

Why some mentally ill patients are rejecting their medication and making the case for 'mad pride.'

By ALISSA QUART

WE DON'T WANT TO BE NORMAL," Will Hall tells me. The 43-year-old has been diagnosed as schizophrenic, and doctors have prescribed antipsychotic medication for him. But Hall would rather value his mentally extreme states than try to suppress them, so he doesn't take his meds. Instead, he practices yoga and avoids coffee and sugar. He is delicate and thin, with dark plum polish on his fingernails and black fashion sneakers on his feet, his half Native American ancestry evident in his dark hair and dark eyes. Cultivated and charismatic, he is also unusually energetic, so much so that he seems to be vibrating even when sitting still.

I met Hall one night at the offices of the Icarus Project in Manhattan. He became a leader of the group—a "mad pride" collective—in 2005 as a way to promote the idea that mental-health diagnoses like bipolar disorder are "dangerous gifts" rather than illnesses. While we talked, members of the group—Icaristas, as they call themselves—scurried around in the purple-painted office, collating mad-pride fliers. Hall explained how the medical establishment has for too long relied heavily on medication and repression of behavior of those deemed "not normal." Icarus and groups like it are challenging the science that psychiatry says is on its side. Hall believes that psychiatrists are prone to making arbitrary distinctions between "crazy" and "healthy," and to using medication as tranquilizers.

"For most people, it used to be, 'Mental illness is a disease—here is a pill you take for it,'" says Hall. "Now that's breaking down." Indeed, Hall came of age in the era of the book "Listening to Prozac." He initially took Prozac after it was prescribed to him for depression in 1990. But he was not simply depressed, and he soon had a manic reaction to Prozac, a not uncommon side effect. In his frenetic state, Hall went on to lose a job at an environmental organization. He soon 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. Eventually, he went to a mental-health clinic and was swiftly locked up. Soon after, he was diagnosed with schizophrenia. He was put in



Listening to Mad

restraints and hospitalized against his will, he says. For the next year, he bounced in and out of a public psychiatric hospital that he likens to a prison. The humiliation and what he experienced as the failure of the medication were what turned him against traditional treatment. Since then, Hall has been asking whether his treatment was really necessary. He felt sloshily medicated, as if he couldn't really live his life.

Hall and Icarus are not alone in asking these questions. They are part of a new generation of activists trying to change the treatment and stigma attached to mental illness. Welcome to Mad Pride, a budding grassroots movement, where people who have been defined as mentally ill reframe their conditions and celebrate unusual

(some call them "spectacular") ways of processing information and emotion.

Just as some deaf activists prefer to embrace their inability to hear rather than "cure" it with cochlear implants, members of Icarus reject the notion that the things that are called mental illness are simply something to be rid of. Icarus members cast themselves as a dam in the cascade of new diagnoses like bipolar and ADHD. The group, which now has a membership of 8,000 people across the U.S., argues that mental-health conditions can be made into "something beautiful." They mean that one can transform what are often considered simply horrible diseases into an ecstatic, creative, productive or broadly "spiritual" condition. As Hall puts

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Madness

it, he hopes Icarus will “push the emergence of mental diversity.”

Embracing “mental diversity” is one thing, but questioning the need for medication in today’s pill-popping world is controversial—and there have been instances in which those who experience mental extremes harm themselves or others. Icaristas argue that some of the severely mentally ill may avoid taking medication, because for some the drugs don’t seem to help, yet produce difficult side effects. And while some side effects like cognitive impairment are surely debilitating, others are more subtle, such as the vague feeling that people are not themselves. Icaristas call themselves “pro-choice” about meds—some do take their drugs, but others refuse.

MENTAL DIVERSITY: *Hall, who has schizophrenia, argues for acceptance of ‘different minds’*

Mad pride has its roots in the mad-liberation movement of the 1960s and ’70s, when maverick psychiatrists started questioning the boundaries between sane and insane, and patients began to resist psychiatric care that they considered coercive. But today the emphasis is on support groups, alternative health and reconsidering diagnostic labeling that can still doom patients to a lifetime of battling stigma. Icarus also frames its mission as a somewhat literary one—helping “to navigate the space between brilliance and madness.” Even the name Icarus, with its origin in 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 a literary cast.

Although Icarus and Hall focus on those diagnosed as mentally ill, their work has much broader implications. Talking to Hall, I was acutely aware just how much their stance reflects on the rest of us—the “normal” minds that can’t read through a book undistracted, the lightly depressed people, the everyday drunks who tend toward volatility, the people who “just” have trouble making eye contact, those ordinary Americans who memorize every possible detail about Angelina Jolie.

After all, aren’t we all more odd than we are normal? And aren’t so many of us one bad experience away from a mental-health diagnosis that could potentially limit us? Aren’t “normal” minds now struggling with questions of competence, consistency or sincerity? Icarus is likewise asking why we are so keen to correct every little deficit—it argues that we instead need to embrace the range of human existence.

While some critics might view Icaristas as irresponsible, their skepticism about drugs isn’t entirely unfounded. Lately, a number of antipsychotic drugs have been found to cause some troubling side effects.

There are, of course, questions as to whether mad pride and Icarus have gone too far. While to his knowledge no members have gravely harmed themselves (or others), Hall acknowledges that not everyone can handle the Icarus approach. “People can go too fast and get too excited about not using medication, and we warn people against throwing their meds away, being too ambitious and doing it alone,” he says.

But is this stance the answer? Jonathan Stanley, a director of the Treatment Advocacy Center, a nonprofit working to provide treatment for the mentally ill, is

somewhat critical. Stanley, who suffers from bipolar illness with psychotic features, argues that medication is indispensable for people with bipolar disease or with schizophrenia. Stanley’s group also supports mandatory hospitalization for some people suffering severe mental illness—a practice that Icarus calls “forced treatment.”

Scholars like Peter Kramer, author of “Listening to Prozac” and “Against Depression,” also take a darker view of mental extremes. “Psychotic depression is a disease,” Kramer says. As the intellectual who helped to popularize the widespread use of antidepressants, Kramer is nonetheless enthusiastic about Icarus as a community for mad pride. Yet he still argues that mental-health diagnoses are very significant. “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,” he says.

For his part, Hall remains articulate, impassioned and unmedicated. He lives independently, in an apartment with a roommate in Oregon, where he is getting a master’s in psychology at a psychoanalytic institute. He maintains a large num-

Psychiatrists are prone to making arbitrary distinctions between ‘crazy’ and ‘healthy,’ Hall says.

ber of friendships, although his relationships, he says, are rather tumultuous.

Nevertheless, it’s not so easy. Hall periodically descends into dreadful mental states. He considers harming himself or develops paranoid fantasies about his colleagues and neighbors. Occasionally, he thinks that plants are communicating with him. (Though in his mother’s Native American culture, he points out, this would be valued as an ability to communicate with the spirit world.)

On another night, I had dinner with eight Icarus members at a Thai restaurant in midtown Manhattan. Over Singha beer, they joked about an imaginary psychoactive medication called Sustain, meant to cure “activist burnout.” It was hard to imagine at the dinner what Hall had suffered. While he and his “mad” allies were still clearly outsiders, they had taken their suffering and created from it an all-too-rare thing: a community. ■