

Sulewski, J. S., Kugler, R., & Kramer, J. (2010). Spreading a positive message about work, earnings and benefits through peer networking: Findings from the Peer Employment Benefits Network. *Journal of Vocational Rehabilitation*.  
<http://doi.org/10.3233/JVR-2010-0506>. © 2010 Reprinted with Permission of the Journal of Vocational Rehabilitation, IOS Press.

**Spreading a positive message about work, earnings and benefits through peer networking: Findings from the Peer Employment Benefits Network**

Jennifer Sullivan Sulewski Ph.D., Research Associate, Institute for Community Inclusion, University of Massachusetts, Boston

Rick Kugler, MS, CPRP, Training Associate Institute for Community Inclusion, University of Massachusetts, Boston

John Kramer, Ph.D., Research Associate, Institute for Community Inclusion, University of Massachusetts, Boston

Corresponding Author: Jennifer Sullivan Sulewski Ph.D.

Institute for Community Inclusion  
University of Massachusetts, Boston  
100 Morrissey Blvd.  
Boston, MA 02125  
(617) 287-4356 (Phone)  
(617) 287-4352 (Fax)  
Jennifer.sulewski@umb.edu

## Abstract

Misunderstanding and fears about the impact of earnings on benefits represent a significant barrier in the return-to-work efforts of people with disabilities. This pilot project evaluated an approach to spreading a positive message about work and dispelling myths about the effects of work on Social Security benefits through outreach and networking in the disability community. A peer leadership project was developed by enlisting 33 people with disabilities, mainly through disability advocacy organizations, who had experience with disability benefits. They received several days of basic training about work incentives, networking strategies, and community resources that support employment. These peer leaders then developed and pursued outreach plans in their communities.

Peer leaders reported making 1046 contacts through their personal networks. 130 of the people contacted participated in a survey rating the quality of the interaction and their activities involving employment. The majority of respondents reported they had received helpful information from the peer leaders and had less concern about the negative effects of work on benefits; approximately one-quarter took some steps toward going to work. The evidence from this project suggests that a peer to peer approach may be effective in promoting a positive message about and creating interest in employment.

Keywords: Work incentives, benefits, outreach, peer, employment, work, dissemination

## **Spreading a positive message about work, earnings and benefits through peer networking: Findings from the Peer Employment Benefits Network**

People with disabilities of working age are employed at a drastically reduced level compared to their peers without disabilities. The employment rate for people with disabilities of working age hovers at approximately 37%, compared with 80% for people without disabilities in the same age group [1,2,3]. Yet the N.O.D./Harris Survey of Americans with Disabilities found that 67% of people with disabilities who were not employed responded that they would like to be working [4]. These findings suggest that many people with disabilities who would like to work are either not able to find work (unemployed) or not seeking employment (out of the labor force). Addressing the barriers that prevent those individuals from seeking or finding employment could potentially lead to a substantial increase in the employment rate of people with disabilities.

A major barrier to workforce participation by people with disabilities has been fear that earnings will cause the loss of government benefits, both cash and health coverage [5,6]. State Medicaid agency representatives report that loss of health and cash benefits is a major barrier to workforce participation for beneficiaries [6]. Some people with disabilities also have housing subsidies and food stamps, which are affected by changes in their income [7]. For beneficiaries, the decision to make a work attempt can be anxiety-provoking, and the fear of losing benefits often results in individuals limiting workforce participation or not working at all [5,7].

Work incentives legislation has been developed to support and encourage people receiving Social Security benefits to transition to the workplace [7]. These work

incentives make it possible for beneficiaries to continue to receive either part or all their cash benefits and also include some provisions that protect health coverage for beneficiaries who work. The Plan to Achieve Self-Support (PASS), Impairment-Related Work Expenses (IRWE), and Blind Work Expenses (BWE) allow individuals to set aside money, resources, and expenses to be excluded from total earned income calculations. In addition, many states offer Medicaid Buy-In programs that further expand health coverage for working people with disabilities. The Ticket to Work and Work Incentives Improvement Act of 1999 establishes a range of benefits planning, advocacy, health care, and employment support options to encourage Social Security (SSA) beneficiaries to participate in the workforce, with the goal of providing disability beneficiaries with opportunities to achieve steady, long-term employment that generates sufficient earnings to be removed from SSA cash benefits [11].

Data show that these work incentive provisions continue to be underutilized. In 2004, the mean number of beneficiaries enrolled per state in the PASS, IRWE and BWE programs respectively was 32, 137, and 57 [12]. Less than 2 percent of working SSI beneficiaries used a work incentive such as a PASS or IRWE as of 2007 [13].

An important step needed to increase the use of work incentives is to increase awareness of the provisions on the part of beneficiaries. The Work Incentive Planning and Assistance (WIPA) projects were designed to provide access to clear and individualized information on benefits, work incentives and employment, and have been considered a “key service” to enable beneficiaries considering work to make informed choices [5,14]. In a study of Social Security disability beneficiaries in Vermont, those who received benefits planning, advice, management, and counseling had substantially higher earnings

than those who did not receive the same services, even controlling for pre-existing earnings advantages, key demographic earnings predictors, and Social Security beneficiary type [14]. In another study, benefits planning was found to motivate SSA beneficiaries with Traumatic Brain Injury to attempt or increase work activity. Furthermore, “those who received more intensive benefits planning services showed a greater likelihood to take those important steps toward productivity and independence” [15] (pg. 122-123). O’Brien, Revell and West [5] found that with the provision of quality benefits planning, SSA beneficiaries become “knowledgeable about the potential impact of employment on their benefits, and they are better positioned to make informed choices about their employment goals” [5] (pg. 109). In examining the utilization of benefits planning from the perspective of the beneficiary, Cloutier, Hagner, Malloy and Cotton [16] noted the increased sense of self-direction, choice, control and confidence when recipients were provided accurate information about incentives and education that addressed concerns about benefit loss.

The WIPA projects have an important role in spreading the word about Social Security Work Incentives among beneficiaries, but the 620 nationwide WIPA staff alone cannot reach the estimated 6.8 million workers receiving disability benefits [17]. As of September 2006, only 252,235 beneficiaries had had contact with a WIPA program [18]. Many people among the 6 million beneficiaries who have not come into contact with a WIPA project are still misinformed or distrustful about the effects of employment and earnings on benefits and a relatively small number of trained professionals is likely not the most cost-effective way to reach out to all of them.

One potential approach to sharing benefits information is the use of peer to peer networking. The use of peer services in counseling and information exchange has been associated with positive outcomes in a variety of settings. In California, a number of community health clinics enlisted young people to be trained for education and outreach as peer providers involving reproductive health. Young women who received peer services were more likely to engage in consistent and effective use of birth control [19]. An observational study of a 6- month peer counseling approach involving women who were newly diagnosed and in treatment for breast cancer looked at the effects of peer reported that newly diagnosed women who received peer services showed significant improvements in emotional well-being and self efficacy and were more likely to pursue information and resources about cancer [20]. Hartford Hospital in Connecticut funded a study to look at the outcomes of peer counseling to help pregnant women abstain from smoking. While the effort did not significantly increase abstinence from smoking, it did help many of the women reduce smoking, which subsequently yielded positive outcomes on infant health [21]. A randomized controlled study was performed in Boston to determine the effectiveness of motivational interviewing, delivered by peers who were substance users in recovery, for cocaine and heroin users[23]. The intervention proved effective and in helping drug users both abstain from and/or reduce opiate and cocaine use [23]. Peer counselors have been a central component of Independent Living Centers (which assist people with disabilities) since the beginning of the Independent Living Movement in the 1970s [24].

A number of research projects have examined peer-provided supports involving people with mental illness, with methods ranging from description and process assessment to

randomized-controlled trials. While there is limited research that rigorously compares services delivered by peers to services delivered by non-peers, in general findings suggest that peer services are comparable to, and possibly more effective than, non-peer services in clinical, social, and employment outcomes [25, 26]. In one study comparing individuals with peer-provided case management to those with professional case management, those with peer-provided services felt more respected and understood by their case manager, which led to better engagement in treatment [27]. Another study found that participants in peer-run services had better social functioning compared to those receiving traditional mental health services only [28]. A study of homeless veterans with mental illness found that veterans who received peer counseling were more likely to be employed and to live in their own residence after participating in peer counseling, but was unable to collect sufficient data from control group participants to make a comparison [29]. Results from a longitudinal study involving consumers with co-occurring mental health and substance abuse disorders demonstrated that people who received services through a peer support program seemed to have benefited in terms of both reduced hospitalizations and increased community tenure [30].

The Peer Employment Benefits Network (PEBN) was an approach piloted in Massachusetts in 2006-2007 to test the idea of spreading positive messages about employment and work incentives through peer to peer networking. In 2005 a multi-stakeholder leadership team for the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) identified the negative “word on the street” about the effect of employment on benefits as a major barrier to people with disabilities pursuing employment. The team felt that within the disability

community the “word on the street” reinforced the notion that employment would lead to the loss of benefits and that would compromise a beneficiary’s financial well being. The Leadership Team charged a steering committee that include benefits experts, individuals with disabilities, service providers and MI-CEO grant staff with the development of a peer to peer strategy that would help to change the “word on the street” and encourage individuals with disabilities to attempt or increase employment. The approach was piloted in 2006 in two metropolitan areas (Group 1). Due to promising evaluations of Group 1, the approach was introduced in two additional metropolitan areas in 2007 (Group 2) with slight modifications based on the Group 1 findings.

The project had three goals. First, individuals with disabilities would become more informed about benefits and employment. Next, they would have more positive attitudes about their ability to go back to work. And finally, these individuals would take steps toward entering employment or in some way improving their current employment situation.

## **Method**

### *Participants*

The project involved two sets of study participants. The first was the peer leader group, a group of people with disabilities primarily recruited through Independent Living Centers, psychosocial programs based on the clubhouse model, and day treatment programs.

Potential peer leaders were asked to complete an application to participate in the pilot project. The applicants were asked to describe their interest in employment, how they might use their social networks to outreach to peers with disabilities, and their experiences with the Social Security Administration. We hypothesized that people who



expressed positive attitudes about employment, possessed an extended social network and had direct experience with SSA would be a good match for the project. Project staff reviewed all applications with these criteria in mind and all but one were accepted.

Eighteen peer leaders from the Boston and Worcester metropolitan regions participated in Group 1 (2006), but only 13 of those consented to have their data included in the evaluation findings. In Group 2 (2007), 15 peer leaders participated in the project from the Lawrence, Lowell and Fitchburg areas; all 15 consented to participate in the evaluation.

A second group of study participants was the population of people with disabilities with whom the peer leaders networked or conducted outreach. Given the “viral” nature of the project, and our desire not to interfere in peer to peer relationships, we do not know the precise number of people in this group. Peer leaders did report making over 1,000 contacts with peers over the lifetime of the project (as described in the Results section), but the actual number of people was likely lower than this since people who were contacted in more than one month could be counted multiple times.

### *Intervention*

Peer leaders received several days of training (18 hours over 4 days for Group 1 and 18 hours over 3 days for Group 2). Training topics included a basic overview of SSI and SSDI benefits and the Social Security Work Incentives, counseling and communication techniques, and networking and outreach strategies. Identifying resources in the community (i.e. WIPA, vocational rehabilitation services) for information and employment support was emphasized. The goal was not to create benefits counselors but to create a cadre of people who could dispel common myths about work and benefits,

providing information, encouragement, and empowerment to peers as they made decisions about employment. At the end of the training each peer leader developed a networking plan to guide his or her outreach activities.

After the training series, the peer leaders conducted outreach for six months. The outreach strategies were individualized based on each person's own social networks. They did their outreach in the regions where they lived or received services. Project staff convened monthly meetings with the peer leaders in each region. The meetings provided an opportunity for peer leaders to review the Work Incentives content, get updates, pursue questions and answers about additional resources or challenges in the outreach effort, and network with each other. The project staff also collected data on peer leaders' outreach efforts. On several occasions the meetings included a guest speaker on an employment-related topic. The peer leaders received a stipend of \$100.00/day for their participation in training activities and an additional \$85.00/month for six months for participation in the pilot. The stipend was considered compensation for leaders' participation in evaluation activities. Their outreach activities were considered to be a volunteer effort.

#### *Data collection*

The program evaluation was designed to assess the effectiveness of the project on multiple levels. The key evaluation questions were: (1) Did peer leaders gain knowledge about work, benefits, and how to support peers toward employment & financial empowerment? (2) Did peer leaders "spread the word" through outreach to others? (3) Did peer leaders share a positive message and accurate information about employment in their outreach? (4) Were people who talked to peer leaders better informed about benefits

and employment and did they have more positive attitudes toward employment? (5) Did people take steps toward entering employment or improving their employment status as a result of their contact with the project?

Evaluation of the project involved seven data collection activities: (1) pre- and post-tests of peer leaders' knowledge and attitudes before and after training, (2) self-reports of peer leaders' outreach to other persons with disabilities, (3) a self-mailer survey handed out by peer leaders to people they talked to, (4) follow-up phone calls with some self-mailer survey respondents, (5) interviews with key informants at organizations peer leaders were involved in, (6) interviews with representatives from local Work Incentives Planning and Assistance (WIPA) programs, and (7) interviews with peer leaders. The seven data collection activities are summarized in Table 1.

[INSERT TABLE 1 HERE]

“The pre-tests were administered to all peer leaders at the beginning of the first day of training and post-tests were administered at the end of the final day of training. These tests assessed peer leaders' knowledge and attitudes about benefits, work incentives, and employment before and after the PEBN training. Their purpose was to assess the effectiveness of the training in increasing peer leaders' knowledge and to aid in development of future trainings. Thirteen peer leaders in Group 1 and fifteen peer leaders in Group 2 completed the pre- and post-tests.

Peer leader self-reports were collected from each active peer leader at each monthly meeting during the six-month follow-up period. The self-report covered the number and types of outreach conducted by the peer leader in the previous month, the topics covered,

and how peers responded to the outreach. A total of 144 self-reports was collected over the two project groups.

Self-mailer surveys were handed out to peer leaders at the end of training and at each follow-up meeting, and the peer leaders were encouraged to hand out the surveys to people they talked to. The self-mailer survey asked participants what the peer leader had talked about with them, what they had learned as a result of the interaction, whether the interaction had affected their level of concern about going to work, and whether they had taken any action toward changing their work status since talking to the peer leader. As an incentive to return the survey, all respondents were mailed a \$5 Dunkin Donuts gift certificate. In total, 130 self-mailer surveys were returned. We do not have a precise tally of the number of surveys distributed, but in their monthly self-report forms, peer leaders reported handing out a total of 597 surveys, meaning the 130 returned represent an approximate response rate of 22%.

Follow-up phone interviews were conducted with self-mailer survey respondents who agreed to a follow-up interview. These interviews, which were conducted about 2 months after the survey was received, were used to identify any actions those individuals had taken and/or changes in their employment status since talking to the peer leader.

Respondents were offered an additional \$5 Dunkin' Donuts card for participating in an interview. The response rate for these calls was small: in total, 33 follow-up interviews were conducted out of 90 survey respondents who agreed to a call, for a response rate of 37%. Another 40 survey respondents did not agree to participate in a follow-up call.

Interviews of key informants, including staff and leadership, in disability organizations the peer leaders were involved with, such as Independent Living Centers and clubhouses,

were intended to gain an organizational perspective on the project and a sense of whether the project affected attitudes or actions among the people involved in or served by the organization. Questions focused on the response to the project at the organization and the impact of peer leaders on members and staff. Interviews were completed by telephone with four organizations in Group 1 and 2 organizations in Group 2.

Representatives from the WIPA programs were interviewed to determine if they had seen any increase in referrals due to the pilot projects. One representative from each of the two Massachusetts WIPA programs was interviewed after each regional pilot, for a total of four interviews with three people. Three took place by phone and one by e-mail.

The interviews with peer leaders were conducted approximately 3 months after the end of the outreach phase of the project. We attempted to conduct interviews with each of the peer leaders who participated in the project for at least three of the six months. These interviews were intended to gain more information about the peer leaders' experiences with the project, what effect it had on their lives, and what suggestions they might have for improving the project in the future. Twenty peer leaders participated in follow-up interviews. All interviews took place in person. Fourteen of the 20 interviews were recorded and transcribed. Of the remaining 6, two were not recorded because the peer leader did not want to be recorded and four were recorded but the recordings were lost due to a hard drive failure. The interviewers also took field notes, which were used as the data source for those interviews that were not recorded or for which the recordings were lost.

While the evaluation design assessed the outcomes of the project both for peer leaders and for those whom peer leaders contacted as part of their outreach, this paper focuses on

the findings related to the latter population (those outreached to); as such we focus on the findings from the self-reports of peer leaders' outreach, the self-mailer survey, the follow-up interviews with self-mailer survey respondents, and the interviews with key informants and WIPA programs. A future manuscript will present the outcomes for the peer leaders themselves, focusing primarily on the pre- and post-test data and the peer leader interview data.

## **Results**

All quantitative data (pre- and post-test data, peer leader self-report data, and self-mailer survey responses) were entered into a database. We generated summary statistics for these data using SPSS for the Mac. Due to the small n and the descriptive nature of the data, more sophisticated analyses were not needed for most of the data. For pre- and post-data, we also conducted matched-pairs t-tests to determine significance.

For the qualitative data from the telephone and in-person interviews, coding and memo-writing were the primary tools for analysis. We coded all interview data using Atlas.ti software and used memo-writing to further develop themes.

### *Did peer leaders “spread the word” through outreach to others?*

In their self-reports, peer leaders were asked to report on how many people they talked to about benefits and employment, and were further asked to divide those contacts into “formal,” “informal,” or “both”. “Formal” outreach refers to situations where peer leaders gave a presentation to a group of people, while “informal” outreach refers to individual or small group discussions. “Both” refers to situations where the peer leader engaged in formal outreach, such as a presentation, with some informal follow-up conversations afterwards.

Overall, peer leaders reported 1046 formal and informal outreach activities, with each outreach activity representing talking to someone with a disability about employment and benefits (Table 2). Since peer leaders were asked each month how many people they talked to in that month, individuals to whom peer leaders talked to multiple times may have been counted more than once. Peer leaders in Group 1 reported more informal than formal outreach, while peer leaders in Group 2 reported making more formal outreach. Group 2 had more contacts overall, due to a combination of more self-reports submitted and more contacts (especially formal contacts) reported per report. The higher number of contacts for Group 2 may be partly attributable to the higher proportion of formal contacts, since formal presentations reached more people at once.

[INSERT TABLE 2 HERE]

*Did peer leaders share a positive message and accurate information about employment in their outreach?*

Peer leaders almost always reported in their self-reports that they gave people information on benefits and employment and on employment resources in their region, indicating that their outreach efforts were related to the target topics of the project. Referrals to benefits planning, vocational rehabilitation, or other employment services were less common but still reported in the majority of self-reports. See Table 3 for a summary of how many peer leaders provided each type of information.

[INSERT TABLE 3 HERE]

Peer leaders also reported using specific information from the training in their outreach. They reported that the information on employment and benefits, including the

effects of earnings on SSI/SSDI benefits, the differences between SSI and SSDI, and the SSDI 9 month trial work period helped them in outreach efforts.

*Were people who talked to peer leaders better informed about benefits and employment and did they have more positive attitudes toward employment?*

We used two mechanisms to find out if talking to a peer leader was helpful to people. We asked 1) peer leaders to describe the response to their outreach, and 2) individuals who responded to our self-mailer survey whether they found the interaction helpful.

All the peer leaders reported in at least one self-report that individuals responded positively to the information presented and found it helpful. Two Group 1 peer leaders and six in Group 2 reported that people showed interest by asking questions. In Group 2, three peer leaders reported that people were “shocked” or “surprised” by the information they presented, while a fourth reported that people were confused or disbelieving.

Information on vocational rehabilitation services, benefits planning, and employment support services were identified by peer leaders as especially valuable to people they talked to.

Consistent with the peer leaders’ reports, most respondents to the self-mailer survey (66/68 in Group 1 and 58/62 in Group 2) responded “yes” when asked if the interaction with the peer leader was helpful to them. When asked if they had learned something new about each of four topics that were particularly relevant to the project (benefits and employment, how to improve their economic status, employment resources, and BPAO/WIPA), the majority of respondents reported that they had (see Table 4).

[INSERT TABLE 4 HERE]



Responses to the telephone follow-up survey reinforced the finding that people learned something new, with 7/11 respondents in Group 1 and 11/22 in Group 2 saying they had gained new information when they talked to a peer leader. People reported learning that it is possible to work to a certain extent and still receive benefits (Groups I & II), about the SSDI 9 month trial work period (Group 1), that it is possible to get back on SSDI without a waiting period for 3 years after ending the trial work period (Group 1), that it is possible to retain health benefits through CommonHealth (the Massachusetts Medicaid Buy-In (Group 1), about employment resources such as vocational rehabilitation and ongoing job supports (Group 1), about accommodations (Group 2), and about Substantial Gainful Activity (Group 2). A few people had the following particularly positive assessments of their conversation with the peer leader: the “[Peer leader] is very knowledgeable and makes things quite clear. She really knows her stuff” (Group 1); “It was inspirational” (Group 1); and “I would highly recommend this leader to do this kind of training again. She is very knowledgeable” (Group 2).

On average, respondents to the self-mailer survey reported being less concerned about the effects of work on their benefits after talking with the peer leader. Respondents were asked to rate their level of concern on a scale from 1 (very concerned) to 4 (not at all concerned). The average level of concern before talking to a peer leader was 2.1 in Group 1 and 2.2 in Group 2; after talking to the peer leader it was 2.6 in both groups. The difference in rating, while small, was statistically significant ( $p < .05$ ) based on a paired t-test.

In the follow-up phone calls, most Group 1 interviewees (8/11) said the conversation made them feel different about their employment prospects. One person said she felt

“much less panicked” about how working would affect her prescription drug coverage and also that she could use the trial work period to see how she would feel about working full time. In Group 2, however, only 6/22 phone interviewees said they felt different about their employment prospects.

An additional source of information on the helpfulness of the PEBN peer leaders was the interviews conducted with disability organization staff. These staff interviewees generally had a positive response to the PEBN effort, reporting that the project was beneficial to both individuals with disabilities and agency staff. Comments from staff interviewees included that peer leaders were able to provide up-to-date information and reduce individuals’ confusion and fear about benefits and employment. For example, staff at one (Group 1) organization heard comments such as, “I was worried about the effects of working on my benefits, but then I talked to the peer leader and she reassured me and that’s why I’m at this job now.” A staff member at another Group 1 organization noted, “You can see people’s eyes get bigger when they realize they can make \$900 a month above their SSDI.” A Group 2 interviewee reported that, as a result of the PEBN, more people at the organization were realizing that they could work without losing health insurance and benefits. Peer leaders were also reported to be helpful in keeping the agency staff up to date and in assisting the agency staff to help more people. For example, at a Group 1 organization the staff reported that peer leaders helped field some of the more basic benefits questions so that the employment staff could work with those who had more complex benefits planning needs. Similarly, a Group 2 organization reported that more people were coming to the agency’s benefits specialist with questions.

*Did people take steps toward entering employment or improving their employment status as a result of their contact with the project?*

We also asked the self-mailer survey respondents if they had taken any of several particular steps toward changing their employment status. The steps were: “Looking for a job,” “scheduling a meeting with a benefits planner,” “contacting an employment support provider or the state vocational rehabilitation agency,” or “visiting a One Stop Career Center or job fair.” In Group 1, one-quarter to one-third of respondents to the self-mailer survey reported having taken some action since talking to the peer leader (see Table 5). Fewer respondents in Group 2 reported having taken some action. The most common action reported in both phases was “looking for a job.”

[INSERT TABLE 5 HERE]

At the time of the follow-up phone interviews, there were still few respondents who reported actual changes in employment status. The lack of job changes is not entirely surprising given the short time frame of the follow-up. Respondents did, however, report taking steps toward employment, particularly in the Group 1 group. Eight of the 11 Group 1 interviewees said they had taken some steps toward finding a job or changing their employment status; 2 more were already working or looking for work before they started talking to the peer leader. Steps being taken included: being on the waiting list for a Transitional Employment (TE) job through the Clubhouse, working with a job coach, looking for jobs in the paper, and asking about educational options at an employment support provider agency. The interviewee who reported feeling “much less panicked” about how working would affect her benefits went on to take on a full-time job at a nursing facility.

In contrast, the majority of Group 2 interviewees were not working or taking steps toward employment. Six people did take steps such as: looking for jobs in the paper, switching agencies, and thinking about getting temporary holiday work. One person reduced his or her hours in order not to jeopardize benefits. The 13 Group 2 interviewees who did not make attempts to change their employment status mostly cited other major life issues (i.e. mental health) to be barriers. Two of the 13 said they planned on taking action at a later point.

### **Discussion**

According to their self-report data, overall the PEBN peer leaders “spread the word” about work incentives and employment, with 28 peer leaders reaching out to hundreds of others with disabilities. Both peer leaders and self-mailer survey respondents reported that the outreach covered relevant topics, including information on benefits and employment and on local employment resources. Self-mailer survey respondents reported learning more about the key topics targeted by the project and reported, on average, a small decrease in fears about going to work. There was limited evidence of changes in employment status, but that is not surprising given the short time frame of follow-up, the breadth of factors that play into an individual’s decision to seek employment, and the amount of time and effort it can take to get from wanting to work to having a job.

Respondents to both the self-mailer survey and the follow-up interviews reported taking actions toward working, such as looking for a job or seeking out an employment support provider.

There was more evidence of steps taken toward employment in Group 1 than in Group 2, with several factors potentially accounting for the differences between the groups. First,

there may be differences in the populations due to differences in the types of organizations at which peer leaders conducted outreach. For example, some Group 1 peer leaders conducted outreach at employment agencies and day treatment centers, where people may have already been supported to work toward employment goals, where most Group 2 outreach took place at clubhouses and more informal venues, where there may not have as many been other sources of encouragement or support toward employment. Second, the different outreach strategies used by the two groups may have had an effect on outcomes. Perhaps the more informal, one-on-one approach to outreach by Group 1 was more effective than the group presentations used by Group 2, or perhaps the informal approach to outreach attracted a more select group of people who were already interested in employment. A third possible explanation can be found by looking at labor market indicators across the different years and the different locales of the trainees. In 2006 the unemployment rate was 5.0% in metropolitan Worcester and 4.3% in the Boston/Quincy/Cambridge area [31], the geographic regions covered by Group 1. In 2007, the rates were 5.7% in the Fitchburg/Leominster metropolitan area, 6.7% in the Lawrence/Methuen/Salem area, and 4.6% in the Lowell/Billerica/Chelmsford area [31], the area covered by Group 2. The higher unemployment rates in the Group 2 time and locations, especially in Fitchburg and Lawrence, may partly explain the lower employment outcomes in Group 2 since a lack of available jobs in the community may have served as a deterrent to seeking employment.

#### *Study limitations*

This project was designed as a pilot intervention and evaluation, not as a full-fledged research study. As such, the study was primarily exploratory and has several limitations.

First, both the geographic regions for the pilots and the individual participants were selected to maximize success of the intervention, not to represent a larger population. Therefore, generalizability of the findings is limited. In addition, we did not have a comparison group so we cannot make statements about the effectiveness of the PEBN compared to other approaches to sharing benefits and employment information.

Second, our reliance on self-reports and self-mailer surveys to determine the extent and content of peer leaders' outreach makes it difficult to verify the accuracy of those data. These data collection mechanisms were our attempt to deal with the methodological conundrum of trying to study peer to peer interactions without intruding on or altering the nature of the interaction itself. Gathering data from both peer leaders and those they interacted with provided a way of triangulating findings, but each of these mechanisms had its own flaws. The peer leader self-reports left open the possibility of inaccurate reporting due to anything from difficulty remembering the details of the outreach to a desire to over-report in order to please the program staff. The self-mailer survey, in turn, captured only a small proportion of the total interactions reported by peer leaders, due to a combination of peer leaders not handing out surveys to everyone they talked to and people they talked to not mailing it in. Since we did not have any record of to whom the surveys had been distributed to (a deliberate choice to protect the anonymity of the peer to peer discussions), we could not conduct any follow-up with non-respondents. The self-mailer survey responses could therefore be biased due to both differences between those who took the initiative to fill out and mail the survey and those who did not and differences between those to whom peer leaders gave a survey and those to whom they did not.

Third, the short time-frame of follow-up (both in the self-mailer survey and in the follow-up calls) did not allow for following participants long enough to realistically expect to see any change in employment status. A longer term longitudinal approach would be required to assess if the approach led to any lasting change in employment status for those involved in the project. Moreover, having accurate information about benefits information and work incentives only removes one of a number of potential barriers to employment for people with disabilities. Many barriers may still remain. Addressing the benefits factor alone may not in fact lead to an appreciable increase in employment rate without also addressing those other barriers.

#### *Policy and practice recommendations*

This study suggests that peer outreach may be a valuable addition to other efforts SSA and rehabilitation professionals use to promote employment among the disability community. For example, there is a substantial and growing cadre of paid peer professionals, particularly in Independent Living Centers and, increasingly in mental health services. These peer professionals could be provided continuing education options to expand their knowledge on employment resources and work incentives so that they can spread the message to their clientele.

#### *Future research*

There are several possible areas for future research into the topic of peer to peer information sharing and employment. First, longer term longitudinal data could lead to a better determination of both whether or not peer leaders continue to be a resource over time and whether employment activity levels increase over time after the introduction of the PEBN. A follow-up study could be conducted with the two groups of peer leaders and

the populations they did outreach to, to determine, a few years later, what, if any, lasting effects there may have been. Alternatively, a new study could be conducted with a new group of peer leaders, including from the start a longer term longitudinal approach to evaluation.

Second, different approaches could be used to attempt a more accurate determination of the outcomes from the peer to peer networking. For example, practice conversations could be incorporated in the project to assess how well peer leaders are understanding and sharing the information they learned. Another possibility would be for data collection from the agencies with which peer leaders do their networking to be used to assess overall organizational learning and attitude change. Further research could also be conducted on the social networks of people with disabilities and how and what information is spread through those networks.

Finally, benefits information is only one aspect of many involved in the decision to pursue employment. It would be helpful, both for this initiative and for a variety of other public policy questions, to examine in more detail the thought processes involved in choosing employment, including cultural, political, and economic factors, and the roles of work incentives and benefits information, as well as of peer counseling, in those decisions.



### Acknowledgements

The Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) is a collaborative project of the Center for Health Policy and Research at UMass Medical School, the Institute for Community Inclusion at UMass Boston and the Massachusetts Executive Office of Health and Human Services. This grant is funded by the Centers for Medicare and Medicaid Services (CFDA #93-768). For more information, visit [www.mi-ceo.org](http://www.mi-ceo.org). Our thanks to the many people who have contributed to the design and implementation of the Peer Employment Benefits Network, particularly Cindy Thomas, Amy Gelb, Allison Fleming and Brooke Dennee-Sommers of the ICI; the Benefits Planning Work Group of the MI-CEO Leadership Team; and all of the Peer leaders who have participated in the project. The opinions contained herein are those of the grantee and project participants and do not necessarily reflect those of the Centers for Medicare and Medicaid Services.

## References

- [1] U.S. Census Bureau. 2005 American Community Survey [Data file]. Available from the U.S. Census Bureau Web site, <http://www.census.gov/acs/www> (2005)
- [2] Rehabilitation Research and Training Center on Disability Demographics and Statistics. (2005). 2004 Disability Status Reports. Ithaca, NY: Cornell University.
- [3] R. V. Burkhauser, and D. C. Stapleton, The decline in the employment rate for people with disabilities: Bad data, bad health, or bad policy? *Journal of Vocational Rehabilitation*, **20** (2004), 185-201.
- [4] National Organization on Disability (2002). Key Findings: 2000 N.O.D./Harris Survey of Americans with Disabilities.  
<http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=862>
- [5] D. E O'Brien, G. Revell, and M. West, The impact of the current employment policy environment on the self determination of people with disabilities. *Journal of Vocational Rehabilitation*, **19** (2003), 105-118.
- [6] J. S. Sulewski, D. S. Gilmore, and S. M. Foley, Medicaid and employment of people with disabilities: Findings from the national survey of state systems and employment for people with disabilities. *Journal of Disability Policy Studies*, **17**(3) (2006), 158-165.
- [7] National Council on Disability. (2005). The social security administration's efforts to promote employment for people with disabilities: New solutions for old problems. Retrieved January 5, 2007, from  
<http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>
- [8] U.S. General Accounting Office (1996). SSA Disability: Program redesign necessary to encourage return to work. Washington, DC: Author.
- [9] U.S. General Accounting Office (1997). Social Security: Disability programs lag in promoting return to work. Washington, DC: Author.
- [10] U.S. General Accounting Office (1998). Social Security Disability Insurance: Multiple factors affect beneficiaries' ability to return to work. Washington, DC: Author.
- [11] P. Wehman and G. Revell, Lessons learned from the provision and funding of employment services for the MR/DD population: Implications for assessing the adequacy of the SSA Ticket to Work. *Journal of Disability Policy Studies*, **16**(2) (2005), 84-101.
- [12] K. Fichthorn and D. Gilmore, (2005) SSA Work Incentives Enrollment, 1990-2004 (Data Note No. 3). Boston: University of Massachusetts Boston, Institute for Community Inclusion.
- [13] Social Security Administration, (2008). SSI Annual Statistical Report, 2007. Retrieved July 7, 2009, from  
[http://www.ssa.gov/policy/docs/statcomps/ssi\\_asr/2007/index.html](http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2007/index.html)
- [14] T. Tremblay, H. Xie, J. Smith, and R. Drake, The impact of specialized benefits counseling services on social security administration disability beneficiaries in Vermont. *Journal of Rehabilitation*, **70**(2) (2004), 5-11.

- [15] P. Wehman, P. Targett, M. West, and J. Kregel, Productive work and employment for persons with Traumatic Brain Injury-What have we learned after twenty years? *Journal of Head Trauma Rehabilitation*, **20**(2) (2005), 115-127.
- [16] H. Cloutier, D. Hagner, J. Malloy, and P. Cotton, Choice and control over resources: New Hampshire's Individual Career Account demonstration projects. *Journal of Rehabilitation*, **72**(2) (2006), 4-11.
- [17] J. Kennedy, and M.F. Olney, Factors associated with workforce participation among SSDI beneficiaries. *Journal of Rehabilitation*, **72**(4) (2006), 24-30.
- [18] Virginia Commonwealth University. (2006). National Report. Retrieved January 8, 2007, from <http://www.vcu-barc.org/NatReport/CurrentReport.html>
- [19] C. Brindis, S. Peterson, Geierstanger, N. Wilcox, V. McCarter and A. Hubbard, Evaluation of a peer provider reproductive health service model for adolescents, *Perspectives on Sexual and Reproductive Health*, **37**(2) (2005), 85-91.
- [20] J. Giese-Davis, C. Bliss-Isberg, K. Carson, P. Star, J. Donaghy, M. J. Cordova, N. Stevens, L. Wittenberg, C. Batten and D. Spiegel, The effect of peer counseling on quality of life following diagnosis of breast cancer: an observational study. *Psycho-Oncology*, **15** (2006), 1014-1022.
- [21] C. S. Malchodi, C. Oncken, E. A. Dornelas, L. Caramanica, E. Gregonis, and S. L. Curry, The effects of peer counseling on smoking cessation and reduction. *Obstetrics & Gynecology*, **101**(3) (2003), 504-510.
- [22] S. Min, J. Whitecraft, A. B. Rothbard, and M. S. Salzer, Peer support for persons with co-occurring disorders and community tenure: a survival analysis. *Psychiatric Rehabilitation Journal*, **30**(3) (2007), 207-213.
- [23] J. Bernstein, E. Bernstein, K. Tassiopoulos, T. Heeren, S. Levenson, and R. Hingson, Brief motivational intervention at a clinic visit reduces cocaine and heroin use. *Drug and Alcohol Dependence*, **77** (2005), 49-59.
- [24] Shapiro, J.P., *No Pity: People with Disabilities Forging a New Civil Rights Movement*. (1994) New York: Times Books.
- [25] P. Solomon, Peer support/provided services: Underlying processes, benefits and critical ingredients. *Psychiatric Rehabilitation Journal* **27**(4) (2004), 392-401
- [26] P. Solomon and J. Draine, The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, **25**(1) (2001), 20-27.
- [27] D. Sells, L. Davidson, C. Jewell, P. Falzer, and M. Rowe. The treatment relationship in peer-based and regular case management services for clients with severe mental illness. *Psychiatric Services*, **57** (2006), 1179-1184.
- [28] P.T. Yanos, L.H.Primavera, and E.L. Knight. Consumer-run service participation, recovery of social functioning, and the mediating role of psychological factors. *Psychiatric Services*, **52**(4) (2001), 493.
- [29] E. Weissman, N. Covell, M. Kushner, J. Irwin, and S. Essock. Implementing peer-assisted case management to help homeless veterans with mental illness transition to independent housing. *Community Mental Health Journal*, **41**(3) (2005), 267-276.
- [30] S.-Y. Min, J. Whitecraft, A.B. Rothbard, and M.S. Salzer. A peer support for persons with co-occurring disorders and community tenure: A survival analysis. *Psychiatric Rehabilitation Journal*, **30**(3) (2007), 207-213.

[31] Massachusetts Executive Office of Labor and Workforce Development (2008). Labor force and unemployment data. Accessed November 25, 2008 at [http://lmi2.detma.org/Lmi/lmi\\_lur\\_a.asp](http://lmi2.detma.org/Lmi/lmi_lur_a.asp).

## Tables

TABLE 1  
PARTICIPANTS & DATA COLLECTION ACTIVITIES

Participants	Activities	Group 1	Group 2	Total N
Peer leaders with Disabilities	Pre/post tests	13	15	28
	Monthly outreach tracking (6 months)	60	84	144
	Interviews	8	12	20
People with Disabilities who Contacted Peer leaders	Self-mailer survey	68	62	130
	Phone follow ups	11	22	33
Key staff and leadership in disability organizations	Phone Interviews	4	2	6
Representatives from the Work Incentives Planning and Assistance programs	Phone/Email Interviews	2	2	2*

\*Each WIPA representative was interviewed twice, once after each project, so although four interviews took place, there were only two participants.

TABLE 2  
SELF-REPORTED PEER –LEADER CONTACTS

Group	Reports received	Contacts reported			Contacts per self-report
		Informal	Formal	Total*	
1	60	211	171	369	6.2
2	84	246	492	677	8.1
Total	144	457	663	1046	7.3

\* Some contacts were both formal and informal

TABLE 3  
 INFORMATION PROVIDED, AS REPORTED IN PEER LEADER SELF-  
 REPORTS (N=130)

Group	Information on benefits and employment		Information on employment resources		Referrals to WIPA, VR, etc.	
	#	%	#	%	%	
Group 1	58	97	53	88	39	65
Group 2	75	89	72	86	58	69
Total	133	92	125	87	97	67

TABLE 4  
WHAT SELF-MAILER SURVEY RESPONDENTS REPORTED LEARNING  
FROM PEER LEADERS  
(N=130)

Did you learn something new about...	Group 1 (n=68)		Group 2 (n=62)	
	#	%	#	%
Benefits & employment	66	97.	53	94
How to improve your economic status	57	84	46	74
Employment resources & supports for people with disabilities	57	84	47	76
BPAO/WIPA	47	69	33	53



TABLE 5  
 ACTIONS SELF-MAILER SURVEY RESPONDENTS REPORTED TAKING  
 SINCE TALKING TO THE PEER LEADER  
 (n=130)

	Group 1 (n=68)		Group 2 (n=62)	
	#	%	#	%
Looked for a job	28	41	17	27
Contacted an employment support provider or the Mass. Rehab Commission	23	34	13	21
Visited a One Stop Career Center or a job fair	20	29	13	21
Scheduled a meeting with a benefits planner	18	26	8	13