

Embarking into Recovery

Gareth Fenley

Tall, dark, and bald, dressed in a white T-shirt and patched jeans, Charles Willis scowls at the box of matches in his hand. They remind him of the time he burned a family's house down when he was trying to cook dinner. "I'm leaving you behind," he says, and sets the box down on stage.

From the table heaped with objects before him, Willis picks up a small bottle and announces that he hates taking medication. Then he faces the audience with a wide grin and says, "But I must admit, I feel better since I've been taking it than I ever have before, so I'll take you along." He places the bottle in an orange knapsack. Willis also puts in a tape player that repeats messages accusing him of being bad, just to remind himself of where he's been. He discards his cigarettes triumphantly, saying he might as well quit them just like the alcohol and crack.

After completing a series of choices about what to take home from rehab, Willis exits with his bag. The audience applauds enthusiastically.

The Story of Recovery: A Play was created in suburban Atlanta this spring by people who have been admitted to psychiatric facilities and released, whether once or many times. One by one, the actors stepped onto a community college stage set with props from their own personal collections. Speaking in monologues, they made their own selections of what to leave behind and what to put in a suitcase or travel bag for use in the future. They adopted new identities as Certified Peer Specialists whose mission is to carry the message of mental health recovery to others.

The play was inspired by *The Lives They Left Behind: Suitcases from a State Hospital Attic*. The 2008 book and its website at www.suitcaseexhibit.org present an exhibition that offers a self-described "moving—and devastating—group portrait of 20th century American psychiatric care." The book focuses on the first half of the century, when it was common to be institutionalized for decades until one's body was buried on hospital grounds. The exhibit's curators reconstructed the lives of selected former residents of New York's Willard State Hospital. The politically charged interpretation that suffuses the project is based on interviews and artifacts. The most evocative items are the contents of suitcases stored in a forgotten attic.

The last names of the profiled New Yorkers could not be used due to privacy laws. The actors in Georgia's autobiographical play advertised it to the public using their full names: Charles Willis, Dionne Tillis, and Carol Coussons de Reyes. They stated in a flyer: "In ages past, we lost our lives. With one admission to the hospital, we were never heard from again Today, we are more than the lives we left behind. We are moving forward and walking into our dreams!"

Hospitalization forged a perspective on mental illness for these playwrights, and for me as well. Our own original, profoundly eccentric and isolating experiences within our minds became the collective reality of being classified and treated in locked buildings. And we lived to walk out.

I had seen private therapists for many years and was thoroughly accustomed to quiet waiting rooms where names are not exchanged. But on that chaotic night in the emergency room when a doctor pronounced that I would be committed and transported to a mental hospital, I was so completely unwilling to accept my vivid image of being warehoused forever on some ward that I attempted to end my life for the first time.

Today I, too, am a Certified Peer Specialist. I carry every day a reminder of the program that started me walking in the direction of this dream, a yellow plastic key holder I was given by staff at a halfway house. I work at the Medical College of Georgia in a job funded by the state's Division of Consumer Relations and Recovery. I have learned to call myself a "consumer" in the sense that I receive psychiatric services.

As a formally recognized and paid job, the peer specialist role is new. Georgia, the first state to provide Medicaid-reimbursable mental health services that are specifically designated as peer-to-peer, certified its first class of training graduates in 2001. The National Association of Peer Specialists formed in 2004, and its upcoming national conference in Philadelphia will be just the second ever.

Nevertheless, an empowerment perspective on mental health has been strengthening for many years in the United States. Our psychiatric hospitals have long been shaped not only by crusaders and reformers within the mental health professions, journalism, and philanthropy, but also by people who were patients. In 1908, Clifford Beers published his autobiographical *A Mind That Found Itself* and founded the Connecticut Society for Mental Hygiene, ancestor of today's Mental Health America.

In 1956, the organization melted down discarded chains and shackles from asylums into a 300-pound bell that “serves as a powerful reminder that the invisible chains of misunderstanding and discrimination continue to bind people with mental illnesses,” according to its website today.

With mass deinstitutionalization in the 1970s, groups of former patients (some of whom called themselves ex-inmates, others survivors, still others consumers or clients if they voluntarily stayed in treatment) formed the Insane Liberation Front, the Mental Patients Liberation Alliance, and other groups that were framed in the political terms of responding to oppressive institutions. This wave of grassroots activism became known as the C/S/X (consumer/survivor/expatient) movement. Simultaneously, parents of patients formed their own groups around the country, which coalesced into the National Alliance for the Mentally Ill (NAMI) at a national meeting in 1979 in Madison, Wisconsin.

Positioned as the most conservative of the prominent social advocacy groups in mental health, NAMI quickly gained clout through alliances with influential professionals, politicians and pharmaceutical companies. NAMI endorsed system reforms that embraced a greater role for involuntary treatment in the community, which was anathema to most on the C/S/X side. Later, NAMI shifted its focus to “consumer inclusion” and changed its name to the subtly but meaningfully different National Alliance on Mental Illness.

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Meanwhile, the loose and shifting coalitions among the most radical groups with a human rights analysis evolved into MindFreedom International, which today claims to unite 100 C/S/X organizations. Two more of the many grassroots organizations in the middle of the spectrum are the diagnosis-specific Schizophrenics Anonymous and the Depression and Bipolar Support Alliance, which offer support groups around the country.

This is just a sampling of the legacy of consumer activism being inherited by young people being diagnosed today. Abetted by their energy, collective projects organized by self-identified consumers and survivors are now emerging at an accelerated pace. We are aided by the trend toward recovery in mental health practice, by government and industry funding, and by a social trend toward celebrating openness about stigmatized conditions that is seen in everything from homosexuality to cancer.

One of the primary themes heard from leaders among people who have mental illness is that we are the experts on our own experiences. Yet when psychosis started to sneak in and out of my life, accompanied by the mood fluctuations that had always flowed through me, I did not feel like an expert. Derailed thoughts were terrifying and confusing. Who would be my confidante, my guide? My parents were believers in psychotherapy, and I made my way in that direction voluntarily, at least as long as I could remain at liberty. My efforts were conducted privately and individually. I had no sense of belonging to any group with respect to what seemed to me an aberrant style of feeling and thinking.

Eventually, during one particularly severe depression, I told a therapist that I was ready to “give up” and try medication. She didn’t believe in pills, and told me I needed more therapy. That wasn’t helping me, so I drifted out of her care and spent a lot of time in bed. Eventually, I dragged myself up by getting a job that challenged me to think and adhere to a rigid hour-by-hour schedule.

In the context of mental health, I thought of myself as a client back then in the 1990s, before my hospital experience. The name consumer was and still is used primarily within the public mental health system where, ironically, there is the most coercion and the least ability to shop among products and services. Consumerism applies more and more today, though, as competition grows in economic and intellectual markets for the attention of people who were once routinely surrendered to the care of the state.

Pharmaceuticals are now sold with increasing assertiveness directly to the people who are going to use them, including drugs available only by prescription. While many medical professionals are beginning to shun the most overt drug-peddling gimmickry, advocacy groups racing to meet consumer demand for “independent” information and support are gobbling up funding from the drug makers. Medications have websites fully stocked with goodies such as branded printable wallet cards and symptom diaries.

Alternatively, the Internet can be a gathering spot for people seeking antiestablishment advice. Shoppers can browse MindFreedom's "Mad Market" of books explaining how to get off psychiatric medications. They can watch videos of Mad Pride events modeled after Gay Pride. People seeking answers and support can easily join electronic lists on which members exchange and generate unconventional views about the origins of voices or conspiracies. Online users cluster in chat rooms, some moderated with various restrictions, and others where anything goes.

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When people who live with severe mental illness mix together, whether virtually or physically, it becomes clear that rapid changes in technology, social attitudes and medical practice have caused tormenting discontinuities. The fight for attention, heart and soul to prevent or encourage madness is increasingly focused toward younger and younger people. Kids are now growing up on antipsychotics for the first time in history. What will happen when they turn eighteen?

Some teach at Alternatives, the annual conference organized by the federally funded National Empowerment Center. Alternatives has a call for proposals encouraging youth to present workshops, resulting in titles such as "Righteous Anger: Young, Drugged, and Locked Up; Recovered to Tell the Story." MindFreedom is planning a youth project to network among kids with that kind of story. The Hearing Voices movement, which is predominantly based in Britain, Australia and New Zealand so far, hopes to take root in North America with support groups that allow the individual to draw his or her own conclusions about the nature of voices.

Some college students major in the new interdisciplinary field of Disability Studies, which applies radical criticism to the medical model. The field asserts that disability is a socially assigned role, not a psychological or physical outcome. People with disabilities in this field see themselves as a legitimately entitled minority group whose bodies and minds are a resource that has been exploited by oppressive doctors.

On the other hand, some who are friendly to psychiatry organize NAMI groups on campus to offer education, support and advocacy. Founded by the aging parents of adults, NAMI today has set a strategic goal to become the nation's premier consumer organization. It is launching major campaigns to bring teenagers and parents of younger children into its fold. The national board of directors supports striking "eradication of mental illnesses" out of NAMI's mission statement and replacing it with language embracing "recovery, resiliency and support" to yield a "full and meaningful life." Some NAMI literature has shifted away from describing mental illness as a horrid nightmare into these uplifting words, found in the 2008 national convention program: "Learn about mental illness from those with the lived experience, and find inspiration in the sharing of common challenges and successes."

In a cultural and countercultural soup of influences, young people sample different worldviews of mental illness, post about their experiences in confessional or satirical blogs and homemade videos, and watch television. A lot of television. That's one thing that unites the generations among people with severe mental illness. Of course, average Americans guzzle TV too, and enterprising marketers capitalize on it.

It seems that mental illness is on every channel these days. Celebrities are disclosing their psychiatric diagnoses with increasing frequency. The "What a Difference a Friend Makes" Ad Council campaign tells young people that recovery is where it's at for mental illness, and stigma is uncool. What's next? *Lunatic Eye for the Normal Guy*?

Maybe the answer can be found on MTV, which has fallen far behind YouTube as the cutting edge of media these days, but is still known for youth appeal. The network partnered with NAMI to air a documentary in May called *True Life: I Have Schizophrenia*.

The show profiles three young people with psychotic disorders who are shown over several months interacting with their parents, alone, with friends, and in support groups. Amber, a college student, pushes herself to achieve with the help of medication and gives a speech about schizophrenia. Josh, a sometimes volatile laborer and drifter, refuses medication, smokes a lot of marijuana, and listens to animals talking. Ben is the least active; his main activities are smoking cigarettes, taking fifteen pills a day, sleeping, and watching television.

In one agitated sequence, Josh asks the camera whether it is society that has the disability, not himself. For her part, Amber says that maybe her “new normal” can be better than the old normal. They both seem to be agreeing that their conditions are here to stay and others around them have the responsibility of accommodating them in the community.

For me, recovery means daring to take and encourage risks. Recovery takes us all outside our comfort zones. This is a revolutionary change from a paternalistic model of treatment in which the system’s goal is to set limits, up to and including lifetime confinement, that minimize risk in my life. I don’t want to minimize risk. I want to optimize it. I want choice and responsibility, instead of being sheltered by authorities, away from “false hopes” that could lead to failures.

No matter how much evidence we gather that says tigers live longer and more peacefully in the zoo, I don’t think we should put all the tigers in the zoo. Not for me is life a journey to the grave with the intention of dying at a “ripe old age.” I would rather use up or wear out my gifts, including my ability to reflect upon my own suffering, on the journey of recovery.

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