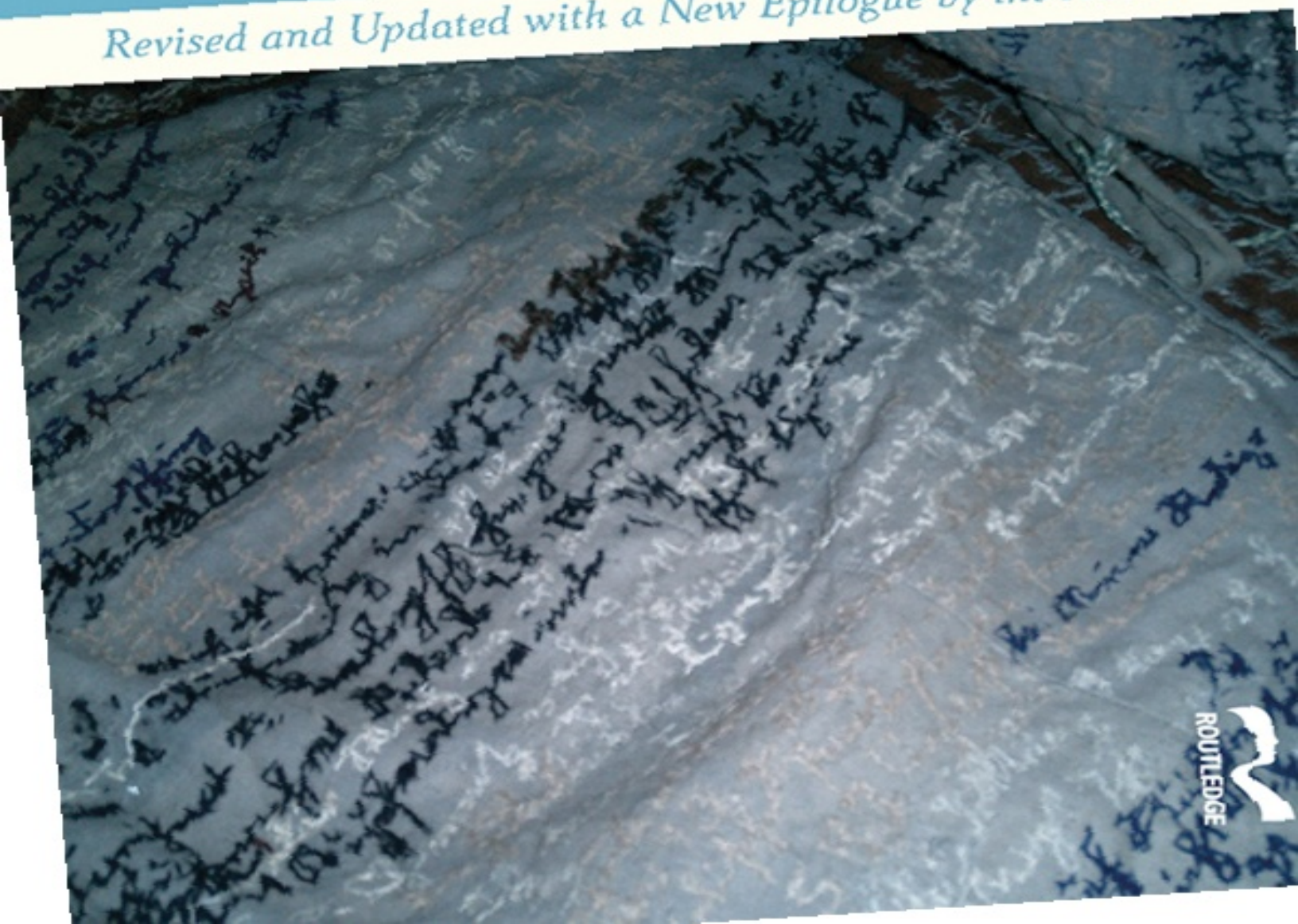


GAIL A. HORNSTEIN

Agnes's Jacket

A PSYCHOLOGIST'S SEARCH FOR
THE MEANINGS OF MADNESS

Revised and Updated with a New Epilogue by the Author



ROUTLEDGE

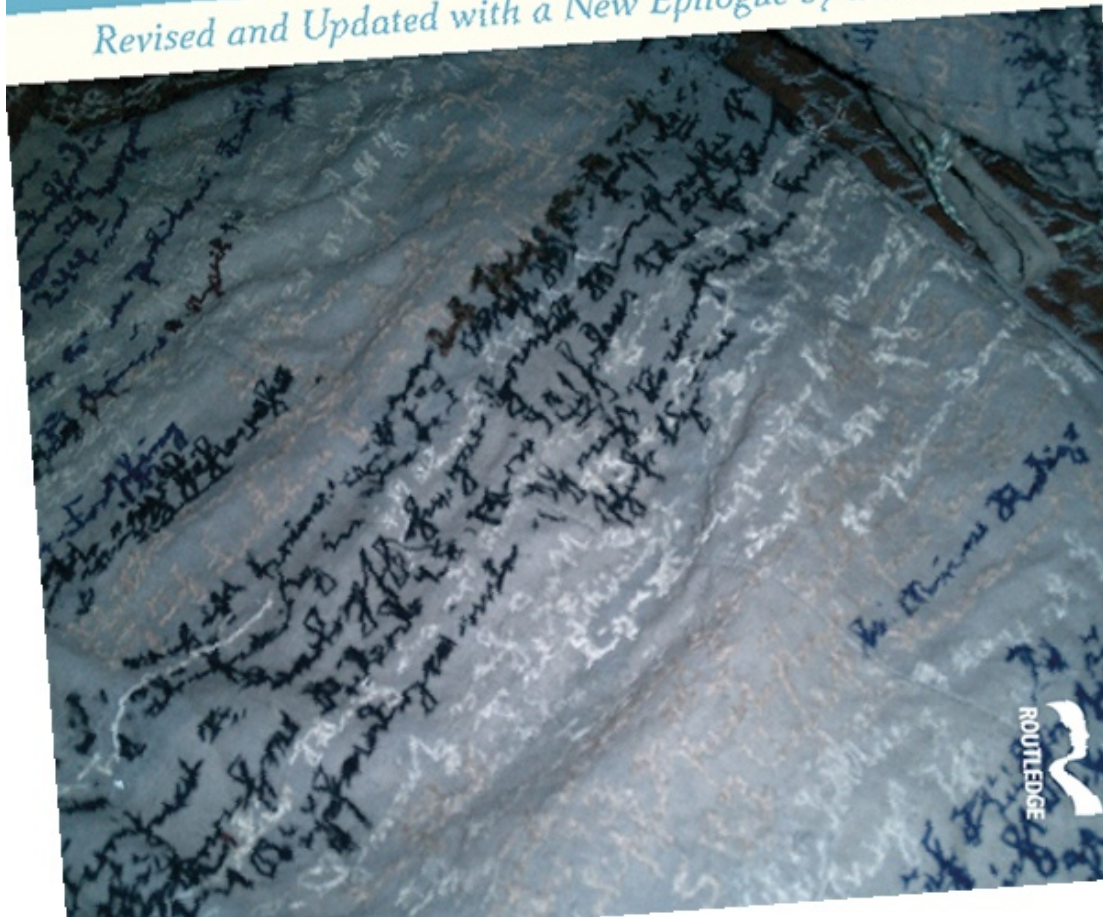


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In a Victorian-era German asylum, seamstress Agnes Richter painstakingly stitched a mysterious autobiographical text into every inch of the jacket she created from her institutional uniform. Despite every attempt to silence them, hundreds of other psychiatric patients have managed to get their stories out, or to publish them on their own. Today, in a vibrant network of peer-advocacy groups all over the world, those with firsthand experience of emotional distress are working together to unravel the mysteries of madness and to help one another recover. *Agnes's Jacket* tells their story, focusing especially on the Hearing Voices Network (HVN), an international collaboration of professionals, people with lived experience, and their families and friends who have been working to develop an alternative approach to coping with voices, visions, and other extreme states that is empowering and useful and does not start from the assumption that such people have a chronic illness.

A vast gulf exists between the way medicine explains psychiatric conditions and the experiences of those who suffer. Hornstein's work helps us to bridge that gulf, guiding us through the inner lives of those diagnosed with schizophrenia, bipolar illness, depression, and paranoia, and emerging with nothing less than a new model for understanding one another and ourselves.

Gail A. Hornstein is Professor of Psychology at Mount Holyoke College and author of *To Redeem One Person Is to Redeem the World: The Life of Frieda Fromm-Reichmann*. Her articles, interviews, and opinion pieces on the history and current practice of psychology, psychiatry, and psychoanalysis

have appeared in many scholarly and popular publications, and she speaks widely about innovations in mental health practice across the United States, the United Kingdom, and Europe. Hornstein's *Bibliography of First-Person Narratives of Madness in English* (now in its fifth edition) lists more than 1,000 books by people who have written about madness from their own experience; it is used by researchers, clinicians, educators, and peer-advocacy groups around the world.

“In one of those rare books with an accessible, readable approach to fairly hard-core research, Hornstein tells the story about her own experiences with groups of people who are eager to engage with alternative forms of psychological treatment and who are for the most part rejecting the labels and rituals prescribed by mainstream doctors, hospitals, social workers, and caretakers. ...[Hornstein] had me thinking about the very largest issues: the idea that once a person is diagnosed with mental illness of any kind, that all experience becomes filtered through and defined by that label.”

—Psychology Today

“Fascinating. ...Gail Hornstein’s volume does a superb job of introducing the reader to a plethora of nontraditional literature on phenomena all too readily excused as biological in origin today. ...”

—Contemporary Psychology

“... A remarkable book about the capacity of people with mental illness to understand their psychosis, navigate their daily lives, and support and counsel others in the same situation. ...For most practicing psychiatrists who learned to medicate psychosis aggressively but never to ‘interview’ psychosis, this book suggests a more balanced approach to treatment. ...Hornstein shows that people with psychotic episodes are ‘experts by experience’ and are helpful to others who face similar challenges. ... In *Agnes’s Jacket*, Hornstein has shown with clarity why we should listen to our patients and why we should have great respect for their listening to each other. This is a hopeful book about a devastating illness. I recommend it to psychiatrists and therapists, to trainees, to patients, and to their families.”

—Book Forum

“. ...the fascinating avenues Hornstein pursues and the humanity and thoroughness of this exploration make a serious contribution to critiques of contemporary psychiatry.”

—Publishers Weekly

“In this rich and important work, psychologist Gail Hornstein, the biographer of Frieda Fromm-Reichmann, has taken the rare step of writing a history, right up to the present, of the patient’s experience of mental health treatment – from the patient’s perspective. ☒ Hornstein makes the fascinating point that in no other branch of medicine but psychiatry do the voices of so many of the doctors and so many of the patients differ so dramatically. ...Yet from beginning to end, *Agnes’s Jacket* reads respectfully. Although the content is critical of convention, and critical to the point of eye-opening, the tone is moderate, the research substantial, the logic seamless, and the message, ultimately, redeeming.”

—Journal of the American Academy of Psychoanalysis

“Reading *Agnes’s Jacket* changed the course of my life. In this book Gail Hornstein undertakes a remarkable investigation into the experiences of people who—like me—have found themselves caught up in the ‘mad world’ of mental illness. In this compelling account of a personal quest spanning centuries and continents, seeking to better comprehend what it is to go mad, Hornstein

connects us to a whole new world of hitherto hidden networks, radical voices and marvelous stories of survival, recovery and beyond.”

—**Bobby Baker, author of *Diary Drawings: Mental Illness and Me***

“It would be difficult to over-praise this book. Beautifully written, combining intellectual rigor with the tension of a detective story, it uses historical and modern material to document the struggles and opposition faced by those called mad who simply wish to tell their own stories. A superb addition to the increasing number of critiques of the medicalization of distress.”

—**Mary Boyle, Professor Emerita of Clinical Psychology,
University of East London**

“An insightful and eloquent exploration of the subjective experiences of madness. The curiosity and wisdom of the author illuminates our understanding of the complex mysteries of the human condition.”

—**Jacqui Dillon, National Chair of the
Hearing Voices Network, England**

“An engaging and genuinely progressive piece of research and analysis. Gail Horn-stein is refreshingly frank about the complicated responses of patients, and deftly raises questions about authority, who speaks for whom, and why.”

—**Dorothy Allison, author of *Bastard Out of Carolina***

Agnes's Jacket

A Psychologist's Search for the Meanings of Madness

Revised and Updated with a New Epilogue by the Author

Gail A. Hornstein

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6

Freedom Center

Summer 2004

I return to the United States, my head fizzing with ideas and questions. How can there be a huge network of “voice hearers” in Britain that no one in America has ever heard of? How can the clinical psychology division of the British Psychological Society be reframing its approach to incorporate work by the Hearing Voices Network, whereas in the United States, clinical psychologists are fighting for the right to prescribe medication? Where are the psychiatric survivor groups that must exist in the society that invented the idea of “self-help” in the first place?

Given the far greater power of the drug companies in the United States, I can see why activists here might want to stay under the radar. But they still have to be covertly signaling their presence to potential members, the way gay groups did in the 1950s. Even though HVN is now able to be more open about its work in Britain, thanks to the National Health Service’s interest in its approach, a lot of the network’s organizing still takes place outside any formal structure, which gives me a sense of what to look for.

After several fruitless weeks of Internet searching, I get a break. The events section of my local newspaper has a listing for a meeting titled Speak Out on Madness, sponsored by a group called Freedom Center. The notice describes them as an organization “offering peer support and advocacy by and for people labeled with mental illness.” *Sounds perfect.*

It's a steamy July evening when I set off for the speak-out in nearby Northampton, Massachusetts. The Unitarian Church is right next to Town Hall, and I follow the signs around to a side entrance. An old stairway leads to a meeting room built, bunkerlike, a half level below ground. About fifty people are milling around, waiting for things to start. Many seem to be students from the Smith College School for Social Work just down the block. The others appear to be formerly institutionalized mental patients. (Here, unlike London, it's easy to tell the two groups apart; ex-patients usually don't have the money to dress well, and the budding social workers are trying to look professional.) There's a long table and a microphone at the front, making the occasion feel like a hundred other panel discussions I've attended in four decades as an academic. I take a seat in the back row and flip open my notebook. The stylish young woman next to me waves to two friends at the door, and they plop down beside her, laughing and joking about their evening of "fieldwork."

Ten minutes later, we're sitting in rapt silence like everybody else in the room, mesmerized by speakers totally different from the patients in textbooks.

Oryx Cohen, a curly-haired man in his thirties, introduces himself as the co-founder of Freedom Center. Draping his six-foot, four-inch frame around a battered wooden lectern, he talks about the deep depression he'd suffered as a college student. Feeling increasingly isolated from his classmates and lacking confidence in his schoolwork, Oryx spent weeks unable to drag himself out of bed. Eventually, he managed to complete his studies and go on to graduate school. But then the opposite happened—he couldn't sleep, started speaking nonstop, and felt he had insights to which other people weren't privy.

One day, driving down a highway in Massachusetts, Oryx decided he was no longer constrained by the laws of physics and could fly his car over long distances. He ended up in the emergency room, and then on a psych ward. "They told me I was mentally ill, bipolar," Oryx says, shaking his head as if the idea still mystified him. "They said there was something wrong with my brain chemistry and I'd have to be on medication for the rest of my life. That

was it. They didn't ask me anything about who I was before the accident; it didn't matter. I was nothing but a list of symptoms. The meaning of all my earlier experiences just went out the window."

The social work student next to me is muttering "Wow!" and writing down everything Oryx says on a small notepad stamped "Freudian slips." A disheveled-looking man two rows from the front yells out, "Hey, the same thing happened to me, too!" Oryx nods thoughtfully at him and says, "When the speakers finish, there'll be time for testimony from other people here. Maybe you'll tell us your story then." The man stands up, scans the room with blazing eyes, and says, "I sure will!" He sinks back in his chair, and I take a deep breath. This clearly isn't going to be your typical panel discussion; I suddenly feel as if I'm back at HVN.

"After I got out of the hospital," Oryx says, "I tried to work out for myself what my feelings meant." He decided that what his doctors were calling "mania" was his mind's way of protecting him from the depression that had been so unbearable. It was an extreme response, but it was adaptive, at least up to a point. Grinning broadly, Oryx says he weaned himself off the medication his doctors insisted he take and is now fully recovered from his "chemical imbalance" and "bipolar illness." Instead of the chronic mental patient he'd been told he'd become, he finished graduate school, got a good job, and married a colleague.

At the end of his testimony, Oryx talks about how he and Will Hall, a friend diagnosed as schizophrenic, had joined forces to start Freedom Center. They wanted to help others recover on their own, as they'd each done. Oryx says that he and Will sought to create a structure outside the mental health system where people diagnosed as being "mentally ill" could come together, talk about their experiences, and help one another learn to cope with them.

I listen with growing excitement to the other speakers, thrilled to have stumbled onto an American analogue to HVN right here in my neighborhood. People in Britain could never believe it when I told them there were no hearing voices groups, as far as I knew, in the United States. But the psychiatric survivor movement was clearly international, so

American groups of some kind had to exist. Freedom Center appeared to be one of them.

Five other people give testimony when Oryx finishes. Their stories are as powerful as his was. At the break, I say a few words to Catherine, who'd talked about "self-harm" as a way to keep herself alive after years of sexual abuse. "Doctors call it a 'suicide attempt,'" she'd said, "but it's really the opposite. It's a coping mechanism." I flinch when I see her arms up close; they're covered from wrist to shoulder with scars from the dozens of times she's cut herself.

When the speak-out finishes, I'm eager to meet Oryx and the other speakers. I introduce myself to a few people and ask them if they know about the Hearing Voices Network. "Its whole framework for understanding madness is practically identical to yours at Freedom Center. I've just come back from meeting hundreds of people in Britain who are doing just what you're talking about." They say they've never heard of HVN. I ask if I might attend one of their regular meetings to learn more about Freedom Center's work. "We don't allow observers," Oryx warns. "You can come as an ally, but only if you're open to talking about your own experience." I say, "No problem." Weeks later, I discover what those words really mean.

Parking my car in the numbered off-street space reserved for one of my therapist friends, I walk across Center Street to the grand Masonic Lodge. After its recent renovation, the building has filled up with the offices of chiropractors, acupuncturists, and psychotherapists. I go around to a side door and knock loudly, as a small hand-lettered sign taped to the front of the building instructs. When the buzzer sounds to release the lock, I walk past a playroom and the sanctuary of a local Quaker group to enter a small meeting room. Twenty people sit on folding chairs around a simulated wood table. It's my third Freedom Center support group meeting.

I'm a bit intimidated by being here. The group seems a lot more embattled than HVN did. Because the NHS in Britain is run by administrators, not physicians, it's far less ideological than health care systems are in the United States. Approaches that "deliver good value for money" (like HVN's peer

support) have a decent chance of being considered as reasonable alternatives to expensive medication. Psychiatric survivor groups in the United Kingdom are often able to form partnerships with professionals. But in the United States, psychiatry is entirely controlled by doctors, who have a direct economic interest in siding with the drug companies and preventing patients from treating themselves. Freedom Center had some of its initial funding from the Department of Mental Health (DMH) cut because it was considered too critical of the medical model, and this has only served to make the group's members fiercer and more outspoken. I agreed not to come as simply an observer, but so far I haven't said anything at these meetings.

I seem to be a bit late this evening; people are already talking, which makes me even more nervous. James, this week's facilitator, nods in my direction as I slip into an empty seat. "We're going around the circle so each person can have a chance to say something if they want to," he says. "Patty? What about you?" James smiles encouragingly at the woman I just happened to sit next to.

"Yeah, I could use some support," she says, brandishing a sheet of paper in the air. "I've spent the whole week writing this letter. I want that fucking psychiatrist to have to listen to what I have to say." Several others around the circle groan in recognition. "DMH is paying him to see me for an hour," Patty continues, "but after ten minutes he starts trying to get rid of me. For him, only one thing exists: my medication. As long as I'm taking it, he doesn't give a shit about what else is happening."

I roll my head from side to side in an unsuccessful attempt to loosen the tight muscles in my neck. Like everyone else at the meeting, I share Patty's outrage. She deserves better treatment than she's getting. But it's hard for me to absorb the details of what she's saying. In about two minutes, she'll finish and all eyes will turn to me. I have to figure out whether to speak, and if so, what to say.

The first two times I came to Freedom Center, the facilitator ran the group like a Quaker meeting, just waiting for people to share something. James isn't doing this. Except for me, everyone in the room is a psychiatric patient. Some have just gotten off the local psych ward and are desperately trying to

cope well enough to keep from being locked up again. Others are looking for the encouragement or understanding they can't find inside the mental health system. I'm new, and my role is ambiguous. The way I introduce myself makes a difference.

Patty stops talking. James smiles at me. Mumbling "I don't have anything to say right now" would get him to go on to Catherine, sitting on my other side. But this feels like a bad move, casting me as the typical psychologist, hiding behind anonymity while everyone else spills their guts and risks hearing how the group responds. I can't dissemble; mental patients are famous for sniffing out bullshitters. The last thing they need is someone else lying to them. Besides, this is the one place where they can speak openly. When Oryx first introduced me to Will Hall, the other co-founder, Will had warned, "You'd better not be a tourist. We don't want any anthropologists, either. We're not a bunch of natives, letting you visit our indigenous community. Freedom Center isn't a field site for participant observation." I'd agreed with him.

Now James is smoothing the neat white beard that makes him look like an English teacher. "Gail?" he says in a friendly tone. I take a deep breath and wait, like everyone else, to hear what comes out of my mouth. "Some of you already know," I plunge in, "that I'm a psychologist. But I'm not a therapist. I don't treat anyone. I've never sent someone to a hospital or administered a medication." I'd learned to introduce myself this way at HVN meetings; it always seemed to reduce people's anxiety about who I was. After a few chuckles, I go on. "I'm a professor at a nearby college." A woman I don't recognize blurts out, "Where?" I say "Mount Holyoke," and she nods with interest. I can see people digesting this information and thinking, "Wow. We've bagged a big one. Mount Holyoke is one of the area's most elite institutions. What's she doing here with us crazy people?"

I try to ignore all of this and just speak naturally. "I teach in the psychology department, but sometimes I feel as cut off from my colleagues as Patty does from her psychiatrist. It's a great job in many ways, I know that," I rush on, suddenly aware that I'm one of few people in the room with a job at all. "But it's hard to feel so isolated from people you see on a daily

basis, year after year. I have colleagues who teach that schizophrenia is a genetic brain disease. I work down the hall from people who give electric shocks to pigeons or cut up rat brains.” My voice quavers. I had no idea how painful it would be to say these things.

The room is silent. People hear what I don’t say. “I can’t challenge most of what happens at work,” I stumble on, “even though I find it morally offensive and potentially problematic for students.”

“Why not? You have tenure, don’t you?” Randy interrupts. Her tone is challenging, but not hostile. *She wants to see if I’ll stand up to her. This is how people in the group talk to each other.*

“Yes, I do have tenure,” I say quietly. “But it’s still risky to confront people. It’s not as if psychology is an exact science. People teach whatever they believe. I don’t want my colleagues telling me what to say in my own courses. They already think I’m crazy. I don’t want to have to deal with any more of their animosity.” I’m startled by the words that are tumbling out of my mouth; I’d never intended to be this revealing.

“Well, yes, it is a risk,” says Randy, nodding. “But you can take it.” She grins mischievously and hands me the bag of pretzels that’s been circulating. “You’re tougher than you think.”

I take this as a cue to stop and look at James. He smiles. *I feel as if I’ve just passed some test, one harder than I was anticipating.* I crunch a pretzel and sink back in my chair, deeply relieved to have this introduction over with. I guess I’m a lot more upset about being a psychologist than I’ve let on to myself. The gap between what I was taught and what I’m starting to understand about mental illness is widening. I’m in a precarious position, not clearly on anyone’s side. I can’t just sit quietly in these meetings and listen; in the contentious world of American psychiatry, that’s an untenable position. I like Will and Oryx’s word *ally* to describe my role, but I’m not sure what that actually means in practice.

The young woman next to me, who’d talked so powerfully about self-harm at the speak-out, mutters “I’m Catherine. I don’t really feel like saying anything tonight.” She lowers her head and tucks her legs beneath her. She’s elegantly dressed in a slinky black dress and boots with stiletto heels, but her

frightened look makes her seem like a teenager who's borrowed an older sister's party clothes. Everyone sits quietly for a minute or two, creating a space for her to change her mind and say something else. She doesn't look up, so James turns to the man sitting next to her.

"I'm Tom," he says. "I just got off the psych ward two days ago. I could really use some support. My wife's filed for divorce and I'm about to lose my house. I agreed to go into the hospital for a week because I was afraid I'd kill myself." He pauses for a breath, and I can feel people tune to his frequency. I'm startled by how attractive he is. *He could be a model for men's hair gel or aftershave. Who'd ever guess he's a mental patient?*

"All they wanted to do was give me more meds," Tom goes on. "I kept telling the nurses that I needed to talk to somebody, but they said that could wait until I calmed down." A sigh fills the room. Half the people in the group have had experiences like this.

Tom starts to laugh. "The best part was when they sent me to occupational therapy and made me spend two hours making a napkin ring. I gave it to my five-year-old son when I got out and he seems to like it, but geez, I'm the guy who ordinarily works as an electrician doing high-end commercial installations."

"I've got quite a few of those napkin rings," says David, and everyone starts laughing.

"Boy, it's good to be here," Tom says. "I can't talk to my family about any of this stuff. My parents want to help me, but they just don't get it. You have to know firsthand what it's like to be on one of these wards." A line from Agnes Richter's jacket that's recently been deciphered suddenly comes back to me: "*I plunge headlong into disaster.*" Was that how Tom felt last week? David breaks in, "Yeah, but even if you do know what those wards are like, nobody believes you. Page one in the staff manual reads: 'Mental patients lack insight. They don't accurately perceive their surroundings or other people's feelings. Never trust what they say.'"

People greet me by name when I arrive at the next meeting. Carl, one of Freedom Center's key organizers, is handing out sheets of paper. "Before we

get started tonight,” he says, “I want to make sure everyone knows about the demonstration planned for that shrink get-together in Boston in a few weeks.” Carl was among the first people to respond enthusiastically to the idea of a support and advocacy group for people “labeled with mental illness.” A veteran of the movement’s first wave in the late sixties, he’s been participating in demonstrations at American Psychiatric Association (APA) meetings since his work with the Mental Patients’ Liberation Front in Berkeley in 1971. It’s been a long time since those heady days when defending the rights of mad people was seen as part of a broader “struggle for liberation,” but Carl thinks psychiatrists still ought to be reminded that patients have their own ideas about treatment.

In Britain, there are a lot more opportunities for patients and psychiatrists to work collaboratively. There are conferences like Beyond Belief, and the NHS is increasingly hiring voice hearers and other current or former patients as consultants they refer to as “experts by experience.” Activist groups still sometimes hold demonstrations, but in general, they don’t feel as marginalized and as angry as American patients since they’re working in an environment that’s far more supportive of new ideas.

I tune back into Carl’s plans for the action at the APA conference. “Lucky for us, their meeting happens to be scheduled on Halloween,” he laughs, checking that everyone’s got a flyer with the time and date. “We’ve chosen ‘Psychiatry Is Scary’ for our theme. Some people are going to dress up as giant syringes or drug company representatives and distribute vouchers for free holiday vacations. I’m planning to make a box of little labels with diagnoses written on them. Some will be real, and some I’ll make up. I’m going to stand outside the conference hotel and hand them out to people at random and ask them to wear one next to their name badges.”

“Wow—what a great idea!” says Randy. “I’ll come if I can get a ride with somebody. I’d love to plaster a diagnosis on that smarmy shrink who signed an order to have me locked up ten minutes after he met me.”

“Great!” says Carl. “Love to have you. Boy, those DSM categories are so weird. I’m having a really hard time making up fake labels because the real ones are so laughable. Wait, I’ll give you an example.” He fishes in the pocket

of his torn black chinos and pulls out a fistful of little white slips of paper. “Okay, who knows which is the real one? Mathematics Disorder or Inadequate Personality?”

Will says, “Well, I’m going to guess the math one, but only because I know kids are the big new market for the drug companies.” He rips open a bag of ginger cookies and lays them out on a paper plate. A lot of people have brought food tonight; it adds a nice feel. I’ve always thought that the tea breaks and trips to the pub that follow every meeting in Britain are part of what creates more closeness among people in the mental health community over there. Randy slops some lentil soup into a bowl, her hand shaking. *A hangover? Some side effect of her medication?* No one says anything.

So many people are at tonight’s meeting that more chairs have to be dragged in from the next room. Before anyone else can speak, Carl says, “Actually, I could use some support myself. All this advocacy stuff has started getting to me.” Five minutes ago, he was laughing about the crazy shrinks. Now he looks as if he might burst into tears.

“Some of you know Alice, the woman I’ve been trying to help out,” says Carl. A few people nod, and everyone else is suddenly silent, as if the opening chord of the church organ has just sounded. There’s a reverence to people’s attentiveness to one another. “She’s been in and out of the psych ward here in town,” he goes on. “A few days ago, she started marching in a circle around the local mental health center. The staff got very freaked out and called the cops. Alice is locked up again now. She’s pretty desperate, but won’t let anyone help. I went up to see her at the hospital the other day, and she threw a shoe at me and started screaming about the paramilitaries that were after her.”

“That must’ve been really hard for you,” James murmurs. “I mean, you walked all the way out there to see her and she just dissed you.”

“Yeah, I was pretty upset,” Carl says, “but not because of how she was with me. I know she’s not the easiest person to deal with, but I can really understand why she’s so angry at everybody. I’ve been locked up enough

times myself to know how trapped it makes you feel. It's Alice's right to decide who she wants to see."

He gets up and pours himself a cup of apple cider from a bottle on the side table. No one says anything. A person's turn for support doesn't end until they've signaled that they're ready for the group to move on.

"I was trying to give Alice some of the herbal remedies I know she counts on to tone down the worst of her moods," Carl says. "The nurses always confiscate that stuff as soon as you get admitted. I thought the least I could do was to go over to the natural food store and get a few bottles of that tincture Alice takes when she feels most stressed. But I didn't even get a chance to slip them to her. Some advocate I am!" He slumps in his chair. The two-day stubble and grimy T-shirt add to his dejected look.

"Hey, how long do these meetings last anyway?" a woman in the corner suddenly yells. She's already come in and out twice in the past half hour. Now she's winding a long, ratty scarf around her shoulders and tapping her foot loudly.

"Two hours," says James.

"Shit, that's longer than I can take," she snaps, grabbing the plastic shopping bag under her chair and bolting to the exit. Will follows her into the hall. Their muffled conversation seeps under the closed door.

"Carl, as I've been listening to you, I've been thinking about the AIDS work I used to do," says James in a very quiet tone. "Sometimes it left me feeling just so drained. My heart was in the right place, but that wasn't necessarily enough to make people in desperate circumstances feel that I was helping them." James takes a few sips of tea from the mug he's tightly clutching. "Sometimes nothing seems right to the person. You just have to do the best you can and not blame yourself."

Randy says, "Yeah, he's right. I have times when even my best friends seem alien. You just have to find a way to let Alice know that you're still there for her. Maybe you could write her a note. Or maybe the beds on the psych ward will fill up quickly like they did last month and she'll be out of there in a few days anyway."

The local hospital has a locked ward with only twenty beds, so people are constantly being sent there and released as soon as somebody else needs the space. Until about forty years ago, Northampton was home to one of the largest state psychiatric hospitals in New England, housing thousands of patients and serving as the area's largest employer. But by the late 1990s, the place had become a crumbling shell, casting its ghostly shadow over anything having to do with mental health in western Massachusetts. It's no accident that Freedom Center was founded here, and people like Alice remind those who've lived in town a long time what things were like in earlier decades. When Northampton State Hospital was ordered closed after a lawsuit filed on behalf of patients was finally won, people previously locked up were now routinely found wandering the streets.

Catherine shifts around in the seat next to me. Then she takes a deep breath, clears her throat, and says, "Um, I think, um, I'd like to say something." A few people shoot her encouraging looks. Randy says, "Sure, Catherine. Why don't you take some time right now?"

"Uh, okay. I was just wondering if anybody knew how to get some fake meds? Something that would make it look like I was taking the pills I've been prescribed but wouldn't actually zone me out the way they do..."

"Is somebody watching you?" Randy interrupts. "Do you have to prove you're being 'compliant with medication'? That's how my psychiatrist always threatens me. If I don't take the shit he's pushing, he says he'll have me forcibly injected. Hey, whatever happened to that fucking war on drugs?"

"No, it's not like that," Catherine says. Even though I'm sitting right next to her, her words are hard to make out. She's hunched over, her long hair hanging in her face, like a child who thinks that if she covers her eyes, nobody will be able to see her. "It's my boyfriend. He's the one who's keeping track of everything I do. He says he's trying to take care of me, that he's the only one who knows how I feel, and whatever he does is for my own good."

"I've heard that one before!" Randy sneers. "Watch out—that 'for your own good' shit is always dangerous."

“He doesn’t let me leave the apartment,” Catherine says in a barely audible voice. “I do go to work, but he says I’ve got to come right home after that. He thinks I’m mentally disturbed and might flip out at any moment. But I think it’s those meds I’m taking that are making me so volatile.”

“I know how you feel,” says Will. “I was okay until I had a toxic reaction to Prozac. That’s what landed me in the hospital. But it’s risky to try to fool your boyfriend by taking fake pills. It’s too easy for him to figure it out and retaliate.”

“How’d you get here tonight?” Carl asks.

“I lied about where I was going,” says Catherine, starting to cough. Her body shakes; her eyes are watering. No one says anything for a few moments.

“It sounds like you feel really trapped,” says Carl, passing her a throat lozenge. She pops it into her mouth and sighs deeply. “Lately, I’ve been cutting myself. I feel invisible. I’m afraid of people. It’s just him and me. I never look at anyone else because he’s always accusing me of getting involved with other men. It’s hard to tell what’s real and what’s not. Sometimes it’s like I don’t exist. Cutting makes me feel more real. I can see the scar and know it’s there.”

For a few minutes, no one speaks, giving Catherine whatever space she needs. Then Randy says quietly, “I used to do that, too. You’re brave to come here. I know how scary it is to feel like there’s no escape.”

Catherine mutters, “Yeah, it sure is.” Then suddenly she stands up, grabs her jacket, and says, “I gotta go. I’ve already been out for more than an hour.”

“Take care,” says Carl, picking up the small notebook that’s slipped from Catherine’s pocket and gently handing it to her. “Remember, you’re always welcome here.”

For the next two years, I go to Freedom Center meetings religiously. I hear dozens of stories like these. Every week, as I drive home, I replay the group’s responses in my mind, trying to understand what has just taken place. The same people psychiatrists consider “unable to empathize with the needs of others” seem to be extraordinarily helpful to one another. They offer

practical suggestions, insightful interpretations, and a wealth of information on everything from the biochemistry of psychiatric medication to the best disability benefits counselor in the area.

Even more mystifying, they manage to do all this without anyone seeming to be running things. People take turns serving as facilitator, but in no sense are they “in charge” of the meeting. After three decades of attending professional conferences, foundation-sponsored “strategic planning sessions,” and countless college faculty meetings—few of which accomplished a fraction of what gets done in the average Freedom Center support group meeting—I’m having trouble grasping how the group manages to work so efficiently.

People’s sense of urgency is certainly a crucial component. Even those who are attending their first meeting quickly sense how seriously everyone takes what’s being said. Stakes are high, the need is great, and there’s simply not a lot of time to waste. In addition to offering individual support to members, Freedom Center also works politically to try to improve the quality of mental health services in the local area.

Before each meeting gets started, people give updates on current activities. There’s a quick discussion of next steps, and then the group turns to its most important work—offering support to those who need it. Meetings never run past the allotted time; the room is rented by the hour, and there aren’t sufficient funds to pay for more. Yet it’s rare to hear anyone say, “We need to move on to the next person,” or “Try to wind it up; we’ve got a long agenda” (comments heard at most faculty meetings I’ve attended). During support time, even people who say the same thing every week or aren’t very coherent are thoughtfully listened to. No one monopolizes the discussion, and people show a sensitivity toward one another that is astonishingly consistent and genuine.

Witnessing this process profoundly affects me. Again and again, I show up at one of these meetings filled with worry about some personal difficulty or frustrated with my colleagues or mired in impotent despair about the state of the world. As I listen to people talk about trauma far more serious than anything I’ve experienced, or watch as they help one another develop

effective coping strategies, I marvel at the transformation of my own feelings. No matter how unhappy or stressed out I am when I arrive, after an hour or two at a Freedom Center meeting, I feel refreshed, energized, and better able to rise to my own challenges. I didn't start out as someone who'd come to the group for support, but after two years, I certainly have a vivid sense of how powerful it often is.

7

Prisoner Abuse

Northampton, Massachusetts, Spring 2004

The buzzer sounds. I rise, signaling that I'll go down and open the building's front door. I often do this at Freedom Center meetings as a way to take a brief break when things are too intense or, as now, to be a helpful member of the group in one of the few ways that doesn't complicate my role. Halfway down the stairs, I see who it is—Alice. *Uh, oh. This might be difficult.*

"Hi, Alice," I say warmly. "How are you?"

Her head is down, hair shielding her face. "Not good." Her tone is guarded. "Carl has gone totally nuts. He's been ordering me around, as if I were his servant."

Something's going to happen. She usually seems fine when I open the door. We have our little routine—she asks how I am, or we joke about hearing voices if the building's intercom doesn't shut off right away. I follow her up the stairs. As I slip back into my seat, I see Will shoot Randy a look. Uncertainty? Apprehension? Does Alice know we spent half of last week's meeting talking about her? She's incredibly intuitive—even if she doesn't know, she can probably sense something.

She dumps a large stack of books and magazines on the table with a loud thud. James jumps slightly in the chair next to me. Robert is describing some new video about psychiatry at Bellevue Hospital in New York. "It shows how they treat us—like animals," he spits out, fingers drumming the table, frustrated by people's lack of response.

“Should we turn to the support part of the meeting?” Randy interrupts, suddenly assuming her role as facilitator. “Who needs some support?”

Alice rummages through her stack of papers and thrusts a magazine forward on the table in front of her. “I do!” she announces. “They’ve been torturing me all week. I don’t know what to do. There’ve been men in my house. They somehow get in when I’m gone. I think it’s the same guys who are in that paramilitary group, the one run by Bob Hendricks, the lawyer who stole \$20,000 from my bank account.” Her face is pale, her cheeks sunken. She looks as though she hasn’t eaten or slept for a long time. Her gray cashmere sweater isn’t buttoned properly; otherwise, she’s dressed neatly, like the Vassar student she once was.

No one says anything. The events of last week’s meeting echo in everyone’s head but Alice’s. Worried by some of her recent behavior, people had talked about what the group might do to help her, despite an unwritten rule not to discuss members who aren’t present. Suddenly, Alice puts her head on the table and starts to sob. This is a highly unusual thing to do at a Freedom Center meeting. People may tear up as they talk, but crying is somehow out of bounds, like yelling or banging the cups around.

“What’s being done to me is just like what’s happening to them!” She shoves a magazine toward the center of the table. All I can see are a lot of glossy black-and-white photographs. “They’re torturing me just like those prisoners in the jail in Iraq. They’ve been doing it for years, but no one’s writing about it in the *New Yorker*!” Now she’s yelling. “No one cares what happens to people being tortured in mental hospitals!” *She’s right. And for her, they’re pretty much the same thing. This prisoner abuse scandal has completely dominated the news for days. It must be like reliving whatever happened to her as a child all over again.*

“I can’t concentrate on anything you’re saying with those gruesome photos in front of me,” Will says quietly. “Can’t you just put that magazine away?”

“No one wants to see what’s happening, even you!” Alice spits out. Her voice is venomous. Hair hanging in her face, eyes blazing, she looks possessed. “No one believes me! They can shoot you full of Haldol until

you're lying helpless on the floor, like I was. I couldn't move. It was like I had been electrocuted. No one takes pictures of mental patients and puts them in magazines! No one believes me when I say I've been tortured, too!" Tears stream down her face. Will looks at the floor. James shifts uneasily in the chair next to me. Randy, this week's facilitator, goes into the adjoining kitchen and returns with a glass of water. No one's spoken since Alice's outburst.

"I believe you," I say, my voice low, my gaze focused directly at her. *There may not be men raping her this week in Northampton, but clearly something happened to make her so terror stricken.* Alice stops crying and looks warily in my direction. "I believe you" I say again, very quietly.

Will looks up at the clock. "Maybe—"

Alice interrupts, yelling again. "You shut up! I never get to have a turn in these meetings! As soon as I start talking, it's time to move on!" Will sits stunned, his unspoken comment swallowed by this tirade. There are ground rules at these meetings. People don't simply tell each other to shut up.

"Those men in the National Guard are going to appear again at my house tonight. They've been raping me. I thought it had stopped when they were sent off to Afghanistan. You know that colonel in the Guard, the one who's friends with the lawyer? He has a guy posted on my street. As soon as I go into my house, they call each other on cell phones and send the Guard guys over. They always know just when I'm ready to go to sleep. I think the guy who's posted sits in a car a few doors away, watching to see which light I turn on. I've started creeping upstairs in the dark, so they can't tell which room I go into."

"Alice, can I just ask you something?" James says quickly as she pauses for a breath. She stops and looks at him. He stumbles on. "This all sounds terrible, but is there something we can actually do that might help?" People always ask this question when someone pours out an overwhelming story like this. It signals recognition of the enormity of the problem, the impossibility of easy answers, and a realistic sense of the group's limitations.

"That's what I started to ask," says Will. "I just wanted to know what we could do. I wasn't trying to shut you up." He takes a swig of water from the

bottle next to him. “I don’t like being talked to that way either.” Alice looks across the room. She doesn’t answer Will or even acknowledge what he’s said. I slip into the kitchen for a drink. I put my glass of water on the table, see that Randy’s is empty, and go back and get some for her, too.

Alice resumes, her tone a bit more subdued. “I want to go away for the weekend, but I’m afraid to leave. I know that as soon as I’m out of my house, they’ll come in and reprogram my computer.”

Randy seizes the opportunity. “Would it help if someone stayed in your house while you were gone and kept an eye on things?” Alice looks doubtful. “I guess, well, maybe...” People start suggesting other alternatives. Alice stops talking and sinks back in her chair. Earlier, she’d talked about needing someone to break the spell.

“What if you stayed with me for a couple of nights?” Barbara suddenly breaks in. “I think you live pretty close to me. You could get some sleep and not have to worry about anyone breaking in.”

“Yeah, maybe. But what if they traced me to your house?”

“Just for a few days,” Barbara says again. People start nodding. “It could help,” says Will, clearly relieved that someone’s hit upon something.

Alice shoves the *New Yorker* back into her bag. She looks calmer. A siren wails outside; the police station is next door. “I’ve said enough,” she says in a firm tone. “Who else needs support?”

A week later, I arrive to find Oryx talking about how much he’s looking forward to the golfing season. I laughed the first time I heard him mention this, having never thought of golf as the recreational choice of “bipolar” people. Alice slips into the chair next to me. She perches at the edge of the seat, eyes darting from side to side, like a soldier on guard duty. *Something has happened. She didn’t even say hello to me.* I nudge my chair over a few inches to give her more space.

“I want some of those cookies,” Patty announces loudly. Michael slides the package across the table, glancing at Alice and then at me. *He knows what’s going on with her. They spend a lot of time together.*

“I guess we should start,” Will says. “Who wants some support time?” Everyone sits silently for a few moments, clearing a path. Arrangements and meeting details float away, as people prepare themselves for whatever is about to happen. Alice is clutching the sides of her chair, head down, her usually thick, soft hair in limp clumps shrouding her face.

“Please somebody help me,” she starts to moan. “I need help. Help. I can’t stand it anymore.”

She’s never sounded like this before, as if she’s being tortured right on the spot. “They broke into my house again, and kept raping me, over and over. I’ve been sleeping in my car. Finally I left and drove down to Virginia, where I lived years ago.” She’s shaking her head, as if she can’t believe her own words.

No one says anything. It’s irrelevant whether there were actually any men this week; it felt like rape to Alice, and that’s what matters. She’s blinking rapidly, pushing against the arms of the chair, ready to run, even these few words perhaps too much.

“Tell us what happened,” Josh says, his voice unexpected, soft and even. Josh speaks so seldom that his words are like a tuning fork, aligning everyone to the same note.

Alice sits back, letting her back touch the chair for the first time since she’s come in. I’m careful not to look at her. There isn’t much hugging or hand squeezing at Freedom Center. People hold one another with their attention, but they don’t push the person to respond. A long moment passes in silence. Then Alice says quietly, “I hate sleeping in my car. I went over to the Smith College gym this morning to take a shower, but they were fixing something in the locker room and I couldn’t get in.” I notice a rusty stain on her Icelandic sweater. *Blood? Did she ever cut herself? Didn’t seem the type. Pain too much on the surface.*

“Why don’t you come over and stay with me for a few days?” says Sandra. She hands Alice a bowl of the vegetable soup she’s brought. I fish a spoon out of the package in front of me and slide it over. Alice begins eating soup, carefully spooning each bite away from her, the way people do at dinner at the Oxford college where I’d spent a term.

“The guy who broke into my house is the one who’s the colonel in the Air National Guard. He was off on a training exercise until last month. That’s why I wasn’t bothered until a few weeks ago.” She pauses for another bite of soup. Alice never speaks with her mouth full. “He’s pals with the lawyer, the guy who wants to force me out of my house. They want to sell it and use the money to finance their surveillance operation.”

Eventually, the conversation shifts focus. Alice has agreed to stay at Sandra’s apartment for a few nights and has settled into listening quietly as others talk. Randy describes her visit to the methadone clinic and her painful struggle to stay off heroin. Robert goes back to the Bellevue video, speaking movingly of his efforts to keep his nephew from being given antidepressants at school. James says he’s been feeling a lot happier lately and is grateful for the group’s help when things were more difficult.

Suddenly, Alice leans forward and bangs her head loudly on the table. “I’m ruined, annihilated,” she declares. Her current difficulties clearly haven’t impaired her dramatic abilities. Before anyone can respond, Alice shoves her stacks of papers into the woven bag she always carries and stomps out.

Four days later, while standing in the middle of a busy street yelling at passersby that she’s been kept in mental hospitals for twenty-five years and is being tortured and needs someone to help her, Alice is apprehended by the police. They take her to a psychiatric ward at a hospital some distance away. The scenario she most feared—being locked up against her will—has thus been brought about by her own actions, which must have been especially distressing.

Privately, I think it might help for her to be hospitalized for a while—if only to get her away from the terror of her house—but still, she must be frightened. When an e-mail with the number of the pay phone on her ward is circulated among Freedom Center members, I decide to call her, even though I usually keep more distance.

We have a good talk. Phone calls are a welcome diversion for people on the ward; the young woman who answers is clearly wishing for a call of her own. Alice says that her house had been broken into, so she’d driven to a

Salvation Army thrift store in a nearby town to replace some of the items that had been stolen. “What really upset me was that the tapes of the interviews I’ve been doing with other trauma victims were missing,” she says.

“What interviews are these?” I ask, expecting yet another account of the paramilitaries.

“Well, I got a small grant from the local mental health outreach organization,” Alice says in the tone of a colleague discussing her latest research. “They have a funding program to support survivor oral history studies. I’m interviewing other women who have been raped or beaten up like I was.”

Her voice drops to a whisper. “A team of men worked me over last week. They’ve been doing this routinely. That’s the main reason I had to get out of Northampton.”

“The whole situation sounds very upsetting,” I say, trying to go for the feeling rather than any specific content in what she’s saying, the way people always do at support group meetings.

“The police arrested me outside the thrift shop,” Alice says in a firmer tone. “They put handcuffs on me and said I had the choice of going to the hospital with them or being taken by ambulance. I picked the police car, which surprised them.”

She’s silent for a long moment and then begins to cry quietly. “This is the anniversary of the weekend I bought my house. I thought I’d be safe there. Now it’s the place I’m being tortured by those men who want to steal the property.” She blows her nose loudly into the phone.

“Alice,” I say. “You sound exhausted. Maybe you can at least get some rest while you’re in the hospital.” She says she’ll think about it.

The next day, I walk into my office to find an urgent message from a man who says he’s the social worker on her ward. “We understand that you are Alice’s therapist. Please call us immediately.” I laugh, dialing the phone. Alice clearly hasn’t lost her knack for needling the authorities.

“I know Alice, but I’m not her therapist,” I tell Mr. Barnes in the first sentence of what turns out to be a lengthy conversation.

“Yeah, I figured that, as soon as I heard your Mount Holyoke voice mail. But maybe you can help us anyway. We’re trying to decide if it’s safe to release her.”

He tells me that Alice had indeed been at the local thrift shop. She’d been walking around with a knife in her hand, which was why the police were called. She’d threatened to kill herself.

“Since she got here a few days ago, she’s seemed fine,” he says. “She refused the medication the psychiatrist wanted to prescribe. Since she signed herself in voluntarily, we can’t force her to take it. There’s not much else we can do for her here. I realize you’re not a therapist, but you do know her better than we do. I’m just interested in your sense of things. Do you think it’s safe to release her? Does she have any supports in the community? She’s referred to her membership in Freedom Center. Are you familiar with that organization?”

I tell him I’m in no position to make a judgment about Alice’s safety. I describe Freedom Center and say how impressed I am with their work. But there’s no way for me to know what Alice will or will not do outside the hospital. I give Mr. Barnes Will’s phone number and suggest he might be a helpful resource.

Two days later, there’s a message from Alice on my voice mail. “I’m back home,” she says in a relaxed tone. “I just wanted to let you know that there are a lot of people who hear voices on that ward. I know you’re interested in this topic, so I thought you might want to follow up.”

And for the first two years that I and everyone else at Freedom Center know Artie, he stays on the even keel he'd started showing at that second week's meeting. He has a job, he is in therapy, he's in a singing group, and he is a regular at the yoga class. He comes to support meetings every week (unless his group has a gig), and he becomes so skilled a facilitator that he takes over whenever Will or some of the other core members aren't able to be there. We all think he has his shit together, that whatever had happened to him in New York is over now. I have tape-recorded four hours of intense conversation with him, and the two of us occasionally go out with some others for a drink after a support group meeting. I feel as if I know Artie pretty well and that he isn't any crazier than most people.

Then I leave Massachusetts for a year's research in England. I get a few weird e-mail messages from Artie, but I don't pay that much attention to them. When I see Will and Oryx at a conference, though, they tell me that Artie has started speeding up again. I don't hear the details until after he's been fired from his job, picked fights with half the members of Freedom Center, and been asked by some members to stop trying to facilitate support group meetings.

But by the time I get back to Massachusetts some months later, Artie is back on level ground. The crash sounds terrible—far worse than the other times—and when we get together to talk, he seems deeply shaken by the whole experience. Yet even though he was telling me about landing in one of Massachusetts's roughest psychiatric institutions (Bridgewater State Hospital, where Frederick Wiseman's chilling documentary *Titicut Follies* had been made in the 1960s), the fact that we are discussing this over a meal in the same pleasant café where we always meet makes it seem as if he is talking about someone else.

Artie's doctors say that he's got a cyclic disease with periods of remission between psychotic "episodes." But to me, the punctuation goes the opposite way—he's a guy who lives an ordinary life with the occasional very difficult patch, patches more difficult than most people's. The way you choose to parse the complexities of his life shapes your core view of who he is—a man with an incurable brain disease or someone who's had some pretty painful

chosen, but which nevertheless had a profound effect on their understanding of themselves.

In addition to the hundreds of narratives that have been published by individual patients, there are some key collections of madness experiences. In 1964, Bert Kaplan edited a volume called *The Inner World of Mental Illness: A Series of First-Person Accounts of What It Was Like*. In 1972, a group of current and former patients in San Francisco began to put out a newsletter “designed to bring together and disseminate information about the psychiatric system and alternatives to it.” *Madness Network News* gained a wide circulation, and in 1974, the *Madness Network News Reader* was published in book form. Also in 1974, Michael Glenn published another collection titled *Voices from the Asylum*; twenty years later, Jeffrey L. Geller and Maxine Harris edited *Women of the Asylum: Voices from Behind the Walls, 1840–1945*, bringing the perspectives of more than two dozen female patients to a broad audience. In 1997, four pamphlets written by seventeenth- and eighteenth-century English patients were reissued by Allan Ingram under the title *Voices of Madness*.

Today, thanks to the psychiatric survivor movement, more and more first-person accounts are being published, either by alternative presses or by patients themselves. Readers now have a huge range of alternative views of madness and recovery available to them. There are also a number of oral history collections, preserving the experiences of people unlikely to write books. In the United States, oral histories are available through MindFreedom International (www.mindfreedom.org), the New York State Archives (www.nysarchives.org), the Alaska Mental Health Consumer Web (www.akmhcweb.org), M-Power in Massachusetts (www.m-power.org), and Freedom Center (www.freedom-center.org), to name only some of the major sources. Patients flock to record their testimonies: When MindFreedom launched its oral history project, telling potential participants the purpose was “to gather stories of survival, recovery, empowerment, and self-determination from the perspective of the psychiatric survivor or ex-patient,” hundreds of people responded, wanting to participate.

psychotherapy (or not), praise their doctors or claim that psychiatry is a means of thought control. Policing members' actions is the last thing that those who have been, as David Oaks, executive director of MindFreedom, puts it, "on the sharp end of the needle" would ever want to do to one another.

Similarities among psychiatric survivor groups in different countries are much more striking than their differences. But there is one key distinction between groups in the United Kingdom and the United States. As Chamberlin notes, "In the United States, former patients have found that they work best when they exclude mental health professionals (and other non-patients) from their organizations." In Britain, in contrast, alliances between professionals and patients are common. There are many reasons for this—the effects of a national health service, being in a smaller country, etc.—but the key factor is the prevalence of social and community viewpoints within the health professions. British psychiatrists (and psychologists and nurses) are far more likely than their US counterparts to think that psychosis is caused by trauma and thus to support the work of patient-led support groups. In the United States, biological psychiatry is so dominant that patients' views of mental illness often end up being diametrically opposed to those of mental health professionals.

I got a vivid sense of these opposing viewpoints when I arrived at a Freedom Center meeting one evening in May 2004 to find cofounder Will Hall gleefully describing his recent visit to an APA convention. He was part of a small group of activists who'd demonstrated in front of the Javits Center in New York, protesting psychiatry's use of toxic and unscientific treatments. Will's personal contribution was to create a gigantic \$5,000 check—the kind displayed at fund-raising events or on game shows—with "Your Name Here" in huge letters, which he offered as a reward to any psychiatrist who could provide empirical evidence of a biochemical basis for mental illness.

"I stood in front of a giant ad for Abilify," he told the group. "Since it's one of the best-selling neuroleptic drugs on the market, a lot of psychiatrists

came over to look at my check. It was definitely the right thing to catch their attention.”

“What would you have done if anybody did offer evidence? You don’t have \$5,000,” Oryx said. He and Will, as cofounders of the group, both knew perfectly well that Freedom Center had no budget to fund extravagant gestures like this.

“I wasn’t worried. No chance of that.

”“Did you see any of the exhibits inside?” David asked. “I went to a demo at one of those conventions, and we snuck in to check out some of the booths where they sell the shock treatment machines and all the new drugs.”

Will shook his head. “Nah, I wasn’t dressed right. There were security guards all over the place. They have to be careful not to let anything happen to these shrinks.”

“Like encountering a mental patient on the loose!” Patty interjected, cracking everyone up.

Will said, “I thought it would be fun to get one of the tote bags they were handing out, the one with ads for Effexor on the front. That’s the drug that almost killed me. I thought I might put a skull and crossbones over the name and take it grocery shopping.”

At the end of her paper on the history of the psychiatric survivor movement, Judi Chamberlin made the crucial point that most mental patients have never participated in *any* activist organization, and many don’t even know there *is* a movement. Although patients continue to protest their treatment—as they have throughout most of psychiatry’s history—few do so in organized ways. Most protest occurs, as it always has, at a private, invisible level, as people find their own quiet means of fighting back against a system that often seems coercive and arbitrary.

One time-honored method of protest is to “tongue” medication, hiding it inside the mouth and spitting it out or flushing it down the toilet at an unsupervised moment. Patients also constantly lie to hospital staff about how they feel so they can be released more quickly. When coercive staff are on duty, patients may suddenly become “angry” or “violent,” lashing out at

biological psychiatry. Both groups have moved toward closer collaboration, especially in the United Kingdom, although there remain significant tensions between professionals and experts by experience in the United States, partly because of the economic challenge that peer-support groups represent to a system with a fee-for-service model.

In the years since *Agnes's Jacket* was first published, I have maintained occasional contact with many of the people I wrote about; sadly, several have died. Others, like Jacqui Dillon, have become my friends and closest colleagues. Nicky Nicholls now displays and sells her artwork, and a biography is being published about her. Helen Chadwick is living in retirement in a beautiful part of England. To the surprise of many people, Will Hall, formerly of Freedom Center, became a psychotherapist. Betty Rigby, while a patient on a supposedly secure psychiatric ward, tragically killed herself. But many of the other people featured in the book are well and thriving.

Freedom Center no longer exists as an organization, although its spirit lives on in the local community, and some of its members played key roles in developing the WMRLC. Like many feminist organizations of an earlier era, Freedom Center played an important role at a particular moment but to have continued beyond that would have contradicted some of its core critical assumptions. As more and more peer-run services gain state support, and as alternatives like peer respites and hearing voices groups spread more broadly across the United States, activism often takes a different form. When the danger is co-optation by a system willing to adopt “recovery” and “peer support” as catchphrases without putting into place the changes that would make them realities, writing a successful grant application might be more useful than organizing a demonstration. (Although there are still some vibrant examples of those: my current favorites are the protests that feature the slogan “You bet your ass I’m paranoid!”)

Things are starting to change in the mental health system in the United States in terms of the range of alternatives, but Britain and other countries continue to be far ahead of us, and even their media are starting to offer more accurate portrayals. The BBC and state-funded arts organizations in

Acknowledgments

Forty years ago, as a graduate student in psychology, I proposed to write my PhD dissertation on “peer interaction among hospitalized psychiatric patients.” The first-person narratives I found so compelling were filled with accounts of powerful connections between patients; I wanted to document the importance of these relationships. It took months for authorities at the local state hospital to approve my project, but finally I was able to set out for my first day of observation. I sat quietly for an hour, getting the feel of the ward and chatting with a few patients who struck up conversations. Then, for reasons that remain unknown to me to this day, I was told by a hospital official that an error had been made, my project could not be conducted at that institution, and I would have to leave immediately. My advisor urged me to choose another topic for my PhD; eventually, seeing no alternative, I reluctantly agreed.

This book is obviously very different from whatever I might have written as a graduate student in the 1970s, but my belief in the centrality of peer relationships among patients remained unchanged. Yet it’s only under current conditions—when patients are no longer locked up and can decide for themselves who to talk to—that I can finally demonstrate the power of their shared experiences. I am deeply grateful to the many, many current and former patients who trusted me enough to speak openly and movingly about the emotional distress they have experienced. I hope that I have conveyed even a fraction of the courage, tenacity, and resilience of the people whose stories I tell here.

The Testimony Project participants in particular—by using their real names, agreeing to be videotaped, and making their interviews accessible at

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