

MAD STUDIES READER

Interdisciplinary Innovations in Mental Health

Edited by Bradley Lewis, Alisha Ali and Jazmine Russell



"The *Mad Studies Reader* brings the world of mental health together with the world of critical intellectual scholarship and activism. It is invaluable reading that works out the central problem of sanism in the way we treat mental differences. I have no doubt it will be an instant classic and a 'go to' resource for people in the mad pride movement, disability studies, health humanities, narrative medicine, arts for health, critical mental health, and anyone interested in the complexities of today's mental health concerns."

Danielle Spencer, PhD, Program in Narrative Medicine, Columbia University and author of Metagnosis: Revelatory Narratives of Health and Identity

"In the relentless quest for liberation, echoes have resonated through time—voices of scholars, storytellers, and activists narrating the tale of defiance. The *Mad Studies Reader* stands as a testament within the tapestry of social justice movements embroiled in this struggle for emancipation. For me, its arrival marks a critical juncture, a turning tide where the silenced voices of society's marginalized find amplification. Mad people being recognized as bearers of transformative wisdom capable of reshaping our world."

Vesper Moore, Activist and host of GET MAD! podcast devoted to transformative mental health, mad pride, and disability justice

"So many questions: Do medical models want to eradicate mental illness? What is anti-psychiatry? Could depression be poetry? What does epistemic justice look like for mental health? Does capitalism fuel mental illness? In response to these questions and many more, The *Mad Studies Reader* is what our futuristic-politociz ed-neurodivergent-justice-fueled-(re)educational process needs to look like."

Jennifer Mullan, PhD, *Psychotherapist and author of* Decolonizing Therapy: Oppression, Historical Trauma, and Politicizing your Practice

"A groundbreaking cornucopia of art, activism, and critical thought. Required reading for artists, students, scholars and anyone interested in mental health."

Jussi Valtonen, PhD, Novelist and psychologist, They Know Not What They Do

Mad

Studies

Reader

Interdisciplinary
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Mental Health

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s s a	As a practitioner, activist, and scholar with lived experience, Will Hall, in his writing, draws from his own life and from his extensive knowledge of radical mental health scholarship. This piece challenges us to think beyond the dominant model of schizophrenia as a medical condition that must be treated through medical means, at times violently forced, and invites us into the inner world of a young man who is more than simply an illness.	
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i	This chapter is a blogpost on the activist website Mad in America (madinamerica. com) by the founder of the website. Whitaker's post provides an informal but informative snapshot into the energy and excitement around Mad in America, the mad pride movement, and its active growth around the world.	
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Letter to the Mother of a "Schizophrenic"

WE MUST DO BETTER THAN FORCED TREATMENT

Will Hall

Summary

In this chapter, written as a letter to the mother of a son who is dealing with trauma and extreme states, Will Hall presents the case against forced psychiatric treatment. Hall tells a compassionate story of his encounter with this young man and reflects on his own reactions to him as one who has also been labeled with mental illness. His reflections reveal the dangers of reducing sufferers to patients who must receive treatment even if it violates their own desires. Hall also reveals to us the complex and brilliant mind of the son as he grapples with reality and nonreality. We learn that there can be viable relational alternatives to mainstream medical treatment for schizophrenia—grounded in trust, respect, and humanity—that could better serve this son and countless others. Forced treatment remains a controversial issue in psychiatry among patients, clinicians, and family members. By telling this very human story, Hall shows us what individuals and families could gain if we expanded our thinking about schizophrenia, trauma, and treatment and made space for human connection.

*

A few months ago I met your son. He said he would be waiting for us in the Berkeley park near where he sleeps outside at night, but at the last minute he called and was in San Francisco. He said he was at "the Mrs. Doubtfire house" with a photograph of his best friend, and that the photo showed numbers and codes predicting Robin Williams' suicide. He found the house where Williams made one of his films and was trying to talk to the owner: it was all part of a complex plan, marked mathematically in signs and omens he was collecting.

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We drove across the Bay, worried. Were we too late? Would he be arrested and end up in the hospital again, this time for trespassing and harassment, a psychotic man caught bothering someone at a private residence?

When the GPS showed we were getting near the address he gave, I started to see people milling around, a commotion, cars stopped. My first thought was that something had happened. Maybe we weren't in time, maybe he was already in trouble with the police, arrested at the house he seemed obsessed with?

At Steiner and Broadway, we found your son, sitting on the sidewalk—but he wasn't alone. He wasn't the only one interested in the Mrs. Doubtfire house. The sidewalk was strewn with flowers, and dozens of other people were also there. What first seemed crazy, now seemed normal: many people, like your son, were drawn to the private residence where a Robin Williams film was made, to commemorate the actor's suicide with a pilgrimage.

I walked up to your son and greeted him, unsure how this young disheveled man would respond to me. I had been told he was considered "severely mentally ill," the worst of the worse, so beyond reach in his delusions that clinicians were considering using force to bring him to the hospital for treatment. But as soon as we made eye contact I was surprised. There was a clear feeling of affinity and communication. He explained in rapid speech about the numbers and messages on the photo, Robin Williams' middle name, and the sidewalk code. It was all part, he said, of an alphanumeric psyche that communicates to him through signs and coincidences.

It was exhilarating and exhausting keeping up with the math calculations, anagrams, and nimble associations that flowed when he spoke. But he also at times talked normally, planned a walk up the street to a coffeehouse, and explained what had happened about our meeting. I lost the thread at different points in our discussion, but one thing was clear: your son is brilliant. I was not surprised when he told us he got a perfect score on the SAT. "It was easy," he explained when I asked. "Anyone can get a perfect score if they take the practice tests."

We were quickly engrossed in conversation, and when he suddenly wove the author Kurt Vonnegut into the pattern, my eyes widened. Just moments before our meeting I was talking with my colleague, telling my own story of meeting Vonnegut. And now here your son was mentioning the author. I was amazed by the coincidence. As your son's talk became wilder and more complex, referencing the Earth Consciousness Coordinating Office, SEGA Dreamcast, and numerology, and as he did math equations instantly to prove his obscure points, I sensed an uncanny power and clairvoyance in the air. I was in the presence of someone in a different reality, but a reality with its own validity, its own strange truth. A different spiritual view.

Perhaps I am eager to emphasize your son's talents because today he finds himself so fallen. I don't romanticize the suffering that he, or anyone, endures. His unusual thoughts and behavior led to a diagnosis of schizophrenia and seem to be part of deeper emotional distress he is struggling with. I don't romanticize because I've been through psychosis and altered states myself. I've been diagnosed schizophrenic, many years and many life lessons ago, moving on with my life only after I found ways to embrace different realities and still live in this one.

So when we met your son I was completely surprised. The "severely mentally ill man" I was told needed to be forced into treatment was intelligent, creative, sensitive—and also making sense. Like someone distracted by something immensely important, he related to us in bits and pieces as he sat in conversation. Living on the street and pursuing an almost incomprehensible "calorie game" of coincidences on food wrappers isn't much of a life, perhaps. And maybe it's not really a choice—at least not a choice that most of us would make, concerned more with getting by than we are with art, spirit, and creativity. What surprised me was the connection I had with your son. Because I took the time, and perhaps I also have the background and skill, I was quickly able to begin a friendship.

By taking interest in his wild visions, not dismissing them as delusional, and by telling him about my own mystical states, not acting like an expert to control him, we began to make a bond. I spoke with respect and interest in his world, rather than trying to convince him he "needs help." What, after all, could be more insulting than telling someone their life's creative and spiritual obsession is just the sign they need help? That it has no value? By setting aside the professional impulse to control and fix, I quickly discovered, standing on that cold sidewalk and then over hot tea in a cafe, that your son is able to have a conversation, can relate, communicate, even plan his day and discuss his options. Some topics were clearly pained, skipped over for something else, and he was often strangely distracted—but it was after all our first meeting, and I sensed some terrible and unspoken traumas present that were still not ready to be recognized. To me, clearly, he was not "unreachable."

That we had a connection in just a short time made it very hard for me to understand why you or anyone would want to use force—to use violence—to get him into mental health treatment. A traumatic assault, instant mistrust, betrayal, restraint, then a complex web of threat, coercion, and numbing medications to impose compliance, possibly a revolving door of re-hospitalization, more medications, more threats and force and police... Surely creating a relationship, building trust, and interacting with compassion over time is a much better way to show concern and offer help?

When you think you know what is best for someone, it might seem faster to send a patrol car and force them off the streets and into a locked hospital cell. But would that really be safer? For whom? Or would it push someone farther away, undermine the connection needed to find a real way out of crisis?

You've become an outspoken public advocate of new legislation to empower clinicians to intervene drastically in the life of your son and others like him. In pushing for so-called "Laura's Law" the idea is to pressure, through force, compliance with medication and hospital care. Your son, homeless and in an altered state, is today held up as a perfect example of why force is needed. I share your desire to help people in need; that's why I went to meet your son in the first place. And I agree that our broken mental health system needs fixing, including new legislation and new services. I do want your son to get support. I want there to be more resources, more access to services, more connection, more caring, more healing. But I do not see your son, or people like him, as so "unreachable" that they cannot form a relationship with someone genuinely interested. That just wasn't the man I met that day. I don't see him as so less than human that his own voice and perspective should

be ignored, rather than understood. I don't see strange beliefs and outsider lifestyle on the street in any way justifying the violence of forced treatment. I don't see him as any different than any other human being, a human who would be terribly damaged by the violence of force, confinement, and assault, regardless of it being perpetrated in the name of "help."

That day I met a man possessed by a mysterious artistic and spiritual quest that others around him can't understand. He is homeless and perhaps very afraid deep down, but he is a person with feelings, vulnerabilities, and emotions. Alongside the rapid-fire associations that I couldn't keep up with, he was also capable of connecting. His pilgrimage to Robin William's Mrs. Doubtfire house wasn't some lone obsessive symptom, the sign of schizophrenia and a broken brain, but understandable when put in context. His ranting was not a meaningless mutter but a creative and encyclopedic stream of enormous intellect. Yes, he seemed to be in touch with some other reality, an altered state that demanded most of his attention. Yes, I would love to see him living indoors, less afraid, more cared for, and more caring for himself. I'd like to see the many homeless people in the Bay Area have the same. But no, this is not a man I would want to force into restraints, injections, and confinement. I would not want anyone to be subjected to such violence—and it is violence, as people who have endured it will tell you. I would not want to destroy my emerging friendship with him with such an attack, because I know it is friendship—long, slow, developing connection and understanding—that can truly heal people who are tumbling in the abyss of madness.

Concerned and wanting to help, wouldn't it be better for us to find the resources to gently befriend your son, to learn more about him, create trust, and meet him in his life and world? Even if this took patience, skill, and effort? Isn't this how we want others to approach us if we seem, in their opinion, to be in need of help? Don't we want our voice respected if we disagree with someone about what is best for us? How can friendship and trust possibly come out of violence?

Again and again, I am told the "severely mentally ill" are impaired and incapable, not quite human. I am told they are like dementia patients wandering in the snow, with no capacity and no cure, not to be listened to or related to. I am told they must be controlled by our interventions regardless of their own preferences, regardless of the trauma that forced treatment can inflict, regardless of the simple duty we have to regard others with care, compassion, and respect, regardless of the guarantees of dignity we afford others in our constitution and legal system. I am told the "high utilizers" and "frequent flyers" burden services because they are different than the rest of us. I am told the human need for patience doesn't apply to these somehow less-than-human people.

And when I finally do meet the people carrying that terrible, stigmatizing label of schizophrenia, what do I find? I find—a human being. A human who responds to the same listening and curiosity that I, or anyone, responds to. I find a human who is above all terrified, absolutely terrified, by some horrible trauma we may not see or understand. A human being who shows all the signs of flight and mistrust that go along with trauma. A person who may seem completely bizarre but who still responds to kindness and interest— and recoils, as we all would, from the rough handling

and cold dismissal so often practiced by mental health professionals. Listening and curiosity might take skill and affinity, to be sure, when someone is in an alternate reality. But that just makes it our responsibility to provide that skill and affinity. Do we really want to add more force and more violence to a traumatized person's life, just because we were not interested in finding a different way?

Your son may be frightened, may be in a different reality, may spend most of his time very far away from human connection. But his life, like everyone's, makes sense when you take time to understand it. He deserves hope for change, and he deserves careful, skilled efforts to reach him and to connect—not the quick fix falsely promised by the use of force.

Even under the best of circumstances, mothers and sons sometimes have a hard time communicating. Many young people refuse help—just because the hand that offers it is the hand of a parent they are in conflict with. Perhaps the need for independence is stronger than the need to find refuge in the arms of a parent. Perhaps children flee their parents in spite of themselves, because of some complex reality they are seeking to overcome. So maybe the help that is needed is not just for the sick individual but for repairing a broken relationship. I say this because after my own recovery from what was called "schizophrenia," I became a counselor with families. I see again and again—and the colleagues I work with also see again and again—that by rebuilding relationships, not tearing them down with force, healing can occur. A young person whose promising life and career were interrupted by psychosis can regain hope for that possible future.

A simple look at the research literature over the past 50 years shows that recovery from what is diagnosed schizophrenia is well documented and a real possibility—for everyone. Not a guarantee, but a possibility worth striving for. It is only in the past few decades that we forget this basic clinical truth about the prognosis of schizophrenia and psychosis, and instead predict chronic, long-term illness for everyone. Such a prediction threatens to become a self-fulfilling prophecy, as we lower our expectations, give up hope, and relegate people to a lifetime of being controlled and warehoused in the identity of "severely mentally ill."

I do believe help is needed, help not just for your son, but help for everyone in the family affected by the strange and overwhelming experience of psychosis. But when parents, who are alone and desperate to change their children, resort to pleas for force and coercion, they risk sacrificing the very connection and bond that can be the pathway toward getting better.

I hear the claim that Yes, we should respect the right to refuse help, but when people are suffering so greatly and everything else has been tried, we have no choice but to infringe on freedom. This is false. We haven't already tried everything we can. We have not tried everything we can with your son, or with you. There is a huge wellspring of creative possibilities, skills, and resources possible if we just direct our mental health system to try harder and do better for you and your son—and the many people like you. It takes money, vision, and political willpower, but people struggling with mental illness deserve the dignity of true help, not false promises.

We can, and must, do better. We must think outside of the false choice between coercive help or no help. We might start by asking people who have recovered from

psychosis—and there are many—what they needed to get better and give them a leading role in shaping our mental health policies. We might start by respecting people's decision to avoid treatment and seek to understand the decision rather than overpower the person making it. When you have been traumatized by those offering help, avoiding treatment might even be a sign of health, not madness.

Maybe some of us, when we are terrified, discover different realities to hide in. And maybe some of us, when we are terrified about people we love, reach for desperate measures—like forced treatment policies and Laura's Law—to help. I believe that people who are afraid, perhaps such as your son and yourself, need caring, kindness, patience, and listening. Trying to force you, or him, to change may only drive us all farther apart.

I believe it is often the most brilliant, sensitive, artistic, and yes sometimes even visionary, telepathic, and prophetic people who get overwhelmed by madness. We need to discover who they are and meet them as we would ourselves want to be met, rather than giving up hope for human connection.

At the cafe where we talked, the waiter was polite, but kept his eye on your son, seeing only a dirty and homeless schizophrenic, not the human being I was getting to know, not the son you love dearly. When we said goodbye, I tried to imagine what it would be like, living rough on the street, facing suspicion or worse from everyone I passed. I imagine it would be lonely, that I might fall asleep at night missing my childhood home, missing my mother.