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EMBRACING RECOVERY:

A SIMPLE YET POWERFUL VISION

"They said I would never get better. I would always be mentally ill. They said I would be in and out of mental hospitals the rest of my life. I could never be the person I was before my mental illness. I made up my mind in the hospital that I would prove them wrong."[1]

At age 31, Andrea Schmook, quoted above, believed she was the Virgin Mary. Wearing a veil fashioned from a bird cage cover, Ms. Schmook was taken into custody by the Alaska State Police after dropping off her eight-year-old daughter and five-year-old son at school in Anchorage. She was hospitalized, diagnosed with acute paranoid schizophrenia.

During the eight years that she lived with active symptoms of her condition, Ms. Schmook developed "a burning desire to get well" and embarked on a long-term effort to accomplish this goal.[2]

Now 54, Ms. Schmook notes that she has not used psychiatric medications or experienced symptoms of mental illness for the past 15 years. Since 1996, she has served as chief of consumer affairs for the Illinois Office of Mental Health, a role that includes providing education and training on recovery to people with psychiatric disabilities, family members and others throughout Illinois. In addition, Ms. Schmook is active at the national level with a number of mental health organizations and research activities.

Ms. Schmook's story, and those of many other individuals with psychiatric disabilities, reflects what William A. Anthony, Ph.D., executive director of Boston University's Center for Psychiatric Rehabilitation, calls the "simple yet powerful"[3] vision of mental health recovery: *people with psychiatric disabilities can and do recover*. It is a vision supported by research that contradicts the notion of serious mental illness as a lifelong, debilitating condition that renders a person unable to work or pursue other activities and goals that help make life fulfilling.

The most frequently cited research in support of the view that persons with psychiatric disabilities can recover was conducted by Courtenay Harding, Ph.D., and colleagues. Their study looked at outcomes for 269 severely disabled patients discharged in the mid-1950's from the Vermont Psychiatric Center Hospital who then received services from a pioneering, community-based public psychiatric rehabilitation program.[4] Individuals selected for the study had been hospitalized continuously for six years and had demonstrated only a modest response to treatment with the antipsychotic medication chlorpromazine.

Interviewed by members of the research team more than three decades later, 34 percent of the living cohort had achieved full recovery in both psychiatric status and social functioning; an additional 34 percent had improved significantly in both areas (Researchers successfully traced 97 percent of the original group). Recovery is defined in this study as having no current symptoms of mental illness, using no medications, being employed, relating well to family and friends, and being integrated into the community.[5] A series of European studies have also found that one-half to two-thirds of patients with schizophrenia significantly improve or recover.[6]

Experiencing Recovery

Asking 10 people to describe their experience of recovery is likely to elicit 10 different responses. "Recovery is as individual as the individual," explains Yvette Sangster, founder and executive director of Advocacy Unlimited, Inc., of Wethersfield, Connecticut, an agency operated by people who receive mental health services that provides information and support for Connecticut residents with psychiatric disabilities. Some people use different terms to describe the recovery process—such as transformation or healing.

Despite the differences, a core set of common themes emerges from both the research on recovery and individual experiences. Ruth Ralph, Ph.D., and Kathryn Kidder, M.A., of the Edmund S. Muskie School of Public Service at the University of Maine and members of the Recovery Advisory Group, a working group of researchers supported by the Center for Mental Health Services, the National Technical Assistance Center for State Mental Health Planning and the Human Services Research Institute, have developed a model of recovery.

The model includes both internal (e.g., cognitive, emotional, spiritual and physical) and external (participation in activities, self-care and social relations and supports) factors. It also identifies a series of key stages in the recovery process: initial anguish at one's condition and its impact on one's life, including the impact of stigma; an awakening that results in awareness that things can change; insight into how one's life can change; creation of an action plan; development of a "determined commitment" to get well; and a sense of well-being, empowerment and recovery. "Recovery is not linear. One goes back and forth between the various stages as one heals and grows," the researchers note. "However, these stages reflect the movement toward recovery and healing as described in the literature, in our group discussions, and in our experiences."[7]

Mary Ellen Copeland, a Vermont-based mental health educator and author, emphasizes that recovery moves people forward, not back, and that the recovery process is less about returning to one's former self than about discovering who one can become. Typically, one thinks of the ability to work, to reside in housing of one's choice and to have friends as key indicators of recovery. However, such external factors are "necessary but not sufficient" aspects of recovery, according to Laurie Curtis, M.A., an associate clinical professor at Trinity College in Burlington, Vermont. Ms. Curtis emphasizes that internal factors such as a sense of well-being and increased hope and self-esteem are also important components of recovery.

The question of whether a person can fully recover from a psychiatric disability generates a lively debate. For some people, including Ms. Schmook, recovery has included no longer experiencing symptoms of mental illness or needing to take medication. Others experience recovery as a life-long effort to live fully, sometimes with the help of medication and/or with the ongoing presence of symptoms at certain intervals in their lives.

Serious mental illness represents the severing from society of a person with severe emotional distress, according to Daniel Fisher, M.D., Ph.D., executive director of the National Empowerment Center, in Lawrence, Massachusetts, one of three national information and technical assistance centers funded by the federal Center for Mental Health Services operated by people who receive mental health services. In Dr. Fisher's view, a person has recovered when he or she regains primary control of major life decisions and functions in a significant and valued social role, even though the person may continue to use medications and experience emotional distress. Once a person has recovered, his or her emotional distress can no longer be considered a symptom, he believes.

An individual's vision of recovery can also be influenced by his or her definition of mental illness. Based in part on recent neuroscientific research, a number of individuals and mental health organizations now consider serious

mental illnesses to be disorders of the brain, much as diabetes is a disorder of the pancreas. Others subscribe to a broader view that includes environmental and sociocultural influences in the development of pyschiatric disabilities. "The recovery vision transcends the arguments about whether severe mental illness is caused by physical and/or psychosocial factors," according to Dr. Anthony.[8] What matters most, many say, is that people have an acceptable way to understand their condition and to move on from there.

Some people contend that recovering from the trauma associated with a diagnosis of serious mental illness can present as much of a challenge as recovering from the condition itself. A sense of hopelessness and lowered expectations often become key stumbling blocks. In addition, people with psychiatric disabilities may be traumatized or re-traumatized by experiences such as involuntary hospitalization and/or medication, the use of seclusion and restraint, being stigmatized and loss of control over life decisions.

Small Triumphs and Simple Acts of Courage

Mental health recovery often begins with what Patricia Deegan, Ph.D., director of training at the National Empowerment Center, calls an "awakening" that is followed by the development of a "personal plan of action." The plan may not be elaborate or even fully thought out at first, but it can propel a person to embark on a series of "small triumphs and simple acts of courage"[9] that over time lead to a renewed sense of hope, self-confidence, engagement with the world and life achievements.

For Ms. Schmook the recovery process began with her decision to get well in the face of skepticism from many mental health providers and her own doubts and fears. Throughout the early years of her recovery, Ms. Schmook continued to work, despite one therapist's suggestion that she go on welfare. Initially she worked in her sister's court reporting business in Anchorage. Later she was employed at an engineering firm, where she says, "no one had a problem with me being mentally ill." When she returned to work after an acute episode, co-workers would "hug me and tell me how proud they were that I survived," Ms. Schmook recalls. To help her cope during subsequent acute episodes without needing to be hospitalized, Ms. Schmook and her two children would move into her sister's home, where they were cared for by her sister and other family members. "They were always talking to me, telling me how much they loved me, even when I couldn't respond," she recalls. Family members also challenged her not to let her condition keep her from living a full life and continued to remind her that she had the ability, and responsibility, to make choices for herself and her children. During this period, Ms. Schmook changed doctors and therapists a number of times, searching for someone who believed she could get well. Finally, a doctor responded simply, "I don't know" when she asked him if she would get better. "For the first time, someone didn't tell me 'no' or that 'people with mental illness do not get better,'" she remembers. "He gave me hope."[10]

With that hope, Ms. Schmook began to take increasing responsibility for herself and her mental health. "I realized that nobody was going to 'fix' me," she recalls. She continued to gather strength from her family and surround herself with those whom she refers to as "possibility thinking" people. She eventually found therapists and therapy groups more in tune with her goal of recovery. She adopted the philosophy set out in a self-help book given to her by her sister that "whatever you can conceive and believe, you can achieve."

Implications for Public Mental Health Systems

Developing a mental health service system focused on recovery "is not like implementing a program or rolling out an initiative," explains Michael F. Hogan, Ph.D., director of the Ohio Department of Mental Health, which began to incorporate the concept of recovery into mental health services in the early 1990's. "It requires fundamental changes in people's understanding of the business of mental health care." These changes include enlisting the participation of persons with psychatric disabilities, family members and other stakeholders in the process of redefining the goals and activities of state and local mental health systems; employing people with psychiatric disabilities in policymaking, administrative, professional and paraprofessional positions at the state and local levels; and supporting the development of peer-run, self- help programs as acceptable adjuncts or alternatives to professionally run services. [See *Focus on the States* on page 7.] Another key element of programs that promote recovery is that they offer opportunities for consumers to reach for their goals.

Ultimately, according to Darby Penney, director of recipient affairs for the New York State Office of Mental Health, what matters more than any specific program model is "the attitude with which services are delivered." People with psychiatric disabilities want to be treated as persons of worth and dignity who have the right and ability to aspire to goals that they choose, not those chosen for them. They seek recognition and support, but not paternalistic or patronizing care. Finally, they want to be seen as complete and worthwhile human beings.

[1]Schmook, A. (1994). "They Said I Would Never Get Better." L. Spaniol and M. Koehler (eds.), The Experience of Recovery. Boston: Center for Psychiatric Rehabilitation.

[2]Ibid.

[3]Anthony, W. (1993) "Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s." Psychosocial Rehabilitation Journal 16(4) 11-23

[4]Harding, C., Brooks, G., Ashikaga, T., et al. (1987). "The Vermont Longitudinal Study of Persons with Severe Mental Illness." American Journal of Psychiatry 144(6) 718-726.

[5]Harding, M. and Zahniser, J. (1994). "Empirical Correction of Seven Myths about Schizophrenia with Implications for Treatment." Acta Psychiatr Scand 90 (suppl 384), 140-146.

[6]Ibid.

[7]Ralph, R., and Kidder, K. (1999). A Compendium of Recovery and Related Instruments. Cambridge, MA: The Evaluation Center@HSRI.

[8]Anthony, W. (1993). Editorial. Psychosocial Rehabilitation Journal 16(4) 11-23.

[9]Deegan, P. (1996). "Recovery as a Journey of the Heart." Psychosocial Rehabilitation Journal 19(3) 91-97.

[10]Schmook, 1994.