

## **WHOSE REALITY IS IT ANYWAY? CONSUMERS/SURVIVORS/EX-PATIENTS CAN SPEAK FOR THEMSELVES**



RONALD BASSMAN is a licensed psychologist and a psychiatric survivor who works for the New York Office of Mental Health Bureau of Recipient Affairs as the coordinator of self-help and empowerment projects. He is a member of the APA task force on Serious Mental Illness, faculty member of the Center for the Study of Issues in Public Mental Health, and president of the National Association for Rights Protection and Advocacy.

### **Summary**

The author uses personal narrative to vividly describe his entry into the mental health system with a diagnosis of schizophrenia. Based on his experience, he describes and criticizes a mental health system that forces people to endure oppressive treatments in the name of help. Interweaving first-hand experience as a patient with his later training as a psychologist, he challenges the biomedical brain disease model and advocates for self-help, empowerment, and peer-run alternatives. The history of the almost 30-year-old movement of activist consumers/survivors/ex-patients is described and introduced as offering promising possibilities for creating innovative options for services. Questions are raised as to why mental health professionals have absented themselves from speaking out against the obvious abuses, rights violations, discrimination, and social injustices faced by people who are diagnosed and treated for madness. An invitation is extended for professionals to modify and reconsider the usefulness of the expert role and instead to form new partnerships of collaboration and advocacy.

They rode in silence to Fair Oaks Hospital, parents aching for the recovery of a broken child. One powerful certainty bridged their differences—their son would never be abandoned. Without

knowing who was enemy or ally, a deadly threat propelled them on their mission.

Determined, unyielding tenacity was their strength. She was anxious, frightened, but above all, angry and intolerant of her own ignorance. He was unexpressive, appreciative of the control driving afforded. The car was his domain; the children hers. The unity mobilized by crisis muted years of quarreling. She would soon be asked to let down the walls of privacy that insulated and protected her family. The traditions and history of many generations made it impossible to trust the dreaded authorities. But the new danger required the summoning of strength from the deepest of human wells . . . a mother's resolve. Father would remain impassive; a lifetime of inaction would not be transcended. With an odd mixture of resignation and hope, they looked to the doctor for answers.

"What's wrong with him?" my parents pleaded. "He's always been a good boy. When will he get better? What should we do? How did this happen? Whose fault is it?"

The questions were for the doctor, but later would be asked of God. A broken foot was for the doctor, but a broken boy, who is to treat such a sickness? Their generation had witnessed the medical miracles of modern science. They regarded the doctor with reverence. Indeed, the doctor was royalty.

The doctor asked endless probing questions. She wished she could explain in Yiddish, but the doctor was a gentile; he would not understand her family regardless of the language. She forced herself to try—his guidance was desperately needed. The immigrant's dilemma, the inability to communicate in English, was for her always a source of pain and humiliation. She never forgave herself for her lack of education. Her husband's understanding of English could not compensate for his lack of knowledge about his children's lives. All he could do was help his wife understand the doctor's questions. As always, she would make the decisions. His typical response to crisis was activated; defenses went up as he distanced himself from the outside world.

"He is a very sick boy," the doctor declared. "You must authorize us to treat him in the way we know best; otherwise he could be in a mental hospital for the rest of his life. You have to follow our instructions and leave him to us or we won't be able to help him."

Alone and isolated, I in the locked seclusion room, mom and dad trying to deal with the mystifying loss of a once promising son, we could have been worlds apart, but we were just in adjoining build-

ings facing our shared helplessness from different angles. Locked in that room, my family and I lost my 23rd birthday.

I cried out, “Help me, let me out of here. You . . . over here, come here. I’m in here . . . can’t you see me. You . . . stop, don’t go. Just talk to me, tell me where I am. Come back. Open the door. Someone do something. I don’t belong here, I didn’t do anything. Somebody made a mistake. Is anybody out there? Please.”

*I have to figure out why I’m locked in this room. What am I being punished for? I don’t feel good. I don’t feel right, I can’t think straight. Why won’t anyone talk to me? God . . . I’m naked . . . my clothes, where are my clothes? I’ve got to do something. Are they watching me? Maybe it’s a test. I can’t stand it in here. I need space to walk, to breathe. I’m suffocating in here . . . I’m going to die if I don’t get out of this room. I can’t yell anymore, my throat’s too dry and sore. I can’t just wait. They want me to yell. It’s a test. They’re watching me to see what I’ll do. They’re trying to make me change. They won’t change me. I won’t give in.*

“Open this door. I demand my rights. You can’t do this to me. I’ll tear this room apart. . . . I’ll get you. You can’t do this to me. Is there anyone out there? You better listen. . . . I’ll be good.” *Please hear me.*

My belief in fairness was severely damaged during my first few months of confinement. Foolishly, I continued to demand rights that I believed I had, only to discover that I would pay dearly for my ignorance at playing the hospital game. My angry demand, “You can’t do this to me,” was met with increases of my medication and extended stays in the seclusion room. My anger, my resistance, my noncompliance were serious concerns to the staff. I was not responding quickly enough to my psychiatric cocktail mixes made up of large doses of Thorazine, Stelazine, and intimidation.

My introduction to my new treatment was announced by my mother. “The hospital gave you a complete physical examination . . . you’re in perfect health.” A too brief elated thought, *They’re going to let me go home.* The hope flew away quickly when next my mother said, “The doctors are going to give you insulin treatments and that will make you better so you can come home.” A series of 40 insulin coma treatments was supposed to kill the dreaded disease even if it also destroyed my memory and whatever else (spirit) dared to get in its path and fueled my belief that I was not sick.

At some point during that series of coma treatments I began answering the psychiatrist’s questions in a more acceptable manner. My senses were dulled and my memory began to fail. I was

becoming an automaton. They were impressed with my “progress.” I became a good hospital patient and acquired privileges. Docile and trustworthy, I had an unlocked room and was permitted visitors.

My friends Elliott, Jack, and Julian were allowed to visit me for the first time. The three of them stood across from me in my room, and we tried to talk. They were as nervous and ill at ease as I. I couldn’t think of anything to say. What could I say? We had no common experience to share. My reflexes and thinking were slowed down. I was embarrassed to be seen in my forlorn, defeated condition. My thoughts and feelings centered on pain, loss, and humiliation. They didn’t take their coats off. I was probably relieved that their visit was short, but I did notice a small voice welling up inside of me. . . . *Please help me get out of here . . . take me with you . . . do something . . . don’t you see they’re killing me.*

I could not say it out loud. The game had become a part of me. Appearance was everything. I did not want them to know. I will not look desperate or crazy. I won’t take the risk of being put back into seclusion or having the drugs increased or having my series of shock treatments extended. I will continue to be bland, apathetic, a threat to no one.

My friends left. Quickly, the sadness and hurt swept over me filling the emptiness inside and momentarily overpowering the deadening effects of the drugs. I could not block out the hurt; the tears came, but I made sure the staff did not see. Crying in public is inappropriate.

Months later I shuffled into the office, physically demonstrating the hospital’s successful transformation of anger, fear, and defiance into apathetic compliance. Defeated and dejected, I was too weak to resist the psychiatrist’s argument to my parents at my discharge meeting. His job was to convince us that I was an incurable “schizophrenic.” I was 23 years old when that prosecuting doctor, serving also as judge and jury, sentenced me to a life of, at best, controlled madness. With the smug certainty of a bookie, the doctor told my family that my chances of making it without being hospitalized again were very slim. His medical orders were stated with an absolute authority that discouraged any challenge. Barely acknowledging my presence, he nodded toward me and declared, “Your son has to take medication for the rest of his life and must return to the hospital regularly for outpatient treatment. He

should not see any of his old friends. If his behavior changes or he gets upset, let me know.”

Innocence vanquished, the life I once knew was gone forever.

#### A PLEA FOR HUMILITY: LOOKING AT THE IMMATERIAL DYNAMIC OF HEALTH

In ancient Persia the first healers were priests. Their practice was based on the principle that the devil had created 99,999 diseases that should be treated by a combination of magic and hygiene. They favored the use of spells on the grounds that although they might not cure the illness, they would not kill the patient—which was more than could be said for drugs and physical treatments (Durant, 1954). In the treatment of “mental illness,” the credo *do no harm* has too easily been ignored.

Attempts to unlock the mysteries of the disordered mind and the belief in its centrality to the understanding of human experience have attracted, stimulated, and frustrated “great thinkers” throughout our recorded history. Today, modern medicine through its biochemical model of illness has ascended to the position of pre-eminent authority in the understanding, care, and treatment of “mental illness.” With an absolute certainty that parallels papal infallibility, organized medicine has promoted unproven dogma as scientific fact. Diagnosed into being objects, imprisoned with or without walls, cut off from meaningful dialogue, the psychiatric consumer/survivor/ex-patient (*c/s/x*) must adapt to an other-constructed, authority-blessed reality.

To attempt to understand what another feels, to be there with another is difficult even when one can rely on reference points drawn from similar experiences. But what of the attempts to be empathic with those who confuse or frighten us, where disorder and spontaneity give the appearance of random unpredictability? It is easier to attend to and be open to the experience of an *other* when the listener is told about the pain, rather than being right there with him while the psychic turbulence is being experienced.

What is crazy? Does it have an edge, an invisible boundary one steps over, or is it like falling off a mountain cliff? Falling onto the craggy ledges of the cliff may provide temporary porches of respite. Some may tumble into that black hole propelled by the pushes of seen and unseen forces from within and without. Those unlucky

enough to fall to the bottom suffer a hell that eludes description to all but the gifted artist. Once trapped, the slippery shiny sides of that imaginary yet real hole rebuff and taunt one's attempts at escape. Family, friends, and doctors drop ropes and ladders to offer their help, but absolute obedience is too steep a price for that assistance. Passion, drive, self-respect, and long-held dreams should not be regarded as excess baggage to be discarded before the ascent. And for some, the bottom of the hole is on paradoxically higher ground than the plane from which their stumble or leap originated. It is in the construction and articulation of the frame that the experience is positively or negatively defined.

Alone and surrounded by others, painful silence punctuated by unbearable noise, nothing is predictable. The confused darkness of dread, terror, and loneliness make night and day indistinguishable. Reality's laws have exploded. The self has disintegrated. All is possible. Nothing is doable. Yet, for those who are able to look into and see beyond their distorted reflections in the glistening, magical rock-solid walls of their mad confinement, hope can illuminate a vision of possibility for a better tomorrow (Bassman, 1999).

Drawing on my personal experience of madness and confirmed in conversations with many psychiatrically labeled people encountered in my work of the past 5 years, I have learned that some such people are in distress whereas others are not. Before people are officially labeled and treated for "schizophrenia" or "bipolar disorder," they are not necessarily suffering. People can and do enjoy an altered state in which mysteries, freedom, and transformative possibilities beckon. Gammill (1986) saw beyond some of the inaccurate theorizing and depictions of people "suffering" from "schizophrenia" as weak-willed and unable to take responsibility, and observed instead that there was a great deal of self-direction operating. However, postulating that the "preschizophrenic" made choices is only partially true. Such fixed-state theories that postulate a "preschizophrenic" condition that later manifests itself in "schizophrenia" string together too many unproven assumptions, not the least of which is calling a way of being and behaving sick and naming it "schizophrenia." Beyond the *choice* of sickness or wellness, the individual makes many choices every day; some are automatic and habitual, whereas others contain a fully conscious awareness not often accessible to the chronically normal.

Carl Jung (1958), R. D. Laing (1968), and John Weir Perry (1974) described feats of courage and heroism associated with one's

descent into psychosis, and the struggles and necessary battles to survive and overcome. Yale University's John Strauss (1992), internationally renowned psychiatrist and expert on "schizophrenia," told how his perspective has changed over the years. Once an investigator engaged in the identification of psychopathology, he now attempts to see the whole person. Strauss spoke of the great courage he has seen displayed by people living under extreme stress in near impossible circumstances. Expressing embarrassment at what he called psychiatry's rubber gloves approach to people, Strauss compared the methods of the biographer, who studies and researches a subject for years, with the absolute diagnostic and predictive statements required of psychiatrists based only on a 20-minute mental status examination. The disrespect for one's life story demonstrated in diagnostic interviews too easily breeds expedient shortcuts that masquerade as help.

I am not suggesting that the travails associated with madness can be simply explained as the adventures of heroes engaged in mythical quests to find their identity. But I do believe that each person's journey into and out of their altered states is unique and charged with heroic possibilities. Our understanding of these quintessential human conditions is severely limited by a Western societal penchant for accepting too facile generalizations and labels that do more to obscure than describe.

*Magical thinking*, the attributing of causation to unrelated phenomenon with disregard for the evidence, does not distinguish psychopathology from eccentricity or gifted insight. Weeks and James (1996) wrote, "Objective cannot always be distinguished from subjective intuitions . . . . Thus under certain circumstances a person's grasp of reality may be made to feel false . . . . It has been said, uncharitably, that while neurotics construct castles in the air, psychotics live in them. This formula is not only unkind: it is wrong. It overlooks the essential role played by fantasy in human affairs" (p. 36).

Feeling or being different, whether one sees oneself as touched with a gift or suffering a curse, sets one moving on an uncharted course. Too easily, stress, life circumstances, temperament, and motivations can lead one to misconstrue meaning and misapply knowledge. With the combination of naivete and desperation, and lacking supportive and empathic anchors, one might easily aggrandize this gift/curse and twist it into an overgeneralizing, all-powerful escape that is needed to replace an undesired self and an

accumulation of unsatisfactory life choices. In her article on the role of will in “schizophrenia,” Hoover (1971) only glimpsed the extraordinary strength of will available when one’s life is disengaged from habitual constraints. To those outside the process, what is primarily witnessed is a powerful oppositional resistance.

#### IN QUEST OF BECOMING: CAN IT BE OTHER THAN A RISKY PERSONAL JOURNEY?

How do you react to being trapped? Do you permit the frustration and hopelessness to expand and permeate all parts of your being, to take over your whole life? Only 22, I would not or could not accept the inevitable conclusions that life events were pushing on me. I knew I had to change something. Earlier, searching for the keys to transformation, I had studied psychology to discover the secrets of change. At some juncture during that summer preceding my first bout with generic “madness,” I glimpsed my doorway—*not caring* would set me free. In Thomas Merton’s book, *The Seven Storey Mountain* (1948), he wrote of his admiration for the peaceful freedom of the Trappist monks. Rather than excelling from standing out, the most successful monk is the one who best blends in and is never noticed. Merton wrote that the Trappist monk is free from the constraints of living in the projected imagination of others and thus having to submit always to their perceived judgments. That summer in 1966, I was dabbling in that principle of freedom, but I lacked the faith, knowledge, discipline, and commitment of the Trappists. I also lacked a community of support.

Once diagnosed and treated for a “major mental illness,” your life’s course is deeply affected by how you integrate that experience into your identity. The number of obstacles you need to overcome after you have been hospitalized and permanently labeled discourages the “recovered” from being open about their experiences and becoming role models who could inspire hope in others. Engaged in an all-consuming struggle to stay out of the hospital and survive, I distanced myself from my psychiatric history by becoming a member of the “hidden recovered.” What I experienced before and during my hospitalization demanded a new way of understanding in order for me to reconstruct my self in a form other than mental patient.

My desperate search for answers in psychology books was a fruitless endeavor. In 1971, Barnes and Noble did not provide coffee-drinking comfortable reading rooms, nor did they have shelves overflowing with self-help and New Age books to explain the heretofore unfathomable with a plethora of alternative reality explanations for those who chose to be believers. Then, the few romantic alternatives I could find to the despairing medical predictions of a disease that would run a lifelong deteriorating course were the works of R. D. Laing, Harry Stack Sullivan, and William Reich, but they were at that time too difficult for me to comprehend and did not connect with my experience. Books like *I Never Promised You a Rose Garden* (Greenberg, 1964) made me long for a therapist with the caring warmth and incisive brilliance attributed to Frieda Fromm-Reichmann, but I knew that my answers would have to be found elsewhere. Then, I was too damaged to be verbal enough, or open enough, or interesting enough (having the requisite ego strength) to be a suitable candidate for such insight-driven therapy. At that same time, my search for answers from professional experts sidetracked me from participating in the beginning of a movement in New York and California that was intent on transforming the roles of mental patients by liberating them from “mentalism” (Chamberlin, 1990). The birthing and development of the consumer/survivor movement did not come to my attention until 20 more years had passed. However, I persevered in my quest to find meaning through education; I eventually returned to school and succeeded in fulfilling my long-held dream of becoming a licensed psychologist.

#### THE C/S/X MOVEMENT

Today, having earned the “credentials” and respect of my professional colleagues and my *c/s/x* peers, I have the opportunity to speak out and advocate for those who have lost their voices. Too many of us have been made to accept the too strongly promoted, most current beliefs about “mental illness” with its pronouncements of lifetime disability and its associated demand to downsize one’s dreams and aspirations. Others define realistic expectations for us as low stress jobs in the 4F fields: Filth, Filing, Food, and Fetching. Too many have learned to survive by becoming helplessly and hopelessly compliant. I join with my *c/s/x* peers in an expand-

ing social movement, a rights movement that has never before existed. Always in the past, mental health reform has been driven by the passion and leadership of a few special individuals, and when their time has passed, the reform and progress has ended. The hope now is that through the discovery of each other, the bonding and alliances, the once isolated closeted recovering, the recovered and transformed will find validation with others who have shared their experience of confusion, pain, and oppression. Having rediscovered the personal truths of their experience, they will no longer allow themselves to be defined by labels that deny their dignity and value as whole people with diverse strengths and weaknesses.

I had no exposure to the concept of a *c/s/x* movement in 1974 when I received my Ph.D. When I think about the development of that movement, it seems almost as if it or I traveled in parallel universes. Here I was feeling alone, different and continuously studying, searching and wondering if there was anyone out there who could understand or connect with my experience. At that very same time, some people who were lumped together as “mental patients” began rejecting the inevitability of passively accepting their powerless place in the world. After first co-opting their own pejorative labels (Insane Liberation Front, National Alliance of Psychiatric Survivors, Mental Patients Liberation Alliance) to draw attention to their new activism, these *c/s/x* activists used those same names to self-identify their relationship to the mental health system. The early names, “mental patient” and “client,” were closely tied to the mental health system. The people who identified with names like “consumer” and “ex-patient” tended to be dissatisfied with existing mental health services but believed in the gradual reform of the system. They wanted more and better services that valued their participation. “Ex-inmate” and “psychiatric survivor” became the names favored by those who rejected the medical model of mental illness and its legal mandate to provide forced treatments. Regardless of where these new activists stood on the name continuum, they shared beliefs in the need to have their rights restored and protected (Bassman, 1997a). To be empowered and to advocate for user-controlled alternatives were common goals. For the psychiatric survivor as well as the consumer, the need for quality alternatives to forced treatment was a priority. No issue was more powerfully charged than *forced treatment*. The value of self-help begins with the free and noncoercive

choice exercised by participants. The denial of freedom in all its involuntary treatment forms cannot be overestimated in its implicit and explicit consequences (see Thomas Szasz's many critiques of psychiatry's reliance on force beginning in 1961 with *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*).

When you are no longer permitted to assume responsibility for your own health and actions, you are profoundly affected. Even those consumers who are grateful for what they construe as a life-saving intervention face the prodigious task of disengaging from their journey down the narrow regimented circular path of passive dependency. Others, after having been forced into a hospital, avoid mental health treatment, preferring a homeless life on the streets.

#### FORCED TREATMENT: AN OXYMORON

In a seminal research study supported by the California Department of Mental Health and conducted by c/s/x researchers, 55% of the people who had been involuntarily hospitalized reported that they would avoid treatment out of fear of involuntary commitment (Campbell & Schraiber, 1989). The authors reported that 93% of 234 clients felt that their human rights were violated. Among the freedoms taken away were the right to refuse treatment, the right to make choices, the right to have basic needs met outside of institutions, the freedom of self-determination, the freedom from incarceration with no crime committed, the right to refuse forced drugging and restraints, communication rights, the right to due process, and the right to be fully informed about the treatment and its side effects.

Attorney Susan Stefan (1994) questioned the validity of current conceptions of the term *involuntary*. Are you really voluntary when that status is dependent on your abdication of the right to refuse? And when you attempt to exercise your right to request discharge only to find that your status is changed from voluntary to involuntary, can you any longer ignore the truth about your confinement? Stefan cut through the "lie of voluntariness" and provided a more accurate look at the absence of choice in a mental hospital:

Imagine yourself in an institution. The people in power have complete authority to discharge you or keep you, to take away your so-

called privileges—outdoor exercise, visitation, whatever; to put you in seclusion or even restraints if they interpret that your conduct requires it. Think of the courage it takes to say no, to object, to resist, in that situation. Now realize that under the law, everything that any institutionalized person does without objection is considered done voluntarily by the law. (p. 12)

When consumers/survivors talk about what helped them, they generally credit some person who believed in them, who respected them; someone who made a genuine person-to-person connection with them. Often cited as a barrier to recovery is the inability to trust that accompanies the loss of one's freedom of choice. Psychiatrist Loren Mosher (1994) lamented the gross irony attendant to the branch of medicine that is supposed to be the most expert in the use of the patient-doctor relationship:

Psychiatry's current biologic Zeitgeist supports the position that it is not possible to have a therapeutic relationship with a person with a "diseased brain"; hence, coercion is justified. This rationalization flies in the face of decades of clinical experience and research indicating that while often more difficult, it is usually possible to establish a collaborative relationship with even the most disturbed and disturbing persons. When this is not possible, it is usually the result of multiple experiences of betrayed trust, which are then reinforced by involuntary hospitalization. It is very difficult to trust doctors who cannot only behave like cops, but also deny to themselves that is what they are doing. (p. 261)

There is a cruel joke well-known to consumers/survivors: You are put in a mental hospital for acting like you are crazy, but once you are in the hospital, you are punished if you do not act normal in an environment that is abnormal. For many, their first excursion into the world of psychiatric illness was made with an expectation to find help and relief. The need to find explanations, understanding, and above all a safe haven is rarely honored. More often they are confronted with a hospital reality that is far more frightening than they could have imagined.

## SELF-HELP AND EMPOWERMENT

The c/s/x's gross dissatisfaction with the existing mental health system *is not a denial of the need for help, but rather a criticism of what is passing for help*. People who felt the abuses and inadequa-

cies of the mental health system, who felt betrayed by unfulfilled promises of help joined together to produce their own mutual support alternatives. They designed alternatives to counteract professionals' control over treatment, the view of patient input as irrelevant, the system's demand for mandatory patient participation in routinized activities and the pathologizing of patients' refusal to do so, and the dehumanizing focus on symptoms combined with neglect of a patient's history, strengths, and capacities for competence (McLean, 1994).

Rose and Black (1985) countered the medical community's claim that a biochemically based diagnosis of mental illness alleviates stigma. Instead, Rose and Black postulated that the medical model actually blames the victim and artificially separates the "subject" from the "objective" social world. Activists in the physical disability movement testify, by virtue of their experience, that stigma and discrimination are not alleviated because they are perceived to have no control over the cause of their disabilities. When the "mental patient" is viewed as a victim of a brain disease, at best, he or she becomes the object of pity. Even if pity is considered to be of positive value, the psychiatric survivor believes that the loss of personal responsibility for one's life and the diminution of hope is too steep a cost for sympathy. Empowerment serves to transform the passive objects called mental patients to active persons fully capable of changing the conditions that created such devaluing oppression. The medical model has ignored the multiple conditions that contribute to an individual's specific situation. In the self-help model, the personal and the political are irreversibly enmeshed.

Within the *c/s/x* movement, the once frightened and beaten down, the voice-hearers, the traumatized, the victims of tardive dyskinesia have banded together with their peers to advocate and lobby for rights, create self-help alternatives, share successful coping strategies, and inspire and instill hope through the personal examples of their lived lives. *C/s/x* activists speak of empowerment and liberation.

We are refusing to allow others to speak for us and are reclaiming ownership of our experience. When we look for therapy or help, we are looking for active collaborative relationships where power inequities are minimized. We have learned that we thrive on choice, hope, and possibility. And we wither and atrophy from force and coercion. Having learned from personal experience that all of

our rights can be taken away from us, we know that we must fight to keep our rights, and thus we may be suspicious of those who offer themselves as helpers. We resonate with the insight of an unknown aboriginal woman who said, "If you're coming to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, let us work together."

Today, self-help is well-known and accepted as a supplemental support in most areas of health care. Self-help support groups assemble around issues of cancer survival, diabetes, obesity, grief, personal growth, gender, race, and community concerns. Self-help referral services and clearinghouses keep extensive lists of existing services that are easily accessible by 800 numbers throughout the United States. Yet, apart from the peer-support model of Alcoholics Anonymous and the *c/s/x* self-help initiatives, there is little challenge to the primacy of experts by most of the self-help groups centering around issues of health and well-being. Many forms of self-help are supportive of and secondary to "expert" professional opinions. Rappaport (1981) credited Illich for drawing attention to conflicts in the physical health domain: "The pervasive belief that experts should solve all of our problems in living has created a social and cultural iatrogenesis which extends the sense of alienation and loss of ability to control life even to one's own body" (p. 17).

The self-help phenomenon is one of possibilities, where people of vastly different skills and abilities try to use and make the best out of whatever individual members have to contribute. In self-help groups and other peer-run alternatives, there is an awakening of the ability to trust oneself and others. For many, it is the long absent, genuine invitation to be real in a place of safety and hope, where the exercise of control is an individual responsibility, and you are able to rethink your professionally adjudicated label of incompetence. With everyone being equal, compliance and passive dependency are less valued than in therapy systems with designated experts and associated power imbalances. Inspired by the success stories of their peers, members of self-help groups see the new possibility of working toward goals that they had been told were beyond their reach. In a self-help alternative, each participant is valued for what they have to offer. Being for once in the position to help others feels good and increases self-esteem. With peers you do not have to bury your anger, but instead you have the oppor-

tunity to give it voice in advocacy efforts. Goals are there to be realized as peers struggle to become a caring community of mutual helpers.

Most important, the self-help process allows people to redefine their experience by becoming the active narrators to their own unique stories. Brody (1987) asserted that the meaning we attach to our particular stories is the primary way that suffering is produced or alleviated. He argued that the placebo effect, or healing by symbolic means, occurs best when the meaning of the illness experience is changed in a positive direction.

Activist consumers/survivors see few boundaries to the self-help phenomenon and view the possibilities as only limited by the imagination and creativity of participants. Peer-operated alternatives take many forms. Peer-run telephone *warm lines* provide a service that professionally staffed or professionally backed-up hotlines cannot perform. C/s/xs often experience hotlines as entry points into forced interventions—as a last resort place to call when one is teetering on the edge and about to lose control. If someone is anxious, lonely, frightened, or desperate and calls a hotline staffed by a person who is legally responsible, who is instructed to reduce all risks, who is sensitized to expressions of anger or sadness and its “automatic” potential for triggering violence or suicide, safety is paramount and heroic interventions are standard policy. By contrast, warm lines offer the support of a peer who listens with the mindset of someone who may have been there, a peer who has not been trained to maintain emotional distance, a peer who can identify alternative resources and who is not mandated to “always be safe rather than sorry.”

Peer-operated clubhouses and drop-in centers are showing their value in cities and towns across the United States (Carpinello & Knight, 1992; Mowbray & Tan, 1992). Their emphasis on personal responsibility, camaraderie, and freedom to choose your own level of participation is appealing to people who have lost trust in a coercive system. Clubhouses and drop-in centers are becoming places where the seeds of advocacy and empowerment are nurtured among members.

C/s/xs have formed organizations to develop a variety of housing options. C/s/xs are developing unique crisis response alternatives, such as “crisis hostels” and in-home support. Peers have developed formal and informal outreach networks to people they know who

are experiencing distress and have isolated themselves. C/s/xs are helping their peers navigate the maze of social security disability requirements. Peers are sharing information about medication and coping techniques and educating each other as to their rights.

In New York, creative programs like *Incube* and *Share Your Bounty* were started by c/s/xs who saw needs that were not being met. Peer initiated and operated, Incube provides technical assistance and support for aspiring c/s/x entrepreneurs. Incube is a business incubator helping peers start and run their own businesses. Share Your Bounty (Stastny, 1993) was conceived and developed by inpatients at Bronx State Psychiatric Hospital. Noticing that large amounts of food were being wasted at the hospital, Lenox, an inpatient at that time, suggested that the food could be delivered to homeless and hungry people on the streets of New York City. With the acceptance of key staff and the participation of other residents, a weekly food-run to the Bowery was begun. The functions of this small core group grew more complex and evolved into an organization that distributed food to multiple sites: Grand Central Station, Port Authority Bus Terminal, Central Park, and a number of soup kitchens in Manhattan and the Bronx. After existing informally for more than 3 years, Share Your Bounty applied for and received a 3-year, \$350,000 National Institute of Mental Health grant. The success of Share Your Bounty challenges the commonly held myth that inpatients at a psychiatric hospital are incompetent and incapable.

In dialogues between consumers/survivors and mental health professionals, the New York State Office of Mental Health reported key problem areas identified by c/s/xs:

*Hopelessness.* People are told they will be sick for life. They are taught not to trust their own perceptions. People lose focus on development and growth; there is an overfocus on symptoms.

*Depersonalization.* The system treats clients as objects and with mistrust and defines a person as an "illness." Individuals' behaviors are explained by diagnosis; they become their diagnosis. Diagnosis invalidates the person and interferes with trying to truly understand the person.

*Negative effect on self-image.* A person is never again seen as being the same. There is self-doubt, unworthiness, and a feeling of being less than others. C/s/xs see themselves as being perceived by others as incompetent, violent-out-of-control, retarded, unreliable, able to do only simple work, dangerous to kids, weak, and lazy.

*The theme of loss.* Loss of control over one's life, loss of one's freedom, and loss of trust were expressed. There is a loss of personal identity that is replaced by the identity of illness and a loss of normal coping strategies for those individuals who have experienced being in an institution. Economic loss and loss of family were also cited.

*Isolation, exclusion, and being uninformed.* This includes being unable to explain one's experience to others, not being understood, being isolated, not being enlisted as a collaborator in one's own care, and a perception of distance between "labeler" and "labeled" (Bassman, 1995, p. 6).

Despite the progress, for psychiatric survivors like myself, the heart of the mental health system remains fatally flawed. People with a "mental illness" label reside at the very bottom rung of our culture's pecking order. Beneath them are only "mental illness" combined with other discriminated-against subsets further defined by age, gender, minority race or ethnicity, outsider sexuality, addiction, and frightening communicable diseases (such as AIDS). Our culture's current fascination with bootstrap individualism, the disappearance of community, and the devaluing of empathy and compassion underpin a reluctance to provide public support (such as housing, jobs, education, and a range and choice in health and mental health services) to people in need.

## COLLABORATION WITH MENTAL HEALTH PROFESSIONALS

Fostering understanding and modifying the power inequities between mental health professionals and consumers/survivors is a daunting task. At a recent meeting, there were three of us who were survivors as well as professionals: Peter, a licensed psychiatrist; Celia, the state director of peer specialist services; and I, a licensed psychologist. As soon as we introduced ourselves, and even before we could describe our objectives for the self-help and empowerment training seminar, the challenges by other professionals began:

"What can self-help do that we don't already provide?"

"We're sick and tired of being bashed. We've worked hard to get the education and training to become professionals. We care about the people we treat."

"I resent your telling us that the mental health system does not work. It is working. People are getting the help they need."

We were supposed to lead this seminar to help mental health professionals understand self-help and empowerment services in order to facilitate its implementation at their facilities. In the group of 80, there were administrators, psychologists, social workers, nurses, and a few psychiatrists from the seven downstate psychiatric centers. Understandably, they were threatened by the increasing popularity of low-cost self-help and empowerment services. With rising costs and the shrinking resources allocated to mental health services, the loss of their jobs was an obvious fear. Trained to diagnose pathology and treat people who are too “sick” to be responsible for themselves, these experienced mental health professionals saw their work and skills being devalued by us. Their belief in the efficacy of their roles as benevolent helpers always was supported and sustained by the feedback of other professionals. Now for the first time, they were being held accountable by the people receiving services. The three of us representing a *c/s/x* point of view were challenging the twin standards of maintenance and stabilization as the ultimate measure of success for their “chronic low functioning mental patients.” Our audience of trained clinicians was very uncomfortable with the rejection of key assumptions that underpinned their mandate to provide traditional clinical services. Discouraged by our attempts to raise awareness, we concluded that we would be more effective in creating systemic change in the public mental health system by building grassroots *c/s/x* self-help networks. Staff training would have to wait.

During the 5 years that I have worked in New York as a self-identified psychiatric survivor, I have watched the remarkable growth in the number of *c/s/xs* who have embraced the value of self-help and empowerment. The increases in recipient involvement and participation in their treatment in New York is a direct result of a pilot managed-care Medicaid initiative called the Prepaid Mental Health Plan (PMHP). It is remarkable that self-help and empowerment were included with treatment, support, crisis, and rehabilitation as the five contracted service requirements for the PMHP’s Federal Medicaid waiver. Now, promoted and nurtured through the leadership of the Recipient<sup>1</sup> Affairs Office, the 19 New York psychiatric centers have more than 80 sites with active self-help groups and programs run by recipients. The PMHP, initially motivated by cost savings, became an opportunity for recipients to actively participate in building community by creating alternatives.

The opportunities for consumers/survivors to have genuine input into the planning, implementation, and monitoring of services in a variety of settings are encouraging signs of progress. Exposing clinicians and policy makers to the ideas and experiences of *c/s/xs* is an eye-opening educational experience. Rappaport (1981) recommended that experts turn to nonexperts to discover the multitude of different, paradoxical, and sometimes contradictory ways that people gain control, find meaning, and empower their lives. One example would be the Hearing Voices Network, where people who hear voices share different coping strategies that they have learned through personal experience (i.e., listening to music with headphones, blocking the sound in one ear, identifying triggers).

When I attend taskforce or workgroup meetings and I am there to represent the *c/s/x* point of view, I continue to be surprised by the inability of many professionals to see what is fundamental and extremely obvious to anyone who has been diagnosed and treated for serious mental illness. Working on problems together, even being on opposite sides of an issue, permits professionals and *c/s/xs* to get to know what they like or dislike about a specific person's ideas rather than what they represent as a class or category. When professionals are required to move out of their caretaker roles and look at the whole person, it becomes much more difficult to remain unaware of the oppression faced daily by particular persons in specific real-life situations. When *c/s/xs* no longer have the dubious luxury of having their own and others' obnoxious behavior excused or rationalized, when accountability is expected, a major "all people who . . ." myth is debunked. When people are locked on wards where they have no control of their environment (when they get up in the morning, access to their beds, toothbrushes, cigarettes, or other personal possessions) and are given advanced training in dependency and then discharged into economic ghettos bereft of hope, where bizarre behavior is expected, is it any wonder why those well-publicized yearly stigma-busting campaigns by the Mental Health Association and the National Alliance for the Mentally Ill have no impact? Stigma, discrimination, and patronizing attitudes are undermined when people are working shoulder to shoulder or even shoulder against shoulder as respected adversaries.

## RECIPIENTS SHARE WHAT HELPED IN THEIR RECOVERIES

When I was asked to be part of a work group that was charged with designing a core curriculum for the mandatory training of the staff of 19 state-operated adult inpatient psychiatric centers, it was my chance to facilitate the reclaiming of our stories (Bassman, 1997b). When you become a mental patient, you are no longer a credible narrator of your life story. How you experience the world is unacceptable and is replaced with interpretations that are considered more valid than your perceptions. The project was an ambitious task for our work group. The team was made up of Central Office administrators, facility directors, clinicians, members of the personnel department, myself, and another peer from our Bureau of Recipient Affairs. The projected 3-day, 24-hour training would be presented to all hospital staff who had any patient contact on all three work shifts. The core curriculum training was expected to take 2 years to complete. It was organized into six modules: Team Training, Working in a Changing Environment, Selected Clinical Issues, Cultural Competence, Creating a Safe and Therapeutic Environment, and Recovery. My responsibility was the 3-hour recovery module.

The content of the recovery module was created from input and discussion with recipient leaders throughout the state. Adopting a train-the-trainer model, three of us developed the general threads of the protocol and refined them by doing the initial series of presentations. We then taught recipients from all over the state different ways to present their personal experience as inpatients in a psychiatric hospital and suggested that they give examples of what was and was not helpful. Personal stories were used to illustrate the values and recovery concepts that had been identified consistently by recipients. The key themes were as follows: choice; hope; we are more than our diagnoses; we speak for ourselves; and the importance of peer support, self-help, and empowerment.

Recipients were encouraged to present in teams of three and have supports built in for what could be difficult emotional presentations to hospital staff. All presenters were paid for their preparation, rehearsal, presentation time, and other associated expenses. We strongly supported the requirement that recipient presenters needed to be paid fees that reflected the significant value of their unique expertise. Presenters also were given the opportunity to

participate in 2 days of platform skills training to prepare them for speaking in front of groups of people.

The recovery module gave many of the hospital staff the opportunity to see recovering and recovered people for the first time. Seeing people at their worst had shaped the almost unshakeable attitudes of hospital staff. Now, hearing and seeing first-hand the articulate and thoughtful stories of people who once had been considered hopeless challenged their beliefs about mental illness. Trained to focus on deficits and weakness, they were learning that recovery is a reality for many people. More important, staff were learning about the impact of their relationships with people. When recipients poignantly described such human contact as instrumental in their recovery, several of the aides expressed their pleasure at discovering for the first time that people actually remembered and deeply valued their simple acts of kindness and warmth. "I'll never again assume that people are so out of it that it doesn't matter what I do" and "This made me remember the reasons I got into human services" were typical comments on written evaluations of the recovery module. Of the six core curriculum modules, the recovery module was rated highest by the trainees. Participants spoke of being profoundly touched by hearing powerful human stories that bridged the chasm between patient and caretaker and forced them to think less about differences and more about similarities.

Although the recovery module afforded consumers/survivors the opportunity to teach from their experiences, it was no more than a small opening into a larger culture that oppresses people who do not fit into a narrow range of roles or acceptable modes of personal expression. Recovery is a complex, time-consuming process in which the iatrogenic effects of treatment, crushed dreams, and stigma may be more difficult to overcome than the original condition (Anthony, 1994).

#### CREATING NEW POSSIBILITIES: BUILDING COALITIONS

Now is an important time for mental health professionals to join consumers/survivors in reforming a medically based, drug-dominated oppressive mental health system that is harmful to people who have been diagnosed with major mental illness. Genuine allies are welcome. You are invited to learn about the rich diver-

sity of projects and *c/s/x* literature and research that has been emerging during the past 20 years but is virtually absent from academia, major publications, and mainstream practices.

I deeply appreciate the professionals who are willing to shed the hierarchical role of expert helper in favor of open person-to-person collaboration in a mutually beneficial developmental journey. I am cautiously optimistic and encouraged by the support and openness I am beginning to discover among some psychologists. But overall, as a psychiatric survivor and a psychologist, I am disappointed and embarrassed by the almost complete absence of psychologists from the political arenas where *c/s/xs* have had to speak out without allies.

I encourage professionals to educate themselves by asking about and seeking out the rapidly expanding body of *c/s/x* writings. Find out how a self-identified consumer differs from a self-identified psychiatric survivor. Learn the differences between the consumer/survivor groups and family advocacy groups such as the National Alliance for the Mentally Ill (NAMI). NAMI, a junior partner to the drug companies, purports to speak for and advocate for members' sons and daughters who they believe suffer from a brain disease, a neurobiological disorder from which there is no hope of recovery. Although NAMI has done an excellent job of promoting itself as the voice of families with "mentally ill" members, there are many families who do not believe that their sons' and daughters' destinies are predetermined by their biochemistry. NAMI is currently engaged in an organized, well-financed national campaign to lobby state legislatures to enact involuntary outpatient commitment laws. This campaign shamefully exploits people's fears of violent acts committed by mental patients. Everyone loses something precious when we sacrifice an artificially defined group of people's freedom in an ill-conceived quest to maintain the illusion of control, predictability, and safety.

Will the "mentally ill" continue to serve as the "not us" scapegoat that conveniently diverts people from confronting the always possible terror of life and death? As I watch the growing numbers of people who are diagnosed with some form of "mental illness," and even more sadly, the number of children being prescribed Ritalin and whose diagnoses are preparing them to become the new group of "chronically mentally ill," I shudder at the price being paid to feed our community's need for safety. I ask you to do some introspection to see if your beliefs are supported by the willingness to

take the risks inherent in the actions required to remove the barriers to empowerment for the most disenfranchised among us: the person diagnosed and treated for major “mental illness.”

As a person working to assist others in their struggles—who is often seen as individuals’ and families’ last desperate hope—I urge you to learn how to use your education, talents, and skills in new ways by engaging in an exciting journey of creativity and personal growth in which people support each other as equals and speak of what is in their hearts. To be more effective in the service you provide for a *c/s/x*, it is imperative that you see the *individual* and value that special individual by engaging in a collaborative search to find understanding, meaning, and connection in this person’s unfolding life narrative.

#### REFLECTIONS ON MY OWN TRANSFORMATIVE JOURNEY

My first presentation of a paper at APA went well, but a lot of compliments and requests for reprints are not necessarily reflective of understanding. The audience of psychologists seemed to be stirred by my personal story of recovery/transformation and my description of the evolving *c/s/x* movement. However, I knew that interest, moral indignation, and a stirring of feeling would quickly fade and blend with other information stored in the intellectual realm. The brief glimpse of drama does not stir the playgoer to action.

My wife, Lindsey, our 7-year-old son, Jesse, and I walk up Broadway to find a restaurant for dinner. My mind is drawn to a time 25 years ago. Discharged from my second psychiatric hospitalization, I walked the streets of New York City. Despair and loneliness were my constant companions. I needed people. I wanted to be around people. But how do you relate when your dominating feelings are fear and embarrassment? Emptiness, nothing to say, nothing to contribute. Only with anonymity as a shield could I be with people and not have to face my humiliating inadequacies. How well I remember believing a bleak future with no friends was my destiny. Marriage and children would not be available to one such as I. Dull and slow, devoid of spontaneity, my muffled spirit hurt quietly.

Walking on those same streets embraced by my family’s love, how could I not glow? Whenever I consider those painful times, no

matter how down I might now get, my perspective is always jerked back, and the picture gets clear and bright.

My own good fortune and hard fight for recovery and success have never dimmed the memory of an insider's knowledge of what has been done, *is* being done in the name of treatment—to and for but rarely with—those lacking the power or voice to fight the abuses and keep their basic human rights.

For those unheard voices who have entered the labyrinth of the mental health system, for their families and loved ones who seek understanding and guidance, for the mental health professionals who genuinely struggle with their own and others' frightening existential plight, and for all those activists who demand the absolute entitlement of dignity and respect for everyone, I offer my voice to join them in their continuing fight . . . and to inspire HOPE.

#### NOTE

1. *Recipient*, as in recipient of service, is the term used in place of consumer, survivor, or ex-patient in New York. The Recipient Affairs Office is made up of the director who reports directly to the commissioner and supervises a staff of 12 recipients who work full-time throughout the state.

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