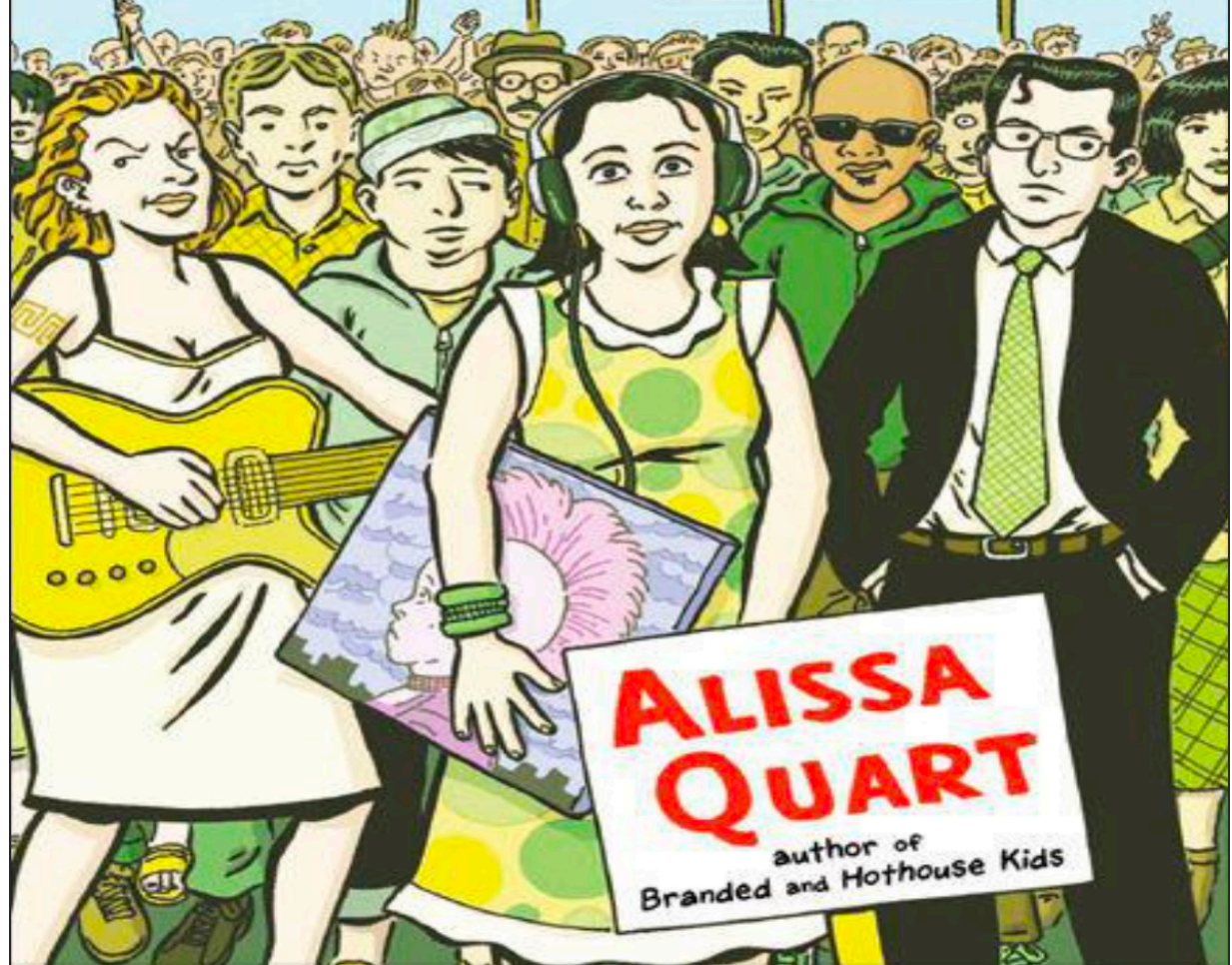


REPUBLIC OF OUTSIDERS

THE POWER OF AMATEURS, DREAMERS, AND REBELS



REPUBLIC

OF

OUTSIDERS

Also by Alissa Quart

*Branded: The Buying and Selling of
Teenagers*

*Hothouse Kids: The Dilemma of the
Gifted Child*

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OUTSIDERS

THE POWER OF AMATEURS,
DREAMERS, AND REBELS

ALISSA QUART

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PART ONE

OUTSIDER MENTALITY

BEYOND SANITY

Twenty years ago, another Mad Pride activist, Will Hall, got depressed. He went to a psychiatrist, who prescribed Prozac. He had a manic reaction, an occasional side effect of the drug, perhaps stemming from the fact that he's bipolar—without mood stabilizers, Prozac has the potential to exacerbate mania. In his manic state, Hall lost his job at an environmental organization. He descended into poverty and started to hear furious voices in his head. He walked the streets of San Francisco night after night, but the voices never quieted. He got so desperate that he went to a clinic for help; he was swiftly locked up. He said he was diagnosed as schizophrenic, hospitalized, and placed in restraints against his will. Then his health insurance ran out. A social worker came and arranged his discharge. He wound up in a homeless shelter and went from there to group homes and programs. He

eventually recovered a little, enough to begin asking whether the treatment he'd received was the most useful to him and other people like him, people he had met in clinics and hospitals.

On the surface, this story is about the fall of a promising young man into pain and out of the ordinary world. But in truth, Will Hall's history led him to become a renegade—and, in a way, to become truly himself. As soon as he was on his own, Hall began to imagine a different kind of treatment for people like him, people with extreme mental states and different ways of thinking. What if he had had someone like him counseling him at the hospital? What if he refused to see himself as a “broken invalid,” as he has written, fearing “what was inside me as signs of my ‘disorder’ ”? What if he refused to turn over authority of his mind and experience to doctors and therapists? He decided to throw himself into what is called

“alternative mental health”: avoiding milk, caffeine, and sugar; embracing yoga and exercise; watching his sleep patterns.

Hall started to read books about mental health and get involved in the budding online mental health scene, where people who called themselves “patient-survivors” met and chatted about their experiences. He wanted to find groups, online or off-, run by people with, as he put it, “severe mental illness labels” themselves. But when he couldn’t find these communities outside the mental health system, Hall and a man named Oryx Cohen started their own such community, the Freedom Center, in 2001, with an Internet radio show and a weekly support group. He posted other people’s stories of their recoveries on the center’s website.

“We don’t want to be normal,” Hall proclaimed. Many say this, but Hall *really* meant it. Like DuBrul, he cut a striking

figure: delicate and thin, with dark plum polish on his fingernails and black fashion sneakers on his feet, his mother's Native American ancestry evident in his dark hair and eyes. He was unusually energetic, seemingly vibrating even when sitting still. He spoke in a precise, scholarly tone, although I could hear a bass line of anger in his voice as well. The medical establishment, he said, has for too long relied on medication and repression of behavior of those deemed "not normal."

Throughout the 2000s, both Hall and DuBrul got better mentally, despite their schizoaffective and bipolar disorders. They led Icarus's growing constellations: the online and IRL ("in real life") meetings across the country, the other "mad people" they trained to help people like themselves avoid what they called forced drugging or hospitalization. Hall and DuBrul told people about prescription side effects and fought

against what they called “drug overmedication.”

Getting better did not mean the end of their challenges. DuBrul still struggled with manic episodes, when he might wind up half dressed on a roof in the middle of the night. Hall still occasionally believed plants were communicating with him. He found an alternative way of interpreting such contact, one that created a normative context in which it was not labeled evidence of insanity. Hearing voices, according to his mother’s Native ancestors, was a sign not of madness but of an ability to communicate with the spirit world. He didn’t think of himself as being antidrug, but he disliked the effect drugs had on him: what they did to his head and his personality, how they made him feel soft and slushy.

DuBrul and Hall offer an inspiring but also, to some, challenging model, not just for the mad but also for many of those

considered “well.” Some supposedly mentally healthy people take sleeping pills or go to couples therapy. Could they learn how to get to sleep without Ambien or take therapy into their own hands, talking with friends about the worst parts of their marriages? Should they? Although *Mad Pride* is not that widely known, the thinking behind it is increasingly part of a therapeutic counterculture: people who have gone off their psychoactive medications for garden-variety depression; those who remain wakeful but now lay off the sleeping pills, seeking to “go natural.”

In the hopes of impacting both the “well” and the mentally ill, Icarus posts videos of its meetings on Vimeo and elsewhere to show members and interested parties how they work. In one video, “Icarus Project Peer Support, Part I—Checkins,” a small group convenes in a book-lined room, and two co-leaders start off the discussion. The

fact that two people share leadership suggests an effort to decenter the authority in the room, even as they explain the rules. One leader starts with the Meeting Agreements, ground rules for the discussion, “to make this a safer space for everyone and to make everyone feel a little more comfortable.”

“Conflict is OK,” says one leader. “It’s how we learn and grow.” Several of the rules acknowledge that there will be disagreement and divergent experience in the room and ask for attention and respect. The other leader encourages “ ‘I’ statements” — “I am hearing,” “I am feeling” — by which attendees can let others know they hear and are reacting to what others say. The rules aspire to a group that is conscientious, aware, and careful.

Neither leader presents herself as an expert or an unimpeachable authority. Both are clear that rules are rules, but that

everyone in the room is equal and deserves equal airtime and respect. (One of the rules is that people who talk a lot will be asked to listen, and those who don't talk much will be encouraged to speak.) The leaders are there to organize the discussion but not to establish hierarchies of knowledge or authenticity. Personal experience is what's authentic. There will be no middleman, no relay of fiat from on high. In this small room, for this small group, the ideal is a level playing field.

One night I spent with the Icaristas was at a party hosted by a psychologist. It was for the publication of a book of photographs of (what else?) a famous mental institution. DuBrul was clearly a star. Thin, with a dusty backpack and a shambolic walk, he gave tremendous embraces; he had a hint of the guru about him. DuBrul was surrounded by young Icarus Project members and was deep in his punk rock alter ego, whom he

called “Sascha Scatter.” At one point he spoke to the assembled shrinks, mentioning his own psychic struggles. He was applauded by these psychologists and analysts, who seemed eager to show their approval of patients as the prime movers in their own recovery.

PATIENTS LIKE ME

The diagnosis and prevalence of psychological disorders have increased dramatically in the past few decades: one in four American adults is said to have one, and the number of people taking medications for all of these newly diagnosed conditions has mushroomed. In 2011, the U.S. Centers for Disease Control studied the 2.7 billion drugs (this includes over-the-counter preparations and dietary supplements) that had been provided, prescribed, or continued during visits to doctors and hospitals in 2007.

Of those, 120.57 million were for

antidepressants. Between 1995 and 2002, the use of antidepressants went up 48 percent. According to another statistic, between 1994 and 2003 the number of children and teenagers diagnosed as bipolar jumped fortyfold. From the mid-1990s through the late 2000s, the rate of antidepressant use went up 400 percent.

In such a social context, the Icarus Project railed against what it considered to be excessive medication and diagnosis. By constantly challenging authority on the basis (at least in part) of their superior knowledge of how they themselves have reacted to diagnosis and treatment, they were arrogating to themselves a kind of authority that competes with the medical establishment's.

Unlike older self-help groups such as Alcoholics Anonymous, the Icarus Project wasn't pushing a particular brand of self-help. Instead, they were pressing for both

skepticism and community. On any given day, the Icaristas scurried around the group's purple-painted office, collating Mad Pride handouts and planning "mad awareness" events at colleges or universities.

They were ordinary people taking back control and treatment of their lives, ambitions, and conditions from experts. Other groups expanded beyond mental health, such as Patients Like Me, a website where people sign up, track their progress and status in terms of illness and treatments (in the most obsessive and detailed ways), and "subscribe" to one another to keep watch on one another's progress. The founders were Jeff Cole and James and Benjamin Heywood, two brothers who decided to build the resource when a third brother was diagnosed with Lou Gehrig's disease. (James eventually became the subject of *His Brother's*

Keeper, a book by journalist Jonathan Weiner.) People with mental health conditions posted videos about their experiences to Patients Like Me. One showed a youngish, bespectacled woman, directing her commentary straight at the camera, somewhat awkwardly: “Hi, my name is Dana. I am not alone.”

Her condition, bipolar disorder, she said, “is not me”; rather, “it’s a part of me.” It’s not a badge, she said, not “a scarlet letter.” In 2012, 172,752 people were using Patients Like Me. Among those on the site in that year, 12,277 had major depression and 9,761 had generalized anxiety disorder. One user in the mental health area of the site was a pink-haired stay-at-home mom who posted about her depression. Of course, like other sites of disintermediation, Patients Like Me can seem underregulated and potentially exploitative; not only is it a support network for people with shared

illnesses, but it also mines and aggregates medical data for health care organizations and companies. (The benefit, however, is that as people with mental health troubles and conditions self-select and make their data available online, it could become far easier for researchers to study the efficacy of certain treatments.)

Carla Rabinowitz, a forty-nine-year-old peer-to-peer organizer for a community access group who is mentally ill and a self-described “mental health recipient,” said the method is “so, so different than traditional psychiatric care. You see people like you who are thriving, people who are struggling. You see what you need to do to keep yourself going. I never ask for diagnoses; I have no idea what people’s diagnoses are.” She added hopefully, “A peer doesn’t pathologize as much as a psychiatrist.” Her organization prefers the idea of closing hospital wards and making community

investments in hospital peer programs instead, under the premise that peer service is cheaper and better.

Icarus and Patients Like Me are encircled by many amateurs like Rabinowitz, including a long tail of other peer-to-peer organizers and thousands of mental health bloggers dedicated to helping themselves. Why should drug companies profit from treatments that the patients found ineffective? these Mad DIYers asked. Why should feelings be medicated? Why should they prefer treatment by professionals to help from friends and fellow sufferers? These activists were, like many of the other renegades I encountered, challenging authority and a “higher” class of expertise. In the Mad Priders’ case, they were angry about drugs’ side effects and aggressive pharmaceutical marketing. In the same spirit, bloggers and Icaristas repeatedly went after the antipsychotic drug

Zyprexa (olanzapine) because the drug's maker, Eli Lilly & Co., had marketed it off-label—selling it to unexpected demographics, such as elderly patients with Alzheimer's and other types of dementia—even though the onset of diabetes had been attributed to use of the drug in some cases. Bloggers helped expose the drug's ill effects. Along with the release of data on the rise of diabetes due to the use of the drug, the mainstream media picked up the patient-advocates' original investigating and reporting. Professional journalists started publishing pieces that questioned usage of the drug. Some of the claims against Zyprexa spurred a class action suit, and as of 2007, at least \$1.2 billion had been paid for injuries sustained because of the drug.

But the Icaristas and people like them were not just interested in cause and effect. They were romantics of a sort, Web-fueled variations on earlier ideas of the outsider.

“For the Outsider, the world is not rational, not orderly . . . truth must be told, chaos must be faced,” wrote Colin Wilson in his 1956 book *The Outsider*, which not coincidentally was a bestseller. The book described the outsider as a nomad, a searching man who didn’t fit into Society with a capital S—someone like the hero of the television show *The Fugitive* or Camus’s *The Stranger*. Their version of the outsider, like the mid-1960s literary one Wilson embraced, tried to turn the stigma of exclusion, and also madness or transgression, into a kind of status, one with protective, alchemical properties.

Part of that romanticism was that DuBrul and Hall and their followers, as well as fellow travelers of the mind on mental health blogs, cast themselves as a human dam against a cascade of new diagnoses. Along with associated groups such as MindFreedom International (which

advertised itself with slogans including “25 Years of Rethinking Psychiatry!” and “United Activism in Mental Health!”), Icaristas saw themselves as part of a small but hardy band who refused to accept the expansion of diagnoses such as bipolar disorder.

The more intellectual Mad Priders deem today’s diagnostic trend to have a colonial cast: the more powerful class of the medical establishment and the pharmaceutical companies are cordoning off people who are “healthy” and calling them “sick” and thus in need of experts’ intervention. They also argue for both public and self-acceptance of different minds. Hall said he hopes Icarus will “push the emergence of mental diversity. I am proud to be who I am and of my extreme states, no matter what the doctors say.”

Unlike the mental health activists and self-help groups of the past, Icaristas aren’t

dogmatic; they don't prescribe a single lifestyle or set of beliefs. Using the diversity of the Internet, they embrace their own complex range of situations and positions on difficult issues such as medication or diagnostic labels. Whereas a dogmatic mental health activist might inveigh against taking any medication, DuBrul's style of activism accepts that not all medication is necessarily bad. The refusal to take medication, after all, wasn't what made them different.

The Icarus Project was a group that defined itself largely through writing. After all, Icarus characterized itself as aiming "to navigate the space between brilliance and madness." The name Icarus, drawn from the Greek myth of a boy who flew to great heights (brilliance) but then came too close to the sun (madness) and hurtled to his death, has an epic cast.

Not all of the Mad Priders had been

professional psychiatric patients in the first place. At some point they probably accepted a severe diagnosis handed down in a frightening, one-way fashion that presented heavy medication as the only serious option. Like many, I had been struck by the haphazard quality of many diagnoses. I knew people who had pulled out their hair and thrown ceramic vases but who had never been labeled anything, and I also knew tempestuous but otherwise quite reliable folk who had been diagnosed with mental illness and institutionalized, often by their own parents when they were minors.

But there were other reasons the Mad Priders seemed more than just marginal outliers. Their mental states are, in many cases, seemingly only more extreme versions of the very recognizable mental states that fill ordinary lives. Between the proudly mad and what the dominant language calls normal there is a continuum

rather than a break. As Adam Phillips wrote in *Going Sane*, “Madness may horrify us, but passion, strange eccentricity, careless and careful transgression” are all “the ingredients of modern individualism.” In fact, the alt-mental-health movement began in earnest in the 1970s, when a number of activists who also were called mentally ill tried to organize an escape from psychiatry.

Judi Chamberlin, confined to a mental hospital in 1966 against her will and diagnosed as schizophrenic, is credited as the founder of the movement. She popularized the use of “Mad Pride” to describe a movement guaranteeing basic human rights to the mentally ill. When Chamberlin was a psychiatric patient, she discovered she had no legal rights. That moved her to co-found the Mental Patients Liberation Front. In her 1978 book *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, she wrote, “That my

depression might be telling me something about my own life was a possibility no one considered, including me.” In the early 1970s, others in the movement followed Chamberlin’s lead and fought for targeted deinstitutionalization of the mentally ill. That had mixed results, leading both to greater independence for the mentally ill and also to increased homelessness and incarceration of people suffering from these disorders when the promised community-based services to replace hospitals were not funded. Many patients were discharged not to pursue their liberation but to free the state of the obligation to care for them.

Another influence on today’s Mad Pride movement came from the academy, which had explored new sociological and philosophical thinking about people with different mental states and their relation to society. In 1960, Thomas Szasz wrote that mental illness is a myth. In his most famous

and most controversial book, *The Manufacture of Madness* (1970), he argued that insanity is just a word, one often misused to control uncommon, imaginative people. When I read one of Szasz's essays in 2009, I had flashes of other examples of this type of argument: Michel Foucault's famous writing on the history of madness and how institutionalized populations were subordinated, surveyed, and policed; and the work of the somewhat batty R.D. Laing, the antipsychiatry psychiatrist who questioned the validity of medical claims about mental illness.

More than two decades after Szasz and other academics and psychiatrists published their romantic theories of madness, a former mental patient named David Oaks, who had his first nervous breakdown while a student at Harvard College, co-founded the Mad Pride group MindFreedom, which extended beyond

traditional psychiatry to include peer counseling. As with the Icarus Project, MindFreedom encouraged members to question the frequency and degree to which psychoactive medications were prescribed. And it brought peers—fellow madmen—into the psychiatric system as actors, rather than solely as people acted upon. After MindFreedom came such patient-run websites as Pendulum, bipolar groups on MySpace, and the extremely active site PsychCentral.

Now fifty-seven, Oaks helped create MindFreedom out of a coalition of thirteen groups; eighty-five groups with ten thousand members are now involved. It started with something called “Support-Ins” and a newsletter dedicated to what Oaks calls “psychiatric survivors,” people who felt they have been abused by the mental health system. MindFreedom held counterconferences to the annual American

Psychiatric Association meeting a number of times over the past twenty years to protest involuntary electroshock and other psychiatric practices. They also traded in a sort of cultural disobedience involving something they call “mad culture,” which resembles many rebel cultures in that it celebrates the upside of being an outsider: the creativity and the otherworldly energies of the manic, for instance, or the intellectual honesty of the melancholic.

Mad Pride rediscovered the value of older programs such as Soteria Houses (the word *soteria* is Greek for “rescue” or “salvation”), which began in Europe decades ago as places where groups of schizophrenics could live together in supportive, non-hospital-like communities. By dwelling in these communities for years, Soteria’s schizophrenics had equivalent and occasionally better results, in terms of employment and social inclusion, than

schizophrenics who received only medication. In the ideal Soteria House, people would have access to medication but would be encouraged to use it with great care, in a limited fashion, and often at dosages lower than generally prescribed.

Mad Priders also pointed to World Health Organization studies of developing nations in which psychoactive medications were not easily available. In such countries, people with schizophrenia were more likely to be employed and integrated into their communities than they are in Western societies. A study conducted in northern Finland also helped support the Mad Pride position by suggesting a conception of psychosis quite different from the one held in the United States: that it results from a breakdown in social relations rather than from a breakdown in the individual. The job of a psychiatrist or counselor is then to rebuild those connections. (More recently,

Eli Lilly sponsored a study that claimed to debunk these findings.)

Bradley Lewis, a professor of psychiatry and humanities at New York University's Gallatin School, champions the Icarus Project and has brought its followers to NYU and celebrated their contributions through a conference partly devoted to their work. He sees Icarus as a Web-based "shadow" service provider, an extrastate element that steps in when health maintenance organizations, psychiatrists, neurologists, and medication fail. Psychiatry is sometimes faulted for devaluing the perspective of patients, defining them as just crazy—as nothing more than their illnesses. The Web and intentional peer groups such as Icarus have changed the equation, in many cases giving individuals more power over their treatment and fate. Amateurs now can preach a Mad Pride message and learn more about alternative

therapies or narratives about mental health. If they believe a medication such as Zyprexa has hurt them, they can take action; find communities of like-minded activists; and, thanks to the reach and connectivity of the Internet, actually be heard. In Icarus chat rooms or on PsychCentral or MindFreedom, people who struggle with their states of mind can become masters of their own stories, instead of simply relying on psychiatrists to tell them what their stories are.

Of the early days of the Web, Philip Dawdy said, “Back when there were modems, you plugged your modems into alternative points of view about psychiatry for the first time.” Dawdy, a sometime journalist who for eighteen years has called himself bipolar, was an omnipresent mental health blogger with the nom de blog Furious Seasons (his blog is now inactive). “For the first time, patients were educated about

their own situation,” he recalled. “So you were suddenly not totally dependent on the psychiatrist down the street, who is getting a \$100 lunch from Eli Lilly.”

Dawdy said he experienced a meaningful example of online intentional peer counseling on New Year’s Eve 2004. He told me that on that night a seventeen-year-old boy posted the following on a MySpace bipolar group: “I want to kill myself.” Dawdy said, “I spent three hours messaging back and forth with that kid, a perfect stranger, telling him not to, until he wrote, ‘I am OK, I’m not going to kill myself.’ ”

The Icarus Project, explained Dawdy, was from the beginning composed of a lot of young people who, like that suicidal seventeen-year-old, almost got “sucked into the mental health system when they were fifteen or twenty-two, had nowhere else to turn, turned to people like Icarus, found a sense of themselves that’s a lot more

helpful than what they are being taught by their doctors. Icarus was for me when I was told I was in their situation.”

To me, Icarus and the not-sane bloggers were also an example of what the theorist Michael Warner calls “counterpublics.” Warner’s term can be used to describe both the neurodiverse and many of the other renegades in this book who frequently turn to writing as a tool for expression and resistance. He sees these groups as creating their own fictions to counter the supreme fiction of the majority group, which never is the true monolith so many imagine it to be. According to his theory, what we usually call the public sphere is based on exclusion, and excluded groups are assigned lesser status. “Counterpublics” attempt to correct this, Warner says. The notion of a “public” is a social fiction, the “normal,” and it becomes the frame for our lives. Counterpublics, such as the Mad

Priders and all the others in this book, carve out separate spaces through writing in particular, through a strong message that people in the broader public may not have heard before and that could potentially change and shape minds.

As counterpublics define themselves through the act of writing, their presence and impact have never been more ubiquitous than they are in 2013. Autism bloggers, for instance, use written language to assert, define, and put forward their outsider opinions. They create public communities now through writing and publishing—self-publishing is, in a way, publishing a self.

While questioning the necessity of some psychoactive medications may seem to be the most shocking and irrational part of their stance—the truly outlaw aspect of their outsider movement—a range of evidence shows that this stance is far from crazy.

Science does prove that drugs can reduce psychological distress, and some people do stabilize on meds. But not all do, and drugs can also worsen people's lives by giving rise to side effects ranging from impotence, diabetes, and obesity to more abstract complaints, such as a tamped-down emotional life or affect.

In addition, the advent of a wide range of new diagnoses, and the new treatments that go with them, has not necessarily led to greater functionality for those being treated. As journalist Robert Whitaker, author of *Anatomy of an Epidemic*, has written, less than 30 percent of patients recover and return to work, down from 85 percent in the pre-pharmacotherapy era. Though labeling and medication can be great tools when used selectively, in the case of manic depression the diagnoses have proliferated faster than YouTube videos.

Bipolar disorder used to be quite rare:

just one in three thousand people was termed manic-depressive in the middle of the last century. Now an estimated two million Americans are told they suffer from some version of the condition. Various circumstances add to the frequency of the diagnosis. For example, some depressed people have a manic experience when exposed to an antidepressant (as Will Hall did) and may subsequently be diagnosed as bipolar when they are simply reacting to a drug or, in his case, are schizoaffective instead. That leads to a small inflation in bipolar diagnoses. In the past ten years, a new pharmaceutical market has been created for bipolar medication, alongside the rise in diagnoses of this condition.

These new diagnoses have flowered at a time when the *Diagnostic and Statistic Manual of Mental Disorders*, the diagnostic manual used by psychiatrists and psychologists, is often followed zealously

and absolutely. Successive editions of the *DSM*—the forthcoming 2013 edition will be *DSM-5*—have tended to expand the definitions of many major diagnoses. It is in this climate that the Mad Prider feels particularly necessary. A few years ago, the psychiatric community started to question whether people diagnosed as schizophrenic should always use medications. The Icarus Project was ready and began talking to newspapers.

The Icarus Project, MindFreedom, and other Mad Priders argue that the emphasis in a new, closer-to-ideal mental health care model would rely on creating community and offering the peer services that can help define that community. And there have been strides toward such a goal. A new independent organization, the National Coalition for Mental Health Recovery, has a lobbyist dedicated to fighting for peer-delivered services for the mentally ill

(admittedly, one is a lonely number compared to the legion of pharmaceutical lobbyists out there).

MindFreedom's Oaks called peer counseling the "solar power of mental health" and added, "We can't hire enough psychiatrists to support people." He dreamed of a day when, at any time of day or night, anyone in need could go online or Skype a peer counselor. There would be a single, united peer-to-peer online mental health service network. People could talk with a sympathetic, knowledgeable stranger "during a dark night of the soul." "It would be the very opposite of Chatroulette," said Oaks.

NOT WELL

Mental health activism such as DuBrul's and Hall's raises challenging ethical issues. There is risk here, real danger—an element largely absent from the alternative communities organized around cultural

products such as music or film or around food or commerce. In *this* community of renegades, the cultural product is the self. Any challenge to its construction, any challenge to the mainstream's ways of defining the self, labeling "defective" selves and treating or restraining them, invites a certain degree of threat to both community and self.

There also is a risk that those in this community will hurt others or themselves. After all, people have committed suicide after stopping or tapering down their medication against medical advice. And researchers have found that in people with schizophrenia, there is a connection between the use of illegal drugs and a rise in the incidence of violent acts (although only a minority of schizophrenics are ever violent). In addition, people with schizophrenia who exhibited past violence and failed to comply with medicines also

ran an increased risk of violent acts. If they weren't careful, these renegades might endanger themselves or others, I thought. Shouldn't Hall be controlling his thoughts with medication so that his plants could sit silently on the windowsill? Shouldn't DuBrul stop romanticizing a condition that still left him standing on the rooftops of buildings at night? It was another paradox of the renegade, a sign of the productive but often potentially dangerous elements of the Web-enabled outsider.

Indeed, conventional mental health advocacy groups do not accept alt-mental-health groups such as Icarus and Mad Pride. They warn against the uncertainty and instability inherent in having outsider DIY communities depend on their friends and allies on the Web, rather than on credentialed professionals. The charge is that people in the alt community deny themselves adequate care or downplay the

seriousness of the neurological or psychological conditions others suffer. John Stanley is a founding board member of the Treatment Advocacy Center, a well-known organization for the mentally ill, and suffers from bipolar illness with psychotic features. He told me that “medication is indispensable for the majority” of people with bipolar disorder or schizophrenia, and he is very critical of “some of the views held in the [Mad Pride] community.” Conversely, many in Mad Pride and Icarus would object to the Treatment Advocacy Center’s support of “forced treatment” when deemed necessary.

Peter Kramer, author of *Against Depression* and *Listening to Prozac*, said that while he remains critical of the frequency with which drugs such as Prozac are prescribed and the too-wide range of situations for which it is prescribed, he isn’t altogether willing to support members of

Icarus who refuse to see their depression as a disease. “Psychotic depression is a disease and has been for most of human history,” he said, arguing that, in most cases, depression is not productive or creative, just stagnant and disabling. Still, Kramer conceded that community support has an important place: “In an ideal world, you’d want good peer support like Icarus—for people to speak up for what’s right for them and have access to resources—and also medication and deep brain stimulation.” Some people diagnosed as mentally ill are genuinely unable to care for themselves. After receiving treatment, some formerly homeless people say psychosis drove them to live on the street and that diagnoses and treatment were their only ways out. The term *insanity* was a useful one for them because it got them the services they needed, however flawed.

Emily Martin, an anthropologist at New

York University and the author of *Bipolar Expeditions* (Martin has bipolar disorder herself), explained, “The Icarus Project wants to valorize that condition—the close-to-the-sun metaphor of Icarus.” She continued, “This goes back a long way—the celebration of the bipolar condition as a sign or a manifestation of a creativity we’d all be happy to have, with CEOs and actors who are said to be bipolar, or Virgin’s Richard Branson. It’s a condition packaged with ability.”

While Martin was critical of the rosy grandeur of this perspective on mental illness, she saw real value in the patient activism and peer-to-peer help that could sometimes go along with that stance.

MAD LOVE

One night I had dinner with eight Icarus members, including DuBrul and Hall, at a Thai restaurant in midtown Manhattan. Over Singha beer, they joked about an

imaginary psychoactive medication called Sustain, meant to cure “activist burnout.” A bottle of red and black placebos that one of the members had created as a joke was passed around, to peals of laughter.

During that dinner, it was hard to imagine that DuBrul and Hall had been in a number of mental hospitals, although Hall was certainly distant—he had a certain cool glassiness as he checked his cell phone while other people were speaking. The bipolar Icaristas attributed this to his schizophrenia, but it could have just been the familiar alienation of someone constantly using a BlackBerry or iPhone—something that is also, of course, the province of “normal” people. (Between the bipolar and the schizophrenic members of the group, there was a narcissism of small differences.)

Another founding member of Icarus, a musician named Madigan Shive, talked

about how her mother had had psychotic episodes that led her to hoard. In her telling, her mother needed not only treatment but also a like-minded community that she lacked.

Shive spoke of how the “activism survivor movement” had saved her from what she called “psychiatric consumerism.” “They’ve given me new labels and a new language,” she said, gesturing at her friends. “I heard voices, but they were peaceful voices that told me intuitive things.” When she was desperate she called or e-mailed the other Mad Priders, she said, and they helped her carry on.

While they sat in the restaurant, joking and planning speaking engagements around the country—they would travel together via bus to campuses to talk about their experiences—it was a demonstration of how small groups of renegades could, no matter how provisionally and how

temporarily, relabel their experiences. While these “mad” allies were still clearly outsiders, they and the neurodiversity activists had taken their isolation and their suffering and created from it an all-too-rare thing: a community.

“We also want to be conscious that there are lots of contradictions,” DuBrul told me at dinner. “I think pharma is evil, but the drugs are helping folks. There are people taking drugs who are ashamed to talk about it.” He also told me that same night, “I’ve been in so much pain. That’s why I want to find the kids like me when I was eighteen. I want to tell them that they’re not alone.”

A year and a half later, I talked to Hall again. He was off medication because he felt the meds had made his thoughts “slurry” but still lived independently, in an apartment with a roommate. He had both girlfriends and boyfriends and maintained a large number of friendships, although they

were often tumultuous. He lived in Portland, Oregon, studying for a master's degree in psychology at the Process Work Institute, a psychotherapy-and body-work-focused institution. All this had happened, he believed, because he had had support groups that enabled him to talk freely about his altered states as well as his everyday triumphs and struggles.

“For most people, it used to be ‘Mental illness is a disease—here is a pill you take for it,’ ” said Hall. “Now that’s breaking down.” Yet his new way of handling his states of being didn’t quiet the voices or the figures, like devils in Renaissance paintings, that still tugged at his mind.

But outcomes are complex. The alt-mental-health crusaders are great metaphors for all of today’s social renegades both in their self-sufficient amateurism and in their ability to actually shock and surprise. (As Phillips wrote in

Going Sane, “The sane can, in the fullest sense, get on with people; the mad are difficult.”)

Nevertheless, the Icaristas and the Mad Pride people, buzzing and chatting online and weaving together their dissent, suggest that our trust in psychiatric labels—a central feature of modern times, when diagnoses are crucial for so many to get access to social services or even appropriate schooling—can cause unneeded suffering and lead to lifetimes of frustration and despair. Like DuBrul and Hall, many struggle with the way labels flatten us, whether the word is *gifted* or *inattentive* or *depressed* or *crazy*. In an age of labels, the Mad Priders have exerted their revenge against the vise of the “mentally ill” diagnosis, easing it open.

At their tenth-anniversary event in Manhattan in 2012, fifty Icaristas milled about a borrowed meeting space by the

Hudson River. DuBrul greeted me near the door with a huge embrace. He now lived in Berkeley, California, where he worked as a gardener and hung out with his friends who had kids, he said. He was stable, thanks in part to a new therapist, he said. At the event, older people mixed with college students. There was a three-year-old in attendance and also a woman in a wheelchair. Easygoing young women meshed with mad people who seemed a little closer to the edge. (DuBrul called the latter group “old-school patient-survivors.”) In one corner, there were publications for sale with defiant titles such as *Cunt Coloring Book*.

After twilight fell, members of the group started to address the audience, five minutes at a time, in a fashion that resembled Occupy Wall Street’s general assemblies—not entirely coincidentally, as their memberships overlapped. DuBrul

cheered the group's ten years of existence, saying that they must have been doing "something right," but he was also startlingly honest about the group's challenges. "People find it [Mad Pride] when they are in a state of crisis or when their friends are," he said. "When they are better, they leave. We have fifteen thousand members on our website, but who holds shit down at Icarus?"

The speaker after him noted that the members who tended to hold things together in the group were the depressives. The bipolar types would have all the plans, and the depressives would then muster enough focus to carry them out, she said. The whole crowd laughed in self-recognition.

It was not a traditional triumphal anniversary event, but the Mad Priders seemed to feel safe in its unblinking honesty. They were yet again turning to the

“expertise” of another former or current patient willing to listen and advise. They found community to be the antidote because they need an alternative sphere—a place where they are understood and a unique service that can’t be simply bought or ingested. As the Icarus Project mantra had it, friends are the best medicine.