*The expertise gleaned from being a patient in a psychiatric hospital is used to train hospital staff in what is helpful to patients and what hurts. The trainers are consumers/survivors/ex-patients in different stages of recovery.*

# Consumers/Survivors/Ex-Patients as Change Facilitators

*Ronald Bassman*

After twenty-two years of living within the acceptable range of normality, my passage into schizophrenia was bewildering to my family. Psychiatrists looking back at my childhood history could perform a psychological autopsy and find warning signs of future mental illness, but those predictions could be made only after the label was already in place. My introduction to madness followed the norm for my diagnosis; I was twenty-two when I was first hospitalized, right in line with the median age for the onset of the first psychotic episode of schizophrenia. I was hospitalized twice for a total thirteen-month inpatient treatment: six months in a private hospital and, later, seven months in a public hospital.

When I was admitted to the hospital I was exhausted, fearful, suspicious, at times paranoid, and emotionally quite labile. Initially I was able to set aside those problems to pursue my most important goal: discharge. Actually right then, with that strong motivation, I was much clearer than the several days preceding my entrance into the hospital. I had pulled myself together for one last-stand battle to prove my sanity. But without help I could not sustain my effort at rationality. Society's soldiers, the guardians and keepers of chronic normalcy, would not allow me to move in and out of reality at my own discretion. The hospital workers spoke with one voice: "You will return the way we tell you or not at all."

The first weekend passed without my getting the opportunity to see a psychiatrist. All my yelling about being a voluntary patient and demanding to sign myself out was to no avail. Monday came and went without me. I got word that a psychiatrist was on the ward, but I was not given the chance to speak with him. He conferred with the nursing staff at their office, and

they went over patient files. He saw no patients that day; he was too busy spending his half-hours on each ward making notes in patients' charts and approving medication orders. I requested an interview. I pleaded for an interview. I demanded an interview. I banged on the office door. The results: seclusion and more Thorazine. Monday drifted away.

I think it was a couple of days later that I again heard that the doctor was on the ward. There was also talk that he was seeing some patients. It was just medication review and questions for a few selected patients. When I saw that the door to his office was open, I stood there trying to make contact. I caught his attention and asked him if he would talk with me. The aides began to usher me away, but he stopped them and asked who I was. Then he flashed a magnanimous smile and said, "You'll have the opportunity to talk with me the next time I'm on the ward." I asked when that would be. "We'll see . . . maybe Friday." My stomach sank—more days and a maybe.

Slipping more and sliding down as if the floor was greased, I had no place to secure a grip. My ability to stay focused on my goal, discharge, had allowed me to mobilize some degree of clarity, but it was no longer working. Confusion grew daily, fed by my anger and exacerbated by the drugs. I was alone, isolated, and unable to communicate or understand what was going on around me. Staff treated me as if I was crazy and saw only the behavior that reinforced their belief system. I felt as if I was in a dream, another kind of reality or dimension, separated by some invisible barrier. I was in a place where only certain messages or interactions could pass through the barrier. None of the things I wanted to communicate could penetrate the barrier; only the mistakes, negatives, and nonaffirmations of me could get through.

The hospital experience fosters regression. You are there because you are perceived to be unable to see to your needs or because you are believed to be a threat to others. You cannot be trusted and must be monitored. How can such a negatively defined role make a person feel more adequate? I vowed not to regress. "I am not a child," I repeated to myself and anyone within earshot.

Only four months after I was admitted, lack of choice forced me to accept the only role that was available to me in this hospital drama: submissive patient. I said the right things and did nothing to draw attention to myself. Lacking the energy to do otherwise, my responses were "appropriate." I became self-protective, selfish, and interested only in meeting my own needs. Earlier my energy had centered on discharge, but now even those requests lacked force. I spoke little, responding only if required. When visitors came, I half listened, my requests focused on material items—cigarettes, money, food. My soul, my Élan vital, had taken a sabbatical. An empty shell was left to deal with physical needs. In brief moments of clarity, I panicked at the thought of never having my vitality return.

Thin skin has been a mixed blessing for me. What helps me now as a therapist, I hated as a child. When practicing psychotherapy, I am respected for my ability to understand and empathize with feelings that go beyond



what is consciously expressed. The child receives no reward for feeling the denied pain of others. As a therapist, I call up experiences from my past to connect with the experience of an *other.* Needs for acceptance, belonging, and recognition, so prominent during my childhood, are easy for me to recall.

I worked hard to get to where I am, and I give credit to myself and to the people who helped and supported me. But I have to believe that some other component was operating—luck or a spiritual, mystical quality. For years I thought I was alone and had defied the odds, slipping through the cracks and escaping the diagnosis that was promised to follow me all my life. I believed that I was an anomaly in my ability to leave my assigned mental patient role, to blend in, get married, be a father, and have a successful career as a psychologist. No more "symptoms," no more medication, no more therapy. Why were there not more people out there like me? To my delight I discovered my peers and found community. There are many of us who have walked through the fire. We who have survived are available to help our brothers and sisters develop their own unique maps for navigating not only their confusing and frightening internal struggles, but the even more damaging spirit-breaking treatments forced on them in unenlightened treatment facilities.

## An Intensive Bottom-to-Top Training of Psychiatric Hospital Staff by Former Patients

At the start of the twenty-first century, we have witnessed first the steep growth and then the rapid decline of the number of publicly run state psychiatric hospitals. Yet despite the smaller number of people being confined to inpatient psychiatric facilities today, these institutions continue to be used as a last-resort safety net for the mental health system. Regardless of one's beliefs concerning the benefits or necessity of treating people in a psychiatric hospital, it is essential to determine what is harmful and what is helpful to people during their stays as inpatients and to implement practices that reflect this knowledge.

How to train all hospital staff to provide the best possible services to patients was the charge given to the designers of the New York State Office of Mental Health's (NYSOMH) *Core Curriculum: Direct Staff Training.* To accomplish this task, the following guidelines were established:

The core curriculum training would be a mandatory, three-day training event.

All ward staff would be trained together as a group and would include all workers who had any direct contact with inpatients: therapy aides, nurses, physicians, psychologists, social workers, housekeepers, administrative staff, and security.

Consumers/survivors/ex-patients (c/s/x) would participate fully in the development and implementation of the core curriculum.

In 1997 the NYSOMH initiated a two-year core curriculum training program for its nineteen state-operated psychiatric centers. The three-day training was divided into six modules:

Module A: Team Training, NYSOMH, and the Changing Nature of Mental Health Services
Module B: Working in a Changing Environment
Module C: Recovery and Mental Health
Module D: Selected Clinical Issues in Mental Health
Module E: Cultural Competence
Module F: Safe and Therapeutic Environment

This chapter cites the results gathered as of January 1, 1999, from exit questionnaires completed by 3,732 staff members and a sample of staff and inpatients from three facilities who completed both pre- and posttraining: a questionnaire, the Ward Atmosphere Scale, and the Work Environment Scale.[1]

As a c/s/x and a psychologist I participated in the planning, development, and implementation of all the modules. However, because of the innovative qualities of the recovery module, most significantly its reliance on c/s/x to develop and provide the training to staff, that module will be the central focus here.

## Development of the Recovery Module

From the beginning, the NYSOMH recognized that expertise developed through the lived experience of persons who had been diagnosed and treated for major mental illness would be a valuable asset for staff training. NYSOMH commissioner James Stone solidified his office's commitment in his introduction to the first statewide train-the-trainer meeting by stating, "During your training you will have an opportunity to hear from individuals who use or have used the services we provide. In participating in this training as your trainers, service recipients are demonstrating the hope gained from new information showing many individuals with severe psychiatric disabilities are able to regain their lives and become productive members of our communities (Bassman, 1997)."

To develop the recovery module, c/s/x leaders across the state were surveyed and asked what they considered the most important elements in recovery. A review of published writings by c/s/x (Campbell and Schraiber, 1989; Chamberlin, 1997; Grobe, 1995; Hirsh and others, 1974; Susko, 1991) demonstrated a consistent emphasis on the same key themes identified by our survey. The following key themes were identified as instrumental to recovery and transformation:

There must be real choices. When people are forced to participate in programs and services not of their choosing, motivation suffers and passivity and learned helplessness develop.



Hope must be nurtured and cultivated.
People must be able to speak for themselves.
People want to be seen as a many-faceted whole person with a variety of strengths and weaknesses. They are individuals, not categories, labels or diagnoses.
Self-help, empowerment, and mutual support are important.
Services need to be provided in a respectful collaboration.
Communication must be two way.
Anger can be a positive force.

The next step was the development of a flexible guide for c/s/x trainers that would allow them to use their unique skills and experience, while also enabling them to cover the key concepts and themes. We had the themes and concepts that we wanted to convey, but wondered how we could get mental hospital staff to listen and learn from people whom they had seen only at their worst, when they were deemed to be so out of control that they needed to be in the strictly structured setting of a mental hospital. In addition, we wanted staff to get more than a few cold intellectual facts; we wanted them to be moved by what they saw and heard.

The solution became obvious: have people tell their stories of recovery. Based on their personal experience, they would talk about what was helpful and what was harmful. C/S/X trainers were encouraged to cover all of the key concepts and to illustrate them with anecdotes from their lives. Those who were unable to draw an example from their own life were encouraged to do a dramatic reading of another c/s/x's story that connected to their experience. People were encouraged to use art, music, games, or any other creative medium for making a point. One trainer decided to begin the training covered by a white sheet to demonstrate that you cannot get to know a person until you really see that person fully.

Another part of the recovery presentations focused on wants and needs. The audience was asked to call out the things they want and need to live a good life. After the exercise, a discussion ensued of the similarities of patients' wants and needs to those of staff (among them were personal goals, choice, social integration, relationships, constitutional and human rights, dignity and respect, health, a decent environment, security, personal satisfaction, and hope).

The three-hour presentation concluded with a discussion of people's beliefs about mental illness, different theories of mental illness, and some discussion of why people find psychiatric drugs problematic.

## Recruiting and Training C/S/X Presenters for the Recovery Module

From the start we wanted to do all we could to make it possible for c/s/x to present in a safe, supportive environment where their participation would

be growth enhancing and that its value would be reflected in adequate financial remuneration for their time and unique expertise. C/S/X would never be asked to present alone and were advised to present in groups of three for mutual support. Facilities staff were asked to have a room available, preferably with beverages and light refreshments, for presenters to relax and debrief with each other after presentations. A staff member at each facility was assigned to be the contact and support person should any unusual needs arise. Periodically presenters from different facilities met together to share their experiences of presenting, exchange helpful techniques of presenting, and network and support each other. Such all-day gatherings were centered around a discussion of questions like the following:

- What were some of the highlights of presenting the recovery module?
- How did staff respond to the training?
- Did you feel that the core curriculum staff were supportive of your efforts?
- What kind of supports did you use after presenting the recovery module?
- How did the training affect your own growth and development?
- What were some of the negative aspects for you during the recovery training? What would you have liked to have seen happen differently?
- What advice or suggestions would you give future c/s/x trainers?

## Reactions of C/S/X Trainers to their Experiences as Presenters

Just about all of the c/s/x trainers were positive about their experiences of presenting their stories to staff. For many, this was an opportunity to find value and give meaning to their intense and often dehumanizing struggles. Following are examples of feedback from the c/s/x trainers that were shared during our group retreat:

- "Made people think. They seemed to look at things in a different light."
- "Doctors and social workers came up to presenters and cried."
- "Great; seeing oneself as equal to professionals."
- "Feel I have a lot to offer."
- "Brought back a lot of feelings I hadn't thought about."
- "Felt the depth of pain for me and my copresenters."
- "Self-esteem and confidence improved."
- "Speaking about personal experiences makes them less painful."
- "Breaking stigma by looking different than people think you will."
- "Learning that there is something more than what we have been taught."

## Evaluation of the Impact of the Recovery Module

Overall findings indicated that the training was well received and viewed positively by approximately 80 percent of the staff. Many of the staff, including the veterans, commented that this was the best training they had ever attended.



The exit questionnaires rated the recovery module highest of the six modules in having the most effect on change. More than half of the staff thought that the recovery training would result in the following improvements:

- Greater staff acceptance of patients' speaking up for their rights.
- A substantial improvement in the respect given to patient privacy.
- See people as individuals rather than just as a diagnosis or a mental patient.
- A substantial effect on ward environment and procedures to enhance recovery.
- Improvement in patients' being able to express their feelings without getting into trouble.
- Patients are being allowed to tell their whole story before staff makes up their mind.

The quarterly reports completed by facility directors confirmed that the recovery module contained the most powerful message. The reports indicated that staff were making positive changes in their relationships to patients, and in committee meetings they were paying more attention to issues of patient respect and privacy. Staff were more willing to accept patient input as relevant and see the value of patients' expressing their concerns.

Results of the more intensive evaluations conducted at three selected facilities confirmed the positive impact of the recovery module. Pre- and posttraining comparisons that staff made indicated statistically significant improvement in the following areas:

- A significant increase in staff's belief that what recipients say should make a difference in treatment
- A significant increase in staff's willingness to attempt to make improvements on the ward in order to enhance recovery possibilities
- A significant increase in staff's belief that people can recover, get out of the hospital, and never come back

Patients residing on the hospital wards completed questionnaires before staff participated in the training and responded again to those questions twelve to fifteen weeks after staff training was completed. Three questions showed statistically significant improvement from the patients' perspectives:

- Staff would allow them freer expression without their getting into trouble.
- Staff saw patients more as individuals and not just as a mental health patient or diagnosis.

- More patients wanted to increase the frequency of their interaction with staff.

## Puncturing Stereotypes: Seeing Real People

How well can we understand someone else's internal experience? The old adage said that you do not have to be a woman who has given birth to be qualified to deliver a baby. But can someone who has not gone through the labor of birthing a baby truly comprehend the magnitude of this process? When a woman talks with another woman about their labor and birthing experiences, there is an immediate understanding and bonding. Can there be empathy without having had a commonality of experience? Of course, empathic understanding is not an all-or-nothing, you-have-it-or-you-do-not proposition. Yet it is difficult to deny that all other things being equal, those who have been through an experience will have a better understanding of a similar experience than those who have not.

The absence of genuine empathy in the treatment of people diagnosed with serious mental illness arises from a long history of fear, misunderstanding, and exclusion. Treatments have often been illogical, nonsensical, and downright cruel. Lobotomies, cold packs, insulin comas, physical beatings, and other forms of torture have been foisted on people as if they were objects that could not think, feel, or express their own wants and needs. Such magical thinking about what constitutes effective treatment was considered science, while the attribution of magical thinking to a potential patient is a key element in the diagnosis of schizophrenia. Often unproven assumptions about mental illness are regarded as facts and strung together to make theories that treatment teams use to ignore or make short shrift of what people say is going on within themselves

How do those who have never been a patient in a mental hospital develop the understanding that is helpful in treating people who have experienced the kinds of thinking, feelings, and behavior that would get them committed to a mental hospital? Through personal experience, c/s/x know the importance of having staff listen and try to understand and accept the validity of their experiences. After a person is hospitalized, it is easy and natural for him or her to spiral downward. The unfamiliar surroundings, the uncertainty as to what will happen next, the probing questions, and the cold and impersonal interactions with staff intensify fear and panic. Many c/s/x are brought to the hospital at night and processed through procedures with no explanation or hint of warmth or human contact.

If someone had sat and talked with us, told us what to expect the next day, would there have been more cooperation? Could I have avoided the forced drugging and disorientation? Would I have been able to avoid seclusion and restraint and the hostile adversarial reactions I felt toward staff?

Staff of inpatient psychiatric hospitals rarely have the opportunity to see people who have recovered and have gone on with their lives. They see



people at their worst, and in artificial micromanaged settings. They do not get the chance to benefit from learning how much value people place on the small acts of kindness and respect that are shown to them. Nor do they learn of the negative impact of thoughtless words and deeds.

Repeatedly staff members approached c/s/x after their presentations to thank them for letting them know that patients really appreciated it when they were related to in a warm and personal way. Particularly effective was the presentation of one c/s/x who told about lying immobile on her bed in the ward staring at the ceiling. She was unable to look at anyone or respond in any way. Yet she fondly remembers one nurse who daily came into the room and ask her if she wanted a blanket or wanted the light turned on or off. And although she did not respond, she has always remembered that nurse's kindness and cites it as an uplifting human connection that helped her recover. Staff were extremely interested and surprised to find out that even people who looked completely unresponsive remained aware, and no matter how disoriented they seemed, they did not lose all of their capabilities.

Mental health therapy aides were especially pleased to learn that so many people were grateful for the very small acts of kindness extended to them. Many c/s/x cited those acts of caring, interest, and respectful listening as the initial building block of their recovery. The feeling that someone believed in them and thought that they could do better cultivated hope.

Another powerful anecdote was told by a c/s/x who was working in a psychiatric hospital as a peer advocate after her own discharge. Her story demonstrated the negative impact of invalidating a person's feelings. She was listening to a woman angrily complain to her about the failure of her advocacy efforts to get what was requested. Since these advocacy efforts were ineffective, she knew that the patient's complaints were justified, and she was willing to listen to her express her disappointment. At that time, a psychiatrist was on the ward, and knowing both the advocate and the patient, he decided to intervene. He faced the advocate and with his back to the patient said condescendingly, "You know some people need to learn that you never get what you want if you get angry at people who are trying to help you." And then he walked away. Immediately this patient began hallucinating and responding to her inner voices, whereas before, although she was angry, she had rationally expressed her displeasure. Now, after being treated as if she was not there by a powerful doctor who had control of her future, she was forced to suppress her feelings and withdraw into her mental patient role. Communication had ended between her and her advocate.

## Conclusion

Those of us who have been through cataclysmic, life-altering experiences are able to provide empathic understanding and serve as models to inspire hope. The capacity to offer meaningful help is not limited to the

consumer/survivor/ex-patient. The examined life is entered into in many ways. Any form of illness or violation of what we have come to expect our minds and bodies to be has the potential to alter the way we construe our experiences and attempt to integrate them into meaningful narratives.

As observers, we are always outside and therefore can only see, measure, and evaluate a particular person through the lens of the most recent snapshot photo that we are encountering now. You are not able to know the unique personal history that an individual construes for himself or herself or predict that person's future. However, your influence on a person's vision of his past and future can open possibilities in the present.

## Note

1. See *Core Curriculum Final Evaluation Report*, Bruce Way & Barbara Stone, NYSOMH Bureau of Performance Measurement, 44 Holland Ave., Albany, NY 12229, December 1, 1999.

## References


Bassman, R. "The Mental Health System: Experiences from Both Sides of the Locked Doors." *Professional Psychology: Research and Practice*, 1997, *28*(3), 238–242.

Campbell, J., and Schraiber, R. *The Well-Being Project: Mental Health Clients Speak for Themselves*. Sacramento: California Department of Mental Health, 1989.

Chamberlin, J. "Confessions of a Non-Compliant Patient." *National Empowerment Center Newsletter*, Summer/Fall 1997, 9, 13.

Grobe, J. (ed.). *Beyond Bedlam: Contemporary Women Psychiatric Survivors Speak Out*. Chicago: Third Side Press, 1995.

Hirsh, S., and others (eds.). *Madness Network News Reader*. San Francisco: Glide Publications, 1974.

Susko, M. (ed.). *Cry of the Invisible: Writings from the Homeless and Survivors of Psychiatric Hospitals*. Baltimore, Md.: Conservatory Press, 1991.

Way, B., and Stone, B. (1999). *Core Curriculum Final Evaluation Report*. Albany, N.Y.: New York State Office of Mental Health, 1999.



*RONALD BASSMAN is coordinator of self-help and empowerment projects for the New York State Office of Mental Health in Albany, New York, and is president of the National Association for Rights Protection and Advocacy.*