

CHANGING PEOPLE'S MINDS

Told by Susan Keese

Joseph Rogers could be mistaken for Santa Claus. This forty-five-year-old man, with his bushy white beard and robust manner, is often called “the Mother Teresa of the consumer movement” or “the Martin Luther King of mental health.” But despite all that he’s accomplished, Joe still struggles with his illness.

Joe remembers the day when he was diagnosed as a paranoid schizophrenic. “It was like a death sentence,” he says. He was only nineteen when he was told he’d spend most of his life in a mental institution. “While most people my age were planning for their future, I was told, ‘You might as well apply for social security.’” But Joe surprised almost everyone. Thirty years later he is a nationally recognized leader in a movement that’s reforming the entire mental-health-care system. He confers with presidents, testifies before Congress, and consults with foreign governments. It’s hard to believe that this man was once homeless, wandering the streets of New York City, fishing through Dumpsters looking for food.

Raised in a troubled household on the outskirts of Orlando, Florida, Joe left home at thirteen. As he drifted, he became increasingly disorganized, isolated, and depressed. Near suicide, he turned for help to an understanding youth worker, a call that probably saved his life.

During his twenties, Joe bounced around from one mental hospital to another and had many painful experiences in the system. Between

hospitalizations, he struggled through beginning classes at a New Jersey community college. “I got lots of insights into my life from the courses I took in psychology,” he says. But his recurring bouts of mental illness made it difficult for him to finish his degree.

One day a professor persuaded him to use his insider’s knowledge of how the system works—and, too often, doesn’t—to make it better. Joe decided to volunteer at a small community mental health center in New Jersey, which, since all the states were downsizing mental hospitals to cut costs, was struggling. “Suddenly this little center, designed for family counseling, was expected to take care of people with serious mental illness. Many had been institutionalized for a long time,” Joe says. “Folks at the center weren’t prepared for this new challenge. Something needed to be done, so I said, ‘Let me work on this.’”

Joe remembered how he had felt when he first came out of the hospital. He spent time with the newcomers, sharing his story and listening to theirs. People found it comforting to talk with others who had “been there.” It made them feel less alone, less afraid, better able to help themselves.

Joe turned these conversations into programs for people in halfway homes. He created a model and set up a number of self-help groups in which former patients supported one another in rebuilding their own lives. His reputation spread as he continued to develop new programs. Ironically, he had to hide his own background. “I had all this experience with inpatients and outpatients, but I couldn’t tell anyone how I got it,” he says.

He moved to Philadelphia, to accept a job with the Mental Health

Association of Southeastern Pennsylvania (MHASP), where he created Project SHARE (Self Help and Advocacy Resource Exchange) to help people who had lived with mental illness in designing programs to meet their own needs. “Hearing the success stories of people whose problems are similar to your own gives a kind of hope you can’t get from professionals,” Joe maintains. He adds, “Many professionals don’t really see these people as equals. They see them as children at best, or mentally retarded at worst. It’s a threat to them to have former patients saying, This is what I want,’ or This works best for me.’ ”

Through Project SHARE, more than five thousand mental health “consumers” have transformed themselves from helpless recipients into helpers and wage earners, become advocates for mental-health care as well as role models for others. Project SHARE has spawned hundreds of peer counseling/support groups and serves as an umbrella organization for twenty projects run by mental-health clients—such as housing programs, drop-in centers, job training, outreach, and advocacy. They’ve also created a national clearinghouse to help consumers around the country organize their own self-help and advocacy groups. “Many people come into our programs, literally homeless and hopeless,” Joe says. “They start as volunteers, then become paid facilitators. They go to school, get new skills, and end up with a new lease on life.” The basic principle is “Helping others is often the best therapy.” It’s the best economy, too. “It costs up to \$1,500 a day to hospitalize someone. For what it once cost to warehouse five hundred people in the state hospital, we’re now serving three thousand in a community setting.”

“Joe Rogers is a visionary who saw the future and pushed for it to

happen,” says Ilene Shane, director of the Disabilities Law Project. “He’s made Pennsylvania a model for consumer-run mental-health programs around the country and the world.”

Joe still suffers from random hallucinations and sometimes hears voices that no one else hears. Every day he and millions of others must try to make it through life while they wait for a cure. But, thanks to Joe and Project SHARE, at least the wait is more hopeful, and life is certainly more meaningful. By helping one another, they are a shining example of what it means to be “our brother’s keeper.” And by educating others about the reality of mental illness, and advocating for change, they are building the road to a better future.

Whatever you can do or dream you can, begin it:

Boldness has genius, power and magic in it.

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Help yourself! If you have a mental illness, believe in your abilities: Organize a self-help/advocacy group for yourself and others who are working toward recovery. Call the **National Mental Health Consumers’ Self-Help Clearinghouse** for information about organizing, getting funding, and more, 800-553-4539; or visit their Web site, www.mhselfhelp.org.