

Recovery: What Helps and What Doesn't

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For the past 15 years, I've been compiling a *Bibliography of First Person Narratives of Madness*, which includes hundreds of stories of recovery like the ones we've heard throughout this Congress. This bibliography is now about to be issued in its 5th edition, with more than 900 first-person accounts dating from the 15th century up until this year. (And these are just the ones that have been published and are in English; no one knows how many others exist in other languages, or in the form of blogs, videotaped testimonies, oral histories, etc.). There are also an increasing number of narratives by family members of psychiatric patients. The people who've written these first-person accounts of madness have had diagnoses of schizophrenia or major depression or bipolar illness or personality disorder; they're people who've experienced every conceivable form of psychiatric treatment, people from every kind of community, living in every kind of circumstance – rich, poor, black, white, treated in public or in private facilities – people who would otherwise have very little in common with one another. The one powerful link they share is their belief in recovery, a belief grounded in testimony, the evidence of experience.

In all the work I've done for the past 10 years as a professor of psychology – research, writing, speaking at dozens of different kinds of conferences and meetings – I've tried to show how our basic assumptions about mental health and mental illness and about how

the mind works have to be radically reconceived if testimony is taken as the starting point. The evidence of experience is complex, layered, and emotionally powerful, in ways that statistical findings or research data never seem to be. So, before I talk specifically about what is now known about what helps and what doesn't, I want to focus for a few minutes on evidence itself. Because how we decide what is true and what is not in psychiatry has never been simple or straightforward.

There's a lot of discussion these days about evidence-based medicine, and the importance of using only approaches that are "proven to be effective." But who decides what is "evidence" or "proof" or "effectiveness"? And what criteria do they rely on to make these judgments?

Scientists like to think of themselves as "objective," and media reports of scientific studies reinforce the idea that research and data are based on technical procedures that are not political. But in psychiatry these efforts are much less successful, because money from the pharmaceutical industry, acrimonious debates in the American Psychiatric Association about what diagnoses to put in the Diagnostic and Statistical Manual of Mental Disorders (DSM), and the obvious inadequacies of existing modes of treatment make psychiatric knowledge seem far from neutral or certain.

I'm not going to focus on the examples of obvious bias which have been exposed in many recent books and articles – the reports of research that are ghostwritten by drug company contractors; the psychiatrists who fail to disclose conflicts of interest; the government agencies like the Food and Drug Administration in the US that yield to pressure to relax their standards for testing a treatment before it is approved for use, and

so on. I want to talk instead about a more basic issue – what kind of data are taken as evidence in psychiatry in the first place.

Let's start with a key example – the randomized controlled trial. This is a particular way of organizing a research study that involves putting people into at least two groups, to see whether a certain treatment works better than some alternative (which might be another method or no treatment at all). The key component of this research paradigm, the part that is considered its greatest strength, is that people are assigned to each of the two or more comparison groups on a *random* basis. This is what ensures that you don't end up with all the men or all the people who are very unwell or all the Afro-Caribbeans in one group rather than the other. Well, fine, but people aren't "variables." They have their own frameworks of meaning, their own ways of making sense of their suffering. And if they're in a research study, how they *think* and *feel* about the "treatment" to which they have been "randomly assigned" has a huge effect on whether it "works" or it doesn't.

When you do research in chemistry or in geology or in astrophysics, the molecules or rock layers or planetary movements that you are studying don't have a viewpoint about their own behavior. They don't feel frustrated or relieved to be in a research study; they don't hope desperately that the method will work or resent being experimented on. But in psychiatry, of course, people feel all these things and much more. Their personal histories crucially shape their response to any intervention and determine how it will be interpreted. There's absolutely nothing random about their thoughts and experiences, and to assume otherwise is either bad science or immorality.

What I am suggesting here is that much of the structure of psychiatric research is flawed from the start. The randomized controlled trial, often called "the gold standard" of research designs, is a method designed for testing drug effectiveness. It cannot meaningfully be used to assess other types of intervention. Psychotherapy, for example, requires a good "fit" between therapist and patient to be effective; the idea of assigning clinicians randomly to determine whether psychotherapy works essentially undermines the whole logic of the method. Peer support is even less amenable to being studied using a randomized trial; imagine how effective it would be to put someone randomly into a support group, regardless of whether its values, interests, and goals fit their needs personally. The reason I am stressing these issues of methodology is because we need to become much more aware of the extent to which the general criteria for "evidence" in psychiatry have been distorted by the use of procedures that take drug treatment as their paradigm. If the very definition of what constitutes a well-designed research study rules out the possibility that approaches other than drug treatment will be taken seriously, then we simply can't accept the so-called "outcome data" uncritically. That's why I'm not organizing my talk today around the kinds of findings about recovery that are typically reported in professional journals in psychiatry and clinical psychology.

So, returning to my key question, "what *does* help in recovery?", I want to focus instead on what we have learned from the evidence of experience, from people's testimonies.

Based on my study of hundreds of first-person accounts, I think there are *four* main factors that are key. No matter how recovery is defined – which is itself a complicated, politicized issue to which I will return later in this talk – there are four factors that people identify as crucial:

1. Being listened to

2. Being believed
3. Having an empathic witness to their suffering
4. Being seen by at least one key person as capable of becoming fully well

These four elements are present even in accounts that are otherwise radically different. Diagnosis, gender, age, nationality, type of treatment – none of these factors is as important as the four elements I just mentioned.

In other words, in striking contrast to what most mental health professionals assume, it isn't a question of deciding which treatment works best (as if one treatment *would* work best for everyone, regardless of experience or circumstances). Instead, the issue is whether there is a match between the explanatory frameworks of doctor and patient as to what caused the problem and what will help to reduce the distress it is causing, and whether the four factors I just outlined are present.

Let's take each one of these in turn. **Being listened to** is crucial to creating a coherent account of your own experience. This is true for everyone, regardless of their mental health history; it's impossible to make sense of what has happened in your life without the opportunity to narrate it to another person. And when people experience extreme states, or very intense emotions, or voices, visions, or unusual sensations, it's even more essential to have someone who will listen uncritically to what they are going through. Often, the only way to make sense of your own experiences is to try to describe or depict them to other people. Being listened to is an essential part of constructing the scaffolding upon which a life narrative can be built.

Being believed is equally important, especially if your account includes trauma or distressing or unusual feelings, events, or actions. Even if the other person hasn't gone through anything similar, their capacity to convey an unambiguous sense of believing what you say can help you to articulate and remember parts of your own experience that might otherwise be forgotten or denied. Being believed is also the key first step in sorting out which of your feelings and actions are normal responses to extreme circumstances.

Having an empathic witness to your suffering is essential to being able to work through trauma of any kind – whether in the past or the present, in the psychiatric system, the family, or in some current situation. Much of the distress of voices or extreme states comes from the isolation and fear that can make a person question what's real. Unless you have someone who can be a witness to your suffering, who can see what you are going through and empathize as a fellow human being, you can't start to work through these feelings. They remain urgent, often overwhelming, until someone acknowledges the reality of the trauma and makes it possible to begin integrating it meaningfully into a broader life narrative.

Finally, **being seen by at least one key person as capable of becoming fully well** is absolutely essential to recovering. By definition, states of despair or anguish of any kind threaten to extinguish a person's capacity to hope. Without at least one person in your life holding on to the potential for you to change, to move forward – however you yourself define that – it's impossible to imagine yourself being different from how you are now. No one can recover their sense of a unique and valued personal identity, their capacity to hope for a life less filled with suffering, or the ability to reach important

personal goals without at least one key person in their life believing in those possibilities and cheering them on.

So, we can now see precisely which factors **do not** help to promote recovery:

1. Being lied to, or not told important information
2. Not being believed, especially about trauma
3. Having no one who can be an empathic witness to what you have endured
4. Being seen as incurable, or as having a lifelong illness, from which recovery cannot occur

It's a tragic fact for so many of us that the psychiatric system often embodies precisely these four "anti-recovery" elements.

The self-fulfilling prophecy is one of the most powerful phenomena in psychology. It can keep a person from recovering, no matter what the circumstances. Regardless of how powerful or targeted a treatment or intervention of any kind is intended to be, recovery depends hugely on what the person *herself* experiences as healing. In other words, for any approach to be effective, the person has to believe in it, and see it as an appropriate response to her own needs.

Because it's **not** the type of treatment in and of itself that determines whether something is experienced as helpful. That's the mistake psychiatrists keep making, to think that it's medication versus psychotherapy versus X, Y, or Z. All of these methods (and many others, including ECT) work for **some** people and not for others. That's been true throughout psychiatry's history, and it's just as true today. (Indeed, I've been arguing for years that the only generalization that can realistically be made about treatment in

psychiatry is that every method that has ever been developed works for **some** people and not for others.) The key issue is whether there is a **match** between the frameworks that the patient and the doctor are using to understand and intervene in what's happening.

Let me give just one example of this. Joanne Greenberg, author of *I Never Promised You a Rose Garden*, strongly shared the view of her therapist, Frieda Fromm-Reichmann, that buried memories and experiences of childhood suffering were at the root of the disturbed behavior that had landed her in a locked ward as a teenager. An intensive four-year psychotherapy was what allowed Greenberg to become fully well for the first time in her life. In contrast, Carol North, author of *Welcome Silence: My Triumph over Schizophrenia*, thought that there was a toxin in her body causing the voices and visions that had been tormenting her for years. When her doctor started treating her with an unusual version of kidney dialysis which filtered her blood and removed what they both assumed were the toxic molecules causing her symptoms, she recovered completely. Even though Greenberg and North were very similar in many respects – age, gender, racial background, symptoms, diagnosis, etc. – radically different approaches worked for each of them because there was a match between their own frameworks of understanding their distress and the interventions their doctors introduced. Once this match of assumptions and metaphors is in place, and the four elements I described above are present, then recovery can happen. And under these conditions, **many** types of intervention are effective.

"Recovery" is a term that is increasingly being used in the traditional world of mental health. Regardless of whether you think this is a useful development or a way of co-opting more radical thinking, there's no question that having a mental health system

focused on recovery rather than lifelong illness is a good thing. But we'd all be better off – including the psychiatrists – if we listened to what people have to say about their own experience of healing, instead of assuming that we know what "recovery" means or that it means the same thing for everyone.

Over the past few weeks, the US government agency responsible for mental health policy (whose name is SAMHSA, which stands for Substance Abuse and Mental Health Services Administration) has been running an online forum for people to express their views on what are termed the "Guiding Principles of Recovery" and to vote for a new "Definition of Recovery" that the agency can adopt for widespread use. SAMHSA says that it wants this "working definition of recovery to help policy makers, providers, funders, peers/consumers and others to design, deliver, and measure integrated and holistic services and supports to more effectively meet the needs of individuals served by behavioral health systems."

It sounds silly to be deciding what recovery is through a process of online voting, but at least it's more democratic than the standard way government agencies operate, with some bureaucrat or group of bureaucrats sitting around a table in an airless conference room making up whatever definition they personally think is appropriate. We'd all rather have mental health policy guided by the views of those whose lives are being affected. But the way that the issue has been framed by this agency of the US government makes it very difficult to effect real change in how recovery will be understood.

To understand what I mean, listen to what they say on their website:

Through the Recovery Support Strategic Initiative, SAMHSA has delineated four major dimensions that are essential to a life in recovery:

- **Health:** overcoming or managing one's disease(s) as well as living in a physically and emotionally healthy way;
- **Home:** a stable and safe place to live;
- **Purpose:** meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society; and
- **Community:** relationships and social networks that provide support, friendship, love, and hope.

Now, some of these ideas sound great; who could dispute the importance of a stable and safe place to live, or social networks that provide support, love, and hope? But can these goals really be achieved if the starting assumption is that people have "a disease" called mental illness that they need to "manage"?

During the two weeks that the online forum allowed people to vote on the definitions and principles of recovery, one of the comments receiving the most votes was: "recovery means fewer days experiencing hallucinations and delusions." Statements like these are hardly surprising given the "managing your disease" assumption inherent in the way the forum was structured.

So, we have to applaud Sera Davidow from the Western Massachusetts Recovery Learning Community and Oryx Cohen and Dan Fisher from the National Empowerment Center who showed how direct action can be effective even in these skewed circumstances. They championed a definition of recovery based on the rallying cry of the disability rights movement – "Nothing about us without us" – which inspired more than 1000 people to vote for the Western Massachusetts Recovery Learning Community's guiding principles of recovery which include: "self-determination and choice, mutuality, optimism, respect, and genuine human relationships."

Of course it remains to be seen whether SAMHSA will in fact rewrite its policies to reflect these principles, which got the most votes. But what this whole experience certainly shows us is that an organized response by the psychiatric survivor community can have powerful results. Regardless of what formal policies SAMHSA or any other government agency elsewhere in the world puts into place, the Hearing Voices Network and the broader survivor movement can continue to embody ways of understanding recovery that can transform the thinking of others.

One reason that the peer support movement is growing so rapidly in psychiatry is that it is founded on those four essential qualities I described earlier as crucial: being listened to, being believed, having an empathic witness, and someone who sees you as capable of becoming fully well. Every single time a person goes to a peer support group, she can feel confident of getting those four things from the group. Unfortunately, no setting within psychiatry is likely to match this, which may be why professionals tend to downplay the importance of patients helping each other.

Hearing voices support groups in particular offer something of crucial importance, something people rarely get anywhere else – validation for even inexplicable or extreme states of mind, and a sense of shared experience with others who have faced similar challenges. So many people who have been helped by HVN or by the other support groups it has inspired – like those in the paranoia network – say they felt like "aliens" or "monsters" until they met others who had gone through similar experiences. Feeling like a human being is absolutely crucial to anyone's recovery, yet it's a sad fact that the psychiatric system can't be counted on to provide this assurance. (Of course it should, and sometimes it does, but unfortunately not often enough.) Patients give up on doctors who insist that their experience isn't actually happening or that their feelings aren't real.

In fact, the most important obstacle to recovery at present is the mental health system's skepticism about whether it's possible, indeed frequent. Here's where frameworks of meaning re-enter the picture. If your doctor believes that your voices are evidence of a mental illness called schizophrenia, which is caused by a dopamine imbalance whose underlying mechanism is unknown, he won't think that you can recover, because there's no treatment he's aware of that can accomplish this goal. In other words, since professionals assume that only their methods count, if these don't work, or if they don't work well enough for enough people, the inescapable conclusion is that recovery from schizophrenia cannot occur. But once each of the terms in this equation is challenged, as HVN has done for the past 25 years, it becomes clear that it's these assumptions about "schizophrenia" and "dopamine imbalance" and "treatment" that are the real impediments to recovery. It was only when patients started going off on their own to help one another that a more nuanced and optimistic view of recovery could emerge.

One of the key assumptions of this new viewpoint is that recovery doesn't mean one general thing; it varies significantly for different people. One person might feel that getting married or having children or buying a house or being able to reach career goals is the mark of recovering. But others wouldn't have chosen to do these kinds of things even if they'd never ended up in the mental health system. To define their recovery in conventional terms like marriage and family doesn't make sense, given their broader sense of themselves. It's disrespectful and simplistic to think that "recovery" could mean exactly the same thing to people who are otherwise very different – in politics, values, culture, or family background. We need to celebrate this diversity and not use mental health status as a rationalization for conformity.

In the feminist movement, we used to say that we'd know we had succeeded when a mediocre woman could be as successful as a mediocre man (i.e., she wouldn't have to be a superwoman just to reach ordinary goals). So I'm looking forward to the day when people with a history in the psychiatric system aren't held either to much higher or much lower standards than everyone else, and can choose to live in whatever ways they themselves define as most meaningful and fulfilling.

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