Recovery: Responsibilities and Roadblocks

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In reviewing the scientific, mental health practitioner, and C/S/X[1] literature regarding recovery from serious mental illness and analyzing them it really is quite clear both (a) what works and (b) what impedes. It is also quite clear many more people can recover from serious mental illness than currently do under Western (primarily medication) treatment. This article discusses the responsibilities for and roadblocks to recovery that has resulted in this unacceptable situation. First, however, some definitions and background.

Definitions and Background

Definitions

The term "what works" is meant to be very broad and much more a way of thinking and principles as contrasted with any particular technique(s). There is a very valid saying pertaining to mental illness that "everything works for some and nothing works for all." There are, however, some principles and specific steps that consistently come up as being helpful in getting people over serious mental illness.

Mental Illness and particularly Serious Mental Illness refers to people who have suffered from psychosis although the same principles probably apply to people diagnosed with depression who have never suffered psychosis, etc., and it is not intended to denigrate their suffering. The problem with "mental illness" as a term is there is a lot of controversy over what it really refers to and the way it is used in the dominant treatment modality (i.e, some type of brain pathology) does not appear to comport with reality.[2] On the other hand, the C/S/X and unbiased scientific literature agree that in the vast majority of cases, leaving aside brain injury and other clearly organic causes, "mental illness" or psychosis is the result of events in the person's life.[3]

Recovery from serious mental illness means a lot of different things to a lot of different people. Dr. Courtenay Harding, probably the pre-eminent researcher on long-term outcomes for people diagnosed with serious mental illness uses the following definition:

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[1] "C/S/X" refers to "Consumers of mental health services," "Survivors of psychiatric treatment" and eX-mental patients."

[2] See, e.g., Brain Disease Hypothesis for Schizophrenia Disconfirmed by All Evidence, by Al Siebert, PhD., Ethical Human Sciences and Services, Vol 1, No. 2 1999.

[3] See, e.g., Community Mental Health: A Practical Guide, by Loren Mosher and Lorenzo Burti, W.W. Norton & Company, 1989; On Our Own: Patient-Controlled Alternatives to the Mental Health System, by Judi Chamberlin, Hawthorn Books, 1978; Effective Psychotherapy of Chronic Schizophrenia, by Nathaniel S. Lehrman, M.D., American Journal of Psychoanalysis, (1982), Vol.42, No. 2: 121-131;

No current signs and symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community and behaving in such a way as to not being able to detect having ever been hospitalized for any kind of psychiatric problems.4

Interestingly, within the C/S/X community, Recovery is often defined much more loosely. In April of 2003, the NO (National Organization) List, an Internet listserv had a discussion thread on exactly this topic: Some of the responses included:

- An individual's opportunity for social activities and places to go is no different than any other citizen.
- An individual has paid or volunteer work if they wish to.
- An individual has a secure roof over his/her head
- An individual is no longer bothered by symptoms that monopolize his/her consciousness and days and nights
- An individual may or may not take medications, do exercises physical or spiritual.
- What is recovered is a sense of self that is not defined by illness, but by abilities and interests and hope for the future.

As used here, recovery means getting past a diagnosis of mental illness to a point where a person enjoys meaningful activity, has relationships, and where psychiatric symptoms, if any, do not dominate or even play a major role in their life.

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I appreciate the literal meaning of recovery; to recover is to "take back." Thus "recovery" is the process of taking back. As I recover - I take back my life.

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To get back a sense of self that is not defined by illness but by abilities and interests and hope for the future.

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For me "recovery" has been a very painful and unfinished, day to day struggle. It takes medicine, ongoing therapy, friends, meaningful work, withdrawing for periods of time, keeping-on-keeping-on.

Thus, recovery means a lot of different things to different people.[5] As used here, recovery means getting past a diagnosis of mental illness to a point where a person enjoys meaningful activity, has relationships, and where psychiatric symptoms, if any, do not dominate or even play a major role in their life.

Background

The importance of award winning science/medical writer, Robert Whitaker's book, Mad in America: Bad Science, Bad Medicine and the Enduring Mistreatment of the Mentally Ill,[6] in putting together the disparate pieces of this story can not be over-estimated. In the Preface, Whitaker talks about how he became interested in researching the story:

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[4] Empirical Correction of Seven Myths About Schizophrenia with Implications for Treatment, by Courtenay M. Harding, Ph.D., and James H. Zahniser, ACTA Psyciatrica Scandinava, 1994: 90 (suppl 384): 140-146, hereafter referred tos "Myths."

[5] Also see, The Recovery Vision for Mental Health Services and Research: A British Perspective, Psychiatric Rehabilitation Journal, Winter 2002, Vol. 25, No. 3.

[6] Perseus Publishing, 2002.

> I bumped into several studies . . . that really struck me as odd. Over the past twenty-five years, outcomes for people in the United States with schizophrenia worsened. They are now no better than they were in the first decades of the twentieth century, when the therapy of the day was to wrap the insane in wet sheets. Even more perplexing, schizophrenia outcomes in the United States and other developed countries today are much worse than in the poor countries of the world.

And after his exhaustive research, the very last sentence of the book concludes:

> [T]oday we can be certain of only one thing: The day will come when people will look back at our current medicines for schizophrenia and the stories we tell to patients about their abnormal brain chemistry, and they will shake their heads in utter disbelief.

In between, Whitaker describes the studies that show how rather than cure chemical imbalances, these drugs, if taken long enough, cause permanent changes in the brain which make relapses much more likely. Even before permanent changes in the brain occur, when someone quits withdrawal (also often called "rebound") effects from the drugs create symptoms that are assumed to be the underlying "mental illness" and the response is usually to restart medications, often at a higher dose.[7]

Dr. Bert Karon, notes:

> Ann-Louise Silver, in a recent paper (Silver, 2000), said that when she first worked at Chestnut Lodge, her schizophrenic patients were not medicated. In more recent years, all of her patients were medicated as a matter of policy. In the premedication days, she had patients who got romantically involved, got married, had children, and related to their spouses and children. In the medication era, none of her patients developed stable marriages and stable relations with spouse and children.8

In her seminal Vermont Longitudinal studies, Dr. Harding found that:

> This group of back-ward patients represented the most severely ill group from Vermont's only state hospital. Two to three decades after a comprehensive rehabilitation program and a planed deinstitutionalization, one-half to two-thirds of these patients were rated as considerably improved or recovered.9

In the follow-up study (Vermont II), Dr. Harding et. al., found

> [O]ne-half to two two-thirds of the sample had achieved considerable improvement or recovered, in contrast to statements in DSM-III that predict a poor outcome for schizophrenic Patients.10

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[7] See, Pavel Muller and Philip Seeman, "Dopaminergic Supersensitivity after Neuroleptics: Time-Course and Specificity, Psychopharmacology 60 (1978), 1-11. Guy Chouinard, “Neuroleptic-induced supersensitivity psychosis,” American Journal of Psychiatry, 135 (1978), 1409-1410; Chouinard, “Neuroleptic-induced supersensitivity psychosis: clinical and pharmacologic characteristics,” American Journal of Psychiatry, 137 (1980), 16-20; George Gardos and Jonathan Cole, “Maintenance Antipsychotic Therapy: Is the Cure Worse than the Disease;” American Journal of Psychiatry, 133, January (1976), pager 32-36 ;Robert Prien, "Discontinuation of Chemotherapy for Chronic Schizophrenics," Hospital and Community Psychiatry, 22 (1971), 20-23; William Carpenter, Jr., "The treatment of acute schizophrenia without drugs: an investigation of some current assumptions," American Journal of Psychiatry, 134 (1977), 14-20; J. Sanbourne Bockoven Comparison of Two Five-Year Follow-Up Studies: 1947 to 1952 and 1967 to 1972, American Journal of Psychiatry, 132 (1975), 796-801.

[8] The Effects of Medicating or not Medicating on the Treatment Process, Bertram P. Karon, Ph.D. Division of Psychoanalysis (39), American Psychological Association, New York, NY, April, 2002. An online version of this paper can be found at http://psychrights.org/Research/Digest/Effective/BKaronMEDICATION.htm.

[9] The Vermont Longitudinal Study of Persons With Severe Mental Illness, I: Methodology, Study Sample, and Overall Status 32 Years Later, by Courtenay M. Harding, Ph.D., George W. Brooks, M.D., Takamaru Ashikaga, Ph.D., John S. Strauss, M.D., and Alan Breier, M.D., American Journal of Psychiatry 144:6, June 1987, 718

In her Myths article Dr. Harding reports:

> Studies have consistently found that half to two thirds of patients significantly improved or recovered, including some cohorts of very chronic cases.

This is in the context of correcting what she calls the myth: "Once a schizophrenic always a schizophrenic."[11]

What Works

Love, support, caring, connections, a safe home, spiritual support, and most important, hope. And taking responsibility. These are the things that work. People who recover cite hope and "someone believed in me; someone believed that I could do it" as the most important things.[12] Research bears this out.[13] A relatively small percentage of people cite medications as important. In Oryx Cohen's study, "Psychiatric Survivor Oral Histories: Implications for Contemporary Mental Health Policy:

> participants' most common recovery strategy was the support of friends and family (at 72 percent). Social activism, exercise, and one-on-one therapy were also commonly reported (69, 61, and 58 percent respectively). Group therapy and psychiatric drugs were only reported by 25 percent of the participants. 14

Cohen goes on to conclude:

> Given the difficulties that participants experienced with psychiatric drugs, it is not surprising that only a fourth felt they assisted in their recovery process. This also happens to be the number of people currently taking medications, and with just two exceptions, the people who felt medications helped were those who were currently taking them.15

It is critical to recognize the importance of this latter finding, which is that the people who recover with medications are the ones who decide for themselves that they are helpful. Other conclusions in Cohen's study are:

> [I]t wasn't one "magic bullet" that “cured” these people. Instead a combination of strategies and circumstances allowed participants to improve their sense of well-being. Along with the importance of having support, participants indicated the importance of things like diet, reading literature, and spirituality.16 Perhaps most importantly, for the majority of participants there came a time when it "all clicked," when they realized that nobody was going to recover for them, they were going to have to find a way to do it themselves.17

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[10] The Vermont Longitudinal Study of Persons With Severe Mental Illness, II: Long-Term Outcomes of Subjects Who Retrospectively Met DSM-III Criteria for Schizophrenia, by Courtenay M. Harding, Ph.D., George W. Brooks, M.D., Takamaru Ashikaga, Ph.D., John S. Strauss, M.D., and Alan Breier, M.D., American Journal of Psychiatry 144:6, June 1987

[11] Infra., note 9.

[12] See, e.g. The Recovery Vision for Mental Health Services and Research: A British Perspective, Psychiatric Rehabilitation Journal, Winter 2002, Vol. 25, No. 3, p. 246.

[13] See, e.g., Dr. Harding's Myths paper Id, at 141; The Rational Organization of Care for Disabling Psychosis -"If I Were Commissioner" N.S Lehrman. M.D. former Clinical Director, Kingsboro Psychiatric Center, Brooklyn NY 4680 words; April, 2002, which can be found at http://akmhcweb.org/articles/iflhermancommissioner.htm; Recovery: The Lived Experience of Rehabilitation, by Patricia E. Deegan, Ph.D., revised version of paper originally published in Psychosocial Rehabilitation Journal, 1988, 11(4), 11-19.

[14] See, http://akmhcweb.org/Research/OralHistories.pdf (Cohen).

[15] Cohen, p. 51.

[16] These were not included in Figure 1 because of space considerations

[17] Cohen, p. 53

In The Experience of Recovery, Patricia Deegan discusses the importance of hope, love and support when she talked about hers and a friend's recovery process:

> Neither the paralyzed man nor I could remember a specific moment when the small and fragile flame of hope and courage illuminated the darkness of our despair. We do remember that even when we had given up, there were those who loved us and did not give up. They did not abandon us. They were powerless to change us and they could not make us better. They could not climb this mountain for us but they were willing to suffer with us. . . . Their love for us was like a constant invitation, calling us forth to be something more than all of this self-pity and despair. The miracle was that gradually my friend and I began to hear and respond to this loving invitation.
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> For 14 years my friend had slouched in front of the television in the hell of his own despair and anguish. For months I sat and smoked cigarettes until it was time to collapse back into a drugged and dreamless sleep. But one day, something changed in us. A tiny, fragile spark of hope appeared and promised that there could be something more than all of this darkness. This is the third phase of recovery. This is the mystery. This is the grace. This is the birth of hope called forth by the possibility of being loved. All of the polemic and technology of psychiatry, psychology, social work and science cannot account for this phenomenon of hope. But those of us who have recovered know that this grace is real. We lived it.18

Dr. Harding, in her Myths paper, describes how the research shows there is always the possibility for recovery:

> Even in the second and third decades of illness, there is still potential for full or partial recovery." All of the recent long-term follow-up investigators have recorded the same findings19

Dr. Loren Mosher, in the Soteria-House studies and their progeny has proven with even more scientific rigor these principles work.[20] In Dr. Mosher's and Dr. Lorenzo's terrific book Community Mental Health a Practical Guide[21], it is stressed the most important things are to support people; to be with them, rather than do to them, to let them be themselves, to establish a therapeutic relationship by rejecting coercion and to allow people to recover through support mechanisms that solve their real problems.

So, we really do know what works and can move to responsibilities and roadblocks.

Responsibilities

From what has already been said, it is clear responsibility for recovery rests in the person wanting to recover. No doctor or spouse or friend or mental health worker can do it for her. The person has to do it. She can get help. She needs love and support to do it, but it is her task and it will likely be a lot of work.

Only she knows what is going on in her head and thus it is her responsibility to learn both to recognize the warning signs and what sorts of things help. Even though these are the person's responsibility, it is important to recognize these learning processes are not necessarily a steady progression. In order to learn what works it is necessary to try things and not necessarily everything

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[18] Deegan, p. 56.
[19] Myths, p. 146. Dr. Harding also specifically talks about the importance of hope at p. 141.
[20] See, Soteria-California and Its Successors: Therapeutic Ingredients, Wie wirkt Soteria?-ein atypische Pssychosenbehandlung kritisch durchleuchtet (Why does Soteria work?-an unusual schizophrenia therapy under examination) Huber: New York and Bonn pp. 13-43, 2001. The English version of this paper, originally presented in German, can be found at http://akmhcweb.org/ncarticles/soteriasuccessingredients.htm.
[21] W.W. Norton & Company, 1989.

will work. The learning process may very well involve relapses. This is part of the recovery process; part of the learning process and should not be viewed as failure.

It is the responsibility of other people to let this process occur. What happens now is that the system, including loved ones, are so afraid of relapses they try to keep people "safe" with the drugs or other treatments, such as Electroshock (yes, it is coming back in the U.S.). However, these drugs have been shown, for most people, to be both physically harmful and unhelpful in the recovery process, especially if used long-term. It is the responsibility of others to allow the person to work out what works for him and her and not resort to forcing drugs, ECT or other treatments on the person when this occurs. Remember, it is ultimately the responsibility of the person to recover and forcing anything on the person is counterproductive to that.

It is also the responsibility of others to let people try the things they want to try. It turns out that people tend to have pretty good ideas about what sorts of things might help them. It may be violin lessons.[22] Even if the idea doesn't ultimately turn out to be successful, it is part of the recovery process because the person needs to find out for herself it isn't part of the answer. Unless the person is allowed to try it, she will be stuck on it. On the other hand, if the person tries the idea and it doesn't work out the way it was hoped, she will have learned that and be able to move on. It is her responsibility to do this and it is other people's responsibility to let it happen.

However, there are other responsibilities involved. Perhaps the biggest is the responsibility of the mental health profession to honestly re-evaluate its assumptions and treatments. All the evidence shows the profession's belief system about the incurability or chronicity of serious mental illness is false. All the evidence shows that the long-term use of neuroleptics and other psychiatric drugs prevent recovery in the majority of cases, cause serious health problems, including early death. No evidence shows serious mental illness is the product of a brain disease or a "chemical imbalance" in the brain.[23] It is the mental health profession's responsibility to conform their practices to reality. It is the mental health profession's responsibility to be honest. To be honest to itself and to be honest to its patients. No therapeutic relationship can be formed if the therapist is not honest to her patient. Just because someone may have been diagnosed with a serious mental illness does not mean they can't tell when they are being lied to. The lies are very destructive.

There is a flip side to responsibility. That is the absolution from responsibility that results from believing mental illness is a disease of the brain; that it is a chemical imbalance. This is the seduction of the bio-medical model. If one accepts it, no one is responsible for it. Parents are absolved from all responsibility in creating the mental illness. That is why the main US parents organization, NAMI (National Alliance for the Mentally Ill) has embraced the idea so completely to the exclusion of consideration of any other explanation and its rejection of all the evidence against this disproven theory. What they fail to see is responsibility does not equate with blame. Sure, one can blame parents who physically and/or sexually assault their children, which so often results in serious psychiatric symptoms.

More often, however, parents are loving and do the best they can, but serious mental illness can still arise out of the relationship. One can't really tell how kids interpret things. In the famous biographical novel, "I Never Promised You a Rose Garden" one can see how family interactions and a child's interpretation of a certain event, caused a very severe psychosis years after the event. In

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[22] See, "If I Were Commissioner," infra., note 13.

[23] See, for example, Brain Disease Hypothesis for Schizophrenia Disconfirmed by All Evidence, by Al Siebert, PhD., Ethical Human Sciences and Services, Vol 1, No. 2 1999.

another instance, a child had a really hard time adjusting to the arrival of his sister and perceived everything as unfair. He acted out and was diagnosed with mental illness. Very heavy medication followed with a poor prognosis until common sense prevailed and he was allowed to work through his issues. He is now fine.

Responsibility does not mean blame. It means responsibility. When responsibility for mental illness is attributed to a defective brain, it relieves everybody of responsibility for both the cause and the cure. It gives responsibility at this point to pills. Pills we now know don't work for most people in terms of recovery. This absolution from responsibility is true for the person as much or more than the parents or providers. Being labeled with a serious mental illness today is virtually absolution from responsibility. Bad behavior is excused as "part of the illness." There is no responsibility on anyone for recovery because it is an incurably defective brain.

These failures of responsibility lead to roadblocks for recovery.

Roadblocks

There are many roadblocks to recovery, but the big three are (1) Destruction of Hope, (2) Abdication of Responsibility, and (3) Insistence on long-term medication. All three of these are manifestations of the same fundamental mistake that mental illness is the product of a defective brain.

Destruction of Hope

Because of the fallacious assumption that mental illness is the product of a defective brain, people are told they will never get better; they will never live full, fulfilling lives. In short, they are told to give up hope. Do we really want a mental health system who's operating principle is " Abandon Hope All Ye Who Enter Here?" Of course not. Most importantly, we have seen that hope is the most important element in recovery. That is why Drs. Mosher and Burti say recovery should be the expectation. We must remove the roadblock of the myth that people don't recover from serious mental illness. We must.

Abdication of Responsibility

It is a sort of double negative, but we must also remove the roadblock of the abdication of responsibility. This roadblock also arises from the myth of the biological cause of mental illness and the person is therefore not responsible for her actions. This roadblock arises from excusing bad behavior because "it is the illness." We know recovery is ultimately the responsibility of the person. It is hard work, there can and most often are setbacks, sometimes many, and we mustn't blame people who falter. What we can do is encourage them in recognizing and assuming their responsibility. We need to remove the roadblock to recovery created by excusing behavior because it is "caused by the illness." This doesn't mean being intolerant of behavior that is merely "weird" or beyond societal norms. It does mean being clear about truly harmful behaviors being unacceptable and the person's ultimate responsibility. It also means being clear that only by assuming personal responsibility can a person recover.

Similarly, we need to remove the road block that exists because other people are absolved from responsibility for their part in the problem. Again, responsibility does not necessarily equate to blame, but if we do not acknowledge other people's part in the process, we are not being honest.

Insistence on Long-Term Medication

While psychiatric medications, particularly the neuroleptics (including the newer "atypicals"), may help some people in the short term, it is crystal clear long-term use is counterproductive to achieving recovery for most people. We must quit insisting that virtually everybody diagnosed with serious mental illness has to take these medications indefinitely. It is not the truth, it is harming people, and it is preventing recovery for many, many people.

Conclusion

Recovery. Responsibility. Roadblocks. We know recovery is possible for many more people diagnosed with serious mental illness than currently do so. The most important reasons for this are failures of responsibility. The responsibility to be honest. The responsibility to be responsible. The responsibility to offer hope. The responsibility to stand up to the drug companies' lies. These failures of responsibility are roadblocks to recovery that must be removed for more people to recovery.