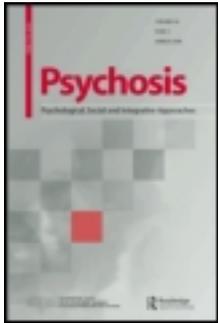


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Ronald Bassman^a

^a The Community Consortium, Albany, New York, USA

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Never give up

Ronald Bassman*

The Community Consortium, Albany, New York, USA

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Four decades after being diagnosed and treated for schizophrenia, the author shares what he feels can be helpful. His transformative journey from being locked in seclusion and being treated with insulin comas and massive amounts of drugs to becoming a licensed psychologist, activist and teacher is described as a means of inspiring hope and perseverance. An invitation is made to think critically about our current state of knowledge and to look at why and how we keep making variations of the same old mistakes. The author speculates on the benefits that can be brought to communities when normal is less rigidly defined and difference is not automatically judged undesirable and in need of modification.

Keywords: recovery; schizophrenia; bipolar; psychosis; mental illness; diversity

Too brief and infrequent are the moments where thoughts and feelings are stilled and we are just present. What is the good life? Exploring, studying and living within and through the phenomena known as madness has made me painfully aware of how little we know about the complexity of being fully human. I am humbled by the daunting task of understanding how to help a person who is lost. I am angered by the psychiatric propaganda whose simplicity makes it so easily acceptable. Whereas my questions have become larger, marketers for the mental health industry supply us with simple answers for our emotional pain. They tell us that drugs and or therapy will make you feel better and allow you to fit in. This partial truth presented as the whole truth becomes the big lie.

As a psychiatric survivor, activist and licensed psychologist I have been engaged for more than four decades in educating myself. My top priority was to construct a wall of immunity so that I might never again be incarcerated in a psychiatric institution. I operated with the belief that my security depended upon being able to fit in and to look and act normal. With few available options, too many of us are forced to fight against our temperaments and diminish the importance of our natural abilities when we aspire to be average. Those of us who are different looking, acting, thinking and feeling pay a steep price when we sacrifice our “being” for the illusion of normalcy.

Recently, I listened to a radio discussion between two women celebrities, one of whom was a famous country singer; the other a liberal talk show host and stand-up comic. Both had recently emerged from their respective closets and had declared publically that they were gay. During a heated discussion of politics, the singer was being asked by the politically liberal host,

*Email: ron@ronalbassman.com

Why do you resist aligning yourself with the political party that is most supportive of LGBT rights? When we talk publically, you say that you have no allegiance to either party.

Justifying her refusal to take a position she said, “I want people to know that my being gay is only one part of the choices and commitments I make. I don’t want people to see me as just a lesbian country singer.”

Yes the world would be a better place if it was so easy. “I’m gay, but please regard me as normal in all the other areas of my life does not work.” Given the existing prejudice to those who are culturally defined as the other, genuine progress requires us to protect and legitimize the worthiness of being different and the many gifts that emerge from human diversity.

Place of birth, culture, religious affiliation and race are a few of the many factors that may favorably or unfavorably alter the opportunity to pursue a desired place within your community. Similarly, being incarcerated in a prison will be instrumental in shaping one’s world view. Or as with me, my being diagnosed with schizophrenia and being locked up in a mental hospital influences how much of my new experience will be filtered through opaque, translucent or transparent lenses. Yes, I would like to believe that we are capable of creating and maintaining milieus where social justice reigns, but since antiquity those who think and look different, have been ostracized, persecuted and forced to recant their beliefs and behavior if they wish to have any chance of being integrated into the community.

Having the sensitivity to perceive underlying not meant to be communicated messages and having them repeatedly denied, struggling to understand and find a way to fit in or just standing out as different are some of the many openings for confusion and pain to take up residence within oneself. There are many opportunities for emotional overwhelm to take root. I wonder if the unique chemical makeup and sensitivity of the individual – the mind-body connection – interacts in such a way so as to deplete us of our natural resources. Unhappiness can be the catalyst for developing symptoms and behavior patterns that at start were helpful but then by overuse become harmful like inflammation’s attack on disorders of the body.

Psychic pain is a powerful motivator. When the pressure is too intense, and you wish that you were anyone but who you are, you may create tiny mental sanctuaries by rejecting conventional interpretations of reality. Those little cracks offer the opportunity for transformation.

I was unhappy, trapped and fighting my descent into hopelessness. Ever-present feelings of inadequacy and the need to hide my weakness filled my consciousness. I convinced myself that if I accepted no limits, everything was possible? I interpreted and attached new meanings to what I experienced and I adopted a new identity. The old way had not worked. I had not fit in. Instead of just getting by and being chronically unhappy, I chose to follow the seductive power of unrestrained possibility. But once you reject consensual reality, when you step across the line into forbidden territory, when choice becomes compulsion, are you able to return? My innocence, lack of training and knowledge about alternative realities made all explanations equally plausible. I stumbled down false trails and into exaggerated notions of self-importance. Familiar feelings of insecurity and powerlessness fuelled by mistrust set loose an overpowering fear that I had never before felt. Paranoia was the name the mental health experts gave to that constellation of feelings. This nightmarish fear kept increasing as if it would keep getting stronger until my mind would burst like a cheap balloon. Once these waking nightmares began, I could not shake the feeling

that I had inadequate protection from the eyes and thoughts of strangers. I had no capacity to erect a barrier that would shield my mind from invasive thoughts. A constant malignant presence was out there waiting to subdue and enslave me. My world was becoming increasingly unpredictable. Every sound and smell had to be attended to and judged as a potential trick or trap. The universe was engaged in a war between good and evil and unless I fulfilled my mission to convert people to goodness, a severe disaster would occur. I was partially right. There was a war going on, but it was struggle within me and if I didn't find a way to integrate the warring identity conflicts within myself, I would be the casualty.

Innocently, I had waded into the sea of madness hoping to find myself. Instead, psychiatry found me. They said I would drown if I did not take the life-line they threw to me. I heard them shouting at me, but wondered why they were so excited about me playing in the waves. I told them I would just tread water until I learned to swim in the turbulence. They said no. I refused to leave the water. I was too young and naive to know that the doctors posed more of a danger than the sea. I was an inexperienced lightweight jutting out my jaw and challenging the mighty, government-sanctioned heavyweight champion. Knocking me out with 40 shots of insulin, the doctors dragged my unconscious body to shore and left my spirit in the sea of madness.

I am sick, you are healthy? I want to be what I am not. I must strive to be more than I am. What you have to offer, I reject. Maybe it is easy for you to fit in. I cannot fit in the way that you say is the only way. I reject your obsession with safety. You will try to make me see the world the way you see it. I will resist. And I will suffer.

Well how healthy are you and how sick am I? You put me in the hospital and electrocuted by brain, you thought that by injecting me with insulin and forcing me into 40 comas I would learn to accept your reality. Do you feel justified because I did not make the proper transition from adolescent to adult? You did not approve of my search to find me. You say you can help people like me. Do you really think our unhappiness, our quests to explore possibilities other than what has been offered to us is always too dangerous? I think the unknown frightens you. Control and predictability soothes you. I believe paradigms shift and scientific truisms are likely to self-destruct in history's cauldron.

Diagnosed schizophrenic, I was no longer the actor/agent possessing rights, but rather if compliant, I could be given privileges. Their treatment worked at making me into a numb non-entity, one who was no longer able to strive, grow and develop

Too weak to reject the psychiatrist's argument to my parents at my discharge meeting, I barely listened to their discussion of my future. Doctor performed his role with mechanical, indifferent efficiency. One purpose informed the discharge meeting: My parents must accept that the patient – me – is 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, 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 should return to the hospital regularly for outpatient treatment. He should not see any of his old friends. If his behavior changes dramatically or he seems to be getting upset, call the hospital immediately."

I, like most who have been diagnosed with schizophrenia, have been told that I have a biochemical disorder, a brain disease. To survive outside of an institution, we are told that we must relinquish our dreams and seek work in low-pressure jobs with few demands. Are we who have been diagnosed with schizophrenia not entitled to wonder who we are and what it means to be fully human and live with integrity?

Forty-plus years ago, after I was discharged from my second psychiatric hospitalization, I aimlessly 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 could I relate to others when my feelings were dominated by fear and embarrassment? Emptiness, nothing to say, nothing to contribute, only with anonymity's protection could I be around people and not be humiliated by my inadequacies. How well I remember believing a bleak future with no friends would be my destiny. Marriage and children would not be available to me. Dull and slow, devoid of spontaneity, I hardly had the energy to hate my life.

How did I avoid the fate of so many whose spirit and life course were arrested by experiences similar to mine? "Why me" is a question I have tried to answer. I believe that a never give up attitude toward hope and possibility was the driving force that sustained me in fighting for the changes that would enable me to pursue the growth I desired.

For most of my life I have studied the phenomena known as madness, my own and others. During those years I have met and had the opportunity to share and learn from extraordinary individuals of great courage, psychiatric survivors who worked to make positive changes so that those who came after them would have it easier. I have also had the privilege of meeting some remarkable mental health professionals whose integrity and pursuit of truth make them outsiders relegated to work at the margins of their respective fields. Forging friendships with my peers, I found community in our shared experience and our passion for helping fellow travelers. We helped ourselves find meaning when we helped others.

1982, three decades ago, I began writing to understand my experiences and gain release from the anger and pain. With slow and steady progress, I had chipped away at the uncertainty and fear of being vulnerable to another battle with schizophrenia, but the fragile peace I made with myself did not vanquish nocturnal dreams of hospital confinement and lost credibility. Too often I forced myself to wake from a nightmare and discovered that I was mouthing the too familiar mantra of the confined mental hospital patient, "You can't do this to me ... it's not fair."

What I started as autobiographical venting grew in scope as my intuitive understanding of mental illness expanded with the study of mainstream professional literature and first-person narratives of madness. My relentless pursuit of understanding was fortified by my exposure and work with others whose experiences validated my own. I owned a unique perspective forged from the experience of living and working on both sides of the locked ward doors – and becoming aware of the invisible but sturdy gates that isolate and exclude the mental patient from full community inclusion.

Attempts to unlock the mysteries of the disordered mind have attracted, stimulated and frustrated great thinkers throughout our recorded history. Today, modern medicine, through its disease 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 in the past was seen only in divinely inspired religious doctrine, organized medicine has promoted unproven dogma as scientific fact.

Psychiatry promotes and delivers treatments derived from a diseased, broken brain theory of mental illness. Simplistic explanations to de-mystify madness prevent us from expanding our knowledge of what is helpful. Those of us who were able to shake off damaging treatments and resist the brainwashing saw no benefit in believing that we had incurable illnesses requiring a lifetime regimen of psychiatric drugs. We, who were able to come out on the other side of our ordeals and positively transform our experiences, know that the biochemical disease model of mental illness attacks our humanity and crushes our spirit.

Sometimes a psychiatric drug will effectively work on the immediate problem and sometimes not. Which drug will work on which person is a gamble, an educated guess at best, made after months or even years of painful guesswork. I am not opposed to using a substance to deal with pain. I am opposed to the subtle coercions, the misrepresentation and lack of full information presented to people who are vulnerable and seeking expert advice. A person in extreme psychic or physical pain will most likely choose to take the quickest, most effective substance for relief. Whether or not it provides temporary relief should not be the only factor that guides the decision. Just as it is dangerous to ignore the guidance that physical pain provides, to anesthetize psychic pain deters us from finding better solutions. Unfortunately, the physical and emotional consequences of our reliance on drugs only emerge and demand attention later.

The treatments that are available for people in extreme emotional states are generally ineffective and often harmful. The search for biochemical solutions has become an obsession. New drugs, rather than decreasing emotional pain have created more severe iatrogenic problems. According to the professional experts, the number of people with mental disorders is increasing. The types of psychiatric disorders in the American Psychiatric Association's best-selling publication, the DSM, keep expanding. Ironically, long-term research from the World Health Organization has shown that people with schizophrenia who live in third world countries recover at a significantly higher rate than in the United States. Manic-Depressive disorder re-named Bipolar disorder and once considered rare, has become the new disease of the day.

At outpatient day treatment programs, I see why I remain suspicious of the benefits of psychiatric drugs. Those intensive outpatient treatment programs offer the usual assortment of social skills, personal hygiene and current events groups. Some individuals amiably attend groups, but are clearly more interested in the availability of cookies and coffee. Most of the attendees alternate between pacing, sleeping in chairs and shuffling outside to smoke. The day treatment centers are predictable and safe, one day or week or month is indistinguishable from another. The glazed eyes, the missing teeth, trembling hands, distended stomachs, slurred speech and other drug-related side effects will not be remarkable there. I look and see squelched dreams and resignation. I wonder what their lives were like and what could have been. Before they became mental patients, how did they envision their futures? Can we say that psychiatric drugs improved their lives? Were there no other possibilities? Isn't there something better we can do for them now? Others have transformed their experiences, why not these people? Where are the alternatives to the one-size-fits-all-drugs-are-the-answer medical model?

Although recovery has now become part of the public mental health lexicon, there is still an authoritarian relationship between treatment providers and clients. True collaboration in a person-to-person relationship must be informed by respect

while minimizing the power inequities. Too often absent is the dignity of risk. One must have the opportunity to fail in order to succeed in growing. I remain frustrated that mental health professionals have been slow to accept the value of experience-based knowledge and have not integrated that wisdom into the services they provide. Too many treatment practices remain tethered to physical interventions, and continue to constrict a person's chances for recovery and transformative growth. Intolerance and lack of support for emotional pain and instability leave psychiatric drugs as the primary treatment option. The resulting drug-induced stability may bypass the current pain, but too easily invites that person to take on the role of chronic mental patient. The precipitating crisis may be deflected, but the opportunity for personal growth and development is sacrificed.

The traditional role of therapist – hourly sessions once per week does not work for a lot of people. We need to offer more than office visits. We need to develop a variety of services designed to meet the specific needs of an individual within a specific context at a specific time and developmental stage of life

From my book *A Fight To Be*:

My ascent from madness to my present state of clarity and self-acceptance was and is a journey whose responsibility always resided within me. However, as I try to describe and share with others what wisdom I acquired, to aid others in their work, I acknowledge one element that I do not understand or take credit for, something that is named or interpreted according to one's unique beliefs and values as luck, fate, karma or God's blessing.

I believe that as long as a person is alive, some seed of hope, some possibility is there waiting to be fertilized. Hope fights the fear, nurtures the courage and inspires the vision and the work required to resist giving up and accepting that your goals are unattainable. Deep in the recesses of our being there are safe sanctuaries, secure hiding places for never fully lost dreams. But sometimes they are hidden so well that we can no longer reach those parts of ourselves. The help we need may come from expected and unexpected sources.

I am morally obligated to shout out my story and hope that it serves as a beacon for those who have been lost in the labyrinth of the mental health system, for the families, lovers and friends 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.

Reference

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