



“Recovery is fundamentally about finding meaningful relationships, activity, work, and reaching and maintaining goals while looking to the future with hope.”

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## People with schizophrenia can—and do—recover

By Xavier Amador, PhD

“Henry has schizophrenia. He will never be the same.” My brother’s doctor said it to me as if reciting a daily meditation.

“What you’ve seen this past year—his dropping out of college, [being] unable to hold a job, and his isolation from his friends and family—will only get worse in the years to come.”

Turning from my mother, he looked me squarely in the eye and added: “I am sorry, but there is no cure and this is a progressive, deteriorating disease. He will need to be on medication for the rest of his life and you will need to develop more realistic expectations about what he can and cannot do.”

I left that meeting in shock. I didn’t understand: The medications had calmed him down, he wasn’t hearing voices, and he didn’t seem paranoid. Yes, he was groggy and slow in his thinking, but he was better as far as I could see.

It was the last semester of my senior year in college and I was about to graduate with a degree in psychology. I read all I could find on schizophrenia. Ironically, I had taken a tutorial with a psychoanalyst the year before called “The Causes and Cure of Schizophrenia.” This was a time when the field was on the cusp of a major research funding commitment for schizophrenia from the National Institute of Mental Health (NIMH), and just nine years before the launch of the Decade of the Brain, a 10-year

program designed to enhance public awareness of the benefits of brain research.

Psychoanalytic notions of the causes of schizophrenia (e.g., bad mothering) and talk of cures were dying out. In their place was a growing belief that schizophrenia was a disorder of the brain—a neurodevelopmental disorder like Parkinson’s disease. But the view that there was no hope for people struck with the disease was alive and well.

From the time my brother was first diagnosed in 1981 until the end of the Decade of the Brain at the turn of the millennium, something remarkable was happening: One by one, people diagnosed with schizophrenia were slowly coming out and saying “I’m here and recovery is possible.” The consumer movement was born. It took hold and changed perceptions about schizophrenia, the focus of research, and public policy.

This likely happened for several reasons, including the partnering of family caregivers with doctors to attack stigma. It was slightly safer to talk about having schizophrenia and then, as more people spoke out, it became the subject of books, news stories, and movies like *A Beautiful Mind*. The message was one of dignity and hope. The inevitable decline that my brother’s doctor predicted was not the only possible story to be told. Recovery was possible.

## What is recovery?

Among the most hopeful lessons I have learned from working with people with schizophrenia is that many can and do recover. But I was blind to my own brother's recovery until only the last few years of his life. I didn't see it, although he did.

What do I mean by recovery? Let me first tell you about what others have said about this vitally important concept.

In 2006, Alan S. Bellack, MD, published a review of the differing concepts of recovery in the NIMH journal *Schizophrenia Bulletin*. In this article, he contrasts the scientific community's concepts with that of consumers and other nonprofessionals.

The scientific community, of which I am a card-carrying member, comes to this question from the medical model. The Remission in Schizophrenia Working Group, comprised of leading psychiatric experts on the disorder, defined recovery as hinging on remission—to be able to function in the community (socially and vocationally) as well as be relatively free of symptoms. They concluded that symptom remission is a necessary but not sufficient step toward recovery.

Many studies that define recovery in a number of different ways have been published. Despite their differences, they tend to agree that the definition of recovery combines improvement in symptoms with better functioning in life (e.g., relationships, school and/or work). In his review of the concept, Bellack writes: "One notable limitation of these criteria is that they do not address the person's subjective appraisal of functioning or the extent to which he or she is satisfied with life. This omission would allow the untenable circumstance of a person being judged recovered by a professional... yet feeling distressed by residual symptoms, stigmatized by the illness,

frustrated by an inability to achieve one's ambitions, and hopeless about the future."

Many consumers and consumer groups offer a definition with a distinctly different emphasis. According to Nora Jacobson, PhD, and Dianne Greenley, MSW, in an article they published in *Psychiatry Services* in 2001, the essential elements of most consumer-defined recovery models involves both internal and external conditions. Internal conditions include attitudes and processes that lead to change, while the external conditions are the experiences, policies, and practices that lead to recovery.

## Lessons I have learned

When I compare consumer-oriented to scientific definitions of recovery, it is readily apparent that the former evolved from very different perspectives, histories, and goals. While scientific definitions focused on a clinical/disease model and the goal of advancing research, consumer definitions evolved from something very much like the civil rights movement. The consumer-oriented definitions of recovery had different goals (e.g., raising consciousness among consumers and their families and changing mental health policies). Rather than researchers, the target audience was consumers, family caregivers, politicians, policymakers, and clinicians.

In the 1980s, I became aware of a growing group of consumers and family members who were voicing extreme dissatisfaction with a paternalistic and failing mental health system. Among these voices a continuum of views existed. At one end, the consumer movement vilified professionals and saw traditional mental health services as causing more problems than it solved, promoting hopelessness and helplessness, causing dependence, and increasing stigma. These consumers and family members identified

themselves as survivors not of mental illness, but of the mental health system. I know my brother Henry and I felt that way—at least in part—for a long time.

On the other end of the spectrum, a more moderate view was expressed. Mental health professionals often failed to promote a sense of hope and optimism, did not give consumers choices, and did not see the value of actively including consumers and family members as partners in treatment. This view is more hopeful because it does not presume a failure to care, only a failure to focus efforts on the bigger picture and the subjective experience of persons with schizophrenia, and on the concerns of their loved ones. This more moderate view is the one I hold today, and I believe it was Henry's view for the last several years of his life.

## My brother's recovery

From a strictly scientific perspective, Henry Amador never recovered. Despite nearly 100 percent adherence to treatment, he continued to exhibit symptoms and was unable to find employment. But from Henry's perspective (and mine), he was managing the symptoms well, both with medicine and coping strategies he had learned over the years, and he had found work. The work paid nothing in dollars but much in the currency of self-respect, dignity, and meaningful activity. And for the last year of his life, Henry had a girlfriend. Mary was someone he talked to every day; they took long walks and they took turns buying each other breakfast at the local diner.

Henry, and others like him, taught me that recovery is fundamentally about finding meaningful relationships, activity, work, and reaching and maintaining goals while looking to the future with hope. It is, I believe, a far more inclusive and hopeful understanding of what recovery is. ★