

# MEANINGFUL EMPLOYMENT FOR INDIVIDUALS WITH MENTAL ILLNESS

## **Introduction**

The New Freedom Commission on Mental Health, tasked with studying the mental health service delivery system and making recommendations “that would enable adults with serious mental illnesses...to live, work, learn, and participate fully in their communities”, identified a lack of employment as a problem inhibiting individuals with mental illness (MI) from fully participating in society.<sup>1</sup> Estimates suggest that only about 1 out of 3 individuals with MI are employed, despite many wanting to work.<sup>2,3</sup> Oftentimes limited access to meaningful employment supports, fear of losing government benefits, cognitive impairments that create challenges in the working world, and other factors are associated with this low employment rate. And yet, employment has been shown to play a vital role in social inclusion and feelings of empowerment.<sup>4</sup> With the growing representation of individuals with psychiatric disabilities within the disability community receiving Social Security benefits, new policies – such as the new Ticket-to-Work regulations – and emerging findings from research are creating opportunities for community organizations to be engaged in innovative programs to facilitate employment. Even so, opportunities for growth in this arena still exist; we must find ways to assist individuals with mental illnesses and other disabilities to consistently obtain jobs that pay more than minimum wage, that offer benefits such as health insurance, and that make them feel socially included in their work environment.

## **Social Security Disability Programs**

Over the past decade, a trend has emerged: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries with psychiatric disabilities represent the largest diagnostic group in either program. With the overall number of individuals insured due to disability by the Social Security Administration increasing from 160.5 million in 1995 to 185.7 million in 2007, individuals with serious mental illness (SMI) represent a growing share: 39% of SSI beneficiaries and 28% of SSDI beneficiaries.<sup>5,6</sup>

SSDI provides benefits to disabled or blind individuals who have contributed to the Social Security Trust Fund through a tax on their earnings. Eligibility for this program is partially based on having earned the required number of work credits, based on a beneficiary's age and when he/she became disabled. After being enrolled in the SSDI program for two years, beneficiaries may receive health insurance through the Medicare program. Beneficiaries do not pay a monthly premium for Part A (Hospital Insurance) coverage, but must pay a monthly premium for Part B coverage (Supplemental Medical Insurance). In 2008, the Part B Supplementary Medical Insurance monthly premium is \$96.40.<sup>7</sup> Unlike the SSDI program, the SSI program is primarily for individuals who have been unable to work due to their disability, and is funded through general tax revenues. Individuals on SSI have access to health insurance through Medicaid, and sometimes receive a "state supplement" to their federal SSI benefits. Depending on a beneficiary's circumstances and work history, it is possible to qualify for both SSI and SSDI programs.

For the purposes of these programs, disability is defined as "the inability to engage in any substantial gainful employment (SGA) because of a medically determinable physical or mental impairment(s) that can be expected to result in death, or that has lasted or that [the Social Security Administration] can expect to last for a continuous period of not less than 12 months."<sup>8</sup> In 2008, the SGA amount for individuals with disabilities other than blindness is \$940 per month. In the SSI program, SGA is used as a factor to determine initial eligibility. In the SSDI program, SGA is used as a factor to decide if a beneficiary's disability continues after returning to work and completing a trial work period (TWP).<sup>9</sup>

### **Federal Laws and Regulations**

There are several federal laws, regulations, and demonstration projects of relevance to employment supports. The Workforce Investment Act of 1998 (WIA), which became effective on July 1, 2000, establishes a national workforce preparation and employment system to assist job seekers in the process of finding employment. This system is comprised of One-Stop Centers, which provide a single point of contact for individuals to receive a wide array of services, including job training, education, and employment. Subsequent to the implementation of WIA, the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) created the Ticket-to-Work Program, which provides Social Security beneficiaries expanded options for access to employment services, vocational rehabilitation services, and other supports. More specifically, the Social Security Administration provides eligible beneficiaries with a 'Ticket' that they may use to

access employment services at One-Stop Centers, state Vocational Rehabilitation agencies, or other Employment Networks (other state or community providers that meet Social Security qualifications). Under TWWIIA, an Employment Network, or EN, does not receive payment from the federal government for their services until the beneficiary either earns a monthly income above the SGA or does not receive cash benefits due to their earnings.<sup>1</sup> As of implementation of the new Ticket to Work regulations, changes have been made to the payment rules that allow ENs to receive reimbursement for services as the beneficiary achieves milestones in obtaining employment and an increase to outcome payments when a beneficiary obtains employment.

Unfortunately, as it was originally created, the Ticket Program had limited beneficiary enrollment and low EN satisfaction. As of December 2004, 10 million Tickets had been mailed to eligible Social Security beneficiaries; of which 83,568 were in use (i.e. beneficiaries have assigned their Ticket to an EN). In addition, ENs reported dissatisfaction with the program; more specifically, they cited issues such as a perceived lack of beneficiary demand for EN services, cumbersome payment mechanisms, and a fear that beneficiaries would be unwilling to leave the Social Security beneficiary rolls. Most importantly, ENs found that the payment structure of the program was “too little, too late”, given that the ENs had to cover their up-front costs themselves.<sup>10</sup> As a result of these and many other comments, the Social Security Administration recently published Amendments to the Ticket to Work and Self-Sufficiency Program Final Rule, which became effective July 21, 2008. Among other changes, this Final Rule provides more funding to ENs up-front and allows ENs to receive reimbursement when beneficiaries work part-time. It is hoped that the changes in the Final Rule create increased incentives for a wide-array of community providers, including community behavioral health organizations, to become ENs.

Through the TWWIIA, the federal government authorized several demonstration projects and initiatives, including the Demonstration to Maintain Independence and Employment (DMIE) program. DMIE, authorized by the Ticket to Work and Work Incentives Improvement Act of 1999, is administered by the Centers for Medicare & Medicaid Services and attempts to provide a comprehensive package of services through Medicaid to individuals with specific physical or mental impairments that could eventually lead to disability. The goal is to provide these services

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<sup>1</sup> Social Security Administration qualifications for eligible beneficiaries and ENs, as well as detailed information regarding EN payments are available at: [http://www.onestops.info/article.php?article\\_id=136&subcat\\_id=108](http://www.onestops.info/article.php?article_id=136&subcat_id=108)

to help the individual remain employed and prevent the need for Social Security benefits. Several states have a DMIE program, including Kansas, Minnesota, and Texas.<sup>11</sup> As part of the program, these states are required to conduct a rigorous evaluation; final results are expected to be available in 2010.

In addition, the Medicaid Buy-In Program, as authorized by the TWWIIA and the Balanced Budget Act of 1997, allows states to expand Medicaid coverage to Social Security beneficiaries with disabilities whose income and assets would normally make them ineligible for Medicaid. In return, these beneficiaries 'buy-in' to the Medicaid program by paying premiums based on their incomes. As of September 2007, 39 states had a Medicaid Buy-In Program, all of whom had some flexibility to shape their programs. Interestingly, an evaluation of enrollment data for 2000 found that when compared to other Medicaid enrollees with disabilities, Medicaid Buy-In enrollees were more likely to have a psychiatric disability (45% vs. 60%, respectively).<sup>12</sup> Approximately 40% of new Medicaid Buy-In enrollees increased their earnings, with younger individuals who earned above the SGA prior to enrollment in the Buy-In program more likely to see earnings increases.<sup>13</sup>

Lastly, it is important to mention an important federal initiative, the Mental Health Treatment Study. This \$50 million randomized controlled trial, funded by the Social Security Administration, is being conducted in 22 cities, over a 24-month period to be completed in 2010. It is testing the assumption that providing SSDI beneficiaries high quality behavioral health services, medication management, and supported employment services will lead to sustained competitive employment and improved clinical outcomes. Preliminary findings suggest that the treatment group has higher rates of both current and recent competitive employment, as compared to the control group. The much-anticipated final results of this study will help us to gain some insight into the policy barriers that prevent SSDI beneficiaries with psychiatric disabilities from returning to work and what policy changes can be made to reduce those barriers.<sup>14</sup>

### **Reasons for Low Employment Rate**

Individuals with psychiatric disabilities represent 27.8% of the entire population of individuals with disabilities who are employed, with less than 1% of SSDI beneficiaries with primary psychiatric impairments employed.<sup>15,16</sup> Of great concern are estimates that suggest that 28.2% of non-institutionalized individuals with a work limitation, aged 18-64, are living in families with

incomes below the poverty line, as compared to 9.3% of non-institutionalized individuals without a work limitation.<sup>17</sup> Despite research showing that many individuals with MI want to work, evidence clearly indicates that many are not working. Even for those that are working, many are not employed in a manner that allows them to accumulate assets or other means to keep themselves from poverty.

Although there are several reasons why this discrepancy occurs, one of the primary reasons is SSI/SSDI beneficiaries' fear of losing benefits, including Medicaid coverage. According to results from a multi-state clinical trials study, only 8% of study participants (72% of whom were Social Security beneficiaries) who returned to full time jobs had mental health coverage.<sup>18</sup> In addition, beneficiaries who are employed must undergo continuing disability review, discouraging beneficiaries to seek jobs because they do not want to put their benefits in doubt. During the first nine non-consecutive months of employment, referred to as the trial work period (TWP), SSDI beneficiaries may receive full benefits as long as they continue to have a disabling impairment (assessed through the continuing disability review). During the 36 consecutive months following the TWP, benefits are paid during months in which a beneficiary's earnings or work activities are below the SGA, or \$940 month. Once over the SGA, beneficiaries are paid benefits during a 'grace period', or three months, after which they no longer receive any benefits unless they re-enroll in the program. For most SSI beneficiaries, the Social Security Administration determines eligibility for benefits based on whether they continue to meet the non-disability requirements, including income and resources.<sup>ii</sup> Many SSI beneficiaries lose benefits, including Medicaid, for this reason. In addition, loss of SSDI/SSI beneficiary status may result in the loss of other needed supports, such as food stamps, housing subsidies, transportation assistance, and utility supplements.<sup>19</sup> Some beneficiaries may be able to avoid this concern by receiving benefits through Section 1619(a) of the Social Security Act, which allows eligible beneficiaries to receive benefits even when their income is above SGA; however, in 2000, only 7.5% of eligible, working beneficiaries were enrolled in this program.<sup>20</sup>

Other factors impact the availability of competitive job opportunities for individuals with MI. For example, they have traditionally struggled to gain access to ongoing employment supports. A

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<sup>ii</sup> For a detailed explanation, including an example, of how SSI eligibility is assessed, please review "Example of Concurrent Benefits and Employment Supports" in the 2008 Red Book. Available via: <http://www.ssa.gov/redbook/eng/supportsexample.htm>

study conducted in the late 1990's of individuals with schizophrenia found that only 23% of those receiving outpatient services received vocational rehabilitation services as well.<sup>21</sup> Another study of about 2,700 adults with disabling mental health disorders in Vermont found that 24% received any employment services and more than half received fewer than six service contacts.<sup>22</sup> The picture is slowly changing. According to research conducted by the National Association of State Mental Health Program Directors Research Institute, 31 states used federal mental health block grant or state general funds for supported employment services in 2005, while many others used local or other funds.<sup>23</sup> As will be discussed later in this paper, the evidence behind employment services is growing, and many community organizations have begun to adapt their service model to include employment supports.

Yet another challenge facing individuals with MI who wish to work are cognitive impairments that impede their ability to get and retain a job placement. Studies have found that cognitive impairments are a common feature to severe mental illness, including for those with schizophrenia and bipolar disorder.<sup>24,25,26</sup> In fact, many studies suggest that remediating or accommodating cognitive impairments may be necessary for successful rehabilitation.<sup>27</sup> Cognitive remediation is a behavioral treatment aimed at improving cognition for individuals who have experienced a decline in neuropsychological functioning. It includes a broad array of interventions that focus on improving the day-to-day functioning of clients. One study randomly assigned 85 individuals with mental illness to a cognitive remediation group or a control group and tracked employment over a 12-month follow-up period. Patients in the cognitive remediation group demonstrated significantly greater improvements over three months than the control group on the measures of overall cognitive functioning, psychomotor speed, and verbal learning. More broadly, those that received the intervention worked more weeks than those that did not over the follow-up period.<sup>28</sup> In research conducted through the Center for Rehabilitation and Recovery at the Coalition of Behavioral Health Agencies in New York City, clients at community mental health centers either received supported employment alone or supported employment and cognitive training. Those that received both supported employment and cognitive training were significantly more likely to work (69% versus 4.8%), worked more jobs, worked more hours, and earned more wages than clients who received supported employment only.<sup>29</sup> Clearly, individuals with MI who have cognitive impairments face additional barriers to attaining meaningful employment; however, cognitive remediation, if available, can assist them in overcoming these barriers.

Lastly, other potential factors, such as low educational attainment, limited access to a regular source of clinical services, and labor force discrimination likely play a role as well. Due to the early onset of many mental illnesses, many youth with mental illness find their education interrupted. According to the U.S. Department of Education, about 50% of children with serious emotional and behavioral disorders drop out of school, as compared to 30% of children with other disabilities.<sup>30</sup> In addition, access to both mental health and primary care providers is often a necessary component to community living for individuals with mental illness. Despite this, individuals with psychotic or bipolar disorders have been found to have significantly reduced odds of having a primary care physician compared to people without those disorders.<sup>31</sup> In 2007, 10.9 million adult respondents to a national survey said they had an unmet need for mental health services, of which 5.4 million did not receive any mental health services in the past year.<sup>32</sup> More specific to job attainment, individuals with mental illness fear discrimination, often rooted in the stigma associated with their illness.<sup>33</sup>

### **Employment Supports**

Although there are various models of providing vocational supports, many believe that growing evidence suggests that supported employment (SE) is the most effective method of mitigating barriers to employment for individuals with MI. Title IV of the Workforce Investment Act of 1998 defines SE as “competitive work in integrated work settings...consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choices of the individuals, for individuals with the most significant disabilities for whom competitive employment has not traditionally occurred; or for whom competitive employment has been interrupted or intermittent as a result of a significant disability”.<sup>34</sup> Evidence-based SE emphasizes the following components: 1) competitive jobs that are based on an individual’s preferences for type and amount of work; 2) work settings in which individuals with mental illness are integrated into the general workforce; 3) job-seeking when the unemployed person expresses interest (in contrast to assessing the person’s job readiness prior to providing vocational services); 4) limited pre-vocational preparation and assessment (i.e. SE does not provide sheltered workshops or other intermediate work experiences); and 5) follow-along supports to assist the individual to maintain his/her job or transition to a new one.<sup>35,36</sup> In an effort to standardize supported employment programs, The Association for Persons in Supported Employment (APSE) has released SE quality

indicators which include sub-categories focused on the individuals who are receiving SE services, personnel who are providing the services, and organizational practices that support quality SE services.<sup>iii</sup> In addition, the Substance Abuse and Mental Health Services Administration (SAMHSA) has released a Supported Employment Toolkit which providers, consumers, state mental health authorities, and other interested parties may use to understand the process of providing SE services.

Numerous studies have shown the positive impact of converting day treatment programs to supported employment programs. Studies have found that after such conversions, clients, families and providers preferred the SE programs and that the program change led to cost savings.<sup>37,38</sup> Interestingly, one randomized controlled trial comparing SE services to traditional vocational services found that 58% of SE clients obtained competitive employment over 12 to 18 months, compared to 21% of clients in the control group.<sup>39</sup> Although most studies have not shown positive nonvocational outcomes (i.e. symptoms, self-esteem, quality of life) it is important to note that they have not found an increase in hospitalization rates, as some expect to occur due to the increased stress of employment.<sup>40</sup> For organizations that choose to offer SE services, organizational factors including strong administrative and programmatic leadership, understanding of the importance of hiring SE staff with both clinical and employment skills, and employing staff who believe in recovery and the evidence-based model for SE services is vital to the success of the program.<sup>41</sup>

Another model of providing employment supports is customized employment (CE). This approach, which often includes elements of supported employment, individualizes the relationship between a job seeker and an employer in ways that meet the needs of both parties. The process should result in a job that fulfills the strengths and interests of the job seeker and meets the workplace needs of the employer. Successful CE opportunities include the following components: 1) meets the needs and interests of the job seeker; 2) uses a personal representative to assist the job seeker; 3) negotiates successfully with potential employers; and 4) builds a system of ongoing supports for the job seeker.<sup>42</sup> Traditionally, CE was used for methadone patients but has since been expanded for use with a wide array of disability populations. Studies suggest that individuals

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<sup>iii</sup> You can review APSE's Supported Employment Quality Indicators by visiting: <http://www.apse.org/docs/QualityIndicators.pdf>

receiving CE services are more likely to obtain competitive employment and informal paid employment, compared to individuals receiving standard vocational counseling.<sup>43</sup>

The Cobb/Douglas Counties Community Service Board (CSB) in Georgia is currently providing CE services to 263 consumers who are all pursuing self-employment, resource ownership, job carving, or job creation. As authorized by WIA, CSB uses Individualized Training Accounts (ITAs) to facilitate partnership between a potential employer and a consumer by using these funds to pay for technology to assist the consumer complete a task at the workplace. Oftentimes, the cost of assistive technology poses a barrier to successful employment for individuals with mental illnesses and other disabilities; ITAs have provided a means to mitigate this barrier. Since 2001, CSB has received multiple grants to fund their activities and created partnerships with local resources, such as the University of Georgia, the Douglas County Chamber of Commerce, the state Vocational Rehabilitation Agency, and Edge Connection, their local micro-enterprise center. In addition, the CSB is providing technical assistance to other providers to help them to develop their CE services.

### **Looking to the Future**

Evidence suggests that individuals with severe and persistent mental illness (SPMI) who are working have reported significantly higher self-esteem than non-working individuals with SPMI.<sup>44</sup> And yet, many are not working. Government and community-based efforts to increase the employment opportunities for individuals with MI have resulted in positive outcomes. However, limited evidence exists about the long-term job retention outcomes for individuals with MI who receive support services. One 10-year follow-up study of a SE program found that although current and recent jobs tended to be competitive and long term (average job tenure was 32 months), few clients of the SE program made the transition to full-time employment with health benefits.<sup>45</sup> The current growth trend in SSDI/SSI beneficiaries with psychiatric disabilities indicates that we must think creatively about interventions and programs targeted to this population. By doing so, we can aspire to a situation in which individuals with mental illness can work in fields and positions of their choosing that builds on their strengths and that meets the needs of their employers.

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