

PROMOTING WORK AMONG SSI/DI BENEFICIARIES WITH SERIOUS MENTAL ILLNESS

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PROMOTING SATISFACTORY WORK EXPERIENCES AMONG SSI/DI BENEFICIARIES WITH SERIOUS MENTAL ILLNESS

One long-range goal of the Ticket to Work and Work Incentives Improvement Act of 1999 (hereafter, TTW) is to save public costs by increasing the proportion of Supplemental Security Income (SSI) and Social Security Disability Insurance (DI) beneficiaries who work, and ultimately the proportion who leave the rolls because they achieve the level of substantial gainful activity (SGA). Related goals include increasing work activity even for beneficiaries who would not be expected to earn their way off the rolls. The Social Security Act and the TTW facilitate the transition to work by providing employment support resources and work incentives for beneficiaries.

This paper focuses on the substantial proportion of people who are SSI/DI beneficiaries by reason of serious mental illness (SMI)—34 percent for SSI and 27 percent for DI.¹ It discusses options for helping people with SMI on the SSI/DI rolls work more. It describes strategies and techniques that are being used to promote employment among people with SMI, as well as the issues and challenges involved in achieving this objective. It ultimately addresses the question of what some realistic goals might be for Social Security programs with respect to promoting work among beneficiaries with SMI.

As we detail in this paper, many people with SMI work, and many others, including some on the SSI/DI rolls, want to work. We start from two premises—(1) that promoting work among people with SMI who want to work is a good thing to do, and (2) that mental illness is poorly understood and managed, both within and beyond the workplace, which contributes in part to its costs to society. Employment is an important route to recovery, economic empowerment, and independence for people with mental illness. But a number of challenges exist, including the nature of SMI, the SSI/DI application process, the appropriateness of available incentives, and the expectation of sustained long-term competitive employment.

We first present background information on the characteristics of people with SMI who receive SSI and DI, the work activity level of people with SMI both on and off the SSI/DI rolls, and Congress' pre-Ticket efforts to increase work participation through incentive provisions such as 1619a, 1619b, and other provisions governing continuing eligibility for benefits and rapid reinstatement if working does not prove viable. We rely for this information on many papers and reports prepared for the Ticket to Work Advisory Panel (Rupp and Bell 2003), which we briefly summarize.

¹ Mental illnesses are disorders such as *schizophrenia*, *schizoaffective disorder*, *bipolar disorder*, *major depressive disorder*, obsessive-compulsive disorder, *panic and other severe anxiety disorders*, autism and pervasive developmental disorders, attention deficit/hyperactivity disorder, borderline personality disorder, and other severe and persistent mental illnesses that affect the brain. The italicized disorders represent the largest groups within the SSI/DI population with mental disorder (excluding mental retardation) as a primary diagnosis. Of these, schizophrenia and schizoaffective disorder are considered psychoses, bipolar and major depressive disorders are considered affective disorders, and the others fall into other psychiatric categories.

We then review the various techniques and strategies for promoting work that have been the subject of demonstration programs sponsored by the Social Security Administration and the Substance Abuse and Mental Health Services Administration (SAMHSA) before Ticket to Work. We also examine how people with SMI, and their employers, handle their employment—what is being called in some places “managing disability.” We describe techniques and approaches available to employers, intermediaries such as Ticket to Work’s employment network (EN) providers, and people with disabilities themselves that increase the odds of successful engagement in work. Competent management of disability may help people with disabilities find and keep work by changing attitudes, skills, and expectations; modifying the work environment and workplace interactions; and increasing skills in handling potentially sensitive situations. On the general public policy assumption that workforce participation is good for people with disabilities just as it is for others in our society, whether or not it leads to self-sufficiency, it is important that techniques for managing disability become more widely known in the workplace and applied when SSI/DI beneficiaries with SMI venture into employment.

1 BACKGROUND

1.1 The SSI and DI Programs

Supplemental Security Income and Social Security Disability Insurance are federal programs providing financial support to adults who have a medically determinable physical or mental impairment that prevents them from engaging in substantial gainful activity.² The impairment must be one that can be expected to result in death or that has lasted, or can be expected to last, for a continuous period of not less than 12 months. DI provides benefits to disabled and blind people who have participated in employment covered by Social Security for 20 of the most recent 40 calendar quarters before applying for DI. DI payment amounts are based on contributions made through FICA taxes on earnings. Qualified recipients must wait five months from the onset of their disability before receiving cash benefits. Determinants of disability under SSI are similar to those under DI. But unlike DI, SSI is a means-tested program that does not require recipients to have a prior work history. SSI provides cash payments to aged, blind, and people with disabilities who have limited income and resources (usually no higher than 75 percent of poverty). Once a person qualifies for SSI, cash benefits start immediately, without the waiting period required under DI.

Given that both SSI and DI beneficiaries have one or more disabilities, the need for health care is likely to be great. As many SSI/DI beneficiaries are unlikely to have the resources to pay for the health care they need, eligibility for public health insurance is a very important aspect of the SSI/DI package. Most DI recipients are ultimately eligible for Medicare, but benefits start only after a lag of 24 months and do not (yet) cover prescription drugs. Most SSI recipients are categorically eligible for Medicaid, and most ultimately receive it. But state application practices vary in the extent to which they facilitate the Medicaid application process.

² This summary relies heavily on Newcomb, Payne, and Wald (2003).

1.2 People with Serious Mental Illness in the SSI/DI Programs

Over the past 20 years, persons with SMI have been the fastest growing populations in the SSI and DI caseloads. A mental illness is the primary impairment for approximately 34 percent of adult non-elderly SSI beneficiaries (about 1.24 million people) and 27 percent of adult non-elderly DI beneficiaries (about 1.50 million people).³ Some of these people are concurrent beneficiaries of both programs. SSI/DI beneficiaries with SMI are younger and in better physical health than most SSI and DI participants. As a result, they tend to have longer projected durations on these programs and are likely to be more costly to the programs relative to beneficiaries with other conditions. Promoting employment among these beneficiaries is clearly good public policy—for both financial and other reasons—but the nature of SMI presents particular challenges to an affected person’s ability to sustain employment.

Salkever (2003) describes employment prospects with respect to the three SMI diagnoses affecting the greatest proportion of SSI/DI beneficiaries between the ages of 18 and 64—major depression and bipolar disorder (both affective disorders which together account for about 15 to 18 percent of beneficiaries), and schizophrenia (about 7 to 10 percent of beneficiaries, including schizoaffective disorders). For our purposes, his basic points are that these illnesses wax and wane, leaving people who have them able to function adequately for stretches of time only to deteriorate periodically when the symptoms of their illness return.⁴ These patterns can substantially reduce their long-term prospects for stable work, and for work at the SGA level, as reflected in national survey data as well as in SSA program data described below.

Salkever (2003) has summarized findings from national surveys on employment among adults with mental disorders (other than mental retardation). Researchers using National Health Interview Survey data from 1982-91 (Yellin and Cisternas 1996) analyzed work activity among people with a self-reported disability, which could be of any type. Results consistently showed the lowest employment rates for people with reported mental disorders, who were employed only about half as often as people with other disabilities but no mental illness. Further, people with psychotic disorders such as schizophrenia had employment rates about half (21 percent) those of all persons with mental disorders (43 percent). Analyses of four national surveys (Mechanic, Bilder, and McAlpine 2002) showed employment rates for persons with serious mental disorders (not including mental retardation) to be between 32 and 61 percent, but for people with schizophrenia the rates were between 22 and 40 percent. Women with major depression are significantly less likely to work than those without this disorder, although having bipolar disorder or dysthymia did not have the same effects on employment. Similar analyses for men did not show negative effects for any of these affective disorders on employment, but dysthymia seemed to have a negative effect on income (Marcotte, Wilcox-Gok, and Redmon 2000). Finally, evidence from a national study of people with schizophrenia (Slade and Salkever 2001) found an employment rate of about 22 percent, but only half of the jobs were in competitive employment without supports. The remaining job situations either had ongoing job coaching or were in noncompetitive work environments.

³ This summary relies heavily on Salkever (2003).

⁴ We reproduce his full discussion as Appendix A.

Low rates of working and earnings among SSI/DI beneficiaries with SMI parallel those for people with SMI in the general population. Relatively few SSI/DI beneficiaries have any earned income. Only about 15 percent of all SSI/DI beneficiaries have any earnings in a 12 month period—a proportion that remains the same regardless of whether beneficiaries do or do not have SMI or which benefits (SSI or DI) they receive. Further, 12-month earnings among those with any earnings are low overall and only half as much for those with SMI (\$2,400) as for those with other disabilities (\$5,400), regardless of program. Working fewer hours, on average (about one-third time vs. one-half time), and earning a lower hourly wage both contribute to these differences (Salkever 2003).

It is quite possible that Social Security's employment supports and TTW programs may help achieve part of the goal of promoting more work activity among SSI/DI beneficiaries, especially given that a substantial share of current beneficiaries want to work. About 10 percent volunteered for Project NetWork (described below) including those with a primary diagnosis of SMI. Interest in working is even more widespread among people with SMI in the general population. In a recent survey for the National Alliance for the Mentally Ill (Hall et al. 2003), two-thirds of respondents who report a mental illness were not working and over half relied on public programs for cash assistance, health care, and other benefits (37 percent reported receiving SSDI and 35 percent reported receiving SSI income). Nevertheless, among the 86 percent of respondents aged 18 to 54, a majority reported a strong interest in working.

However, achieving full self-sufficiency—that is, reducing the SSI/DI rolls by helping people become self-sufficient—is much less certain for people with SMI. The same is probably true for other beneficiaries as well. The nature of the population of individuals on disability benefits under the SSI and DI programs and the process they have gone through to establish eligibility raise these concerns. As other writers have noted (Batavia 2003), people receiving SSI and/or DI:

“...are among those with the most substantial disabilities in our country. They have already been subject to a process whereby they have been found to be so disabled that they cannot work at any job in the economy. Some of them have had to subject themselves to a prolonged process, sometimes involving legal appeals, in which they have had to argue that they are too disabled to work and in which ‘the system’ ultimately agreed with this conclusion.”

That even some of them do try to work, despite their disability, is a reflection of the importance of work to these beneficiaries, as it is to the U.S. population in general. However, work is one thing and employment at a level that will more than simply compensate a disabled person for the loss of SSI/DI cash assistance and health care coverage is another. Techniques for helping people find and keep jobs and for managing disability in the workplace can increase labor force participation, at least for a time. Although there is no guarantee that a substantial proportion of people with SMI currently receiving SSI/DI will achieve self-sufficiency, they are likely to increase work activity among those who value working and would work as much as they could, with proper supports and incentives.

Some socioeconomic characteristics known to affect workforce participation differ substantially between SSI and DI beneficiaries with SMI and those with other disabilities, indicating that it

may be particularly difficult to design structures to increase work participation among beneficiaries with SMI. Beneficiaries with SMI have only about 60 percent of the lifetime work experience of other beneficiaries, measured in mean years of work (for SSI, 5.9 years for those with SMI vs. 9.7 years for others; for DI, 10.9 years for those with SMI vs. 17.5 years for others). Further, among those with SMI, SSI beneficiaries have worked only about half as many years as DI beneficiaries. Education levels do not differ between SMI and other beneficiaries, but neither group has a mean education level equivalent to high school completion (about 10 years for SSI and 11 years for DI beneficiaries).

In a review of over 30 controlled studies conducted between 1985 and 1997 that attempt to identify strong predictors of vocational outcomes for people with psychiatric disabilities, Tsang and colleagues find that functioning prior to disability onset, work history, and social skills are strong and significant predictors of employment, while the results for symptomatology (i.e., abnormalities in moods, thoughts and behaviors resulting from mental illness) and actual diagnosis are much more mixed. Newer research suggests that how well one can think and process information (cognitive functioning) and how supportive one's family is of one's work-related efforts can also improve vocational outcomes significantly (Tsang et al. 2000). A consistent finding among studies looking at supported employment programs specifically is the absence of client-level factors predicting better employment outcomes: diagnosis, symptoms, age, gender, disability status, prior hospitalization, education, and even co-occurring substance abuse are all poor predictors of employment outcomes. While a strong work history does predict better outcomes, even individuals with poor work histories have better employment outcomes when they receive supported employment services compared to traditional vocational services (Bond et al. 2001).

1.3 Pre-Ticket SSI/DI Work Incentives and Demonstrations

The TTW incentive structure builds on earlier efforts to promote work among SSI/DI beneficiaries through legislative and regulatory provisions that expand rehabilitation opportunities, as well as allow beneficiaries to work without risking loss of cash assistance and/or health benefits. The work incentives for SSI and DI participants vary. In general, after certain income disregards, SSI recipients lose \$1 of benefits for every \$2 of earnings. In addition to these work rules, other incentives designed to promote work for SSI recipients include:

- Extended cash benefits while working (Section 1619a);
- Continued Medicaid eligibility even after one would no longer be eligible for SSI cash payments (after exceeding the SSI break-even point), up to some state-specific income threshold (Section 1619b); and
- A disregard of certain impairment related work expenses (IRWEs), or the disregard of certain income for a specified Plan for Achieving Self-Support (PASS).

DI beneficiaries suffer no reduction in benefits until their earnings reach the level of substantial gainful activity, but those who do reach that level for long enough could lose both their DI and Medicare eligibility. In general, DI beneficiaries have the opportunity to work during a trial

period lasting up to nine months, during which eligibility and benefits continue in case the beneficiary is not able to sustain work.

These incentive provisions, structured by Congress, assume an ultimate payoff for Social Security programs in reduced SSI/DI benefit payouts because beneficiaries will eventually work enough to become self-sufficient and leave the rolls. Even with these incentive provisions, however, few beneficiaries, whether with SMI or other disabilities, have any earned income, as we just noted, those with any income do not earn more than a few thousand dollars a year, on average, and even fewer (less than 1 percent) leave the rolls each year due to earned income exceeding eligibility criteria (Rupp and Scott 1998).

2 EXPERIENCE WITH PROMOTING WORK FOR PEOPLE WITH SMI, BOTH ON AND OFF THE SSI/DI ROLLS, AND THEIR IMPLICATIONS

2.1 Findings of Demonstrations to Increase Work Among People with SMI

2.1.1 Project NetWork

In the early 1990s the Social Security Administration mounted a special demonstration program to increase work participation by SSI/DI beneficiaries. This field experiment, Project NetWork, incorporated extensive outreach to beneficiaries and increased their access to return-to-work services. The project identified eligible individuals and, through intensive outreach, invited them to apply. Applicants who qualified (about 60 percent, on average) were designated “participants.” They were divided into treatment and control groups, with only the former receiving the enhanced access. Evaluation results (Rupp and Bell 2003) showed that participants earned much more during the intervention period than nonparticipants. Two caveats are especially important to note, however. First, there were no differences between treatment and control participants—virtually the entire “impact” was due to self-selection, with beneficiaries having characteristics more predictive of work success choosing to apply and being selected at higher rates than beneficiaries with less promising characteristics. So the actual intervention had only the most marginal effects. Second, and at least as important from the point of view of TTW’s eventual ability to bring about the goal of reducing the SSI/DI rolls, average annual earnings of participants, including those with zero earnings, were in the \$3,200-\$3,500 range. Even after eliminating participants who had zero earnings in all of the six follow-up years (36 percent for the treatment group), average annual earnings increase only to about \$5,800—still well below the level that would be needed for self-sufficiency. The only aspects of the Project NetWork evaluation results that hold some promise for the goal of helping beneficiaries with SMI leave the SSI/DI rolls were that beneficiaries with SMI were at least as likely as those with other disabilities to apply for the enhanced work supports and to be selected as participants, and that outcomes for participants with SMI did not differ in any substantial way from the average for all participants, regardless of disability type. These results suggest that beneficiaries with SMI are as interested in working and as capable of predicting their own employment success as beneficiaries with other disabilities.

2.1.1.1 Essential Project NetWork Findings

- People with SMI did not fare any differently than people with other diagnoses—they were actually slightly more interested in working (more applied), and more were selected as participants (considered acceptable).
- People with SMI earned as much, on average, as the sample as a whole, and more than some other disability categories.
- People with SMI were just as good as those with other diagnoses at predicting their own success.
- BUT, only 10 percent of all eligible individuals applied, only 64 percent had earnings in at least one of the six follow-up years, and these job-holders still earned only about \$5,800 a year, on average, during the six year follow-up period (\$3,500 a year if one includes everyone with zero earnings).
- So, the motivation to work exists for some, although earnings potential does not appear to be high.

2.1.2 Employment Intervention Demonstration Program

SAMHSA’s Center for Mental Health Services (CMHS) sponsored the Employment Intervention Demonstration Program (EIDP) beginning in 1995. Its goals were to identify the complex factors involved in securing and maintaining satisfying employment among mental health consumers, and understand how different types of service interventions might improve clients’ chances of working. Eight sites tested nine service models, with two models included at each site. Some models were considered “enhanced” (i.e., the treatment conditions) while others were considered the comparison models. Data were collected on 1,648 EIDP participants from 1996 through 2000.

All participants were mental health consumers. Although 97 percent had held a paying job at some time in their lives, one-third had not done so in the five years before the study began, and only one-fourth had worked 25 or more months out of the prior 60 months. When they did work, most jobs were at minimum wage. At baseline, 12 percent received both SSI and DI, 35 percent received SSI only, 25 percent received DI only, and 28 percent did not receive either benefit.

During the first 24 months of EIDP, participants in the enhanced conditions were more likely than comparison group participants to have done any work for pay, to have worked each month in competitive employment, and to have worked 40 or more hours per month. However, jobs for all working participants tended to be at minimum wage, and to be part-time (19 hours per week, on average). Controlling for many participant characteristics, regression analyses found that people’s employment outcomes improved over time in both enhanced and comparison conditions, but the enhanced group had better outcomes overall and their outcomes increased more over time. As has been found in other studies of individual factors affecting employment (Mechanic et al. 2002; Slade and Salkever 2001), better work histories, fewer symptoms, lower levels of functional impairment (ability to carry out activities of daily living), no other health

problems, and diagnoses other than schizophrenia led to better employment outcomes, over and above the effects of enhanced services. Younger people and those not receiving disability income (which we can take as a proxy for being less disabled) also had better employment outcomes.

Looking at the effects of services, those receiving more total hours of clinical services had poorer vocational outcomes (possibly reflecting poorer mental health status), those receiving more total hours of vocational services had better employment outcomes, and those receiving integrated employment and clinical services had the best outcomes of all. In this final condition, employment services staff could identify situations in which mental health status was interfering with work performance and bring clinical resources into play quickly and appropriately (because the services were integrated) to prevent the situation deteriorating to the point of losing the job.

Vocational services associated with better outcomes included job development, on-site job support, collaboration with employers, vocational assessment, vocational treatment planning, vocational counseling, and transportation. EIDP defined employment and clinical services as high on integration when they were delivered by the same agency, at the same location, using a single case record, and with regularly scheduled and frequent (not less than three times a week) meetings of the vocational and clinical providers (Cook 2003).

Nevertheless, there are some important caveats in the EIDP results. First, more people were on SSI/DI at the 24-month follow-up than had been recipients at baseline. About one-third of the people who began with no benefits were receiving them at follow-up, leaving only 19 percent who do not receive either DI or SSI. The proportion receiving both DI and SSI increased the most. Second, no more than 3 percent of employed participants who received only SSI ever achieved monthly earnings at or above SGA; corresponding proportions for recipients of SSDI only and both DI and SSI are about 4 or 5 percent. Nor did participants reach even these levels until about 18 months into their period of service receipt.

Further, EIDP participants and programs encountered the basic stumbling block that people with SMI had a lot of trouble keeping jobs once they had them. EIDP interventions did improve on the average length of time people with SMI were able to hold their jobs, which is reported in the literature to be about three to four months and rarely longer than six months. But even EIDP interventions could not keep many of the people with initial job placements employed at their first job (although many people were helped to return to employment). In the Maryland site, Lehman and colleagues (2002) reported that over time, enhanced program participants' initial employment levels of about 20 percent declined to the 10 percent experienced by the comparison sample.

Thus despite the investment made in them, even the most successful employment support programs for people with SMI, which do help more people to work for at least some time, do not appear able to help people in ways that might lead to large reductions in the SSI/DI rolls. They can successfully place many clients and can help them extend their job tenure and get new jobs when old ones are lost. But they cannot control the factors that keep their participants operating at or below poverty incomes, or the course of the mental illnesses that affect job tenure. Being casework programs whose obligation is to help their clients access the best supports available, they also help mental health consumers obtain SSA benefits. So work increases, but does not

have the effect of reducing the benefits rolls. And client need persists, leading to increased proportions becoming SSI/DI beneficiaries.

2.1.2.1 Essential EIDP Findings

- During each month starting about nine months into the period of receiving work-related services and continuing through month 24, about 30-35 percent of participants in EIDP's enhanced models had done at least some work for pay.
- During the same follow-up period, even the participants in EIDP's comparison groups—who received “usual” employment-related services—achieved a monthly employment rate of 25 to 30 percent.
- Thus both the enhanced and “usual” employment-related services are considerable improvements over current employment rates for SSI/DI beneficiaries.
- The more vocational services people receive, the better their employment outcomes.
- People who receive a relatively balanced amount of well-integrated and coordinated vocational and clinical services have much better employment outcomes than those who receive non-integrated services.
- EIDP participants earned enough, on average, to save SSI/DI about \$1,800 in benefits per person over a two-year period (about \$74 a month), based on a \$1 reduction in benefits for each \$2 earned, after accounting for disregards.
- While employment outcomes are significant accomplishments for EIDP participants, they remain low overall. With all the help that EIDP offered its participants, and all the jobs that people held, they were not able to get jobs that paid enough to lift them out of poverty, and hence off the SSI/DI rolls. Nor were most able to sustain employment in one job for much beyond six months, and significant gaps (of about 80-100 days) were common between jobs before people went back to work.
- The cost of achieving this level of results is not trivial. Clark and colleagues (1998) estimate that these programs cost about \$3,600-\$3,700 a year per participant, which is more than most of the participants earn, and double the savings realized by the SSI/DI programs.

2.2 Program and Policy Options for Increasing Participation in Employment

Major advances in science and service delivery over the past two decades have led to a virtual revolution in how mental health and illness are understood and managed (Mueser et al. 2002; Drake et al. 2001; Torrey et al. 2001; Goldman et al. 2001). A range of effective, well-documented treatments are available, yet the Surgeon General's 1999 report on mental health (U.S. DHHS 1999) notes that less than one-third of adults with a diagnosable mental disorder receive treatment in any given year. Further, the President's New Freedom Commission on Mental Health cites, as part of its Goal 2, the appropriateness of helping people with major

mental illnesses to achieve as extensive an involvement in productive work as possible, and as they desire (President's New Freedom Commission on Mental Health 2003).

A variety of programs and practical strategies have been developed and proposed to support the employment of people with psychiatric disabilities (Crowther et al. 2003; Bond et al. 2001; Drake et al. 2001). Some have been stimulated by changing views of what people with disabilities can accomplish, and some by the legal requirements of the Americans with Disabilities Act (ADA).⁵ New ways of thinking about the interactions between mental illness and different aspects of workplace culture and environment, as well as how specific characteristics of a job may contribute to stress and mental illness, are also leading to changes in how employers think about mental wellness and work more generally.

Workers with serious mental illnesses may experience any of a wide variety of symptoms that could interfere with productivity at work. These include problems with judgment, attention, concentration, memory, decisionmaking, psychomotor functioning, cognitive processing, and social interactions and communications. To address these difficulties, a strong focus has been on creating accommodations that workers with mental illness may need to succeed at work. Examples of such accommodations include adjustments needed to help workers maintain stamina and concentration, stay organized and meet deadlines, cope with memory deficits, work effectively with supervisors, interact with coworkers, handle stress and emotions, deal with change, and manage attendance issues.

As serious mental illnesses affect many people who do not receive SSI/DI benefits as well as many who do, we start with approaches that operate at the broadest level of prevention/accommodation for people already in the workforce, then with approaches that are more directly focused on people whose disability has kept them out of the workforce, and finally with approaches for facilitating workforce participation other than specific programs.

2.2.1 Proactive Approaches for Managing Mental Health in the Workplace

Providing employees with mental illnesses with various accommodations is important, but like most traditional approaches to workplace disability-related issues it is reactive rather than proactive. New developments in human resource management have led to a virtual paradigm shift in how disability in the workplace is viewed and treated. As part of what is now known as disability or absence "management," employers, insurers, health care providers, and human resource professionals have come together and developed a variety of approaches designed to prevent mental illness (by reducing workplace factors that may actually contribute to mental illness) and promote mental wellness among workers generally. This shift from a reactive to a proactive stance toward health and disability has primarily focused on physical wellness and safety, but is gradually being extended to mental health issues as well. One consulting firm that specializes in psychiatric disability management suggest four specific tasks that companies

⁵ The legal aspects of employing people with mental health disabilities are an important and growing area of interest but are *not* the focus of this review.

should undertake to directly address mental wellness in their workplace (O'Connor Associates undated):

First, generate employee and supervisory feedback about employer practices and work culture traits that contribute to stress or depression. This process provides HRM [human resource management] with ratings on its disability management practices, mental health-related resources such as EAP [Employer Assistance Program] and Work/Life, and HRM ADA/FMLA [Americans with Disabilities Act/Family and Medical Leave Act] policies. Second, conduct 'audits' of your training and HRM consultant resources to assess their ability to reduce work culture variables that contribute to mental health-related disability. Third, analyze various medical and EAP vendor data to assess their expertise to manage disability (versus just injury or symptoms) and improve mental wellness in your workforce. This will provide HRM the knowledge to create employee management and environmental changes to reduce these costs. Understanding the uses of these data reinforces the value of HRM in the disability management team dynamic (alongside risk management, benefits administration, etc). Fourth, implement a strategic plan for changing work culture and employee management protocols in response to your overall assessment. Such a plan would include staff training, behavioral performance standards for supervisors, and proactive (vs. response-oriented) strategies for reducing disability-related events or behavior in the workplace.

With its focus on prevention and early intervention, the main beneficiaries of workplace disability management practices clearly extend far beyond those with serious mental illnesses (the focus of this review). Yet employers who are aware of and committed to supporting the mental well-being of all employees are also likely to be the ones best able to accommodate those with more serious mental disorders. Research has mapped out the many domains of work that can contribute to stress among workers (Table 1), creating a useful list to work with and consider with respect to making accommodations for people with serious or persistent mental health problems. These same factors that are stressful for workers generally can be detrimental to people with SMI, and may even affect the recurrence of mental disorders that are episodic by nature, such as major depression.

[Table 1 about here]

2.2.2 Employment-Related Accommodations for Mental Health Disabilities

Because mental illness is often "hidden," it can be difficult for employers to distinguish between behaviors that are manifestations of a disability and ones that simply require disciplinary actions. Employers report psychiatric disability to be among the most difficult to identify, accommodate, and manage. They have specific concerns about how to handle performance problems among employees with a mental illness, and many have a variety of misconceptions about the ability of people with mental illness to work with others, the inevitability of employee relations problems resulting from negative co-worker reactions, and the ease with which physical disabilities can be accommodated relative to mental ones (Handrich 2000).

It is important to remember that the functional limitations (abilities to perform various tasks) stemming from mental illness vary from one individual to another, and even over time for the

same individual. In some cases employment-related accommodations are needed to address limitations imposed by the mental condition itself, and in other cases to handle the effects of medications. Also, while DI and SSI beneficiaries clearly have work-limiting conditions, many other people with psychiatric disabilities may not need any accommodations to perform their job and others may need only a few.

Some very practical tools and strategies are now available for employers and others who are involved in helping accommodate people with mental illness. They include such recent publications as the Hogg Foundation for Mental Health's (2000) *Managing Mental Illness in the Workplace: A Practical Guide for Supervisors*, and another by the Job Accommodation Network within the Office of Disability Employment Policy of the U.S. Department of Labor (undated) *Work-Site Accommodation Ideas for Persons with Psychiatric Disabilities* (see Appendix B for specific examples of such accommodations). New websites also offer extensive materials such as the Canadian Mental Health Association's *Working Well: An Employer's Guide to Hiring and Retaining People with Mental Illnesses* (Vandergang 2002), one publication among several available at the association's website, "Routes to Work: Helping People with Mental Illness Secure Mainstream Employment."

Effectively accommodating psychiatric disabilities can require changes in a variety of domains including:

- **Schedule adjustments** such as more breaks, flexible scheduling, a compressed workweek, or part-time work (often these are done to accommodate the side effects of medications).
- **Benefit adjustments** such as using sick leave for therapeutic and other mental health treatments.
- **Support system adjustments** such as training co-workers how to be more supportive and helpful to a given employee.
- **Environmental adjustments** such as changing the location, organization, or noise or lighting level where someone works, or allowing for work to be done off-site.
- **Supervisory style adjustments** such as increasing access and frequency of contact with supervisors, more training of supervisors, and changes in communication style.
- **Assignment adjustments** such as allowing for self-paced work, flexible hours, job sharing, or reduction of tasks.
- **Interpersonal communication adjustments** such as written or recorded communications, rather than verbal only.
- **Assistive devices** such as alarms that can signal appointments, tape recorders, portable computers, light boxes, etc.
- **Job description adjustments** can include reducing less important job responsibilities so that the employee can focus on their primary tasks (Handrich 2000).

In the case of people with SMI, such as those on the SSI/DI rolls, even greater accommodations may be needed in the form of job coaches, counselors, and other support staff from the employer or an independent employment promotion program such as EIDP.

When assessing the need for, adopting, and evaluating accommodations, a variety of issues should be considered: what limitation (or pattern of limitations) the individual with the psychiatric disability is experiencing, how and to what degree the limitation(s) affect the person and his or her job performance, what specific job tasks are being affected, whether the individual with the disability has been asked about his or her needs for accommodation, what accommodations can reduce or eliminate the problems (and whether all resources that can help identify possible accommodations have been used), and the need for regular meetings with the person with a psychiatric disability to evaluate the effectiveness of existing accommodations (Duckworth undated).

Who can make these assessments, suggest accommodations, and implement and evaluate them? Certainly individual employers and employees themselves, and EAP staff whose focus has moved beyond the traditional ones of substance abuse and later physical disabilities. But a host of other individuals and organizations (both formal and informal) can and do provide important supports alongside clinical treatments and interventions. These include case managers, job coaches, job developers, consultants, staff of various employment networks, and others.

2.2.3 Program Options Other Than Permanent Competitive Employment

It is clear from the many research and demonstration programs reviewed above that not all people with SMI who want to work will be able to sustain a permanent competitive job, with or without accommodations or ongoing supports. A variety of other options are available, including supported employment programs and programs that offer employment experiences, work-skill development, or prevocational training. These include hospital-based training and work integration programs, sheltered workshops, transitional employment (working in a job that is "owned" by a rehabilitation agency), work crews, skills training, training in community living, and programs providing assertive community treatment (or ACT). While participation in many of these prevocational types of programs has been shown to have a number of positive outcomes (reducing the length of hospital stays, increasing independent living, preparing people for more intensive work, etc.), they have generally not been found to be effective at leading to permanent employment. Supported employment does better than the other programs at helping people get and keep jobs, but even these more effective programs do not move people to the level of self-sufficiency. Both types of programs increase the time participants spend working, which has implications for SSI/DI program costs. Yet other options that fall in between permanent competitive employment and prevocational programs are innovative approaches such as work integration contracts and social firms/enterprises and cooperatives.

Supported employment programs are an important option for people with SMI. The Rehabilitation Act Amendments of 1986 and 1992 (PL 99-506), define supported employment as:

“Competitive employment in an integrated setting with ongoing-support services for individuals with the most severe disabilities:

- for whom competitive employment has not traditionally occurred or for whom competitive employment has been interrupted or intermittent as a result of a severe disability;
- who, because of the nature and severity of their disabilities, need intensive supported employment services from the designated state unit (Division of Vocational Rehabilitation) and extended services after transition in order to perform this work; or,
- transitional employment for individuals with the most severe disabilities due to mental illness.”

A major review of studies examining different ways of helping people with SMI return to work has found supported employment to be more effective than prevocational training (Crowther et al. 2001; Bond et al. 2001). Supported employment programs place clients directly into competitive jobs but provide on-the-job support from trained “job coaches” or other employment specialists. Crowther and colleagues identify the core principles of supported employment as: (a) the goal is competitive employment in work settings integrated into a community's economy, (b) clients are expected to obtain jobs directly, rather than after lengthy pre-employment training, (c) rehabilitation is an integral component of mental health treatment rather than a separate service, (d) services are based on clients' preferences and choices, (e) assessment is continuous and based on real work experiences, and (f) follow-on support is continued indefinitely. The advantage of supported employment was found in a variety of employment outcomes (not just securing a permanent competitive job), but data on clinical and social functioning, as well as costs, revealed no major differences between supported employment and prevocational training. Interestingly, the studies reviewed included fairly large shares of women, people from ethnic minorities, and people with schizophrenia. The main findings, therefore, are likely to apply to the general population of patients with SMI who would like to work.

Another innovative approach to promoting work among people with SMI is work integration contracts. These contracts, which tend to be used by small to medium-sized businesses as well as community-based agencies, rely on government support that gradually decreases over time (Gaston and Gabriel 2000). In Quebec, for example, employers can receive government grants to cover as much as 85 percent of a worker's salary in the first year and up to 75 percent in later years. The grants can also be used to cover “special needs” including workplace access, accompaniment, assessments, and medical treatment. In one particular program, 10 percent of the 3,000 people with these “work integration” contracts have a serious mental illness and after several years the province contributes 40 percent of their salaries.

Yet other approaches include social firms or enterprises and cooperatives. Social firms are small or medium sized enterprises developed with the primary focus of employing people with disabilities in an environment that is basically similar to a “regular” firm but with appropriate supports offered to anyone who needs them. In these firms, people with disabilities work alongside people without disabilities, have regular work contracts, are paid regular wages, and enjoy the same rights and responsibilities as their nondisabled counterparts: “the balance between commerce and care is the single most critical issue [facing] social firms, and this balance is achieved differently according to the origins of the firm and the orientation of its founders” (Grove et al. 2000). Social firms can be in the service (e.g., office work, recycling,

restaurant, catering, landscaping) or manufacturing sectors (e.g., textiles, computer hardware, furniture); most receive some sort of initial public funding. In some cases they can be required to develop a market analysis and business plan before receiving final government approval. Once established, however, they can be as much as 85 percent self-financing. These efforts are especially popular in Europe where 2,000 social firms and cooperatives (broadly defined) employ as many 47,000 people with disabilities, including many with SMI (Table 2). While the majority of the workers are permanent employees, as many as one-quarter may be engaged in transitional work, and another 10 to 15 percent may be receiving “qualifying training.”

[Table 2 about here]

The case of Italy is especially interesting. Progressive mental health legislation beginning in 1978 stopped admissions to psychiatric hospitals and promoted equal rights, full citizenship, and community integration of people with mental illness, including the right of access to work. A 1991 law established “type B” social cooperatives specifically designed to provide job opportunities for people with disabilities. The cooperatives are eligible for government grants as long as 30 percent or more of their employees are people with disabilities.

2.2.4 Other Options for Increasing Employment Among People with SMI

States have a variety of options open to them to increase employment among people with serious mental illness. First, they can tailor assistance for various public assistance populations they are already serving, including recipients of Temporary Assistance to Needy Families (TANF),⁶ youth with mental illness, and transitional populations such as people leaving community-based treatment facilities. Services should include basic screening, needs assessments, and referrals for treatment, as well as guidance about benefits, early intervention services, and education, training, and other employment services. A second option states have is to expand and modify vocational rehabilitation (VR) services to accommodate the special needs of people with mental illness (the program has traditionally served people with physical and developmental disabilities).

Another important policy option is available through Medicaid regulations—most states have now adopted an option in the Medicaid program called the “psychiatric rehabilitation option” (or “rehab option”) that allows states to offer certain “medically necessary” services (e.g., assistance with daily living skills, social skills, and even training and employment services) to persons with mental illness and have Medicaid share the cost. The employment-related services are limited to prevocational or rehabilitative services that address the symptoms of mental illness in relation to a job, and cannot focus on services or training on how to perform a given job. Only one state, Georgia, has successfully incorporated employment-related services into its Medicaid program; the state even provides for billable peer support in which people with mental illness counsel others who have similar conditions. Through its commitment to move 20 percent of its day treatment clients into supported employment, Georgia has learned two important things: it costs

⁶ In 1998, the Presidential Task Force on the Employment of Adults with Disabilities reported that 28 percent of TANF recipients have mental disorders that may interfere with successful employment, but some states report much higher rates. Oregon, for example, estimates that three-quarters of its welfare population has some type of mental disorder (NGA Center of Best Practices 2003).

less to provide rehabilitative services to people with mental illness than for persons with developmental disabilities, and workers in supported employment need flexible schedules and ongoing, readily accessible anxiety counseling (NGA Center of Best Practices 2003).

Finally, states should make the investments needed to expand professional and non-professional supports for people with mental illness, especially support following employment. A variety of demonstrations have shown the importance of initial and ongoing education, training, and counseling support for the successful employment of people with mental illness. There is a clear need for increasing the numbers and types of professional and nonprofessional supports available to people with mental illness. Professional supports include physicians, clinicians, counselors, and employment specialists, while nonprofessional supports can include employers and coworkers, family, friends, teachers, and clergy. The resources needed to make these investments are costly, but it can be done.

Ten European countries have gone as far as using quota systems when it comes to employing people with disabilities although this approach is becoming less popular over time. Firms that fail to employ a pre-specified percentage of people with disabilities as part of their workforce must pay a “levy” into a pooled fund that is used to promote the employment of people with disabilities. Although this is unlikely to be adopted in the United States, where quotas are generally viewed with suspicion, more positive employer incentives could be used to reward those who are at the forefront of employing people with disabilities. Positive incentives might include public subsidies for disabled employees’ salaries, subsidies for job coaches and other supportive personnel supplied by the employer, allowing employers to deduct the costs of accommodations from tax liabilities, or other forms of tax credits.

3 IMPLICATIONS FOR SOCIAL SECURITY ADMINISTRATION PROGRAMS AND OTHER POLICY STAKEHOLDERS

This paper has summarized results of demonstration programs designed to help people with serious mental illness find and keep jobs, workplace accommodations that may help sustain employment, structured employment opportunities that support people with SMI, and other public policies that reduce some of the barriers that may inhibit interest in working among SSI/DI beneficiaries with SMI. From this review we may conclude that it will be quite difficult to reach the goal of moving substantial numbers of SSI/DI beneficiaries with SMI off the rolls through sustained competitive employment. It will be much less difficult, however, to help many beneficiaries participate in paid work to some degree, and with some reductions in benefit amounts. Thus it may be in the interests of both the Social Security Administration’s disability programs and the beneficiaries themselves to make supports available that would help beneficiaries work as much as they want and as much as they are able.

3.1 Implications Related to the Nature of Serious Mental Illness

As we have seen, the nature of serious mental illness has important implications for what one might reasonably expect to achieve with TTW for this population, and the incentives that are likely to be necessary to promote more employment among this group of SSI/DI beneficiaries. Specifically,

- Serious mental illness often involves periods of less intensive symptoms, but severe symptoms often recur periodically. This means it is very unlikely that many beneficiaries with these conditions will move to steady employment, although they may be able to sustain a series of shorter-term jobs.
- Among SSI/DI beneficiaries with SMI, we may assume that various medications have been tried but have not been able to control their condition enough to permit steady work—otherwise they would not have qualified for benefits.
- SMI symptoms are such that they may interfere with a person’s ability to perform many jobs, especially if no workplace accommodations are made.
- In addition to difficulties inherent in the nature of SMI, SSI/DI beneficiaries with these conditions have other characteristics that limit their ultimate capacity for earnings at the level that would signal no further need for benefits—poor educational attainment, poor work histories, and few skills.

Nevertheless, we have also seen (from Project NetWork) that some SSI/DI beneficiaries with SMI want to work, and that those who are most likely to be able to work are also those that volunteer for programs such as Project NetWork. EIDP results have also shown that some programs designed to help people with SMI get and keep jobs have had some success, especially when they offer integrated clinical services and employment supports. Further, models tested by EIDP that used an approach involving immediate job placement (without much effort to get participants “employment ready”) were indeed able to help many people obtain and keep employment, at least for the short term.

3.2 What Level of Employment Can One Reasonably Expect to Achieve for Beneficiaries with SMI?

We summarize known employment rates for current SSI/DI beneficiaries with SMI plus the results of demonstration programs, and then draw several implications.

- Currently, 15 percent of SSI/DI beneficiaries with SMI have nonzero earnings in any 12-month period. Although we do not have actual data on the proportion working at any given time, given the intermittent nature of work for this population that proportion is likely to be very low—perhaps as low as 5 percent.
- The average annual amount earned by SSI/DI beneficiaries with SMI who have any earnings is very low--\$2,400, and no more than 1 percent earn their way completely off the SSI/DI rolls each year.
- EIDP’s enhanced models were more successful than “services as usual” in helping clients with SMI earn some income from employment. Beginning the demonstration with people who mostly had not worked at all during the five years before the demonstration, interventions were able to increase the odds that the people receiving the treatment conditions would get jobs, keep them longer, and return to work more quickly after losing a job.

- With programs and services more closely resembling EIDP’s treatment conditions than Project NetWork’s, policymakers could aspire to increasing both the proportion of people with any earned income and the level of earned income, as follows:
 - o Increase the proportion with any earned income in a 12-month period, from its current 15 percent to between 20 and 30 percent. This would be an increase of between 33 and 100 percent.
 - o Increase the proportion working at any given time, from what is probably around 5 percent to 10 percent or more.
 - o Increase job tenure.
 - o Reduce the lag between one job and another if a beneficiary has to leave a job.
 - o Increase earnings (by helping participants get jobs with higher pay and/or work more total hours in a year).
- These achievements could save SSA disability programs money in cash benefits, but—
 - o It is not realistic to expect that even these efforts will result in many SSI/DI beneficiaries with SMI completely leaving the rolls and not returning,
 - o Earnings are not likely to enable participants to get the health and mental health care they need without Medicaid, and
 - o The investment in clinical and employment services might or might not be offset by savings in cash benefits.

Assuming that one or more of the goals just described are ones that the Congress can embrace, even in the absence of complete departure from the beneficiary rolls, SSA should explore four aspects of how to accomplish them. These are reviewing and potentially revising the incentive structures for ENs with respect to beneficiaries with SMI, doing the same for the incentive structures facing beneficiaries, exploring options for types of work and work settings that might promote more employment, and exploring options for employment supports and the funding structures that would make them more available.

3.3 Appropriate Incentive Structures

3.3.1 Incentive Structures for Employment Networks

For the SSI/DI programs to achieve any of the outcomes just described, two sets of actors have to have the right incentives—Employment Networks (ENs), and current SSI/DI beneficiaries with SMI. ENs are gatekeepers for TTW. Although the beneficiaries themselves ostensibly have a “Ticket” and can take it to any EN they choose, the ENs also have the right to refuse to serve particular beneficiaries. The obvious reason to do this would be because an EN believes that taking on clients with poor prospects of success is not in its best interests. The design work for

SSA's Adequacy of Incentives Study has focused a good deal on the incentive structure for ENs, but not with specific reference to serving people with severe mental illness. Employers and Employment Networks alike, including traditional vocational rehabilitation programs, have tended to avoid people with SMI because success can be elusive and temporary. Given limited resources for community-based employment services, they more often select those with less severe impairments, especially with current policy emphasizing quick results and competitive employment outcomes. Stigma and ignorance associated with mental illness present other challenges, predisposing employers and ENs toward believing that people with SMI will be difficult to supervise and work with, and because employers report that they in fact have had such difficulties with employees who have a serious mental illness.

The EN incentive structure in TTW is mostly based on the assumption that people will obtain and sustain employment. We have seen that this is probably not a realistic assumption for beneficiaries with SMI. As Cook (2003) concludes on the basis of the EIDP results, hardly any EIDP participants would have met Ticket criteria under which the ENs would get paid, while the supports to assist them even to the relatively low level of work they achieved would have to be expended regardless of results.

For ENs to be willing to serve SSI/DI beneficiaries with SMI, they will probably need an incentive structure that allows payment even though the beneficiaries never leave the rolls. Milestones for people with SMI are more reasonably couched in terms of working "about half-time" for "about six out of twelve months," and "returning to work after job loss," rather than increased pay at steady work. If ENs could get paid for meeting such simplified goals, and get paid annually for each year they help their clients achieve each milestone, Tickets from people with SMI might be more attractive to them.

It may also be interesting to explore the possibilities of constructing some index or formula that pays ENs on the basis of achieving the intermediate goals just described—increasing the number of people with any earned income, the proportion of time working, hourly wages, and hours per week worked, and reducing the down time between jobs—all of these lead to increases in average annual income. Each of these elements of a formula would have to be specific about what SSA would pay for, in terms of percentage increases and other changes. The metric would have to give ENs credit for effort that is under their control, while allowing some leeway for the effects of disease patterns that are not under anyone's control. Allowances would also be needed for ENs to achieve the modified goals through a variety of supported work settings—that is, not strictly in competitive employment without supports. If the EN incentives were right, some ENs might become interested in working with employers and clinical professionals to help create these settings.

Further, the TTW legislation says that to remain in the program, participants have to show "timely progress." If this means progress "toward self-sufficiency," we have seen that most SSI/DI beneficiaries with SMI are not likely to reach, or even approach, that goal. So the legislative requirement works against them and discourages ENs from taking them as clients. Requirements for client progress would have to be altered before most beneficiaries with SMI were a reasonable gamble for ENs. It is not clear whether SSI/DI beneficiaries with other disabilities face circumstances that are as discouraging to work as those faced by people with SMI. The simple fact of mental illnesses' instability—the periodic increases and decreases in

symptoms and problems—makes employment more difficult to sustain than holding a job when one has some physical disabilities. If the needs of beneficiaries are indeed different with respect to promoting work, the Social Security Administration may need to consider modified rules and guidelines for including people with SMI in the Ticket program.

3.3.2 Incentive Structures for Beneficiaries

It is important to recognize some of the major issues that affect the employment decisions of SSI/DI beneficiaries in general, and that apply at least as strongly for those with SMI. If one goal is to have more SSI/DI beneficiaries use their Tickets, program administrators will have to develop ways to overcome the significant disincentives to work that exist. Myriad factors have been identified that reduce the likelihood that beneficiaries will seek to work, although no definitive empirical evidence is available to estimate their relative importance (Wittenburg et al. 2002). We note the ones that policymakers and program administrators are most likely to be able to affect, which include:

- **Strong work disincentives created by SSI/DI rules:** While the work incentives for SSI and DI vary, both programs include high potential marginal tax rates on benefits (Burkhauser and Wittenburg 1996). For SSI, recipients generally lose \$.50 of benefits for every \$1 in earnings. DI beneficiaries risk losing all benefits if their earnings exceed a certain threshold (defined as substantial gainful activity) for an extended period of time. The high implicit tax rates on benefits probably discourage some recipients in these programs from working. Another important issue is the potential for retroactive repayment demands. The Social Security Administration may need to make these demands because the system is slow to register earnings and thus may overpay benefits for some period while beneficiaries are working. Stories circulate among beneficiaries of people who have been required to repay excess benefits as much as a year after the overpayments were made, and who do not have the funds to do so. However often or infrequently this happens, the stories persist and offer a serious disincentive to the much larger number of people who hear them and learn to fear being caught in this situation.
- **Fear of losing health care benefits:** Repeated surveys show that for many people with disabilities, the possibility that they could lose Medicaid as their health insurance without having a replacement is a major obstacle to employment. Because SSI and DI beneficiaries are generally eligible for Medicaid and Medicare, respectively, the potential loss of these benefits through excess earnings represents an important potential disincentive. This is especially true as they are unlikely to be replaced by any employment-linked health benefits, or by benefits offering the level of protection that Medicaid and Medicare give. Stapleton and Tucker (2000) provide the strongest findings to date on this issue, showing that many SSI recipients who do work restrain their earnings to stay below the 1619(b) threshold.
- **Transportation:** While this barrier exists for many people with disabilities, SSI beneficiaries are especially affected because of financial constraints that restrict automobile ownership.

- **Consumer Choice and Control:** Individuals who are forced into available jobs without considering their preferences and needs tend to quit sooner or perform at a level that leads to termination.

A beneficiary's decision to try to work will depend not only on his or her interest in working, but also on a belief that no significant losses will be associated with the attempt and a belief that supports will be available that actually work. The former concern is especially important if, as will likely be the case, working does not succeed in sustained earnings at the level of self-sufficiency. For an incentive structure to succeed in attracting SSI/DI beneficiaries to try employment, it therefore must overcome fears related to loss of benefits, and offer employment-related services that actually help.

- **Assurances that needed benefits will continue:** Most SSI/DI beneficiaries with SMI are likely to need some level of continued cash assistance, and are virtually certain to need ongoing health insurance coverage.
 - The Social Security Administration should clarify, and if necessary change, disregard and other incentive structures to make them more compatible with promoting work among people whose incomes are unlikely ever to exceed the poverty level, even if they work. In addition, accounting mechanisms should be improved to avoid as much as possible any significant lag time in adjusting benefits to income levels. If lag times are unavoidable, the attitude in handling repayment situations needs to be one of good faith and respect rather than an assumption of fraud and abuse. This attitude needs to permeate throughout the disability program when dealing with beneficiaries in these situations, including the line workers with whom the beneficiaries and their caseworkers actually interact.
 - Assurance of continued health care coverage (and coverage of medications for Medicare beneficiaries) could probably do more to attract beneficiaries to employment than any other single modification of current procedures. DI beneficiaries with SMI will also need prescription drug benefits if psychotropic medications play a significant role in enabling them to work. Health insurance coverage through Medicaid or Medicare should never be withdrawn, regardless of earnings, unless it is clearly being replaced by equivalent private employer-based health insurance in a job that people have a reasonable expectation of being able to keep working at for a long time.
 - Policy options to increase working need to assure beneficiaries that they are not jeopardizing their access to SSI/DI and Medicaid when they need it. Despite all the incentive structures that are in place to this effect, their practical administration still leaves many beneficiaries and their caseworkers in doubt that their benefits will be secure if they try working. Both beneficiaries and their mental health providers and/or case managers have to understand and believe the incentives and safeguards, or they will not participate in activities that promote work.

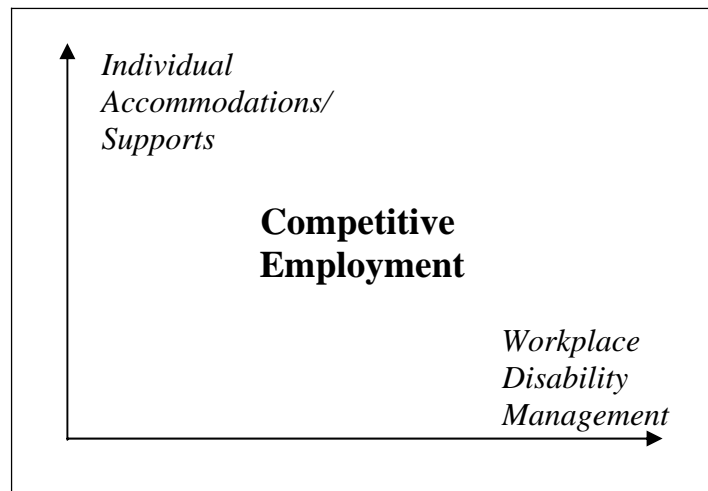
- **Providing services that succeed.** Earlier in the paper we described the characteristics of employment-related services that seem to have the greatest success with this population—integrated employment and clinical services available on a sustained basis. To induce SSI/DI beneficiaries with SMI to use a Ticket, they will have to know a good deal about the types of work-related supports that the Ticket will buy. Given the sources of anxiety about benefits loss that are common for many in this population, the Social Security Administration will need to:
 - Create work-related support systems that truly are appropriate, sustained, and persistent, as well as being easily accessible and available in sufficient volume that those who want to use them can do so (through modifying EN offerings and incentives), and
 - Make sure that beneficiaries and the people closest to them (families and/or caseworkers) know that this is true. Knowledge of and faith in employment-related services spreads through outreach and education, but above all by having a track record of follow-through and commitment that beneficiaries and their families can hear about and be convinced by word of mouth.

3.4 Options for Types of Work and Work Settings

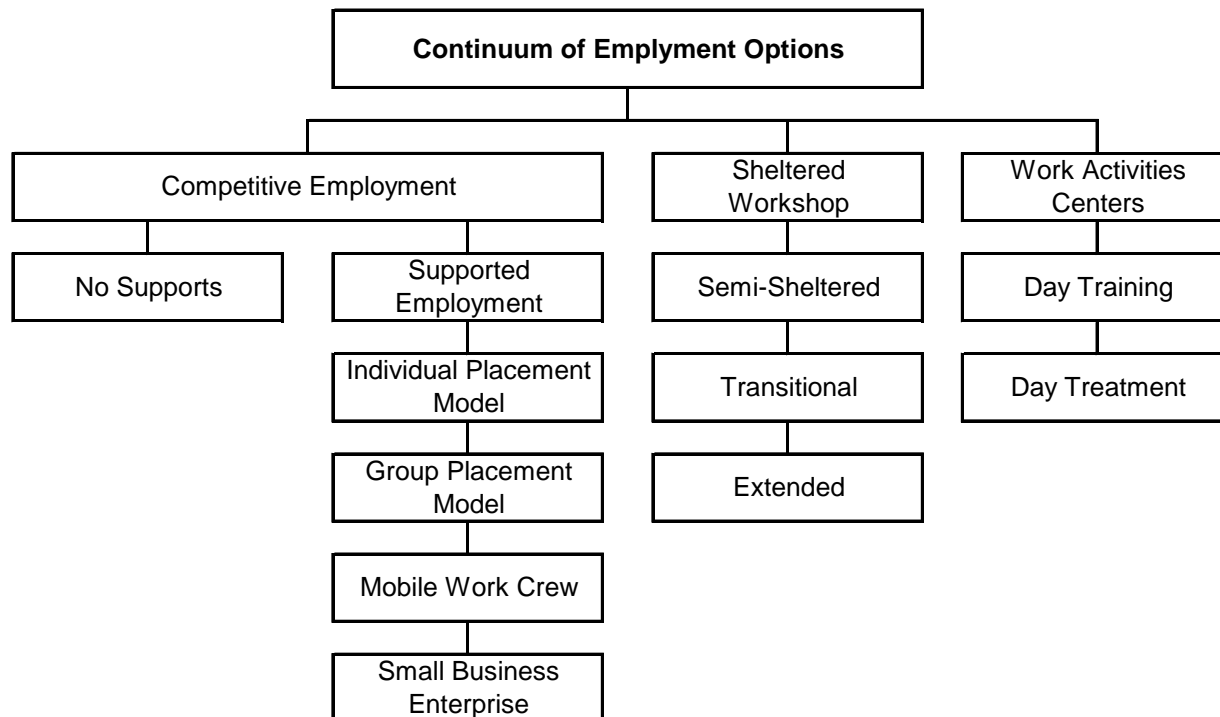
TTW’s goal for SSI/DI beneficiaries is to help them obtain and retain a job in competitive employment, ultimately without formal supports, that produces income sufficient to allow the beneficiaries to leave the SSI/DI rolls, thereby saving the government money. The goal of competitive employment is shared by many other stakeholders interested in increasing opportunities for those with SMI.

The Rehabilitation Act defines supported employment as competitive work in an integrated setting, where “competitive work” refers to work that pays at the same rates as those paid to persons with no disabilities who have similar job functions, and “an integrated setting” is a natural work setting where people without disabilities are also employed. EIDP’s goal was to help participants obtain and keep competitive employment, defined as a job that paid minimum wage or higher; was located in a mainstream, integrated setting; was not set aside for mental health consumers; and was consumer owned (the person can keep working at the job as long as desired). Note that each of these definitions focuses on job characteristics, not on the presence or absence of supports. Both accept that a job can meet the “competitive” criterion and still offer its occupant a wide variety of supports to sustain employment.

Thus “competitive employment” as the term is commonly used in the rehabilitation world includes a wide range of options with respect to both accommodations/supports for individual workers and general workplace characteristics that promote mental well-being and prevent (or minimize the recurrence of) mental illness. The figure below illustrates the independence of these two dimensions, although it is clear that a workplace that manages (mental) disabilities well would also do a good job of accommodating individual workers with mental illnesses, including SMI. It would be interesting to explore whether disabled workers in work settings that do a good job of “managing disability” require fewer individual supports than those holding jobs in less accommodating environments.



In general, supported employment aims to promote social integration and productivity as well as an individual person’s skills and abilities. The “support” parts of supported employment include individualized supports such as transportation, job site training, family support, or any service necessary for the worker to perform the job. These are generally provided at least twice a month, and last for the duration of employment. A wide variety of models of supported employment have been developed over the last decade within this general framework, as illustrated in the following figure and described briefly below.



- **Individual Placement Model**
A community-based job in an integrated work setting for a specific individual with a disability. Initial training and on-going support services may be facilitated by a job coach/employment specialist as well as natural workplace supports.
- **Group Placement Model**
Use of a full-time supervisor and a small group of individuals with disabilities to work in an integrated setting at an industry or corporation. The supervisor and/or group of individuals may be employed by the place of business itself or by a supported employment service provider.
- **Mobile Work Crew**
Use of a full-time supervisor and a small group of supported employees, who travel together to multiple work sites in the community to engage in contracted work.
- **Small Business Enterprise**
A private business, typically a small subcontracting, retail, or prime manufacturing operation, that employs individuals with disabilities. It provides community integration by including people without disabilities as coworkers, and/or through regular, ongoing contact with the general public (New Jersey Department of Human Services 2001).

It is also important to understand that there are many other employment options that fall outside this broad spectrum of (unsupported) competitive employment and supported (competitive) employment. Indeed it can be useful to think of a “continuum of employment” with the various unsupported and supported competitive options at one end, and other forms of work and work-related training at another.

But is competitive employment (meaning full-time, sustained employment) a reasonable goal for many people with SMI, whether SSI/DI beneficiaries? The evidence we summarized above suggests that while many people with SMI want to work and are able to do some work, they are not likely to reach the level of self-sufficiency. Given that most people with SMI on SSI/DI are unlikely ever to become self-sufficient again, might we not want to rethink this goal and whether it should have top priority. There is evidence that work levels can be increased even among this severely disabled population, and those with somewhat lesser levels of mental disability have worked in a variety of settings and done well, even if they never become completely self-sufficient.

It is important to recognize that people with SMI fall along a broad continuum of disability levels, that conditions are likely to fluctuate over time, and that people with SMI may have periods during which work is realistic and desirable, and periods during which it is not feasible. Both programs and benefits will need to be designed to accept and accommodate those fluctuations.

It is useful to think about employment options for people with SMI along a continuum that has (unsupported) competitive employment at the top, followed by supported (competitive) employment, followed by enclave situations and sheltered workshops, and so on. Each works well for some group of people with SMI. The closer one gets to the independent-competitive end of this continuum, the smaller the proportion of people with SMI that will be able to sustain participation. Since our basic conclusion is that promoting work among people with SMI is still worth doing, even though it may not lead to self-sufficiency, we need to consider other options.

3.5 Collaborating with Other Agencies

Some of the options for supporting SSI/DI beneficiaries with SMI in employment will likely require the Social Security Administration to work with a variety of agencies and programs. At the level of direct service delivery to beneficiaries, both employment services and clinical services will need to be involved. But there are also many things that can be done collaboratively with other agencies and organizations to affect the general climate in which people with SMI, including SSI/DI beneficiaries, try to find and keep jobs.

At the broadest societal level, strong stigma and misunderstanding still exist surrounding the nature of mental illnesses and what should be expected of people who suffer from them. Only modest and somewhat mixed changes have been reported in the attitudes and practices of employers, despite the changing political landscape. In general, more negative attitudes and concerns are expressed about employing people with mental or emotional disabilities, particularly in regard to their social skills and ability to function as a part of a team. Salkever

(2002) reports findings that the negative symptoms of many people with severe mental illness (e.g., low affect, poor social skills, inability to handle interpersonal situations, depressive demeanor) have a stronger negative effect on employment success than even florid positive symptoms of mental illness (e.g., hearing voices, talking to invisible people).

It would ultimately be in everyone's interest to see reduced levels of misunderstanding, fear, and resistance on the part of employers and the general public to working with people with SMI. Increased public awareness and education about mental illnesses in general is sorely needed, as is information about the strengths and abilities of people with SMI in relation to work and other aspects of life. This increased awareness would help all people with SMI who want to work.

The Social Security Administration could participate in such an educational campaign, both internally with its own employees and externally in conjunction with other public and private entities. Within DHHS the Center for Mental Health Services is an obvious potential collaborator. The Department of Labor's office of Disability Employment Policy, which runs the Job Accommodation Network, is another, as is the National Institute on Disability and Rehabilitation Research (NIDRR) within the Department of Education. Each is likely to have state equivalents, as well as national associations such as the National Association of State Mental Health Program Directors, that could participate in public and employer education campaigns. Outside the government arena, the National Alliance for the Mentally Ill and other advocacy groups are also possibilities for joining a collaborative educational effort.

Also at the broad societal level, people with SMI, as well as people with less severe types of mental illness and emotional problems, need far better access to mental health treatment. As the Surgeon General's 1999 report and the recent President's New Freedom Commission on Mental Health both note, only about half of the people with serious mental illness in this country get the care they need. State and local mental health systems are not able to serve all the people with SMI who need treatment, let alone other people with mental health needs. Many face severe budgetary constraints and have experienced funding reductions in recent years that have left them even more strapped for resources. Most see their role as limited to mental health treatment; few are actively engaged in the type of cross-agency work (e.g., with employment networks, workforce development agencies, or vocational rehabilitation agencies) that is needed if people with SMI are to be assisted into work opportunities.

The Social Security Administration could set an example in this regard by engaging in more cross-agency work at the federal level to develop federal policies that support realistic expectations for working among people with SMI—including mobilization of the employment and clinical service resources that it will take to increase labor force participation among SSI/DI beneficiaries with SMI. Through its upcoming Mental Health Treatment Study, it could extend the work of EIDP to demonstrate the most useful combinations of treatment and work supports for SSI/DI beneficiaries with SMI. The expectations presented above are best guesses based on combining the information from several already completed studies. The MHTS will be able to verify or modify our guesses as to the potential increases in numbers employed annually and at a point in time, and what investment in employment and clinical supports will be required to achieve those increases.

A genuine commitment to increasing employment among people with SMI involves recognizing the full continuum of employment options (not just competitive employment with or without supports), and encouraging entry—and rewarding progress—anywhere along this continuum. Acting on such a commitment would involve changing policies and practices to increase funding for supported employment and developing the infrastructure needed to bolster a vibrant supported employment sector within local and regional economies. Too few supported employment programs are now available and their continued existence depends on a patchwork of uncertain funding. Greater program availability would translate into greater access for those who might benefit from them. The experience of Italy and other countries suggests that this is not only feasible but economically sensible. For those unable or unwilling to engage in supported employment, other employment-related programs and activities should be made available, including community-based sheltered workshops and other work activities. Doing so affirms the role of work as “a defining feature of human existence. It is the means of sustaining life and of meeting basic needs. But it is also an activity through which individuals affirm their own identity, both to themselves and to those around them. It is crucial to individual choice, to the welfare of families, and to the stability of societies” (Juan Somavia, ILO Director General, June 2001, as quoted in O’Reilly 2003).

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APPENDIX A

Nature of Disorders, Their Treatment, and Employability Implications⁷

Two-thirds or more of all DI and SSI beneficiaries with mental disorders [have] diagnoses that [fall] in the categories of either affective disorders or schizophrenia-related disorders. The specific diagnoses for most of these individuals are serious chronic illnesses, such as major depressive disorder, bipolar disorder (manic depression), and schizophrenia. To better understand the obstacles that these illnesses pose to employment, it is useful to briefly highlight the salient features of their symptomatology, natural history, and susceptibility to treatment.

Major depressive disorder is characterized by depressed mood and loss of interest or capacity to experience pleasure over an extended period of time. While other symptoms vary widely, several that commonly occur may result in substantial reductions in productivity or ability to work. These symptoms include fatigue or lack of energy, diminished ability to think or concentrate, inability to make decisions, and psychomotor retardation. Untreated episodes of major depression last an average of 9 months; one half or more of patients will experience at least one recurrence of episodes and, for a substantial number of patients, a regular pattern of recurrence will occur over a long period of time. Studies of the etiology of major depression have identified a number of predictive factors including genetic endowment, personality type, and gender. Another important factor identified by both statistical and biological evidence is the occurrence of stressful life events and situations. To the extent that workplace experiences may be a source of stress, return to work following the onset of a major depressive episode may increase the risk of recurrence.

Treatment of major depressive disorder has been described as a three-phase process: acute, continuation, and maintenance. The most commonly used treatment modalities in all phases are pharmacotherapy and psychotherapy. Substantial scientific evidence supports the effectiveness of both modalities, separately and in combination, in the acute and continuation treatment phases, though the evidence on psychotherapy pertains mainly to several newer, time-limited depression-specific treatment approaches (cognitive behavioral therapy and interpersonal therapy). Since acute-phase drug and psychotherapy treatments typically require 6 to 8 weeks to produce substantial reductions in symptoms, in cases where a faster response is critical (e.g., because of psychotic or delusional symptoms and/or intense unremitting suicidality), electroconvulsive therapy (ECT) is an effective alternative. Because of expense, patient discomfort, and risk of side effects, however, ECT is not a widely used front-line therapy. All three therapy modes may also be used in the continuation and maintenance treatment phases; ECT is, of course, rarely used, and evidence of psychotherapy effectiveness in the maintenance phase of treatment is weak.

Several aspects of the treatment process are particularly relevant for considering the long-term employment prospects of a person with a chronic major depressive disorder. First, while

⁷ This appendix is reproduced from Salkever (2003), pages 333-335, who, in turn, largely took it from the Surgeon General's Report on Mental Health (1999).

appropriate treatment is often effective and for most patients could be expected to lead to a return to full or nearly full functioning, patient behavior in care seeking and compliance with treatment is a major problem. Patients experiencing severe symptoms may be unwilling to seek treatment promptly as a consequence of these very same symptoms. Medication side effects also often result in patients failing to take medication as prescribed. Limits on insurance coverage may also contribute to these behaviors. Second, empirical evidence reveals that much of the treatment provided is not appropriate, with problems in drug therapies being particularly common. Third, the many patients at a high risk of episode recurrence need long-term treatment and active monitoring of their status and symptoms.

Type I *bipolar disorder* is characterized by alternating manic and depressed states. In the manic phase of the disorder, patients manifest hyperactivity, extreme distractibility, and impaired judgment; psychotic symptoms (e.g., delusions) and paranoia may also occur in this phase. In a less common form of bipolar disorder (Type II), depressive phases are preceded by subsyndromal manic phases (hypomania), which may actually result in increased productivity and creative energy. For Type I bipolar disorder patients, however, occupational role functioning is usually severely impaired during manic states. In addition, patients experiencing subsyndromal manic phases often transition to the more typical (and severe) episodes of mania.

Treatment of bipolar disorders is similar to treatment of major depression but with the addition of mood-stabilizing drugs to prevent recurrence of manic episodes. ECT may also be useful for treating mania, and some drugs developed for other indications (e.g., anticonvulsants, antipsychotics, and calcium channel blockers) have also shown beneficial effects. Hard scientific evidence on treatment effectiveness appears more limited for bipolar patients than for patients with major depression, but available evidence generally suggests a somewhat poorer prognosis for bipolar patients. Compliance is a particularly difficult problem for these patients (especially in their manic phases) and may help to explain the lower rates of relapse prevention.

Schizophrenia is a profoundly disabling chronic disorder that most commonly begins in early adulthood. Symptoms are generally divided into two categories: positive and negative. Positive symptoms include delusions, hallucinations, disorganized speech and thought, difficulty in carrying out goal-directed behavior, unpredictable and bizarre social behaviors, and catatonic behavior. Negative symptoms include flattened affect, lessening of fluency and productivity of speech, and apparent disinterest in goal-directed behaviors. Problems in cognitive functioning (e.g., information processing, abstract categorization, cognitive flexibility, attention, memory, and visual processing) have also been frequently noted in persons with schizophrenia, although cognitive difficulties have not been specifically classified as symptoms of the disorder. Variations over time in symptom levels are common, particularly for positive symptoms; negative symptoms tend to be more persistent and less cyclical. The long-term course of illness varies from person to person, though the majority of patients do not return to the level of mental functioning they enjoyed before they got sick, and approximately 10 percent remain severely ill over long periods of time. On the other hand, in long-term follow-up studies, one-half or more of all patients have shown significant improvement in functioning, probably resulting from both improvements in patients' coping skills and social supports over time and biological factors that bring about reduced symptom levels.

Recommended treatment interventions for schizophrenia are linked to a sequence of four phases in the course of the illness: acute, stabilizing, maintenance, and recovery. Key components of treatment are pharmacotherapy with antipsychotic medications and a variety of psychosocial interventions (supportive psychotherapy, family psychoeducational programming, and psychosocial and vocational rehabilitation). Because the volume and variety of services used by patients is often substantial, coordination and continuity of services is a major concern. The gap between recommended treatment and treatment actually received is also very large; empirical evidence suggests that the rate of conformance of actual treatment with treatment guidelines is less than 50 percent. Specific reasons for this gap include deviations of physician prescribing practices in terms of antipsychotic dosage levels and the lack of access to recommended psychosocial services. Treatment effectiveness in actual practice is also compromised by patient noncompliance with drug regimens, due at least in part to side effects of antipsychotic medications. For this reason, the superior side-effect profiles of the newer “atypical” antipsychotics may be important for achieving better patient outcomes. Models of service delivery, such as assertive case management (ACM) and assertive community treatment (ACT), can be effective at coordinating the wide range of services needed by many patients and achieving reductions in hospitalization and increases in patient integration in the broader community. These models are resource intensive however, requiring relatively low client-staff ratios and participation of multiple disciplines in the treatment team; replications that deviate from these staffing patterns to satisfy program budget constraints may lead to less successful outcomes (McGrew et al. 1994; Salkever et al. 1999).

As has already been suggested, these serious and chronic mental disorders typically have substantial negative impacts on patients’ labor market productivity. Deficits in judgment, attention, decisionmaking, psychomotor functioning, and cognitive processing affect patients’ abilities to carry out and complete even relatively simple job tasks and physical labors. Problems in social interactions and communications with fellow workers and supervisors further compromise their job performance. While these deficits and problems can be ameliorated by treatment interventions, recurrence of acute symptomatic episodes is common and can be brought on by stressful workplace events or by the failure of patients to comply with their treatment regimen. Moreover, side effects of efficacious drug treatments may also impair the patient’s productivity at work.

The negative productivity effects of these major disorders can, of course, be magnified by the presence of comorbidities, such as alcohol or substance abuse, that are common among persons with serious mental disorders. The self-reported diagnosis information from the 1994–95 NHIS-D surveys suggests that these comorbidities are in fact a more widespread problem among beneficiaries with mental disorders. In particular, almost 10 percent of beneficiaries reporting *any* mental disorder (excluding retardation) also reported alcohol or substance abuse problems; in comparison, only about 2 percent of other beneficiaries reported such problems. Data from the EIDP indicate that 64percent had co-occurring substance abuse (Cook 2003).

APPENDIX B

Examples of Workplace Accommodations for People with Psychiatric Disabilities

Maintaining Stamina during the Workday

- Flexible scheduling
- Allow longer or more frequent work breaks
- Provide additional time to learn new responsibilities
- Provide self-paced workload
- Provide backup coverage for when the employee needs to take breaks
- Allow for time off for counseling
- Allow for use of supported employment and job coaches
- Allow employee to work from home during part of the day, or week
- Part-time work schedules

Maintaining Concentration

- Reduce distractions in the work area
- Provide space enclosures or a private office
- Allow for use of white noise or environmental sound machines
- Allow the employee to play soothing music using a cassette player and headset
- Increase natural lighting or provide full spectrum lighting
- Allow the employee to work from home and provide necessary equipment
- Plan for uninterrupted work time
- Allow for frequent breaks
- Divide large assignments into smaller tasks and goals
- Restructure job to include only essential functions

Difficulty Staying Organized and Meeting Deadlines

- Make daily TO-DO lists and check items off as they are completed
- Use several calendars to mark meetings and deadlines
- Remind employee of important deadlines
- Use electronic organizers
- Divide large assignments into smaller tasks and goals

Memory Deficits

- Allow the employee to tape record meetings
- Provide type written minutes of each meeting
- Provide written instructions
- Allow additional training time
- Provide written checklists

Working Effectively with Supervisors

- Provide positive praise and reinforcement
- Provide written job instructions
- Develop written work agreements that include the agreed upon accommodations, clear expectations of responsibilities and the consequences of not meeting performance standards
- Allow for open communication to managers and supervisors
- Establish written long term and short term goals
- Develop strategies to deal with problems before they arise
- Develop a procedure to evaluate the effectiveness of the accommodation

Interacting with Coworkers

- Educate all employees on their right to accommodations
- Provide sensitivity training to coworkers and supervisors
- Do not mandate employees attend work related social functions
- Encourage all employees to move non-work related conversations out of work areas

Difficulty Handling Stress and Emotions

- Provide praise and positive reinforcement
- Refer to counseling and employee assistance programs
- Allow telephone calls during work hours to doctors and others for needed support
- Allow the presence of a support animal
- Allow the employee to take breaks as needed

Attendance Issues

- Provide flexible leave for health problems
- Provide a self-paced work load and flexible hours
- Allow employee to work from home
- Provide part-time work schedule
- Allow employee to make up time

Issues of Change

- Recognize that a change in the office environment or of supervisors may be difficult for a person with a psychiatric disability
- Maintain open channels of communication between the employee and the new and old supervisor in order to ensure an effective transition
- Provide weekly or monthly meetings with the employee to discuss workplace issues and productions levels

Source: Kandra M. Duckworth, *Work-Site Accommodation Ideas for Persons with Psychiatric Disabilities*, Job Accommodation Network, Office of Disability Employment Policy, U.S. Department of Labor, Washington, DC, undated. Available online at <http://janweb.icdi.wvu.edu/media/Psychiatric.html>