

Hearing Voices

Mt Holyoke Professor Gail Hornstein Offers New Model for Understanding Mental Illness

BY DAVID DETMOLD

LEVERETT — Agnes Richter, a seamstress in Austria who was incarcerated in a mental institution in the 1890s, spent years painstakingly stitching her autobiography in an indecipherable text on a jacket she made from an institutional uniform.

Gail Hornstein, a professor of psychiatry at Mt. Holyoke College and a resident of Leverett, has titled her new book after Agnes' jacket. In it, she attempts to explain the nature of madness through the voices of those who hear voices, to see mental illness through the eyes of those who see things the rest of us do not



Gail Hornstein (l) with Janine Roberts at the Leverett Library

or can not see.

In the process, Hornstein has arrived at what she considers to be something of a breakthrough in understanding what it means to be mentally ill, and how people so labeled have formed a

worldwide underground self-help movement to assist in their own recovery — not only from illness, but also from the medical profession which so often fails them.

On Tuesday, January
see VOICES pg 10

VOICES from pg 1

5th, Hornstein appeared at the Leverett Library before a crowd of about two dozen to discuss her new book – *Agnès' Jacket* – published by Rodale Press and available at bookstores everywhere.

Comfortable lecturing extemporaneously after 31 years in front of the classroom, and fervent on the topic she has researched for six years in preparation for the book, Hornstein held the audience in rapt attention.

"I wrote the book to be of interest to a wide range of people, not only people working in mental illness," she began. And she concluded almost an hour later by saying she wanted her readers to "Think about the mind in a much more complicated, creative and resilient way than we often do. We are terrified by mental illness. There's still a huge stigma attached to mental illness. We think about people with mental illness as being profoundly unlike us. And this prevents us from seeing the fundamental commonality between us all."

Hornstein said she has focused in her research primarily on people who are diagnosed with psychoses of one sort or another: schizophrenia, manic depression, paranoia and related disorders. "By definition, people who have experienced psychosis don't have any insight into their situation – their own psychic life – the ori-

gins of their distress. This is a core assumption," of the medical community that attempts to understand and treat them, Hornstein said.

Another core assumption of the psychiatric profession is that people who have suffered from profound problems like psychosis "cannot get better." Their illnesses can be managed, perhaps, but never cured.

Hornstein rejects both these assumptions.

For one thing, she provided her audience on Tuesday with a 700-title bibliography of published works called the "Bibliography of First Person Narratives of Madness – in English," exclusive of works of poetry or dramatic fiction. (See her site, www.gailhornstein.com, for a copy.)

"If hundreds of people have written accounts of their illness and publishers have published them – these aren't ravings in a bottom drawer," or apocryphal screeds stitched on a jacket sleeve – then presumably these people can and do exhibit insights into the nature of their own travails, regardless of medical professionals' ability to apprehend them.

And working together in democratic, patient-led support groups, many of which have welcomed Hornstein into their circles during her years of field work for the book, people who have survived the mental health

profession also demonstrate the ability to "get completely better," Hornstein averred, "through their own efforts and through the fundamental resiliency of human beings."

This optimistic view of mental illness, perhaps needless to say, has not met with a wide welcome among mental health professionals. Hornstein said, "Doctors and psychiatrists are nervous their special services are not the only ones that can help people."

"Of course it is the case that there are people in extreme distress who don't have any insight at the moment, just as there are people in this room who have experienced fear or anger or other extreme states for periods of time during which they don't have much insight. But to say a person with mental illness does not have insights is not only wrong but destructive."

"Psychologists do not take seriously the accounts," of former patients, or refugees from their profession, such as the hundreds of authors represented in the Bibliography of... Madness, Hornstein said. After all, these accounts often take the form of critiques of the mental health system by patients. But by denying the validity of patients' insights, Hornstein said, "We rob ourselves of the understanding of extreme states, emotional problems.... How would we understand mental illness if we looked at it from the point of view of

people who go through these states?"

In contrast to the rich, textured, and varied approaches patients take to explaining or interpreting their own experiences, Hornstein said psychoanalysts' case studies of their patients are generally couched in cold, clinical terms, invariably climaxing with their arrival at the mental institution. "From the point of view of people who experience such situations, that may not be the climax at all," noted Hornstein. "It may be an irritating sidelight."

In the course of her research, Hornstein said she "discovered there were groups of patients who had come together on their own to provide their own support or interpretation for mental health patients, like an underground movement."

She compared this phenomenon to the gay movement in the 1950s in America, where "you would know there were organizations, publications, meetings that connected you to the world of gay people, but straight people wouldn't know about them." She said this "alternate way of thinking about and coping with the world of mental illness," is taking place, by and large, "unknownst to their doctors."

Hornstein said many of these patient support groups were organized under the rubric of "Hearing Voices," and she contrasted this with the medical term

for a common symptom of psychosis, "auditory hallucinations."

"Auditory hallucinations is a pejorative term. By definition, there is something wrong with you if you're having hallucinations. Of course," she added, "we all know the major figures in world religions all had experiences with auditory hallucinations. But hey, we're living in the 21st Century. Things were different when there were burning bushes and water changing into wine."

"Mediums, clairvoyants, very spiritual people" are allowed by other cultures to "hear voices," without being labeled mentally ill, she said, but secular America pathologizes such deviations from the modern norm.

Hornstein said these patient led support groups "bring people together so they can talk about such experiences free from fear or opprobrium." She participates in one such Hearing Voices group now in Holyoke, as a facilitator. Indeed, Hornstein said, she had just come from a meeting of that group prior to her talk at the Leverett Library.

"Against everything you would think from psychiatry, the people in these groups make extraordinarily insightful and useful interpretations and help people make sense of what has happened to them, often very terrifying things, in a context where there is no judgment. The mental

see VOICES page 13

health system is all about judgment."

Responding to questions after her talk, Hornstein gave a few specific examples of how the patient support groups have helped people deal with their particular mental problems. As when one person who feared she was being poisoned through the public water supply was advised to drink bottled water from sealed bottles until she felt calm enough to deal with the source of her fears; or when a person

who imagined coded threats were being delivered to him in the form of specific configurations on car license plates on the street was helped to devise pragmatic coping strategies, while trying to understand the origins of his paranoia.

Incidentally, she said, "People with a diagnosis of paranoia would seem to be the least likely to come together in groups..." a comment that caused sudden laughter in the room, "but in fact, if you have that experience it's an unbelievable relief to meet others who

see things that way."

Hornstein offered some eternal verities about the psychiatric profession. Whether it's tossing people into snake pits, wrapping them in wet sheets, giving them shock treatment, lobotomizing them, institutionalizing them, or medicating them, there are always some people who are helped by any new treatment, others who are not. What's more, regarding psychiatric medication, the treatment *du jour*, "everyone in the field of psychiatric medicine agrees," that roughly a third of patients are helped by medications, another third are helped temporarily until their bodies can no longer tolerate the toxic side effects (or otherwise fail to respond), and another third are not helped by medications at all.

Even so, it is profoundly threatening to the institutions that exist to treat patients with mental illness that their clients may choose self-help groups rather than professional assistance as a means to a cure.

"How could it be that people with serious mental health issues could go off by themselves and help each other?" she asked rhetorically. "Think about Alcoholics Anonymous. Fifty years ago Bill Wilson started AA when 'two drunks got together in a room to help each other.'

And now the average doctor will send people with a drinking problem to AA."

Hornstein said, "This is exactly what is happening now in mental health, worldwide," as thousands of democratic groups are forming to help mental health patients help themselves.

In the process, patients are reframing the language and the paradigms by which mental health issues are discussed and understood. Like the patient leader in Britain who wants to discard the term "delusion" in favor of "unshared beliefs," citing as an example of an unshared belief former prime minister Tony Blair's obsession with Weapons of Mass Destruction in Iraq.

Hornstein said, "If your problem is you feel profoundly isolated from other people, you're hearing voices screaming in your head, those experiences can be helped by people who are deeply motivated to help you, who share your experiences."

As to the "epidemic" of young white boys in America being diagnosed now and medicated for attention deficit disorder, Hornstein said, "I think it's absurd that eight-year-olds have to sit still in their seats all day. If the only way they can get up is to have a diagnosis of mental illness they'll have for the rest of

their lives, what's wrong with this picture?"

Her prescription for her audience, whenever they come in contact with people troubled with mental problems, is to listen to them, "talk to them, let them say what they need, let them say what's frightening them, without anything bad happening to them."

She said a useful alternative to psychiatric institutionalization is being tried in Berlin, where a place called the "Runaway House" has been established, staffed by people who have experienced extreme mental states in the past, to provide a safe environment that is not a hospital where people can work through their own experiences by themselves, if they want to.

Recalling the one third or more of mental patients who find no succor with modern psychiatric medicine, Hornstein repeated the mantra of many patient support groups around the world, - "Freedom of Choice!" - and predicted that mental health system survivors, like the oppressed gay citizens of the world before them, would one day force the resistant institutions that now claim the right to enforce normative values to change, and allow their voices to be heard.

