

A conversation with ...

PSYCHOLOGY PROFESSOR GAIL A. HORNSTEIN

Looking beyond medicine to treat mental illness



GORDON DANIELS

Gail Hornstein, a psychology professor at Mount Holyoke College in South Hadley, says her research has convinced her that those diagnosed with mental illness can help one another cope with their symptoms.

By SUZANNE WILSON
Staff Writer

THE jacket in the title of Gail A. Hornstein's new book, "Agnes's Jacket: A Psychologist's Search for the Meanings of Madness," was made by a woman named Agnes Richter who spent years locked away in asylums for the mentally ill in Germany in the latter half of the 19th century.

"I've never been in the presence of an object this powerful," writes Hornstein of coming face-to-face with the jacket in 2004 in a museum in Heidelberg, Germany.

Richter, the story goes, was a seamstress who made the jacket for herself out of ripped-up scraps of hospital uniforms. But it's not its design, Hornstein writes, that draws scores of people to see it: "It's the intricate text that has been embroidered in five colors over practically every inch of the garment, a needle-and-thread narrative unlike any other."

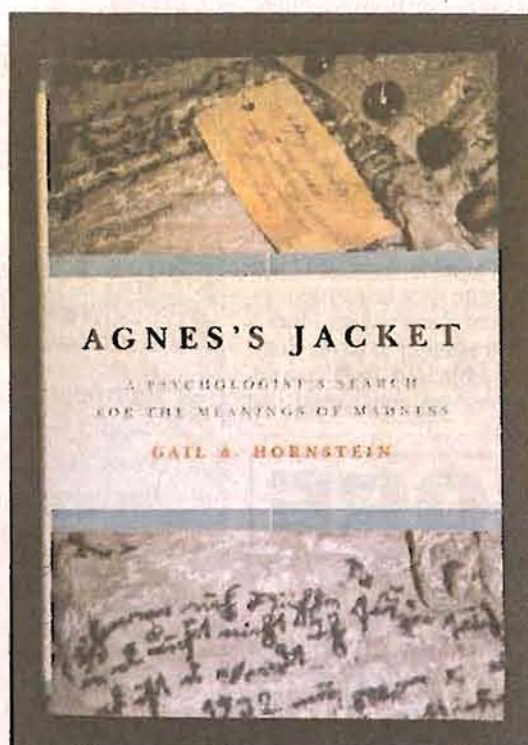
Art historians have long puzzled over the text, which may have been written in a formal, old-fashioned German script that is no longer used. Time and wear have blurred many of the letters, rendering most of the words indistinct,

if not impossible to read. A tag attached to the jacket long ago suggests Richter used the garment as a kind of diary.

For Hornstein, a professor of psychology at Mount Holyoke College in South Hadley, Agnes' jacket is a powerful symbol of the life stories many mental health patients have tried to tell: "What if the mad are trying to tell us something? What if their 'ravings' contain important information? Just because they're difficult to decipher doesn't mean we shouldn't try to make them out. ... What happens if we listen more closely to what people like Agnes are trying to tell us?"

Hornstein's book explores the divide between two theories about the causes of mental illness: the biological point of view that holds that it is a chemical imbalance in the brain that can be treated with medication; and the view that traumatic life events play a crucial role in mental illness and that peer support can help people recover from even major illness such as schizophrenia. Hornstein says the United States, even though the "inventor" of the self-help concept, has been slower than other countries, such as England, to explore its use in the treatment of mental ill-

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Gail Hornstein's book describes how personal stories can be instructive in the treatment of mental illness.

A conservation with psychology professor Gail A. Hornstein

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ness. "We seem to think that peer support is fine for bereavement or cancer support," she said, "but not for serious mental illness."

Her focus is on major forms of illness, such as schizophrenia, psychotic depression or bipolar disorder. "No one knows what causes mental illness," she writes, "much less what leads an individual to break down."

Hornstein, who researched patient narratives and oral histories in addition to doing many of her own interviews, contends that evidence supporting the biological approach is "mixed at best" and, further, that it has failed many psychiatric patients.

Hornstein emphasizes that she is by no means opposed to medication — only to having it be used as the sole or best treatment. "For some people, medication is effective. ... For some people it's effective only for a while, and for some it never works. It's just too limited to think that medication is the be-all and end-all."

Key sections of the book discuss the work of the Freedom Center, a Northampton-based advocacy group for people diagnosed with mental illness. Founded seven years ago, the Freedom Center stresses choice in treatment. Run by people diagnosed with mental illness, the center offers support groups and other activities aimed at helping to control psychotic episodes.

"Northampton should be particularly proud," Hornstein says, "because it's one of the leading activist and support organizations of its kind in the country."

In the United Kingdom, she attended meetings of the Hearing Voices Network, comprising more than 160 support groups for those who hear voices in their heads. The members say that talking about their voices, and their feelings about them, helps them cope with what can be frightening experiences, Hornstein said.

Impressed by the work of the HVN in Europe, Hornstein became a trained facilitator and now co-leads a Hearing Voices group, one of the first of its kind in this country, that meets at the Recovery Learning Community in Holyoke. (See box.)

Hornstein will talk about her work and her book tomorrow at 6:30 p.m. at the Holyoke Public Library, 335 Maple St.

What follows are edited excerpts from a recent interview with Hornstein at Mount Holyoke.

Q: How did you get interested in first-person accounts of madness?

A: I began reading them when I was a teenager and I just found them very gripping, very interesting. Later, when I was a graduate student in psychology, I was so surprised that these accounts weren't considered our

For more information ...

■ Gail Hornstein will discuss her book, "Agnes's Jacket: A Psychologist's Search for the Meanings of Madness," tomorrow at 6:30 p.m. at the Holyoke Public Library, 335 Maple St.

■ The Freedom Center, based in Northampton, offers a nonjudgmental, inclusive support group that is pro-choice regarding treatment for people labeled with mental disorders, on Thursdays, from 7 to 9 p.m. at 43 Center St. Enter at the side door. For information call (877) 677-6424 or email FreedomCenterInfo@gmail.com or go to www.freedom-center.org.

■ A hearing voices group meets at the Recovery Learning Community at 187 High St., Suite 303, Holyoke. This is a drop-in group; preregistration is not required. For information, contact Oryx Cohen, co-director of the RLC and co-facilitator of the group, at 539-5941, Ext. 202.

major source materials about how the mind works, or how madness works. The idea that we have nothing to learn from these people strikes me as very wrong.

Q: Some of those accounts, as you point out in your book, are very well-known — even if they're discounted by medical professionals.

A: People have always been interested in reading these books — like "The Snake Pit" [by Mary Jane Ward], "I Never Promised You a Rose Garden" [by Joanne Greenberg] or "Darkness Invisible" [by William Styron]. People gravitate to them because they know these people are speaking from their own experience.

Q: I liked the fact that you put yourself in the book, and structured it to reflect your own discoveries and own reactions. What led you to that approach?

A: I'm writing about first-person narratives, people giving accounts of their own experience. One of the things that has always been complicated for mental health professionals is that they're always put in the position of giving accounts of other people's experience. ... This felt more honest to me, it didn't make me so different from the people I was writing about.

Q: How did you get people to talk to you?

A: The way I gained access to peer support groups was by saying to people, I'm not a therapist, I've never given anyone a medication, I've never put anyone in a hospital. I want to understand how the mind works. I think you understand something important about it and I want to learn from you.

Q: How does a peer support group help someone, for example, who hears voices?

A: I think people get a much more nuanced understanding of their own experience, a framework for understanding. They can talk with others about when the voices are the worst

and when they're less worse. What are the triggers? What could they do at those moments to have better control? What I find so admirable is that these groups are pragmatic. No one method will work for everyone, but there's an open-minded, nonjudgmental attitude about trying. People are taking on the challenge of figuring out for themselves, what helps me? What coping strategies work for me?

Q: You use neutral phrasing such as "people who have been diagnosed with mental illness," or "labeled with mental illness." Why do the words or names matter so much?

A: I think it matters because it's more accurate. ... It's better than describing them as people "suffering" with mental illness, because they might not be suffering right now. People have better times and less well times. You may have received that diagnosis 10 years ago and it may be more or less relevant to your current experience.

But more to the point, some people get better, even from the most serious mental illnesses like schizophrenia. What my book is about is the fact that they do get better — and second, how they get better.

Q: Where's the evidence for that?

A: There's plenty of evidence already there and it has not been knocked down. It's been ignored, and that's an important point.

In the book, I talk about some very famous studies done by the World Health Organization in the late 1990s. They looked at the incidence of schizophrenia in many countries and the extent to which people recovered from it. They looked at developing countries, such as Nigeria, Colombia and India, and developed countries, including the U.S., U.K. and Denmark.

The WHO staff were astonished to discover that the recovery rate for schizophrenia was

much higher in the developing countries — it was the opposite of what we would usually predict. They ... did the study again, five years later and they found exactly the same thing. Where medication was more prevalent in developed countries, people were more likely to become chronic patients. Whereas in developing countries, there was more family support, people were less likely to be sent away to a hospital, more likely to stay in their communities, and to get less medication. Why haven't the media covered this in the same way they cover the search for a gene causing schizophrenia?

Q: You write that one of the many problems with the biological view of mental illness is that it's pessimistic. What do you mean by that?

A: It's certainly advantageous to the pharmaceutical companies to have people believe they need to be on medications for the rest of their lives and that if they develop side effects, they should take another medication for that. The more complicated question is why physicians are buying into that model.

Q: Why are they?

A: In the United States, for complicated, social, historical reasons, the biological view has completely dominated American psychiatry for the past 30 years or so.

Although we lead the world in many respects of health care, with respect to mental health care, we are far behind. We have a narrower perspective, a smaller range of options, and a much, much heavier reliance on medical treatment.

Q: What's been the response to your book so far?

A: I've had a very diverse audience interested in this book. I've had family members, patients and mental health professionals of many different kinds — though I wouldn't say biological psychiatrists are flocking to my talks — who are constantly grappling with the difficulties of the current mental health system and its inadequacies.

Q: What are you hearing from colleagues who believe in the biological model?

A: I think it's very hard to have taken-for-granted ideas in your field challenged. They want to think schizophrenia is a genetic brain disease, that depression is a chemical imbalance because they've learned that in graduate school and had that view reinforced by other professionals. On the other hand, I've also had [colleagues say] that we need to discuss alternative viewpoints.

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