

This article was one of my first that got a significant audience and response, after it was published by Dan Weisburd in 1997 in the Journal of CAMI (the California chapter of the National Alliance for the Mentally Ill – NAMI) and was subsequently spread around the internet. I am still struck by how many people can't even conceive of the idea of recovery strictly because they feel hopeless. Too often, we have been so concerned about preparing people for the difficulties of "surviving" Schizophrenia and getting them to accept difficult and restrictive treatments that we have seriously oversold hopelessness and closed far too many doors to recovery. Most of the people who have contacted me after reading this simple piece said that it shifted their feelings and beliefs enough to let some hope in and once they felt a little hope the door was open for the entire recovery model.

This article's legacy for me is that recovery begins with hope.

Hope and Schizophrenia

(1992)

Last year a 40 year old man with schizophrenia who has spent much of his life locked up, was dragged in to see me by his father who was his conservator. Although things were going poorly at home, he put on his best face to meet the doctor. He began with his usual opening, "Everything is fine. The medications are working very well. You can just give me refills and save your time and I'll be fine." I sat leisurely getting to know him as I would a new friend, introducing him to other friends, both people with illnesses and staff, and offered to share my popcorn. As I neither moved to hospitalize him or write prescriptions, he became more and more confused and anxious. Finally he blurted out, "What do you want from me? Just tell me what you want and I'll do it." I thought for a moment and then said, "I want you to hope: I want you to hope there can be more to life than staying out of the hospital. I want you to hope that you can use medication to relieve some of your suffering. I want you to hope that your self hasn't been swallowed up by your illness and you can recover the things that make you special." Here was something he couldn't fight against. There was no threat or power struggle. The next time he came back he said, "I've thought about what you said and I want to go back to college". He's started using his medication more regularly, going out socially, working on his fears and returned to painting. It's a slow process with ups and downs, but his recovery has begun with hope.

Many of my colleagues would say I'm being a charlatan, giving unrealistic hope where there is none. Here are my justifications:

There have been a number of studies over many years about the "natural course" of the illness of schizophrenia with widely varying results. In America, in the 1840s when we had moral treatment and believed God would heal people, apparently about 3/4 of

people recovered and went back to their lives in 1 year. In the 1890's, Kraepelin observed a uniform downhill deteriorating course without recovery in his hospital in Germany. The recent Maine and Vermont longitudinal studies of people released from the back wards of hospitals to the community in the 1960's, showed that at least half recovered and became functional again. In our present era of stabilization on medication and SSI benefits, less than 1% ever get off SSI and become self-supporting. What we can reasonably conclude from these differing results is that the outcome of schizophrenia is very plastic. Therefore, the outcomes can be altered drastically by how we respond to the illness.

We carefully teach people that schizophrenia is a genetically based chemical brain illness that isn't anyone's fault. Unfortunately, this gets translated into helplessness on all parts when there's a great deal that everyone can do. Years ago, in London, I went to a conference where I meet three genetically identical triplets, two of whom were diagnosed with schizophrenia and one of whom was diagnosed with manic-depression. The first two had cooperated with their doctors, taken medication regularly, not worked, lived in Board and Care homes and limited stress in their lives. They had avoided hospitalization and appeared to have substantial negative symptoms. The third brother had rebelled against treatment. He had a very tumultuous life with periods of doing well, working and even getting married for several years, interrupted with spectacular psychotic decompensations and hospitalizations. He did not have negative symptoms. I believe that they did not have different underlying biological conditions. I believe that how they responded to their illnesses effected their outcomes so profoundly that it changed diagnostic categories. I'm certainly not advocating rebelling against all treatment, especially medications. I do think we should consider if we really need to make people into "chronic mental patients" to help them. Is everything we lump together as treatment really helpful?

I met a new member of our rehabilitation program recently. She's 22 years old, had been using a variety of drugs beginning at age 15, became psychotic and after an arrest for prostitution at age 21, was hospitalized in the forensic ward for four months. She returned home and has spent the last year "resting" at home, taking medication without any symptoms. Her parents are controlling all her new SSI money, she's not using drugs or getting into any trouble. She wanted to know why I was hassling her about going back to ballet, or college, or 12 step groups, or getting a job, or a car, or dating, when she was satisfied; her family was satisfied, and her psychiatrist was satisfied. I replied that just because she'd had some serious mental and drug problem didn't mean she had to give up on the rest of her life and that it was much harder to get going again if she waited until she was 42 instead of 22.

Recently I had an SSI application returned to me because I had written under prognosis that I was hopeful. They said if I was hopeful, maybe he wasn't really permanently disabled. In an ironic way, they're right. One of the best ways to ensure permanent

disability is to have a hopeless doctor. I've met an incredible number of people who aren't trying to do something, because a doctor said they couldn't do it. So many people have accomplished things that I, with my professional experience and training, absolutely knew were impossible, that I've entirely stopped telling people they can't do something.

One of the most pervasive rationales supporting stabilization instead of recovery, is that stress causes relapses and rehospitalizations. This is actually very hard to demonstrate. It is easy, however, to demonstrate that avoiding relapses are connected to taking medication, having an ongoing supportive case manager or therapist, having a good social support system-friends and/or family, and most importantly, not abusing drugs. Negative symptoms (low energy, poor motivation, emotional blunting, distancing, passivity, etc.) which actually predict disability better than positive symptoms or relapses, are worsened by lack of stimulation, low expectations, inactivity, and hopelessness. Or in other words, by the absence of stress. Avoiding stress avoids the opportunities to build a social network and a life and to combat negative symptoms. It is far clearer that avoiding stress reduces recovery than that it reduces relapses. Often, what we are protecting people from is the opportunity to grow. A recent observer to our program said we have an amazingly high tolerance of failures and keep trying anyway. "Normal" people all fail repeatedly and keep growing anyway. We're often too frightened to "permit", let alone encourage or support, people with mental illness to follow the "normal" developmental path of risks and growth. Sometime it seems we're protecting ourselves from the pain of their failures more than really protecting them. People often succeed on the 5th (or 10th or 20th) job, or apartment, or substance abuse recovery attempt, or girlfriend, or self- management of medication attempt, or whatever. It's our job to keep hope alive, and support ongoing stress and risk taking, through the failures and successes as they recover.

We approach each new person with schizophrenia - regardless of their age, regardless of their response to medication, regardless of their efforts towards rehabilitation and recovery - with chronic disability payments and unemployment, chronic dependency and protectiveness, and chronic social isolation and segregation. For no other medical condition are these the desired outcomes, except maybe leprosy. Behind our scientific rationales for this approach, I believe lurk, stigma and fear. If we see someone in the grocery store stacking cans in a wheelchair, we think what a heroic effort; look at how well that person is going on with life despite their handicaps. If we see someone obviously retarded working, we react the same way. If we see someone obviously psychotic, talking to themselves, making strange gestures, working, we do not react with praise or admiration. We react with fear: Should that person really be here? Shouldn't someone be taking care of them? Are my children safe around them? This fear is irrational since people with mental illness are not more dangerous than the general population, except in so far as they use more drugs and alcohol than the general population. We have to do something about our own fears to actually support people

with serious mental illnesses to recover. Those of us who are mental health professionals, have little to be proud of in this area. We usually refuse to eat with, or use the same bathroom as, or socialize with people with mental illnesses. We rarely hire people with mental illnesses to work along side us. We, with some notably courageous exceptions, rarely are open about our own mental illnesses if we have them. It's more comfortable for us to continue to take care of poor hopeless schizophrenics than to share ourselves and our communities with people with schizophrenia who are trying to reintegrate into society and recover their lives.

In Kraepelin's time, when schizophrenia and hopelessness became scientifically synonymous, about 20% of the patients in his mental institution were there because of epilepsy. Seizures were very frightening, many felt caused by demon possession. "Epileptics" were hospitalized indefinitely. Today, of course, people with seizures are welcomed into our communities and lives, even if their medications don't always control their symptoms. They may have some restrictions, like not driving. Understanding has replaced fear and stigma. I have hope that someday schizophrenia will be viewed as rationally as epilepsy.