Insight

Gareth Fenley

To keep perceiving and working as a person who receives treatment, I make conscious efforts not to turn into someone who thinks like a treater. I share what I learn through my own life and through what others share with me because of our common experiences. That enables my unique contribution as a peer specialist within an academic department of psychiatry.

I like to tell mental health professionals, "From the viewpoint of psychiatry, insight is a measure of how much I agree with you." As I see it from a consumer perspective, my insight is my wisdom. It is a useful awareness of what I experience from my inner self outward. In saying *useful*, I am separating self-awareness that helps sustain me in a practical way from anything that drags me into ruin. This includes how I perceive worldly reality and transcends it, moving into the spiritual realm.

The language we use to express ourselves tells others a story of what our insight reveals to us. In the jargon of my social movement, I can see myself as a psychiatric survivor. Professional practices have caused me devastating harm. For example, I lost my livelihood in two careers, went bankrupt, and became nearly homeless as disabling attacks struck me for four years. The nature of the problem was finally diagnosed and communicated to me last month at a follow-up appointment after an inpatient stay. In the hospital, a nurse had asked me, "Why are your eyes rolled up?" A week later at home, I typed "eyes rolled up" in Google and discovered that I had been suffering oculogyric crisis, a side effect of antipsychotic medication. My psychiatrist confirmed the diagnosis and changed my medications again. That's three med changes within the past month. I mean, that *was* three—I just got off the phone with him, and it's four now.

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I could be angry about it. I was for a bit. But, still believing that psychiatry offers the best approach fitting me, I have continued to return as a voluntary customer. I call myself a consumer. I even choose to keep working peacefully inside the system that poisoned me. That is my vocation at this point in life. Other individuals have developed anti-psychiatric ideology fueled by righteous rage, and they work to abolish what I am trying to reform. They may call me a sell-out or shill. I would rather call them my peers, along with other consumers. We all have been subjected to medicine's most coercive and scientifically primitive specialty.

When I find myself in a mixed group of folks with these perspectives, our conversations may deteriorate into arguments or standoffs in which the intangible is political. I can easily understand why psychiatry so often and so unfortunately generates adversaries. While the treaters believe they intervene with people "crying out for help," the treated much too often feel we are being subjected to uninvited threats, yelling, abuse, violation of rights, or robbery of self-respect. During psychiatric encounters, generations have shouted or sobbed, "I'm not crazy!" We can't reconcile the stigmatized image that society has taught us with the selves we know. To be *crazy* means owning all the ridicule, shame, and terror associated with lunacy.

In recovery, we deal with stigma and keep our lives moving with what we see as meaning and purpose. For some people, chapters in this journey involve leaving treatment behind. Many reflections upon lived experience by ex-patients are deeply insightful. In *The Wind Never Lies* (1), Steven Morgan explains how treatment compliance replaced his authentic inhabiting of self with a dulled, generic life that he found unsatisfying. Aubrey Ellen Shomo's *The Manifesto of a Noncompliant Mental Patient* (2) rebuts psychiatric observations of her conduct point by point. In these brief, recommended readings, both writers explain why they stopped working with physicians and moved on to risk departing from what Morgan calls the "mental illness world view."

The rising enthusiasm for trauma-informed care among mental health recovery leaders stems partly from a rejection of the illness perspective—the viewpoint of the frustrated hospital psychiatrist who scrawled across the page of a chart, "Abysmal lack of insight!!" Survivors may understand psychiatric episodes not in terms of symptoms expressed from within, but as assaults upon the self by a system that attempted what it calls treatment.

There was a time when I resisted treatment, but I later become cooperative and grateful. There are many of us. I asked a friend of mine who has paranoid schizophrenia to share that view with me in words. He loaned me his copy of *I Am Not Sick, I Don't Need Help!: Helping the Seriously Mentally Ill Accept Treatment* (3). This popular book by psychologist Xavier F. Amador, who has done extensive work on insight in psychotic disorders, is explicitly addressed to families and therapists, but it also helped my friend express himself. Amador instructs his readers in how to be helpfully sensitive to persons perceived as needing treatment while they are refusing. Uncommon patience and respect are required for this to work.

As I considered the nature of insight, I met peer specialist Sissy Weaver, who was selected to make a conference presentation as a role model for the National Alliance on Mental Illness. She described hearing voices and receiving several psychiatric diagnoses as her life fell apart and medication made her obese, then regaining athletic fitness and securing work with a consumer-run mental health agency. Remarkably, given the organization that had invited her to speak, Weaver told the audience, "I don't accept that I have a mental illness." I arranged to interview her later to help me understand her view better. "Acceptance would feel like a defeat," she told me as we sat at a table in a public library. "What I have is awareness. I am aware of symptoms and that I need to take medication."

Sissy Weaver is using mental health care in a way that works for her as she pursues her own goals. Nobody seems to be demanding that she dutifully recite, "I accept that I am schizophrenic and I will have to take medication for the rest of my life." I am schizophrenic. I am bipolar. I am sick. I need help, and I will need it forever. Internalizing this psychiatric creed tames treatment resistance at the expense of equating the self with disease.

Novelist Clare Allan, who writes about her own experiences for the British newspaper, *The Guardian* (4), writes that "mental illness can become a way of life as much as a medical condition." She compares it to removal to a faraway place where "everything else falls away: job, home, family, ambitions, the sense that things will ever be different from the way they are now."

I don't take it for granted that I will stay out of that faraway place. I negotiate to keep a semblance of a middle-class lifestyle while remaining aware of what I call mental illness. At tricky moments, it can be like standing with one foot on a dock and the other foot on a boat. Recovery is the art of staying above water—or climbing back out after I've been dunked.

Journaling is one tool that helps me maintain or regain my balance. I have been keeping diaries on and off for more than thirty years. I find it an excellent aid to self-awareness. I am able to privately express my often elusive and sometimes deranged thoughts. Then I can check and reflect on them later, when I'm in a thoughtful and sometimes newly rational state.

Last month, I was writing routinely when I jotted down some thoughts about being the Messiah. I continued to write about other things that were passing through my mind. When I re-read the page, I recognized that something was a bit off. I then picked up the pen again. I wrote that if I am the Messiah and I go to start a new religion, I will have to end my relationship with my life partner and be single, and I would not want to do that because of how much I love her.

It was the thought of loss of family love—not any direct recognition that I'm not the Messiah—that helped to keep me from falling into the water. Over the next few days I was able to process more thinking about this and get to a point where I made the decision to go to a hospital for evaluation and admission.

One evening there, a nurse woke me from a deep sleep induced by medication and asked me to tell my story. I was too groggy to think, and she cued me with the prompt, "You found something bizarre written in your journal." I resented the way she put that, because I didn't find my own thoughts to be bizarre, but I did not contradict her. I have become somewhat wise in the way of hospitals, and have adopted the motto "Go along to get along" for personal use during inpatient stays.

I have intentionally selected "Checking Realities" as the title for this column presenting consumer perspectives. I would not go as far as recovery advocate Linda Buckner, who memorably told an audience of psychiatrists and psychologists, "Take the word *reality* out of your vocabulary." Reality is a very useful concept if we can understand that insights into it vary person by person. Goals form within visions of reality. Insight works for us in a practical fashion to keep us able to sustain movement toward the goals we desire to reach. I turned down what seemed to be a new calling in favor of my family, as well as my job. In the balance of freedom and security, I chose to be relatively secure. I don't believe that a condition named mental illness should deprive a person of the right to pursue happiness.

On behalf of those who are identified as patients, I would like to share a few final bits of advice to professional and family caregivers. Please encourage awareness instead of demanding acceptance. Educate yourself and others at every level. Offer help before involuntary treatment is legally necessary, and gracefully allow us to refuse if we say no. Work to understand why we may not desire treatment. Be sensitive to our own insights as we understand them. Keep extending kind and patient offers to help. Surround us with that which we value on our own terms, instead of intervening in a way that we find harmful. Be mindful of long-term consequences. Respect us and discover what you can learn from us as we are. While these suggestions certainly will not end all the problems of psychiatry, I believe they can make it safer and healthier for all concerned.

References

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