Self-Determination for People with Psychiatric Disabilities: Personal Obstacles and Facilitators

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Although we both have psychiatric disabilities, our respective journeys toward self-determination have been very different. But our stories diverge only in the details; the basics are remarkably similar.

JOSEPH ROGERS:
"In the early '70s, when I was 19 years old and a patient in a Florida state hospital, I had an appointment with the vocational rehabilitation counselor. Standing in front of his desk, I waited while he flipped through my chart. 'I've got nothing much to offer you, since I can see from your chart that you'll never be able to hold a job,' he said finally. With these words, he seemed intent on extinguishing any spark of hope I may have desperately held on to that I would one day be the head of my own household. My spirits sank as I contemplated a lifetime of dependency, during which others would have the power to determine my destiny.

"Luckily, upon my release I moved to a typically short-staffed halfway house. To fill in the gaps, the director had the idea of training some of the residents, including me. A lightbulb switched on: I could help others! By doing so, I gained confidence and stature in my own eyes. This was the beginning of my journey toward self-determination, defined within the mental health arena as 'individuals' rights to direct their own services, to make the decisions concerning their health and well-being (with help from others of their choice, if desired), to be free from involuntary treatment, and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports' (www.psych.uic.edu/UICNRTC/self-determination.htm)."

SUSAN ROGERS

“The first of my two hospitalizations was in 1975. My family, fearing (with cause) that I was suicidal, brought a psychiatric outreach team from the local hospital to my apartment on the Upper West Side of Manhattan. After a brief conversation, I was told that I could either enter the hospital “voluntarily” or “involuntarily” — no third option. Offered this so-called choice, I agreed to go “voluntarily,” and was immediately taken to the locked psychiatric ward of the nearby general hospital.

“That I had ‘agreed’ to be locked up against my will was irrelevant, since I had been given no true alternative; and hearing the key turn in the lock while I was on the wrong side of the door filled me with dread. My prospects had seemed bleak before; now, they seemed desperate.

“But things took a turn for the better when I met my roommates: a medical student, a singer, and a Latin teacher. The fact that these three women had lives outside of their current circumstances gave me hope, and the camaraderie we shared was healing. I thought, maybe there is life after psychiatric hospitalization. Although other events during my three-week stay — such as being force-drugged — were less felicitous, I managed to hold on to some degree of optimism.

“As I had not foreseen, a year later, at an even lower ebb, I checked myself back into the hospital. This time, I was in such despair that I could barely speak. But again the luck of the draw was with me: the psychologist who was assigned to my “case” was warm and human, and, at my request, she “reached across” to hold my hand, despite the fact that mental health professionals are discouraged from making that kind of gesture. At my discharge three weeks later, she gave me her home number and, for the next few weeks, was there to talk with me when I called, often for as much as an hour, some four or five times a week. What she offered me felt like friendship. In fact, I had lucked into a two-for-one deal: a friend and a truly helpful partner in my treatment.

“As I was nearing discharge, I got a third lucky break. Since I had had no visible means of support when I checked into the hospital, it was suggested that I obtain a job before my release. At first uncertain as to how to accomplish this, I decided to call my most recent employer. Telling him I was calling from a psych ward, I explained my dilemma. I said I figured he had probably filled my position but asked if I could come back in any capacity. His immediate response was to let me know that the person who had replaced me was leaving, and to offer me my old job back. This was in spite of the fact that, when I quit six months earlier, I had told him that it was either leave or jump out of my open office window (on the 26th floor).

“But it wasn’t only his support and his faith in me that helped; it was also the job, where I stayed for eight years and was repeatedly promoted. Being gainfully employed at a job I enjoyed and where my work was appreciated and respected was enormously satisfying.”

FACILITATORS AND BARRIERS

In our stories, the personal facilitators and barriers to self-determination are clear: hope versus despair; choice and empowerment versus their absence; effective versus destructive — including forced — mental health treatment; self-confidence versus self-stigma; support from people who believed in us — including peers, mental health professionals and service providers, and employers — versus people who didn’t; and meaningful employment versus a life without meaning. Other important personal facilitators are spirituality (however an individual defines it), and education about oneself, and about one’s illness and symptoms, so that one has more control over one’s own life.

INTERNAL STIGMA

Key among personal barriers to self-determination is internal stigma — the feeling that there is something wrong with us because society tells us there is something wrong with us. In “Stigma Is Social Death: Mental Health Consumers/Survivors Talk About Stigma in Their Lives,” Deborah Reidy writes: “Internalized stigma . . . refers to the process of absorbing into oneself negative societal beliefs and expectations held about people who are stigmatized. Many people who have been stigmatized consider this the most damaging effect, because it becomes independent of external perceptions, and can consequently follow one through life, regardless of the external evidence of success or achievement. . . . [Interviewee] Joel Stanley said, ‘I feel like I’m alone and carrying this big burden. I will probably never have a life like everybody else, get married, have kids, have a house . . . I feel that I’m over the hill, all used up, nobody’s interested in me on any level’ ” (Reidy 1993).

It is difficult to fight the demoralizing impact of stigma, experts say. According to an article called “The Effectiveness of Stigma Coping Orientations: Can Negative Consequences of Mental Illness Labeling Be Avoided?” (Link, et al., 1991), the short answer to the question posed in the title was No.

The authors examined whether people with mental illnesses could lessen the impact of stigma by common coping mechanisms, ranging from secrecy to openness. They found that these methods produced more harm than good, potentially further isolating the labeled person. “None of these coping orientations were effective in diminishing negative labeling effects on unemployment or on psychological distress/demoralization. In fact, the three coping strategies show consistent effects in the direction of producing more stigma, and with respect to withdrawal-avoidance [avoiding situations in which rejection might occur] this effect is significant.”

The authors continued: “Based on these results, we argue that stigma is powerfully reinforced by culture and that its effects are not easily overcome by the coping actions of individuals.”

It should be noted that self-stigma is not experienced by everyone who has a psychiatric disability. According to Patrick W. Corrigan and Amy C. Watson of the Chicago Consortium for Stigma Research, “. . . personal reactions to the stigma of mental illness may result in significant loss in self-esteem for some, while others are energized by prejudice and express righteous anger. Added to this complexity is a third group: persons who neither lose self-esteem nor become righteously angry at stigma, instead seemingly ignoring the effects of public prejudice altogether" (Corrigan & Watson, 2002).

But for those who do experience self-stigma, a major source is the entertainment and news media, which contribute to it in the minds of the general public — as well as in the minds of people labeled mentally ill — by portraying people with psychiatric disabilities as violent and demented, studies show. For example, the National Mental Health Association reported that, according to a survey for the Screen Actors' Guild, characters in prime time television portrayed as having a mental illness are depicted as the most dangerous of all demographic groups: 60 percent were shown to be involved in crime or violence (three times the average rate). In addition, "[s]tudies showed that as many as 75 percent of stories dealing with mental illness focus on violence (Shain and Phillips 1991). Although more recent research suggests the prevalence of these kinds of stories is diminishing (Wahl, et al. 2002), at least a third of stories continue to focus on dangerousness. Also, the vast majority of remaining stories on mental illness either focus on other negative characteristics related to people with the disorder (e.g., unpredictability and unsociability) or on medical treatments. Notably absent are positive stories that highlight recovery of many persons with even the most serious of mental illnesses (Wahl, et al. 2002) [Corrigan, P.W., et al. (in press)]."

SYSTEM RIFE WITH STIGMA

Even worse are the negative messages communicated to us by those who are supposed to — indeed, are *paid* to — help us in our journey toward self-determination: mental health service providers. Such messages may contribute most to our internal stigma.

Many of us are familiar with "You and Me," the poem by Debbie Sesula that has been circulating in the consumer/survivor movement for years <http://www.nisa.on.ca/poetry_contest/Hon%20Mention%20Poems/you_and_me.htm>.

“If you’re overly excited, you’re happy; if I’m overly excited, I’m manic,” it begins, and continues: “If you imagine the phone ringing, you’re stressed out; if I imagine the phone ringing, I’m psychotic.” In 21 short lines, it makes an eloquent statement about stigmatizing labels applied by the mental health system to people with psychiatric disabilities.

Some experts have suggested ways to deal with this problem. In an excerpt from their article “Identifying and Overcoming Mentalism,” by Coni Kalinowski, M.D., a psychiatric consultant, and Pat Risser, a former recipient of mental health services and past president of the National Association for Rights Protection and Advocacy (NARPA) as well as a service provider, the two state that, “[t]o truly address the issue of prejudice in the mental health system and have an impact on the system’s participation in discrimination, it is necessary to look at the attitudes and assumptions underlying mental health jargon” (Memorandum, Spring 2003, Resource Center to Address Discrimination and Stigma).

Kalinowski and Risser write: “The language that has become politically charged in the mental health arena includes terms that communicate condescension, blame, and the perception of labeled people as defective.” This language includes obvious terms such as “basket case and loony tune,” as well as seemingly professional terminology, such as “decompensate.” Kalinowski and Risser continue: “ ’Decompensating’ is an us-them term: under stress ‘we’ may not do well; ‘we’ may cocoon, take to bed, get bummed out, get burned out, get a short fuse, throw plates, scream, call in sick, or need a leave of absence. ‘They’ *decompensate*.”

The authors suggest replacing this term by a brief and accurate description of what’s going on with the person. “For example, ‘After the break-up with her girlfriend, Mary couldn’t sleep. She started pacing at night and complained of hearing voices.’ This brief statement factually describes Mary’s experience and gives meaningful information that begins to suggest interventions that may be helpful.”

Providers who don’t believe in their clients’ capacity for self-determination are an enormous obstacle to achieving that goal, since it is difficult for the client to avoid internalizing such a negative message. Unfortunately, the fact that the mental health system abounds with discrimination and stigma has been so well documented that it has become axiomatic, and is recognized at the highest levels. For example, “Discrimination and Stigma in the Mental Health System” was one of the topics at “Spring to Action: A National Mental Health Symposium to Address Discrimination and Stigma,” sponsored by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration in March 2001 <http://www.samhsa.gov/news/newsreleases/010320ma-stigma.htm>.

CONSUMER/SURVIVOR CONSENSUS

Most lists of personal facilitators and barriers to self-determination might resemble what emerged from the “plank sessions” on Recovery at the first National Summit of Mental Health Consumers and Survivors, held in Portland, Ore., in August 1999. The goal of the Summit was to develop consensus around the issues of greatest concern to consumers and survivors and create action plans for future work. Attendees played an active part in developing one or more of the planks, including the Recovery plank <http://www.mhselfhelp.org/rrecovery.html>.

(Although self-determination and recovery are not identical, there is enough overlap between the two to make the plank report relevant. Indeed, at least one consumer activist — Terry Grimes of Empowerment for Healthy Minds (EFHM) — would prefer to substitute “self-determination” for “recovery.” As Grimes writes on the EFHM Web site: “Most places in the literature where the word ‘recovery’ is used, phrases like social self-determination, empowerment, ability, and the like could be substituted to positive effect. ‘Recovery’ might be best suited to conditions like a respiratory infection, heart attack, broken leg, etc. The on-going journey of living with severe mental illnesses is one of the challenges life lets us work with, but it is a trip of empowerment of self, spirit, thought, and caring about others, not just recovering from a disease or broken body” <http://www.efhm.com/recovdoc.htm>.)

The Recovery plank participants developed a list of the values and principles most important to recovery, as well as personal barriers and personal supports to recovery. In addition, they developed lists of systemic and societal barriers and supports, which we will not reproduce here.

As selected by vote among the Recovery plank participants, the personal barriers that pose the greatest challenge to recovery (and, we would suggest, to self-determination) include (in order of importance from highest to lowest) fear, low self-esteem/self-confidence, fear of success, negative self-talk, lack of coping skills, personal trauma issues, not knowing your rights, and a feeling of hopelessness.

The personal supports seen as most important to recovery (again listed from most to least important) include relationship with God; friends; online support/chat groups; sex; music; having a regular schedule; diet and exercise; getting in touch with nature: hiking, camping, and gardening; hot bath, whirlpool, Jacuzzi; supportive work environment; helping others; pets; tapping into creative ability; writing and journaling.

Values seen as most important to recovery (same order) include hope, responsibility, spirituality, empowerment, sense of humor, respect, belief in self, compassion, courage, honesty, faith, and love. Principles (same order) include having your basic needs met, a belief in recovery, Humanist philosophy (one definition of which is “any outlook or way of life centered on human need and interest”), employment, education, informed choices, peer support, consumer-run drop-in centers, and ability to advocate for oneself and others.

HIERARCHY OF NEEDS

The values, principles, and supports that the Recovery plank participants identified bring to mind Abraham Maslow’s “hierarchy of needs.” Maslow hypothesized that people are motivated by unsatisfied needs. He believed that, before “higher” needs — such as “self-actualization,” which he describes as “becoming everything that one is capable of becoming” — can be addressed, lower needs (such as the need for food and other physiological necessities) must be satisfied. In between are the needs for safety, love/belongingness, and esteem.

Maslow based his theory on his observations of seven contemporaries and nine historical figures — Lincoln, Jefferson, Einstein, Eleanor Roosevelt, Jane Addams, William James, Albert Schweitzer, Aldous Huxley and Spinoza — rather than people with psychiatric disabilities. In fact, he didn't believe anything could be learned from studying such individuals: "The study of crippled, stunted, immature, and unhealthy specimens can yield only a cripple psychology and a cripple philosophy," he wrote in "Motivation and Personality" http://web.utk.edu/~gwynne/maslow.HTM. However, his hierarchy seems as applicable to the general public, including people who have psychiatric disabilities, as to the "self-actualized" figures he studied.

SPIRITUALITY AND MEANING

Abraham Maslow also believed that people had a need for the spiritual, for something beyond themselves: a "higher power" <http://www.mang.canterbury.ac.nz/people/nilakant/spirit/abraham_maslow_and_spirituality.htm>.

However one defines spirituality and meaning, they are clearly important personal facilitators to self-determination and recovery.

For Humanist philosopher Erich Fromm (1900-1980), people make their lives meaningful by living productively, and by using their powers of love and reason to their fullest capacity. For existential psychologist Rollo May (1909-1994), people achieve meaning by being able to live by their highest values, feeling the power of their will to make choices, and being able to love <http://www.geocities.com/~webwinds/frankl/meaning.htm>.

But it is Viktor Frankl's philosophy that truly resonates in regard to the quest for self-determination by people with psychiatric disabilities. For Frankl (1905-1997), who developed a philosophy/therapeutic method called logotherapy in the 1930s, “meaning” is experienced by addressing the demands of whatever situation one is in, figuring out and committing oneself to one's calling, and trusting in an ultimate meaning, which may or may not be called God. Logotherapy is based on the concept that meaning is more important than pleasure. Unlike Maslow’s hierarchy of needs, the philosophy “considers [an individual] as a being whose main concern consists in fulfilling a meaning and in actualizing values, rather than in the mere gratification and satisfaction of drives and instincts” http://www.geocities.com/~webwinds/frankl/quotes.htm. Freedom of choice and responsibility are also central to the philosophy, whose main objective is to help people in their search for meaning, regardless of their life circumstances.

Frankl, who spent three years in Auschwitz, believed that how we choose to act in whatever circumstances we find ourselves in is what counts: “Everything can be taken from a [person] but . . . the last of the human freedoms — to choose one’s attitude in any given set of circumstances, to choose one's own way.” He also wrote: “This was the lesson I had to learn in three years spent [at] Auschwitz and Dachau: those most apt to survive the camps were those oriented toward the future, toward a meaning to be fulfilled by them in the future” <http://www.lifeforum.co.za/about%20us.htm> Although it is not our intention to compare concentration camps to psychiatric institutions, it would seem that logotherapy would have a lot to offer people with psychiatric disabilities in their search for meaning and self-determination.

SELF-ADVOCACY AS A FACILITATOR

Where do you start your journey to self-determination? One place to start would be to begin to make decisions for yourself, and to learn to be your own best advocate.

Because the National Mental Health Consumers’ Self-Help Clearinghouse, an affiliated project of the Mental Health Association of Southeastern Pennsylvania, is committed to helping people with psychiatric disabilities learn to advocate for themselves, the Clearinghouse created the Freedom Self-Advocacy Curriculum

<http://www.mhselfhelp.org/freedom/index.html>, which is now part of the Clearinghouse TEAM (Training, Education, Advocacy, Management) training.

The Freedom Self-Advocacy Curriculum focuses on Attitudes, Skills, and Knowledge to help people improve their self-advocacy skills. For example, among attitudes necessary for being an effective self-advocate are believing in yourself, being assertive, and managing your anger. The training includes problem-solving strategies, such as educating yourself, identifying your rights, breaking down the problem, and developing a solution. Such basics as how to identify the right person to talk to, keeping records, and following up are also covered.

Learning to be an effective self-advocate can change a person’s life. For example, Maurene Woods, who was trained in self-advocacy skills by Advocacy Unlimited, Inc., in Wethersfield, Conn., a consumer-run advocacy educational program, has said: “Before I went into the program, I had been hospitalized constantly for major depression and post-traumatic stress disorder; I was extremely intimidated by the mental health system; I was not able to advocate for my own rights or play an active role in my own treatment plan.” In fact, she said, she didn’t even know what rights or options she had. “I was lost in the system, and the system was not helping me. I hadn’t worked in probably three years.”

But less than a year later, Wood was employed full time as a respite worker in a residential program and was completely self-supporting. “I think I’d still be lost if it hadn’t been for graduating from that program,” she told the Clearinghouse newsletter (“Experts: Self-advocacy training is vital to consumer empowerment,” The Key, Spring ’98, Vol. 4, No. 2).

Self-advocacy can encompass everything from simply speaking up for ourselves in regard to decisions that affect our daily lives, all the way to advocacy for systems change, since that, too, has an impact on our lives.

Something else we can do to facilitate our self-determination is to create an advance directive <http://www.protectionandadvocacy.com/adintro99.htm>. Advance directives allow individuals to specify the treatments they would accept — and those they would not accept — should they be in a position where they cannot speak for themselves. They let us have greater control over our lives, and can give treatment providers important information that can guide them to providing the best quality of care. You can also name another person, someone you trust, to make decisions for you in the event that doctors determine that you do not currently have the capacity to make informed choices on your own. (This is called a Durable Power of Attorney.)

COMMUNITY ORGANIZING

Devoting ourselves to furthering the movement for social change is an important route to self-determination, since such efforts can give our lives real meaning. The consumer/survivor movement, which began more than 30 years ago as an offshoot of the civil rights movement, needs every one of us!

Besides the goals of effecting social change and having a positive impact on our own lives and the lives of others, a byproduct of being involved in the movement is peer support — more simply described as friendship with people who have shared our experiences. Peer support has been proven to promote self-determination. Another effect of working toward social change is the feeling of empowerment engendered by such activity.

JOSEPH ROGERS:

“When I was working as a mental health service provider in the late 1970s in northern New Jersey, I became involved in a statewide community organizing effort and met Judy Banes, a “peer.” Encountering one other person who was not only recovering from mental illness but was also working to effect social change made a big difference in my ability to see that I could not only struggle toward my own recovery but I could do this in a way that would help others and thereby help myself. I found this therapeutic.

“Judy Banes and I organized a demonstration to call attention to some problems at a large psychiatric hospital in the area. Everyone on the picket line was either a current or former patient of that particular institution. All we did was walk in a circle and chant slogans about improving the conditions. It seemed a fairly insignificant effort at the time.

“Then, several years later, during a presentation I made on organizing the movement for social change, someone said he had been on that picket line and that it had transformed his life. Before that, he had been cycling in and out of the hospital. Afterwards, he became active in the movement, and is now operating a consumer-run service in New Jersey.

“He’s not alone: I’ve heard dozens of stories like this from people who credit the experience of walking in a line to protest injustice with helping them realize they could start in a new direction and not continue in their role as ‘mental patient.’ ”

Experts, such as renowned community organizer Saul Alinsky (1909-1972), have noted that encouraging people to confront oppression and to realize that they don’t have to accept the status quo is one way to help them become more resilient and “self-determining.” Not everyone needs to join a picket line. Sometimes just connecting with a peer who has lived through similar experiences can make someone realize that he can change his life and begin to work toward self-determination and recovery. Twelve-step groups are well-known for helping people with substance abuse disorders to achieve this understanding. It may be more difficult for someone with a psychiatric disability to make the kind of immediate change that someone can achieve just by stopping drinking or drugging. But helping people awaken to the fact that self-determination is possible and that they themselves must play a major role in their own recovery should be a major part of the effort at instituting self-determination as a theme in the way consumers get help.

PEER SUPPORT

Many distinguished researchers have noted the importance of peer support to the recovery process. One such researcher is Dr. Courtenay Harding, executive director of Boston University's Institute for the Study of Human Resilience and an author of a landmark study of deinstitutionalized people with psychiatric disabilities in Vermont and Maine who had spent years warehoused in the back wards of mental institutions. “Consumers are wonderful at helping each other, and teaching each other how to take control of their illness,” she told People First, a publication of the Pennsylvania Office of Mental Health and Substance Abuse Services.

The Vermont-Maine study, involving people with serious mental illness, began in the mid-1950s, when 269 people were released from the back wards of Vermont State Hospital and provided with a model rehabilitation program in the community. Thirty years later, 262 of the 269 were located and assessed and it was found that approximately two-thirds of them had achieved significant levels of recovery. This was in contrast to a matched control group of patients released from a Maine state hospital, who had received more traditional treatment and who had not done as well in the community.

“We looked at what happened to them over three decades: who was working and who wasn’t, how independent and well-functioning they were, how many symptoms they had,” said Harding. “The Maine group showed up over the long haul as having many more symptoms, much less employment, and much lower levels of functioning in the community than the Vermont group.” Harding added that the principal difference between Maine and Vermont was that “Vermonters got a whopping psychosocial rehabilitation program and Mainers did not.”

As a result of the study, she said, "We have very strong data showing that community integration, rehabilitation and self-sufficiency models — which was what the Vermonters had — are far superior to the Maine model of medication, entitlements, maintenance and stabilization" (“Recovery Gains Acceptance,” People First, Vol. 9, No. 2, Fall 1999).

PEER SUPPORT AND PSYCHIATRIC REHABILITATION SERVICES

Self-determination is the basis of all consumer-run programs <http://www.mhselfhelp.org/pubs/key/fa02/nfc.html>. If people with mental illnesses are going to move toward recovery rather than languish in programs that are often little better than institutions, consumer-run services are an indispensable component of the “continuum of care.” They are often successful in reaching people who have been wary of more traditional services.

Conversely, an obstacle to self-determination is the lack of support for programs such as these and other kinds of psychiatric rehabilitation programs <http://www.apa.org/monitor/feb00/schizophrenia.html> — designed to improve living skills and to assist people with disabilities in realizing their potential for independence and for useful and productive activity, such as work — that have proved successful in increasing the overall quality of life, independence, employment, social supports, and education of consumer/survivors.

CONCLUSION

Because systemic and societal barriers and facilitators have been so central to our respective efforts to achieve self-determination — and because there is so much overlap among personal, systemic, and societal factors — it has been difficult to limit our discussion only to barriers and facilitators that are strictly personal, as we had been asked to do. But we have done our best to stay within those limits and, at the same time, give an overview of what we believe is helpful or harmful to anyone’s quest for self-determination.

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