability beneficiary status, and ineffective work incentive programs. The article concludes with a discussion of current policy initiatives in health care, mental health, and disability. Recommendations for a comprehensive system of services and supports to address multiple barriers are presented. These include access to affordable health care, including mental health treatment and prescription drug coverage; integrated clinical and vocational services; safe and stable housing that is not threatened by changes in earned income; remedial and post-secondary education and vocational training; benefits counseling and financial literacy education; economic security through asset development; legal aid for dealing with employment discrimination; peer support and self-help to enhance vocational self-image and encourage labor force attachment; and active involvement of U.S. business and employer communities. (*Psychiatric Services* 57:1391–1405, 2006)

Two major policy issues in the United States today are the persistently low employment rate of individuals with disabilities, coupled with dramatic growth in the public disability rolls. Research confirms that both of these trends are magnified among people with psychiatric disabilities. Evidence further suggests that this situation is perpetuated by a series of intended and unintended consequences that arise from

current U.S. health care, disability, labor, and economic policies.

In 2002, the Subcommittee on Employment and Income Supports of the President's New Freedom Commission on Mental Health commissioned a report to examine these issues. I prepared this report, which was reviewed and approved by the Subcommittee (1), and some parts of it were incorporated into the Commission's final report, *Achieving the*

*Promise: Transforming Mental Health Care in America*, issued in 2003 (2). This article is an updated version of the subcommittee report, including more recently published research, a section on new federal policy initiatives in the fields of health care, mental health, and disability, and a series of recommendations, some of which were contained in the original report and others that are my own.

## Prevalence of disabling mental disorders

Of the adult U.S. civilian noninstitutionalized population aged 18 or older, it is estimated that 3.5 percent, or 6.7 million people, have a mental health disability, defined as a mental disorder that interferes with performance of one or more major life activities, such as the ability to live independently, work, attend school, or manage activities of daily living (3). According to the World Health Organization, mental disorders are the leading cause of disability in the United States for individuals between the ages of 15 and 44 years (4). In a nationally representative cohort of noninstitutionalized, working-age adults, mental health conditions were identified as the third leading cause of work disability (5).

## Labor force participation and psychiatric disability

Individuals with disabling mental disorders are less likely to be working and more likely to be unemployed, out of the labor force, or underemployed than those without such disorders. Four nationally representative surveys conducted between 1989 and 1998 found that

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people who had any mental illness (but who were not necessarily disabled by these disorders) had lower employment rates (48 to 73 percent) than people who did not report mental illness (76 to 87 percent) (6). Employment rates for people who met criteria for disabling mental illness were even lower, ranging from 32 to 61 percent, and lower still—22 to 40 percent—among those with diagnoses associated with high levels of disability such as schizophrenia and related disorders.

To be classified as unemployed, individuals must be actively seeking paid work. Individuals who are not seeking employment because of a disability, ill health, or other reasons are referred to as “out of the labor force,” or OLF. In an analysis of data from the Healthcare for Communities study (7), one of the four surveys cited above, the proportion of unemployed among men with disabling mental illness was 27.2 percent and the proportion OLF was 20.8 percent, compared with 4.1 percent and 5.0 percent, respectively, among those with no mental disorder. Almost a quarter (24.7 percent) of women with disabling mental illness were unemployed and 25.8 percent were OLF, compared with 6.7 percent and 14.4 percent, respectively, among women with no mental disorder. Even a college education does not ameliorate this disadvantageous position in the labor market. In the National Health Interview Survey–Disability Supplement (NHIS-D), another of the studies cited above, 43 percent of individuals with mental health disabilities who had college degrees were not working, compared with only 13 percent of college graduates without mental health disabilities (8).

Underemployment or the inadequate utilization of labor (9) is also a serious problem. Underemployment is measured in a number of ways, including being substantially overqualified for the occupation one holds, working less than full-time for economic reasons, and earning very low income (10,11). In the NHIS-D, nearly two-fifths (38 percent) of workers with mental health disabilities had jobs that paid near minimum

**Editor's Note:** This article is the third in a series of papers addressing the goals that were established by the President's New Freedom Commission on Mental Health. The commission called for the transformation of the mental health system so that all Americans have access to high-quality services that promote recovery and opportunities to pursue a meaningful life in the community. The series is supported by a contract with the Substance Abuse and Mental Health Services Administration (SAMHSA). Jeffrey A. Buck, Ph.D., and Anita Everett, M.D., developed the project and are overseeing it for SAMHSA. The series will feature 15 papers on topics such as employment, housing, and leadership, which will be solicited by the journal's editor and peer reviewed. Also planned are case studies from each of the states that received a SAMHSA-funded State Incentive Mental Health Transformation Grant.

wage, compared with only one-fifth (20 percent) of people without disabilities (8). In 1994–1995 people with mental health disabilities earned a median hourly wage of only \$6.33, compared with \$9.23 for those without disabilities, and more than one-third (36 percent) of all workers with mental health disabilities were employed in part-time jobs, compared with only 16 percent of their nondisabled counterparts (8). Among a large group of individuals with psychiatric disabilities participating in a multisite, randomized controlled trial of supported employment services called the Employment Intervention Demonstration Program (EIDP) (12), the majority of those with college degrees (70 percent) earned less than \$10 an hour (equivalent to an annual salary of \$21,000) at their highest-level job, and the majority (54 percent) were employed only part-time.

## Disabling mental disorders and public disability income

Two primary federal programs of benefits and entitlements administered by the Social Security Administration (SSA) currently assist disabled individuals who are unable to work. As argued below, there is evidence that these programs unintentionally discourage those who are capable of returning to work from doing so, thus presenting barriers to employment. Supplemental Security Income (SSI) is a means-tested income assistance program for individuals with disabilities who have little or no income and are unable to engage in substantial gainful activity because of a physical or mental impairment that is expected to last for at least 12 months or result in death (13). According to SSA's Monthly Statistical Snapshot for June 2006 (14), there were approximately 4.1 million SSI recipients between the ages of 18 and 64 years who were classified as disabled, and these individuals received an average of \$470.30 per month (many states supplement this amount to varying degrees).

Social Security Disability Insurance (SSDI) is a social insurance program for disabled individuals that provides monthly benefits to covered individuals who qualify for cash payments based on their prior contribution to the system through a compulsory tax on earnings (13). In June 2006, approximately 6.6 million recipients of SSDI were classified as disabled workers, and they received an average of \$943.40 per month (14). Also in June 2006 an additional 1.4 million individuals were “dual beneficiaries” (14), meaning that they qualified for SSDI on the basis of their tax contributions but received monthly payments low enough to qualify them for SSI under the means test. These programs were originally designed for individuals over 50 years of age with work-related disabilities, but policy analysts have noted that SSDI has evolved to meet a growing number of social welfare needs and new congressional mandates, while SSI has become a large cash-benefit program for a population that is younger and less at-

tached to the labor force than the program was originally intended to support (15).

People with psychiatric disabilities constitute the largest working-age disability group receiving public income supports. In December 2002 they constituted over a third (33.7 percent) of all working-age SSI beneficiaries and over a quarter (28.1 percent) of all disabled workers receiving SSDI benefits (38.2 percent of those younger than age 50 were receiving SSDI benefits) (16). In addition, for more than a decade the number of SSI beneficiaries with psychiatric disabilities has been increasing at a rate higher than total program growth (15). From 1988 to 2001 the number of SSI recipients with psychiatric disabilities more than tripled, from 411,800 to 1.5 million (the total number of all SSI recipients also rose more than two and a half times during that period) (3). The percentage of SSDI recipients with disabling mental disorders also increased over time but not as rapidly. Less than .5 percent of all beneficiaries at any point in time leave the rolls because of employment (17,18), and people with disabling mental illness are no exception. In fact, SSI beneficiaries with psychiatric disabilities are significantly less likely to work than those with other disabilities (19), and SSDI beneficiaries with disabling mental disorders remain on the rolls significantly longer than those with other diagnoses (20).

### **Preference for employment**

Numerous research studies indicate that individuals with disabling mental disorders want to work, consider themselves able to work, and express the need for job training, services, and supports. Opinion surveys repeatedly find that a majority of people with psychiatric disabilities desire paid employment, with many expressing the need for vocational rehabilitation (21–24). In a national household probability survey (NHIS-D), half of all working-age adults with mental health disabilities who were not working considered themselves able to work if supported adequately (25).

### **Questions of the President's Commission Subcommittee**

Given these issues, the President's Commission Subcommittee on Employment and Income Supports, which was charged with making recommendations on employment and income supports, raised a series of questions. Why do so many individuals with disabling mental illness find themselves out of work when so many express the desire to work? Why do they constitute such a disproportionate share of the public disability rolls? Are evidence-based practice services available to help them return to and remain in the labor force? Do most people who want such services receive them? Do public disability policies support or discourage beneficiaries' attempts to work? Do laws protect them from unfair hiring practices and discrimination in the workplace?

The research reviewed here used different definitions of disabling mental disorders, depending on the data sources and research questions. However, unless otherwise noted, all focused on individuals whose mental disorders and related symptoms were disabling—that is, accompanied by impairment that substantially interfered with their ability to manage daily activities (3).

### **Barriers to employment**

#### *Low educational attainment*

Many individuals with disabling mental disorders lack the necessary high school and postsecondary education and training required to build careers. This education and training gap stems from multiple causes. The onset of disabling mental illness occurs early; half of all lifetime cases begin by age 14 and three-quarters by age 24 (26), often interrupting secondary and postsecondary education. This is reflected in the graduation and dropout rates of youths classified as having severe emotional disturbance, a designation equivalent to that of mental health disability among adults. Severe emotional disturbance is defined by emotional, behavioral, or interpersonal difficulties that are experienced over a long period and to a marked degree and that adversely affect a child's educational performance

or ability to relate to teachers, peers, and others (27).

According to the U.S. Department of Education, in school year 1998–1999 the dropout rate for students with severe emotional disturbance was 50.6, the highest of all disability categories (3). The NHIS-D found that only 38 percent of special education students with severe emotional disturbance had graduated from high school, while another 6 percent received a certificate such as a General Equivalency Diploma, and the remaining 56 percent did not complete their schooling (25). The National Longitudinal Transition Study, a survey of young people exiting special education programs in 303 nationally representative school districts, found that youths with severe emotional disturbance had the highest percentage of high school noncompletion and failing grades (28). One to two years after exiting high school, only 18 percent were employed full-time, another 21 percent worked part-time, and their post-high school work experiences were characterized by greater instability than all other disability groups (29).

These gaps in education are important because advanced education is increasingly essential to securing a high-paying, career-advancing job. A multivariate analysis of employment among individuals with disabling mental disorders who participated in the NHIS-D found that education was a significant predictor of employment in executive, administrative, and professional specialty occupations (30). In 2004 all but one of the 50 highest-paying occupations in the United States required a college degree or graduate education (31). Labor market projections for 2004 to 2014 by the federal Bureau of Labor Statistics indicate that among the 20 fastest-growing occupations an associate's or bachelor's degree is the most significant source of training and education for ten of them (31). It is especially important to prepare people with psychiatric disabilities to enter high-growth industries because of research that has found higher employment and retention rates for people with disabilities in these industries; workers with disabilities are

now almost as likely as nondisabled workers to be employed in high-growth industries but not in non-growth industries (32).

### *Lowered productivity*

Another reason for the low labor force participation rates in this population is lower productivity and higher absenteeism that accompany disabling mental disorders, creating an economic burden for workers, their employers, and society at large. In a study of individuals with diagnoses of mood disorders, anxiety disorders, and substance use disorders—but not restricted to those disabled by these disorders—Kessler and Frank (33) found an average of 31 work-cutback days (reduced work activity) per month per 100 workers and an average of 100 work-loss days (days unable to work) per month per 100 workers that were attributable to mental health-related difficulties. In another study, workers with depression—again, not necessarily disabling depression—reported significantly higher health-related “lost productivity time” (hours per week absent plus hour-equivalents per week of reduced performance) than workers without depression, an average of 5.6 hours per week compared with an expected average of 1.5 hours per week, respectively (34).

Analyses of “moment-in-time” work performance found that compared with six other medical conditions, such as arthritis and back pain, major depression was the only condition associated with reductions in both task focus and productivity—approximately 2.3 lost days per month per worker (35). In the recent National Comorbidity Study Replication, bipolar disorder was associated with an annual average of 65.5 lost work days per ill worker and major depressive disorder with 27.2 lost work days (36). On average, those with bipolar disorder experienced \$9,619 annual human capital loss per ill worker, while those with major depression had an annual loss of \$4,426 per worker; projections to the U.S. labor force were \$14.1 billion per year resulting from bipolar disorder and \$36.6 billion resulting from major depression (36).

### *Unfavorable labor market dynamics*

Studies show that labor force participation of people with disabilities is closely tied to overall U.S. labor market dynamics (37). Yelin and colleagues (38) showed that long-term labor market trends from 1970 to 1992, including changes in the gender, age, and ethnic makeup of the U.S. workforce, were mirrored in the labor market participation of individuals with disabilities. However, although people with disabilities experienced proportionally larger gains than nondisabled people during periods of market expansion, they also evidenced greater losses during times of market contraction (38). The combination of mental disorders and disability is particularly severe because the effect of such disorders tends to magnify the effects of disability. According to labor force participation trends from 1982 to 1991, those with disabling mental disorders were 36 percent as likely as all nondisabled persons to be in the labor force, and those with nondisabling mental disorders were 62 percent as likely as nondisabled persons (39). In this study mental disorders were also found to intensify the effects of age and race, in addition to disability status, on labor force participation.

The fact that individuals with disabling mental illness are affected by general labor market trends is evident in the employment patterns in the EIDP study, where those residing in areas with high unemployment had poorer outcomes than those in areas with lower unemployment (40). However, participants receiving evidence-based supported employment services (a model described below) in areas with high unemployment rates had outcomes superior to those in control groups in areas with low unemployment rates. This suggests that use of evidence-based supported employment can help to ameliorate the effects of a poor labor market.

### *Lack of effective vocational services*

Given their desire to work, coupled with low labor force participation, it

is disconcerting that many people with mental illness receive few or no employment services. Among a stratified random sample of persons in two states diagnosed as having schizophrenia, only 23 percent of outpatients were receiving vocational rehabilitation services (41). In a study of 2,749 adults with disabling mental disorders who received services in Vermont, only 24 percent received any employment services and more than half received fewer than six service contacts (42). State mental health authorities have not traditionally viewed vocational rehabilitation as part of their mandate for this population. In a survey conducted by the National Alliance on Mental Illness in the late 1990s, only 16 state mental health authorities required that treatment address vocational rehabilitation goals (43). A survey conducted by the National Association of State Mental Health Program Directors Research Institute in 2004 found that only 36 of 50 state authorities used state general revenue or federal Mental Health Block Grant monies to fund supported employment services (44).

The authority charged with vocational rehabilitation of individuals with disabilities in the United States is the state-federal vocational rehabilitation system. By federal legislative mandate, the Rehabilitation Services Administration (RSA), an agency of the U.S. Department of Education, uses federal and state dollars to fund vocational rehabilitation programs in each state to provide job placement and training services to people with disabilities. In fiscal year 1995, the latest year for which statistics are available, 1.3 million adults were clients of state-run vocational rehabilitation programs, accounting for 12 percent of all Americans estimated to have health conditions or impairments that limited their ability to work (45).

People with disabilities who apply for state vocational rehabilitation services work with a rehabilitation counselor to determine their eligibility for services, select a vocational goal, and develop and implement an individualized plan of services to achieve that goal. According to sec-

tion 102(a) of the Rehabilitation Act of 1973, as amended, eligibility is defined by, first, having a physical or mental impairment that constitutes a substantial impediment to employment, and second, by being capable of benefiting from vocational rehabilitation services to prepare for, secure, retain, or regain employment (46). Those receiving SSI or SSDI or both are presumed to be eligible for state vocational rehabilitation services unless they are deemed too significantly impaired to benefit. Eligibility does not guarantee receipt of services, however, because state programs are now required to serve individuals with the most severe disabilities when there are not enough resources to serve everyone who is eligible (46).

Researchers have studied the effectiveness of state-federal vocational rehabilitation programs over time by examining longitudinal trends in client outcomes. One such trend is toward selectively serving individuals with severe disabilities, the policy shift described above that was instituted in the 1980s. In the early 1990s Andrews and colleagues (47) examined outcomes of all state vocational rehabilitation clients whose cases were closed from 1977 to 1984. They found that the percentage change in number competitively employed at closure had improved significantly among individuals with severe physical disabilities but not among those with severe psychiatric disabilities.

Beginning in 1995 RSA funded a national follow-up study of a random sample of 8,500 applicants, current users, and former users of state vocational rehabilitation services who were tracked for three years (48). Results indicated that, even after the analyses controlled for age, receipt of SSI or SSDI, gross motor function, and cognitive function, individuals with psychiatric disabilities were significantly less likely than those with other disabilities to achieve employment at closure or to achieve competitive employment (48). Further multivariate analyses indicated that services positively associated with achieving employment were job placement, on-the-job training, supported employment, and business

and vocational training. Services associated with competitive employment included job development, job placement, on-the-job training, business and vocational training, and postsecondary education. Individuals with psychiatric disabilities were more likely to earn low wages (defined as no more than \$5 per hour) than high wages (more than \$9 per hour) (49). Moreover, receipt of postsecondary education through a state vocational rehabilitation agency and achievement of a postsecondary degree were both significantly related to higher earnings, even after the analyses controlled for other educational characteristics.

#### *Lack of effective clinical services*

In addition to research showing that individuals with disabling mental disorders receive low levels of vocational services or none at all, a body of research beginning in the 1980s (50) has found that large proportions of this population receive no clinical services and that those who do fail to receive adequate care (51,52). In a national probability survey of U.S. households, 60 percent of individuals diagnosed as having disabling mental illness reported receiving no treatment, 24.7 percent received treatment deemed "not minimally adequate," and only 15.3 percent received minimally adequate treatment, defined as either appropriate psychotropic medication and four or more visits with a doctor or mental health specialist or, when appropriate, eight or more visits with a mental health specialist (53). Failure to receive any psychiatric treatment or appropriate types of services is a critical problem given that integration of clinical and vocational services has been associated with superior employment outcomes in a number of studies (54–56).

#### *Labor force discrimination*

Given the high level of social stigma attached to mental illness in American society, it is not surprising that people with disabling mental disorders experience labor force discrimination (57). In surveys over the past five decades, employers have expressed more negative attitudes

about hiring workers with psychiatric disabilities than about almost any other group (58–60). In 2004 individuals with disabling mental disorders lodged a fifth of all U.S. court cases alleging employment discrimination (61). In a national survey of more than 1,300 individuals with disabling mental disorders, almost a third (32 percent) reported that after disclosure of mental illness they were turned down for a job for which they felt qualified (62). In-depth follow-up interviews with a subsample of 100 respondents from this survey revealed the negative impact of such disclosure by self or others on work outcomes, including instances in which job offers were rescinded or individuals were fired or asked to leave and demotions, reductions in hours or responsibilities, social isolation, and harassment by coworkers (63).

In a national probability sample drawn from the NHIS-D, one-third (32 percent) of individuals with mental health disabilities reported having been fired, laid off or told to resign, refused employment, refused a transfer, refused a promotion, or refused a training opportunity because of their mental disorder (25). Although factors other than discriminatory treatment undoubtedly influenced some of these reports (for example, lower productivity during periods of illness or negative business trends, such as corporate downsizing), it is also likely that many of these accounts reflect illegal and actionable instances of employment discrimination.

Baldwin and Johnson (64) studied disability-related employment discrimination by examining earnings differentials and applying econometric techniques previously used to study race and sex discrimination. After they accounted for productivity differentials related to functional limitations and other productivity-related individual characteristics, such as education, occupation, and part-time employment, large unexplained variance in wage differentials between people with and without disabilities remained. The authors attributed these differentials to discrimination in the labor market

and, in subsequent analyses, showed that wage differentials were even larger for individuals with disabilities that were thought to evoke “greater prejudice” (defined as including mental illness) compared with those with impairments evoking “milder prejudice.”

### *Failure of protective legislation*

One piece of legislation that showed much initial promise for preventing job discrimination is the Americans With Disabilities Act (ADA) (65). Enacted in 1990, this landmark legislation extended civil rights protection to people with disabilities by prohibiting discrimination in employment, state and local government services, public transportation, public accommodations, commercial facilities, and telecommunications. Under the ADA, discrimination in job application procedures, hiring, firing, advancement, compensation, fringe benefits, and job training is prohibited. The law allows individuals with disabilities to request “reasonable accommodations”—changes to the work process or environment that enable workers to perform their jobs. However, these accommodations must not create “undue hardship” for employers, meaning that they must not be unduly expensive, extensive, or disruptive or change the nature or operation of a business. Additionally, individuals seeking accommodations must disclose their disability to employers in order to request and be granted an accommodation (65).

The ADA defines an individual with a disability as someone with a physical or mental impairment that substantially limits one or more major life activities or someone who has a record of such impairment or who is regarded as having such impairment. To be protected from employment discrimination under the ADA, individuals must also be “qualified.” This means that they must meet the skill, experience, education, and other requirements of a position and can perform the essential functions of the position either with or without reasonable accommodations.

Since the law was enacted, ADA protections have become increasing-

ly circumscribed for individuals with psychiatric disabilities and other types of conditions. For example, recent Supreme Court rulings have declared that ADA protections do not extend to workers with illnesses “controlled by medications” (66–68) and those whose limitations are not considered “central to most people’s daily lives” (69,70).

Additional evidence of the failure of the ADA to protect workers with psychiatric disabilities has been found in studies of the ADA claims adjudication process (71). Claims filed by individuals with psychiatric disabilities are more likely to be classified by the Equal Employment Opportunity Commission as “low-priority,” and this priority assignment is associated with a decreased likelihood that a claimant will receive some benefit in the form of an actual monetary payment (compensatory damages or back pay) or projected monetary gain (assumed to co-occur with hiring, promotion, or reinstatement) (72). As a result, claimants with psychiatric disabilities are significantly less likely than those with other disabilities to receive monetary benefits. Despite these outcomes, ADA claims by persons with psychiatric disability constitute 21 percent of all cases brought to trial in federal court in 2004, in which 76 percent of the decisions favored the employer, 24 percent were unresolved, and none favored the claimant (61). The necessity of disclosure in order to request reasonable accommodations or pursue ADA claims is another disadvantage of this law, given anecdotal evidence that disclosure is related to subsequent discrimination, harassment, and isolation (62,63,73).

### *Poverty-level income*

People with disabilities are among the poorest in the nation, especially those with psychiatric disabilities (74,75). However, the proportion of individuals with disabling mental illness who live in poverty or in near-poverty is difficult to estimate from nationally representative surveys because of the ways in which questions are asked and populations defined as well as the choices researchers make in constructing the variables that they ana-

lyze. In one recent analysis of data from the NHIS-D (76), almost a third (31.8 percent) of individuals with mental disabilities fell below the federal poverty line in 1994–1995; however, the definition of mental disability used in this analysis included a wide range of factors, such as diagnoses (for example, schizophrenia, major depression, and antisocial personality) as well as symptoms and impairments (for example, trouble concentrating, confusion and disorientation, and trouble making or keeping friends).

Data from the Survey of Income and Program Participation, a nationally representative household survey conducted by the Bureau of the Census (77), indicate that individuals with activity limitations resulting from mental or emotional problems had a median annual income of \$9,492 in 1997, when the poverty level was \$8,350 for one-person households for persons younger than 65 and \$10,805 for two-person households (78). This suggests that between one-third and one-half of individuals with disabling mental disorders are at or near the poverty level.

Even if persons with disabling mental disorders qualify for SSI or SSDI disability cash payments, the level of benefits in these programs coupled with the tenuous economic and career trajectories of this group constitutes what some policy analysts have referred to as a “poverty trap” (79). The maximum federal SSI benefit is now only about 75 percent of the federal poverty standard for an individual (79). In 2004 the monthly income of a person with a disability receiving SSI benefits was \$564, while the national average monthly rent for a one-bedroom apartment was \$676 (80). Thus, at 105 percent of 2004 SSI benefits, the average national rent for a one-bedroom housing unit exceeded total yearly SSI income. The average annual income of a disabled SSI beneficiary in 2004 was less than a fifth (18.4 percent) of the national one-person median household income (80).

Taken together, this evidence suggests that whether they work, qualify for SSI or SSDI, or receive money from friends and relatives or other sources, income levels of people with psychiatric disabilities are inadequate

to help them meet basic needs for food and shelter, let alone the requisites of education, job training, and job seeking. Poverty-level income prevents individuals with adequate work skills from successful job-seeking when they reside in neighborhoods where jobs are scarce and they cannot afford transportation outside their communities to find work. Poverty disqualifies individuals from holding jobs for which they must provide their own tools, uniforms, or other equipment. Poverty inhibits those with low levels of education and work skills from obtaining postsecondary education or training to enhance their skill levels. Research confirms these barriers, suggesting that poverty is an important mediator of the relationship between mental illness and unemployment, in some cases with a larger influence on labor force participation than the psychiatric disorder itself (81).

#### *Linkage of health care to disability beneficiary status*

Many individuals with severe mental illness rely on disability income support programs for the health care and medication coverage they provide. Individuals on SSI qualify for Medicaid, and those on SSDI qualify for Medicare after a mandatory waiting period of up to two years. In a study of individuals with schizophrenia who were followed for an average of five years after their first hospitalization, 72 percent relied on SSI, SSDI, or Aid to Families With Dependent Children throughout most of the follow-up period (82). Individuals with high-cost major mental disorders and those requiring expensive medications are especially dependent on Medicare and Medicaid because of the lack of parity in most private health and mental health care systems (83,84). This is important because uncontrolled symptoms, impaired functioning, and comorbid medical conditions and illnesses are associated with inability to achieve vocational success in this population (85,86).

#### *Disadvantages upon labor force reentry*

The vulnerability of those who return to work while on the federal disabili-

ty income support rolls is evident in studies showing that most reenter the labor force because of financial need rather than medical improvement (87). Those who do return to work tend to be younger and better educated than those who do not. Their initial post-SSDI jobs are lower paying, and they work for fewer hours than at the job held before they received SSDI. Moreover, the first job attempt after SSDI benefits are terminated has the greatest chance of leading to successful labor force reentry; the likelihood of positive outcomes decreases significantly with subsequent job attempts (88). Finally, although workplace accommodations may extend the average duration of employment for those with disabilities (89), there is evidence that some injured workers who receive job accommodations also receive lower wages, in essence “paying the price” of their own accommodations (90). Evidence that SSI and SSDI recipients with psychiatric disabilities return to jobs that do not provide benefits comes from the EIDP, in which only 24 percent of full-time jobs provided medical coverage, 16 percent dental coverage, 8 percent mental health coverage, and 20 percent sick leave (12).

#### *Employment disincentives*

SSA disability income support policies create a number of unintended employment disincentives that help contribute to under- and unemployment (91). First, federal regulations mandate an administrative review of an individual's disability status upon return to work—called the continuing disability review—which discourages many beneficiaries from seeking employment (18). Second, once they become employed, beneficiaries find that their cash payments are sharply reduced as their earnings increase. SSDI beneficiaries can earn up to SSA's substantial gainful activity (SGA) level each month (\$830 in 2006) with no loss of benefits; however, once earnings exceed that amount for nine nonconsecutive months plus a three-month grace period, all SSDI cash benefits cease—a phenomenon called the “earnings cliff” (92). SSI beneficiaries face a

different penalty; once their earnings reach \$65 per month, their cash payment is reduced by \$1 for \$2 of additional earnings, a tax rate of 50 percent, which far exceeds that paid by the wealthiest individuals (79).

A third disincentive is an “implicit tax” on disabled workers, whose labor force participation and resulting loss of beneficiary status causes them to lose additional benefits, such as health insurance, housing subsidies, utility supplements, transportation stipends, and food stamps (93). Finally, SSDI beneficiaries who return to work in the first 24 months of eligibility become ineligible for health coverage under Medicare, regardless of whether their jobs provide medical benefits (92). Research has indicated that people with psychiatric disabilities are aware of these disincentives and report that they plan their labor force participation accordingly (93,94).

The effects of work disincentives are also evident in studies comparing the employment outcomes of individuals who do and do not receive public disability income support. In the EIDP cohort, those receiving SSI or SSDI cash benefits were significantly less likely to work competitively, to work 40 or more hours per month, and to have high earnings, regardless of study condition, demographic and clinical characteristics, work history, or study site (95). Research on both national and statewide cohorts of state vocational rehabilitation service recipients with psychiatric disabilities has found that employment rates are significantly lower among SSI and SSDI beneficiaries than among nonbeneficiaries, even after the analyses controlled for demographic features, level of family support, and functional impairment (48,96). Veterans with psychiatric (and other) disabilities are less likely to work, earn less money, and work fewer hours if they receive full veterans disability benefits, as opposed to partial benefits, or if they receive more generous benefit amounts; these analyses controlled for a series of confounding demographic and clinical factors (97,98).

Given evidence suggesting that people respond to work disincen-

tives by altering their labor force participation, it follows that policies designed to discourage reliance on disability income may paradoxically discourage substantial work attempts that could lead to exit from the rolls. Instead, many individuals receiving SSI and SSDI find themselves out of the labor force or trapped in low-paying, entry-level jobs where they remain, prevented from realizing their full career potential (79,99).

### ***Ineffective work incentive legislation***

Recognizing this problem, various work incentive provisions have been legislated by Congress. The Employment Opportunities of Disabled Americans Act of 1986 (PL 99-643), Section 1619(b), provided for continued SSI eligibility and access to Medicaid as long as earnings remain below a threshold established by each state (100). Another mechanism permitting individuals to work above SGA while retaining Medicaid benefits was the Medicaid Buy-In state plan option under the Balanced Budget Act of 1997 (101).

The newest piece of disability legislation designed to address work disincentives is the Ticket to Work and Work Incentives Improvement Act of 1999 (102). This legislation was intended to give people with disabilities increased vocational service options and reduce employment disincentives while simultaneously reducing government spending on people with disabilities (103). To accomplish the first objective, vouchers, or "tickets," were mailed to all work-disabled SSI and SSDI beneficiaries to be redeemed for five years of vocational services from providers of their own choosing (104). In addition, Ticket to Work participants were offered free counseling about their benefits and entitlements to help them gauge the effects of employment on their cash benefits and other unearned income. SSA also placed a moratorium on continuing disability reviews for Ticket to Work participants and encouraged state Medicaid buy-ins enabling people to keep their health insurance after cash benefits ceased. Savings for SSA would result from a payment structure based on an "out-

come payment" design in which providers would be paid only for months individuals earned above SGA or only at the time that the beneficiaries left the rolls as a result of employment.

Although anyone can apply to become a Ticket to Work service provider, the vast majority of providers are state vocational rehabilitation authorities, with a much smaller percentage comprised of not-for-profit and for-profit employment and disability programs, businesses, and corporations (105). In the early stages of the program, economists forecasted that the outcome-focused payment system would offer providers too little financial incentive to serve clients with substantial vocational barriers, such as those with psychiatric disabilities (106). They argued that by "backloading" the payment structure to reward providers whose customers rapidly reached earnings levels exceeding SGA, the program lacked incentives for serving populations that would take longer to move into higher-paying, competitive jobs, such as those with psychiatric or intellectual disabilities (107). These predictions were supported by the findings of a study simulating Ticket to Work provider payments that used 24-month earnings of SSDI beneficiaries with psychiatric disabilities who were receiving vocational rehabilitation (104). The study found that earnings of a large majority (74 percent) remained below SGA for two years.

The national evaluation of the Ticket to Work program has identified several problems with its implementation (108). First, the rate of participation in the program is very low. Even in states where it has operated the longest, just 1.1 percent of beneficiaries have assigned their ticket to a provider. Second, the rate of provider participation is similarly low. As of June 2004 only 40 percent of all providers had accepted tickets. Moreover, consistent with the simulation study (104), the evaluators' analysis of providers' costs and revenues suggests that those relying solely on Ticket to Work payments would have lost money after two years of operation. Despite this pes-

simistic picture, Ticket to Work participation is relatively vigorous among individuals with disabling mental disorders, who have the fifth-highest rate of participation among the 21 primary disabling conditions examined (106). At the same time, there is also evidence of reluctance to serve this population because one-third of providers interviewed for the evaluation mentioned psychiatric or other disabilities as a challenge to finding jobs for Ticket to Work beneficiaries.

### **Availability of evidence-based vocational rehabilitation models**

Despite the bleak economic and employment situations of people with severe mental illnesses, accumulated research evidence indicates that they can successfully participate in the open labor market (54,109). That is, they can secure and retain jobs that are socially integrated (that is, where not all coworkers have disabilities), for which anyone can compete (that is, not set aside for individuals with disabilities), that pay minimum wage or above, and that belong to the worker rather than belonging to a mental health or rehabilitation agency.

The service delivery approach with demonstrated efficacy in establishing competitive employment is called supported employment (109). Although a number of evidence-based supported employment models have been developed specifically for this population, they share common features (110). All deliver integrated and coordinated clinical and vocational services that are provided by multidisciplinary teams, including both mental health and rehabilitation professionals, with rapid job search and placement into competitive positions in the client's preferred fields and settings, with the availability of services and supports that are not time limited (111). A multisite randomized, controlled trial of supported employment found that 55 percent of those receiving evidence-based supported employment achieved competitive employment compared with 34 percent of a control group that received services as usual or comparison interventions (95). In

addition, 51 percent worked 40 or more hours in a given month, compared with 39 percent of the control group, and the average salary earned was \$122 per month, compared with \$99 per month for workers in the control group. These results have been confirmed by reviews and meta-analyses of single-site randomized controlled trials of supported employment programs for this population (112–114), showing that this approach is more effective than prevocational training or nonvocational community care.

Although most individuals with psychiatric disabilities do not receive any vocational rehabilitation services, others receive services that are not delivered according to best-practice standards (115). Often they receive employment services from a program that is separate from their clinical provider, with poor or nonexistent coordination between the various parties (116). In other instances their career preferences and individual financial circumstances are not taken into account, and they are offered generic job placements in entry-level positions (84). They may be served by employment staff who have little or no knowledge of mental disorders, psychotropic medications and side effects, work-based stigma and discrimination unique to mental illness, or appropriate vocational assessment techniques for this population. Often, so-called “ongoing” supports have an implicit time limit, after which the consumer is encouraged to “graduate” and services are terminated. This limited service duration is due, in part, to the fact that state vocational rehabilitation services are typically provided for relatively brief time periods, with limited opportunities for ongoing job support (115). Similarly, most vocational rehabilitation services are not reimbursable under Medicaid, even in states that have Medicaid’s Rehabilitation Option, which creates a funding vacuum that helps to account for fact that this population is vastly underserved (110,116).

Taken together, the foregoing body of evidence suggests that people with psychiatric disabilities face a number of formidable, sometimes

interrelated, and often unintended barriers to occupational success and economic security. The next section is a brief discussion of how U.S. policy reform efforts in health care, disability, and mental health have addressed these obstacles in the past several decades. This discussion is followed by recommendations for an integrated system of services and supports, legislative reforms, and business initiatives to address these problems, as called for by the President’s Commission.

## **National policy reform efforts**

### ***Incrementalism in U.S.***

#### ***health care policy reform***

Scholars of the development of recent health care policy in the United States have characterized its approach to change as incrementalist (117). In incrementalism, targeted policy changes and reforms are applied piecemeal to limited populations, as opposed to inclusive, large-scale reforms, such as universal health care or universal mental health parity. Aaron (118) described a “voluntary incrementalism” in which employer-based and market-driven health insurance serves as the primary source of health care coverage for U.S. citizens, while publicly funded programs are broadened to include, as necessary, certain groups outside the labor force depending upon need and political clout.

Since the establishment of the Medicare and Medicaid programs in the 1960s, expansion of publicly funded health care coverage has followed this policy of incremental reform. For example, Congress has extended coverage to selected groups according to age (Medicare for those 65 years of age or older), disability (Medicaid and Medicare provided through SSI and SSDI), income level (Medicaid for impoverished single-parent families and pregnant women), and even organ system (Medicare for end-stage renal disease patients) (119). The disadvantages of this approach include high levels of complexity in eligibility determination and associated difficulties in outreach to and enrollment of targeted groups. The question of higher costs associated with this approach to policy change also remains unresolved.

### ***U.S. disability policy reform***

Employment policy initiatives, such as the ADA and Ticket to Work program, reflect a paradigm shift to a social model of disability (120) as exemplified by the “new paradigm of disability” (121). The new paradigm views disability as an interaction between characteristics of individuals and features of their cultural, social, natural, and built environments; it was adopted in 1999 to guide federally funded disability research (121). In this framework, disability does not lie within the person but in the interface between individuals’ characteristics (such as their functional status or personal or social qualities) and the features of the environments in which they operate. The old paradigm views a person with a disability as someone who cannot function because of an impairment, whereas the new paradigm views this person as someone who needs an accommodation in order to function (122). The new paradigm acknowledges the civil rights of qualified individuals with disabilities to work and to receive accommodations, in contrast to the deficit model of disability that dominated American federal policy for most of the 20th century (123).

Current reforms therefore focus on restructuring public disability policy to remove work disincentives, enhance economic security, improve access to effective services, and protect the rights of workers to freedom from discrimination in hiring and employment. However, debate rages regarding the success of these policy reforms given their uncoordinated, piecemeal nature (124,125). Some analysts argue that a policy approach aimed at correcting specific problems with specific disability programs fails to address a multitude of related problems, adding complexity to the programs that makes the programs more difficult to administer and threatens their long-term fiscal health (79). An additional complication lies in the fact that policies are assembled across multiple federal agencies such as SSA, RSA, and the U.S. Department of Labor. As a result, much U.S. disability policy lacks a coordinated, cohesive focus and policy making occurs far outside the realm of mental health and health care (84).

### *Sequential incrementalism in mental health policy*

In the mental health policy arena, recent decades have also witnessed a deemphasis on broad, comprehensive reforms, such as those championed in the federal Mental Health Systems Act of 1980 (PL96-398) that grew out of the first presidential mental health commission established in 1977 during the Carter administration (126). With the repeal of this act at the beginning of the Reagan administration in 1981, ensuing decades witnessed a period of “quiet success” (127) in policy change, during which advocates, policy makers, and legislators worked to implement many of the specific recommendations that had been made in the 1980 National Plan for the Chronically Mentally Ill (128). These included changes in SSI and SSDI eligibility determination and coverage; expansion of the Medicare mental health benefit; use of Medicaid funding for “new” community mental health services, such as case management and psychosocial rehabilitation; and implementation of a “community support” paradigm that viewed housing, employment, education, vocational rehabilitation, and support services as necessary for community integration, in addition to traditional mental health and substance abuse treatment.

This de facto mental health policy has been described as “sequential incrementalism” (129), referring to its gradual, piecemeal approach to change. Grob and Goldman’s account (129) of policy formation during this period concluded that, by the year 2000, a new federalism had emerged that, paradoxically, increased the role of states in mental health policy formation while also dramatically increasing the federal government’s share of the costs. Another outcome of this series of incremental changes, however, was increased complexity and fragmentation of the service system, a key challenge identified by the second presidential mental health commission.

### *The New Freedom Commission on Mental Health*

Twenty-five years after the Carter presidential commission, George W.

Bush established the President’s New Freedom Commission on Mental Health in 2002. The Commission was charged with identifying policies that would maximize use of existing resources, improve coordination of treatments and services, and promote successful community integration for children and adults with serious mental illness. Early on, Commission members identified unmet needs for employment and income support as major policy issues requiring resolution, which was reflected as a major goal—goal 2—in the Commission’s final report (2). Several of the report’s more specific recommendations are germane to this area. The first is that “return-to-work should be consumer-driven” and the second calls for a dramatic increase in the quality and availability of evidence-based supported employment services.

The report also noted that “return to work should involve a multi-systemic approach” and that states should have “the flexibility to combine federal, state, and local resources in creative, innovative, and more efficient ways, overcoming the bureaucratic boundaries between health care, employment supports, housing and the criminal justice system.” Finally, the report recommended that SSA evaluate the possibility of removing disincentives to employment in the SSI and SSDI programs.

What would a multisystemic approach to employment and income supports look like? It would encompass federal, state, and local systems responsible for employment, income support, supported employment, mental health, health care, housing, education, legal aid, criminal justice, asset accumulation, and other social services, as well as the business community and mental health advocacy communities. Elements of such a system might include

- ◆ Ongoing health care coverage for medical, mental health, and prescription drugs, regardless of the individual’s labor force status

- ◆ Integrated and coordinated clinical services and vocational services shown to promote employment in this population

- ◆ Greater availability of secondary and postsecondary education to help

individuals complete interrupted educational careers and obtain college degrees necessary for success in today’s labor market

- ◆ Benefits planning and financial literacy education regarding the effects of earned income on SSI and SSDI cash payments, as well as development of life-long financial plans

- ◆ Asset development through matched savings accounts called Individual Development Accounts, authorized by the federal Assets for Independence Act (130), allowing low-income workers to accumulate savings for postsecondary education or capitalization of small businesses, thereby building financial security and enabling career development without reduction of SSI or SSDI cash benefits (131)

- ◆ Housing that is safe and affordable for individuals living on SSI or SSDI and that is not threatened by income increases resulting from labor force participation

- ◆ Legal aid to deal with labor force discrimination, ensure access to state and local vocational rehabilitation services, and pursue enforcement of the Americans With Disabilities Act

- ◆ Peer support and self-help to combat mental illness stigma and provide role models for maintaining hope and optimism in the face of daunting barriers

- ◆ Involvement of employers and the business community in education, advocacy, and workforce development efforts that meet the needs of job seekers and organizations employing them.

The New Freedom Commission report also noted that the extreme fragmentation of our country’s mental health system requires that it be transformed. This policy of transformation “calls for profound change; an upheaval and reorganization of what we know, what we do, and how we go about doing it” (132). An extensive review of the literature on transformation noted that it is a complex, multi-dimensional process operating on many levels that requires visionary leadership, mobilization of scarce resources, persuasive communication, careful coordination of activities, and incorporation of ongoing feedback and readjustment of activities to

reach particular goals (133). To accomplish such a challenging agenda, the translation of research into practice is essential. Knowledge translation addresses the vexing problem, in the fields of both physical and behavioral health, of underutilization of evidence-based practice in designing and operating service systems (134–136). Although similar to dissemination or diffusion, translation is distinguished by its emphasis on application of knowledge to systems rather than groups or organizations and by an interactive and engaged process between research and systems of care (137–139).

The aforementioned trends offer the possibility that evidence-based return-to-work services can be coupled with public policy reforms and increased mental health and disability activism to promote employment and economic security for people with psychiatric disabilities. Policy reforms might include changes in Medicaid funding that make supported employment a reimbursable service integral to mental health recovery, removal of work disincentives, labor market restructuring through tax breaks and incentives for workers and employers, and enhanced access to postsecondary education and vocational training, in addition to addressing the causes and consequences of labor force discrimination. Reform also requires the stimulation and nurturance of transformational leadership at all levels of public policy formation and implementation, aimed at the translation of research into practice across entire systems.

Given the inertia and resistance to change of large state and federal bureaucracies, we might ask who will take the lead in either large-scale transformation efforts or gradual reforms? July 2005 saw the release of an action agenda created by seven cabinet-level departments of the federal government—Health and Human Services, Education, Housing and Urban Development, Justice, Labor, Veterans Affairs, and SSA. The agenda is entitled *Transforming Mental Health Care in America* (140). The report endorses the concept of transformation and presents 70 specific steps that will be taken by federal

agencies. Many of the steps focus on enhancing employment opportunities and access to employment services. Around the same time, the Campaign for Mental Health Reform, a collaboration of 16 national mental health advocacy organizations, released its own report, *Emergency Response: A Roadmap for Federal Action on America's Mental Health Crisis*, also endorsing the need for transformation and calling for the improvement of employment outcomes and elimination of disincentives for economic self-sufficiency (141).

Many of the changes being discussed and debated have trade-offs that need to be considered in policy decision making. For example, instituting a \$1 for \$2 income disregard for SSDI beneficiaries, so that they could retain half of their employment earnings as well as disability cash benefits and entitlements, may not encourage individuals to earn more and leave the rolls but instead may make it more comfortable to remain on the rolls indefinitely (142). Increasing the generosity of SSI and SSDI benefits may also result in “induced entry,” which occurs when individuals enter the rolls who would not otherwise have done so (143). Scholars attempting to estimate the effects of induced entry resulting from implementing a \$1 for \$2 disregard in the SSDI program have predicted increases in the rolls, ranging from a low of 75,000 to a high of 400,000 new beneficiaries over a ten-year period, which would cost between \$410 million and \$5.1 billion (143–145). Others argue that such a policy change might reasonably be expected to result in budget neutrality or even savings to SSA in returned cash benefits or “induced exit” resulting from larger numbers of individuals leaving the rolls (146). Still others caution against the use of work incentive programs for individuals with disabilities, noting that there is little convincing evidence of their effectiveness in studies of other populations, such as welfare recipients (147).

As these issues are discussed and debated, advocacy organizations including those for people in recovery from mental illness, their families, disability advocates, and others can

contribute a “value critical” policy analysis to this change process, which is based on social justice and economic fairness through the use of taxpayer dollars (148,149).

As is evident from the foregoing and also noted in the New Freedom Commission's report, researchers must assume responsibility for creating policy-relevant knowledge by carefully matching policy questions with appropriate research designs (81,115,150). First and foremost, a better understanding of labor force participation by people with psychiatric disabilities is needed on both regional and national levels, using standard labor force indicators collected from representative samples (111, 150). Second, meaningful data must be gathered and analyzed regarding access to, use of, and results of employment services across multiple state agencies by developing integrated reporting and management information systems along with classification of services and outcomes that is applicable across delivery systems (42). Third, analysis of administrative data and follow-up research designs should be used to locate and interview individuals who seek but do not receive state and local employment services as well as those who are accepted as clients but who leave service systems before their rehabilitation plans are implemented (115).

Fourth, qualitative, ethnographic studies of experiences with discrimination in the job-seeking process and at the workplace are needed to gain a better understanding of how inequality persists in the face of legislation designed to combat it (123). Fifth, interviews with key informants within and outside large delivery systems can help us identify areas of inefficiency, inadequate resource allocation, and bureaucratic “irrationality” in organizational operation (115). Sixth, we must insist on the use and linkage of electronic records in state and federal systems, in a way that maintains client privacy and confidentiality, to address questions regarding cost-effectiveness and cost-benefit ratios of clinical and vocational rehabilitation services, disability income support, and Medicaid and Medicare coverage (99).

## Conclusions

Regardless of whether the coming decades witness wide-scale policy transformation or piecemeal reform, change will depend on the political will of federal, state, and local governments as well as the actions of people with psychiatric disabilities and other advocates, given their already ongoing role in active transformation of the mental health system (151). Observers have noted that the public's interest in the welfare of this population waxes and wanes in cycles (84). Nevertheless, in difficult economic times such as these, efforts to enhance employment and economic self-sufficiency should be perceived as risks worth taking, given the potential for a more productive, more diverse, better prepared, and more highly motivated workforce. Great promise lies in the enhancement of our country's economy and its human capital by implementing responsive and responsible policies that address work and income support. These policies have the potential to benefit all U.S. citizens, not just those with psychiatric disabilities.

## Acknowledgments

This article is based on a report prepared for the Subcommittee on Employment and Income Supports of the President's New Freedom Commission on Mental Health. The author is grateful to subcommittee members and Commission staff for their active engagement in discussing both research and policy issues described herein. Also acknowledged are the intellectual contributions of Jane K. Burke-Miller, M.S., Dennis D. Grey, B.A., Jessica A. Jonikas, M.A., David E. Marcotte, Ph.D., and Carol A. Petersen, M.Ed. Preparation of this article was funded, in part, by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education and the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (cooperative agreement H133-B05-0003). The contents of this article do not represent the policy or position of any federal agency and no endorsement by the federal government should be inferred.

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