

**THE RESEARCH AND TRAINING CENTER IN  
REHABILITATION FOR PERSONS WITH LONG-TERM MENTAL ILLNESS  
1994 – 1999**

**SUMMARY OF RESEARCH ACCOMPLISHMENTS  
WITH TRAINING AND DISSEMINATION HIGHLIGHTS**

**THE CENTER FOR PSYCHIATRIC REHABILITATION  
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES  
BOSTON UNIVERSITY**

**RESEARCH PROJECT GOALS**

- I. Explore how people with severe psychiatric conditions maintain professional and managerial careers
- II. Define a new service modality of personal assistant services for people with psychiatric disabilities and assess its national proliferation and implementation
- III. Identify indicators of recovery from mental illness through the eyes of consumers of psychiatric rehabilitation services
- IV. Facilitate the acquisition of professional computer careers for individuals with severe psychiatric disabilities
- V. Survey and train people with psychiatric disabilities, their families, and service providers on utilizing the federal Social Security Work Incentives for gaining employment
- VI. Document and describe best practices for overcoming stigma and discrimination of people with psychiatric disabilities on the workplace and in training settings.

## RESEARCH ACTIVITIES AND SAMPLES ACQUIRED

- I. Surveyed 501 managers and professionals with serious mental illness who have maintained such employment in the past five years.
- II. Held focus groups with local consumers and advocates to define psychiatric personal assistance services. Conducted a needs assessment mail survey with 462 consumers in 15 states on these services. Conducted a national policy and implementation analysis of these services through phone interviews and document reviews with relevant state agencies.
- III. A quantitative assessment was conducted with 100 consumers on their quality of life including their employment, income, service utilization, and use of medications. A sub-sample of 20 individuals gave in-depth qualitative interviews every six months for over 4 years on the meaning and process of recovery.
- IV. Sixty individuals in four groups were given classroom instruction in industry-standard computer and office skills, followed by a two-month internship and on-going individual support to acquire and maintain competitive employment. Additional supports provided were: peer support, tutoring, linkage to community resources, outreach, recovery seminars, and a ten-week seminar in employment success and satisfaction for one-half of the students. Students were taught “keeping” skills necessary to sustain competitive employment. Assessments of work adjustment, acquisition of social and interpersonal skills, job tenure, and job satisfaction were conducted.
- V. A national survey of over 800 people, predominantly consumers of mental health services, was conducted and used to develop three different types of trainings on using the Social Security Work Incentives. A training to increase the awareness of and improve attitudes towards using the Incentives was conducted with nearly 200 individuals in SSA Region I states. Intensive training for developing skills for applying and using the Incentives was also conducted with 61 people. In addition, seven mental health consumers were also intensively trained in how to apply and use the Incentives. They in turn provided training on the Incentives to over 150 people.
- VI. Focus groups with employers, consumers, and advocates were held to develop an understanding of best practices in overcoming discrimination against people with psychiatric disabilities in the workplace. Findings of this process were used to develop a telephone interview guide. A recruitment and nomination process followed to identify companies and colleges that can exemplify these practices. Over 35 in-depth interviews were conducted with such organizations across the country.

## RESEARCH FINDINGS

- I. Many individuals with significant and ongoing psychiatric disability are able to acquire and maintain full-time and well-paid positions in high level careers such as: managers and executives, technical specialists, and health and mental health professionals. Traditional mental health supports, personal drive, flexibility and understanding on the job, and social supports contributes to this successful employment picture. Findings provide a landscape of promise to others with severe psychiatric conditions while serving to re-shape typical pessimistic attitudes held by mental health professionals on the work potential of those with this severe condition.
- II. Personal Assistant Services is a little-used service modality for people with psychiatric disabilities and most state administrators typically confuse it with rehabilitation services. Consumers of mental health services however, are able to articulate this model of services for themselves. Consumers surveyed expressed a need for PAS to help them with transportation, emotional support, and with negotiating social service agencies. While such help is highly valued, the extent of anticipated need for these services is modest.
- III. A qualitative analysis of the recovery process of mental illness shows that recovery is hindered by issues surrounding poverty, losses, physical health problems, substance abuse, as well as personal fears of failure, fears of the impact of the illness, and a very low sense of self-efficacy and self-esteem. Recovery is a slow path that often plateaus after gains and setbacks. Recovery is facilitated through hope, experiences that produce trust in oneself and others, supports, and personal resiliency. Through recovery, desires are ignited for a satisfying life that includes family ties, emotional relationships, work, and higher standards of living.
- IV. The computer training program succeeded with a 90% attendance rate and a 3% attrition rate. Combining supported education and supported employment had a positive impact on consumer vocational, psycho-social, and service utilization outcomes which were also enhanced by the Recovery seminar. Outcome employment rate for participants is being presently analyzed.
- V. A national survey showed that many consumers have worries about using the Social Security Work Incentives. As many as a third to a half of those surveyed had fears about the Social Security systems that were strong enough to impact their willingness to work. A primary worry was about losing health insurance. Training to promote awareness of, and ability to use, the Incentives had a strong positive impact on both participants' knowledge of the Incentives and on their overall attitudes about the Social Security system. Training activities were highly evaluated by participants as well.
- VI. Consumers and family members value this research on anti-discriminatory practices and are able to nominate numerous work and educational organizations that exemplify them. Best practices often revolve around the commitment displayed by individual key members of an organization. On the other hand, employers are highly fearful of the threat of litigation for discriminatory practices. Many organizations are unwilling to discuss this topic with researchers.

## RESEARCH IMPACT AND ADDITIONAL ACHIEVEMENTS

- I. Results of the study on professionals and managers with psychiatric disabilities was publicized through a press release which was reprinted and expanded in numerous media outlets including major newspapers, Internet health and mental health websites, radio announcements in several cities, and reports in popular and mental health magazines and newsletters. There are pending: a cable TV show, a book, and a documentary film on this topic. Results have also been presented in several national mental health conferences and workshops. This project led to another federally funded grant that will provide a longitudinal study of the participants of this survey while expanding the research focus to studying the ability to sustain employment.
- II. Articles on Personal Assistant Services are in preparation for professional journals. Findings have been presented to national and international audiences. A collaboration with the Research and Training Center on Personal Assistant Services at the World Institute on Disability was established so that data are shared and there is a mutual project that continues this work.
- III. Understanding of the meaning and process of recovery from mental illness has been presented at thirty national and international conferences on mental health and psycho-social rehabilitation in the U.S., Canada, Thailand and Singapore. Data from the study have been published in a professional article and in a book chapter. Other publications are in progress.
- IV. During 1999, presentations about the computer skills training program were made on both the state and national level to approximately 200 people in mental health and in employment conferences. Articles on the project have been published this year in *The Chronicle of Higher Education*, *The Boston Globe*, *The Clinical Psychiatry News*, and the *Mental Health News Alert*. A research publication summarizing the results of the project is underway. Consumers, families, and professionals have access to information about this project on the Center Web site.

This project is continuing as a service provided by the Center for Psychiatric Rehabilitation. Funding for participants is accomplished through a contract with Massachusetts Rehabilitation Commission and Job Partnership Training Act funds. Corporate relationships have also evolved from this project including internships/employment for participants and financial donations from IBM/Lotus Philanthropy, Fidelity Investments, Gillette, and Andersen Consulting. A newly funded service research project, the Recovery Center will offer computer training courses and job keeping seminars that evolved from this project. Alumni of the original research project have been hired as computer instructors and research assistants in the Recovery Center. Jay Neugeboren, author of the recent book *Imagining Robert*, spoke at the annual graduation of consumer participants. Other speakers in the recent past have included the second first Lady, Tipper Gore, and Daniel Fisher, M.D., a psychiatrist/survivor.

- V. The Director of the project on anti-discriminatory practices was invited to participate on the President's Task Force on Employment Committee sponsored by the National Association of State Mental Health Program Directors. This was in particular to share her expertise in employment and in Social Security Work Incentives issues. This committee has surveyed all state mental health authorities about employment services and needs for people with

psychiatric disabilities and one of the major barriers identified was the use of the Social Security Work Incentives. The NASMHPD President's Task Force committee also organized and sponsored a 2-day Senior Executive Training Institute on Employment for state mental health administrators in Alexandria, VA on March 11-12, 1999. The Project Director wrote and published an article in *American Rehabilitation* called *Encouraging Disclosure of Psychiatric Disability: Mental Health Consumer and Service Provider Perspectives on What Employers Can Do* and in the Journal of the California Alliance for the Mentally Ill entitled *Personal Experiences in Negotiating Reasonable Accommodations*.

### TRAINING AND DISSEMINATION HIGHLIGHTS

- Development of the Center's World Wide Web site (<http://www.bu.edu/sarpsych>). Since its development in 1998, the site has received approximately 4,000 visitors per month. The site undergoes continuous revisions and development.
- The Center has responded to approximately 800 requests for information per year (telephone, mail and e-mail) during the 5 year grant.
- The Center has hosted approximately 500 international visitors from countries as diverse as China, New Zealand, Australia, Japan, Taiwan, Western and Eastern Europe, and South America.
- The Center assisted in writing of one of the first texts on supported education: *Supported education and psychiatric rehabilitation: Models and methods* for persons with mental illness recently published by the International Association of Psychosocial Rehabilitation Centers.
- The Center published 12 issues of the *Community Support Network News* on critical topics in the field of psychiatric rehabilitation and disseminated them to thousands of practitioners and administrators.
- A revision of the seminal text, *Psychiatric Rehabilitation*, was completed by Center staff during this grant period and is currently in production for a scheduled 2000 publication.
- Over the 5 year grant period, the Center has trained and presented to several thousand consumers, family members, vocational rehabilitation practitioners, mental health and rehabilitation administrators, mental health practitioners, educators, and researchers at different levels of expertise.
- The Center has sponsored two national conferences, two regional conferences,
- 3 research colloquia, and 25 workshops with several workshops provided multiple times. A total of 3,750 individuals participated in those conferences, colloquia, and workshops.
- The Resource Information Service at the Center tested methods of dissemination and their effectiveness on an annual basis.
- The Center, in conjunction with the Department of Rehabilitation Counseling, educated 9 doctoral students with a specialization in psychiatric rehabilitation and 6 post-doctoral fellows. Courses were also taught to a total of 69 masters and doctoral students.

**RESEARCH AND TRAINING ACTIVITIES SPONSORED BY THE:**

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