The Meanings of Madness

Gail Hornstein speaks about her recent book

Mount Holyoke College psychology professor Gail Hornstein has always had an interest in first-person portraits of mental illness: accounts often created by patients with minimal supplies, sometimes smuggled out of the asylums where they were recorded. Her book, *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness*, began as a means to underscore the importance of such narratives. In her introduction, Hornstein writes, "Madness is more code than chemistry..." The project quickly became more. From nineteenth-century German asylum inmate Agnes Richter's inscrutable embroidered jacket-turned-document, to testimony from contemporary peer support groups, she creates a portrait not only of the complexities of mental illness, but of its frontiers. Her book offers fascinating possibilities for a world in which mental patients might be welcomed into a more active role in both their own treatment and humanity's search to understand of the mysteries of sanity.

Gail Hornstein

You describe patients being sedated against their will, receiving electric shock therapy; how prevalent is that sort of treatment in America today?

What we have instead are short-stay psychiatric wards in general hospitals. And we have prisons. That's where mental patients are typically institutionalized. Involuntary treatment is, unfortunately, still very, very common, including involuntary shock treatment and medication.

Describe the book's premise.

What I'm talking about is the crucial importance of listening to people's own accounts of their experience, so as to make sense of it. It's not that the medical model can't be helpful to people. But the medical model which conceptualizes people's emotionally distressed states as mental "illness" often focuses attention away from people's *description* of their experience. My core claim, which comes directly from talking to hundreds of people who have had these experiences, is that the emotional state and the forms of thinking that get diagnosed as mental illness have *everything* to do with people's own descriptions of what their experience is like. Understanding what someone's experience is like is key to helping them get better. [Pure] medicalization of the situation, within our present knowledge of "mental illness," is very, very inadequate.

You write, "We are hugely dependent on the reactions of others to make sense of what is happening to us..."

If both of us were in the same room and suddenly we heard a loud noise, the first thing we would do is look at one another and say, "Did you hear that?" Now, if I said, "did you hear that?" and you looked at me as if I were nuts and you said, "no, I didn't hear anything," I would start to wonder what was going on in my own mind. But if you said, "yeah! I heard that!" Now it's a normal reaction. There are thousands and thousands of experiences that all of us have all the time like this. A lot of what gets diagnosed as "mental illness" are unusual states of mind, unusual perceptions that aren't shared by others.

Are you suggesting the diagnosis is somewhat subjective?

I'm saying "mental illness" has to be put into quotes, because it's so contextually based. It's so variable in different historical contexts, in different cultural contexts. It's not like if you have diabetes and you go to a doctor and they look at your insulin level in your blood. There, you've got a metric. Any doctor looking at that metric can say, "This is an abnormal level." You don't have that in the world of psychiatry. A person can come with a set of symptoms, and they'd be diagnosed one way in one country, and another way in another country. Or one way by one psychiatrist and another way by another psychiatrist.

Where does this leave chemical imbalances and other biological explanations of mental illness?

"Chemical imbalance" is a phrase that was invented by the marketing arm of pharmaceutical companies in the 1990s to help sell psychiatric medications. There's no way to measure such a thing. There's no "balance" against which to assess a "chemical imbalance." So, if someone says you're depressed, [an explanation] that's usually used is "you have too much of a certain neurotransmitter in your brain." It was never the case for you or for anyone else that the "normal" levels of that neurotransmitter were measured against which your so-called "imbalance" could be assessed. There is no way to measure these things; there's only people's descriptions.

If they said, "Take these drugs—sometimes they work though we don't know why," nobody would buy them?

Exactly, although that's a more correct statement. That's why I think talking to people who have themselves experienced emotional distress is an absolutely core part of our understanding. Many people for whom medications have some positive effect are also distressed by the fact that these same medications have many, many side effects that tend to get worse over time. Sometimes these medications are helpful for them for a period of time, but then they stop working. Or, the person develops a toxic reaction to them, which can happen with any medication a person is on for a number of years. What could that person have been doing all along to learn some better coping strategies to deal with the difficulties in their lives, in addition to or aside from taking the medication?

Drugs alone aren't the cure?

One of the key claims of my book is that, when people experience very, very distressed states—the kind that get them diagnosed with things like schizophrenia—typically something traumatic has happened to them. So if a person has, let's say, sexual abuse over a period of time, which is very, very common precursor to having hallucinations: what do we mean when we talk about "curing" that problem? What I would mean is helping that person work through the reality of what happened to them.

Being able to integrate it?

"Integrate" is exactly the right word to use. You need to have a context to work through it, whether that's psychotherapy, or a peer support group, or journaling, or a variety of other things people to do to make sense of difficult things that happen to them.

It can be difficult to separate our response to mental illness from cultural feelings about being "in control" of our mental capacity. Perhaps it's easier to turn tangible medical approach ?

Let's think about a category like attention deficit disorder. Think about those words: "attention *deficit*." That's making a presumption that there is some "normal" level of attention, of which you have a deficit. Now, the people to whom that label is most often given are boys, seven, eight, nine, ten years old. One of the things that we know about boy behavior is that boys of that age tend to be very active; they're very interested in sports, they're very interested in running around. Now if they're in a school, where the budget has been cut, and there are more children in that class than really should be, and the teacher is not getting adequate compensation to be able to meet with the children individually if they're are having difficulties—we see a context in which the creation of a diagnosis like ADD, with its medication, fits perfectly. This diagnosis has only recently been invented. Why didn't we have that category 30 years ago? Well, we could say it's because we didn't understand enough about the brain. Or, we could say its because we had classrooms with more teachers.

Tell me about the Hearing Voices Network.

A minority of people are able to find a psychotherapist who will help them explore the meaning of their experiences. But the average person with a psychotic diagnosis does not have access to psychotherapy, and is only given medication, which works sometimes but not other times. I've seen this movement—Hearing Voices Net-

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work—begin in Britain about 20 years ago, and it's spread all over the world. It began as a result of people being frustrated with this method of treatment; wanting to have the opportunity to think about why [they are] hearing these voices.

These groups are not therapy groups. They are not run by a mental health professional, they are not intended to change people the way a therapy group is. They are *peer* support groups. Typically, they have facilitators, often a voice hearer and someone who is sympathetic to the peer approach. Hearing Voices groups help people make sense of their own experiences, and figure out what coping strategies could they adopt to enable them to deal with this experience and help them get past it besides taking medication or going to a psychiatric hospital.

Since the publication of the book, I've helped to start such a group here in Holyoke, Massachusetts, which I co-facilitate Oryx Cohen at the Recovery Learning Center.

Has your work changed your thinking?

I've amassed quite a bibliography of first person accounts of madness, written from as long ago as the 15th century to as recently as last year. What is clear to me from those accounts is that people who have experienced mental illness want us to say we really don't *know* the causes. The more we take an attitude of humility, the better this will serve. Even people who have been very seriously distressed *can* get better. I'm really optimistic and hopeful, based on my experiences talking to so many people who have experienced mental illness firsthand.