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# Crazy Enough to Care

PEER COUNSELING, LONG USED IN THE HUMANE TREATMENT OF THE MENTALLY ILL, IS GETTING NEW ATTENTION AS A COST SAVER BECAUSE OF THE AFFORDABLE CARE ACT

BRAD EDMONDSON

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THE HEADQUARTERS OF THE Baltic Street Agency, a nonprofit dedicated to helping patients with mental illnesses, is located on a narrow, tree-lined street in the Cobble Hill section of Brooklyn. Terry Thompson and Anthony Sgarlato have been meeting here regularly for the past year. Both are local guys in their 50s, though on the surface they don't seem to have much else in common. Sgarlato, a counselor at Baltic Street, is an Italian American from nearby Bay Ridge, with combed-back hair and a wide stance. Thompson, his client, is muscular and black, with a shaved head and a pair of sunglasses shielding his eyes.

Thompson spent 31 years in state prisons, much of that time in psych wards. One day, upon learning that his wife had died of breast cancer—he hadn't even known she was sick—he suffered a psychiatric breakdown. "I ended up wearing a hospital gown in an isolation cell," Thompson said. "They were giving me so many different kinds of drugs that I had no idea what was happening to me. Then my sentence was up, and they just showed me the door. So there I was, boom, back on the street, still sick, with no safe place to live."

Thompson said that his parole officer told him all the things he couldn't do, but that nobody told him where to find the support he needed. He could have knocked around until he broke the law again and ended up back in prison. Instead, he found Baltic Street. "Terry was very hot when he came in here," Sgarlato said. "I could tell

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he was feeling me out. So I just listened, but I also made sure I stood up to him. After a while, he calmed down, and we reached an understanding.” Eight months after his first visit to the agency, Terry had found an apartment and was looking for a job. He wants to earn a college degree so that he, too, can become a counselor.

What distinguishes Sgarlato from any number of his colleagues is that he himself has suffered from mental illness, having experienced his first psychiatric crisis as a teenager and spent decades in and out of institutions. He is what’s known in the mental health community as a peer: someone with a psychiatric condition who serves others with similar problems. Look closely inside any hospital and you’re likely to find excellent psychiatrists and nurses who successfully—and secretly—manage problems of their own. Peers, however, rely on openness. They usually work for small nonprofit organizations, earning a fraction of a professional’s salary. Some work at crisis diversion apartments, watching someone for a night or two, so that hospitalization can be avoided. Other peers act as bridgers—accompanying people with serious, multiple conditions to the doctor and translating for them—or work at so-called clubhouses, such as Fountain House in Manhattan, which offers rehabilitation through the mutual support of residents. And peer-run agencies such as Baltic Street coordinate subsidized housing and services, cobbling together a support network that helps clients get back on their feet.

*Inside the Buffalo State Hospital, designed by H.H. Richardson: in the 20th century, mental institutions increasingly became pictures of despair.*



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Peer counseling has always existed on the fringes of medicine. The first organizations started in the 1940s, during the early years of the civil rights movement. Many more were launched in the 1960s and '70s, inspired by the dogma and methodology of 12-step programs, New Age thinking, and the general do-it-yourself ethos of that era. In those days, peer activists were waging an all-out war on psychiatry—partly in response to such depictions as Jack Nicholson's Oscar-winning 1975 portrayal of a rebellious patient in *One Flew Over the Cuckoo's Nest*. Four decades later, peer counseling is about to become mainstream—thanks in big part to the Patient Protection and Affordable Care Act of 2010.

Of the roughly 32 million uninsured Americans required by law to enroll in health insurance plans by 2014, about half—or 16 million—will sign up for Medicaid. And of those new enrollees, one-third will have preexisting mental health or substance abuse conditions. Not surprisingly, state governments (which will implement the law) are desperate to cut costs. People with chronic psychiatric conditions, after all, are among the most expensive to insure because their crises usually lead to emergency room visits and lengthy stays in institutions, at a cost of thousands of dollars a day. Many mentally ill patients cope by smoking, abusing drugs, or overeating, leading to an increased risk of cancer, diabetes, and other expensive “co-morbidities.” One study published in 2000 estimated that people with psychiatric or substance abuse problems consume 44 percent of all the cigarettes sold in the United States. This is one reason why the average life expectancy of an American with a chronic mental illness is about 25 years shorter than the national average.

America is about to undergo a massive shift in how health care is paid for, and at the state level, the responses have been varied. South Carolina, for example, slashed mental health spending 39 percent between 2009 and 2012, and nine other states cut their mental health budgets more than 10 percent over that same period, according to the National Alliance on Mental Illness, leaving significantly more people on the street, in jail, or dead. In other states, the objective is to replace custodial care, which is often inefficient and inhumane. The new model of care encourages a far greater degree of independence, and at a fraction of the cost of hospital wards. Consider that the state of New York spends about \$220,000 a year to keep one person in the Buffalo Psychiatric Center. Now compare that with the annual direct cost of supported housing in Buffalo—about \$8,000 per person, according to Joe Woodward, director of a peer-run housing agency in western New York.

About 25 million adults in this country suffer from serious psychological distress; some surveys estimate that half of all Americans will have a diagnosable psychiatric condition at some point in their lives. And yet, the mentally ill are a largely forgotten part of the population. Governments especially seem to deal with the problem by ignoring it. The major obstacle—still, to this day—is social stigma, which the sociolo-

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gist Erving Goffman elegantly defined as “the process by which the reaction of others spoils normal identity.” This stigma is what peers can best combat. “People may not know how to make recovery happen, but that doesn’t mean that it can’t happen,” said John Allen, a peer activist for decades and now the director of the Office of Consumer Affairs at New York State’s Office of Mental Health. “I believe that recovery is possible for every human being.”

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THREE WEEKS BEFORE he died, President John F. Kennedy signed the Community Mental Health Centers Construction Act, announcing that “the mentally ill and the mentally retarded need no longer be alien to our affections or beyond the help of our communities.” (JFK had painful knowledge of the dangers of psychiatric surgery: his younger sister Rosemary was prone to mood swings and violent outbursts. In 1941, when she was 23, the family gambled on a new procedure, and Rosemary got a lobotomy that reduced her to a near-vegetative state.) The point of the 1963 act was to empty state mental hospitals, where conditions had become scandalous, and replace them with clinics and subsidized housing. The introduction of psychotropic medications such as Thorazine in the mid-1950s—and the subsequent advent of Medicare and Medicaid—made this plan possible. As a result, the number of patients in public mental hospitals dropped from 558,000 in 1955, when the U.S. population was about 165 million, to 475,000 in 1965, the year Medicare and Medicaid went into effect. The number plunged to 337,000 in 1970 and 138,000 in 1980. Today it hovers around 50,000, with the total U.S. population approaching 313 million.

The problem with this “deinstitutionalization” policy was that in most places, the coordinated network of clinics, social centers, and subsidized housing that President Kennedy envisioned never materialized. Most of the patients released from mental hospitals in the 1960s and ’70s had no place to go. Many achieved stable lives, but others could not adjust, and the result was a sharp increase in both homelessness and incarceration. Deinstitutionalization was one reason why the number of Americans in jails and prisons increased from about 500,000 in 1980 to almost 2.3 million in 2008. According to a 2005 survey by the Bureau of Justice Statistics, about 50 percent of inmates in state prisons reported symptoms of depression, psychosis, or mania, and 34 percent of those prisoners were treated for a mental health problem. Prisoners who disobey commands are usually written up and sent to solitary confinement. Prisoners who are severely depressed or are hearing voices don’t get a pass, even if they don’t understand the command, and even though solitary confinement usually worsens their condition. To make matters worse, more than half of all ex-cons with a serious mental illness are eventually rearrested and returned to jail, usually because they have violated the terms of their parole. The mental illnesses of these “frequent fliers” often explain their parole violations.

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The subsidized-housing-and-clinic plan hasn't always worked so well, either. Out at the far end of Brooklyn, beyond the rides and restaurants of Coney Island, stands a cluster of large, privately owned assisted-living centers known as adult homes. Between 12,000 and 18,000 people live in adult homes in New York State: similar facilities are common elsewhere. Tenants of these residences give landlords about 87 percent of the Social Security payments they receive for having psychiatric disabilities, and in return the tenants get a double-occupancy room, meals, and medicine. "I call it the gulag archipelago," said Norman Bloomfield, who has lived for the past decade at Surf Manor, a dismal four-story structure that is home to 200 people. Every weekday morning, buses stop to take some of his neighbors to day-care programs. Many others live in a haze of meals, meds, television, cigarettes, and sleep. "It can go on this way for years," says Bloomfield. "Lifetimes."

Bloomfield is a small, intense man with long gray hair who usually carries a sheaf of papers relating to his agenda—he is an activist who presents the concerns of residents at hearings, protests, and court dates. Most of the people he lives with are capable of living more independently, he says, and indeed, one of Bloomfield's current causes is a lawsuit demanding that New York State allow the residents of adult homes to choose other kinds of supported housing, such as subsidized apartments or smaller group homes. Disability Advocates, Inc. (DAI) filed the suit in 2003 after articles in *The New York Times* (the series won a Pulitzer Prize) exposed the horrific squalor and hopelessness in the homes, where suicidal residents died while unsupervised, murders occurred, and people roasted to death in rooms that had no air-conditioners or fans. (Back in 1887, Nellie Bly published a series of pieces just like it for Joseph Pulitzer's *New York World* after she lived undercover at the New York City Lunatic Asylum for 10 days.) DAI won its lawsuit in federal district court in 2009, but the state of New York appealed, and a court panel's decision is pending.

Adult homes, Bloomfield said, "exploit their residents and do things to keep us passive and stagnant. People who try to take control of their lives face all kinds of intimidation. And the doctors who come here are like poachers. They have a captive population for billing Medicaid and Medicare, and they milk us for all they can get. But there's no coordination of care. I've learned that mental illness has nothing to do with a person's creativity or character. Some of my neighbors are the most beautiful, funny, generous people I know. Some of the people who work here are scoundrels. But we're the ones with the stigma."

Bloomfield, who studied anthropology at New York University and has lived at Surf Manor for the past decade, in many ways resembles the conscientious objectors who went to work as attendants at state hospitals during World War II. Nobody cared much about conditions there, either, until the COs started taking notes and photos and giving them to the press.

Patient activism in mental health care has a long and little-known history. One of

the pioneers was Clifford Beers, who graduated from Yale and established a national organization called Mental Health America. His 1908 memoir, *A Mind That Found Itself*, is still one of the best descriptions of what it feels like to succumb to paranoia and depression. “A pen rather than a lance has been my weapon of offense and defense,” Beers writes. “For with its point I have felt sure that I should one day prick the civic conscience into a compassionate activity.” And then there’s Dorothea Dix, a successful writer and schoolteacher who suffered a nervous breakdown in 1836 and recuperated in England before returning to the United States. Between 1841 and the beginning of the Civil War, Dix went on grueling road trips to observe the conditions of mentally ill inmates in prisons and poorhouses. She wrote reports to state legislatures detailing the hair-raising things she saw—mentally ill people languishing next to hardened criminals, young women chained to walls, rats by the bucketful—and urged them to build insane asylums like the one that had cured her. Dix was directly responsible for the construction of at least 30 of these institutions.



*The compassionate care practiced at the Retreat (shown here in the 1880s) inspired Dorothea Dix to campaign for better mental hospitals in America.*

The asylum that served as Dix’s model was the Retreat, founded by Quakers in 1796 in the northern English city of York. One 18th-century doctor, George Cheyne, estimated in 1733 that about one-third of his patients suffered from depression, which he called “the English malady.” And yet, in those days, mental illness was believed to make a person insensate and therefore subhuman—which meant that patients were often housed like animals and slept naked on filthy piles of straw in unheated rooms. The York Retreat was a reaction to that mode of thinking. Quakers believe that every person contains a divine spirit, which should be coaxed out and revealed. If the spirit is blocked by sickness or sorrow, Quakers feel compelled to remove the obstacle.

The Retreat’s founder, William Tuke, was a successful merchant with no medical training. Yet his family ran the place for four generations and set enduring standards for compassionate care. The Tukes knew what they were dealing with. William’s grandson Samuel wrote that he and several other members of his family possessed “a tinge of melancholy,” although he added, “this tinge I sometimes think I would not be without. If it deepens the gloomier shades of our course, it gives a richness to the livelier parts.”

The Retreat was a place, as Samuel Tuke wrote, “in which the unhappy might find

a refuge; a quiet haven in which the shattered bark might obtain the means of reparation or of safety.” As the years went by, the Tukes devised a detailed protocol that called for medical and surgical measures—bloodletting, purgatives, and emetics—only as a last resort, instead emphasizing new ideas like exercise therapy, pet therapy, and occupational therapy. To calm maniacs down, Samuel Tuke recommended feeding them meat, cheese, bread, and beer until they fell asleep. But the most important element of care was friendship. “The attendant on the insane ought sedulously to endeavor to gain their confidence and esteem,” wrote Tuke. The job of the caregiver was “to arrest their attention, and fix it on objects opposite to their illusions; to call into action, as much as possible, every remaining power and principle of the mind; and to remember that, in the wreck of the intellect, the affections not infrequently survive.”

Philippe Pinel, a French physician who was operating a Paris asylum along similar lines, named the new therapy *traitement moral*; the French word *moral* signified an emphasis on reinforcing self-esteem and social routines. Samuel Tuke translated Pinel’s term as “moral treatment” and eagerly changed the emphasis to ethics. While putting moral treatment into practice at the Retreat, he went on the offensive against other, less humane institutions, such as the neighboring York Lunatic Asylum. Tuke and the Quakers eventually took over the asylum’s board of directors, triggering a parliamentary inquiry that exposed the horrors of English lunatic asylums to the world.

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AMERICA’S FIRST INSTITUTION for moral treatment—Friends Asylum, opened in 1817 by the Philadelphia Yearly Meeting—was modeled on the Retreat and emphasized the restorative power of sunlight, fresh air, good food, and physical activity. It was an “asylum” in the purest sense of the word, which in Greek means “shelter” or “protection from danger.” You wouldn’t have known, looking upon the place, that residents were incarcerated there: the iron bars that held the windows in place, for example, were painted to look like wood. The successes of the Friends Asylum (which still exists in the same building today, as Friends Hospital) inspired similar institutions in Boston, New York City, Hartford, and Charleston, all of which were operating by 1824. By 1890, 115 public and 38 private institutions were scattered across the country, housing 74,000 people. Most of these places, however, weren’t nearly as friendly as Friends. Somewhere along the way, “asylum” became synonymous with “scary.”

Today, when we think of insane asylums, we conjure up scenes from *One Flew Over the Cuckoo’s Nest* or *Shutter Island*, where it’s always dark and stormy and evil doctors spend their days experimenting on patients. Former patients of mental hospitals often call themselves survivors, confirming the pervading hopelessness at most such institutions. So how did the Tuke family’s humanitarian breakthrough turn into a horror movie?

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For one thing, insane asylums have nearly always been located on the outskirts of town, ostensibly to expose patients to the benefits of nature, but also to separate them from their families and neighborhoods. In effect the policy of isolation became a way to sweep the streets. (During the 1850s, for example, immigrants accounted for more than three-quarters of those admitted to the New York City Lunatic Asylum, in the relatively remote environs of Roosevelt Island.) A larger mistake is defining mental illness exclusively as a medical problem. Doctors are trained to look for cures. Their time is limited. But a recovery can take place only if the patient has the means to get a job, find a place to stay, rejoin a community.

Starting in the 1870s, state-funded insane asylums became huge stone edifices, designed by such leading architects of the day as H. H. Richardson and Frederick Withers, employing thousands, micromanaged by doctors who took themselves very seriously and became powerful as a consequence. Although the big asylums did help cure some people, they were much more successful as political projects. New York City's Bloomingdale Asylum, for example, which opened in 1821, existed because of two decades of lobbying by Thomas Eddy, a Philadelphia-born Quaker who sat on the New York Hospital's board of governors and was a friend of New York City Mayor DeWitt Clinton. In 1816, Clinton was trying to finance the Erie Canal, and he needed Eddy's help in selling European bonds. Each lobbied on the other's behalf. The New York State Legislature approved the funds to build Bloomingdale and asked for a canal financing plan at precisely the same time, which suggests a quid pro quo. Of course, Clinton was a politician who governed by spoils; he knew that state funds for public works projects—asylums, canals, whatever—allowed him to dole out favors to his political friends.

Lost in the political shuffle were the patients themselves, especially the “incurables.” When the Bloomingdale Asylum opened, it did not take incurables; instead of looking for the divine spark in every soul, its administrators focused only on those who, in someone's judgment, were worth saving. In 1869, the first state-funded asylum specifically for incurable cases opened in a remote farm community in upstate New York, about 45 miles southwest of Syracuse. The Willard Asylum for the Insane became a self-contained village of several thousand people, most of whom had been labeled hopeless. Willard had its own railroad, and an in-house concert band performed in a large auditorium on campus. Patients operated a farm that produced most of the community's food. Life for many of those early residents was more comfortable than what

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they had experienced in jail cells and poorhouse basements. But they were expected to remain there forever, and they almost never had visitors.

Today, Willard is a hamlet most people pass through at highway speed. On its western edge, Seneca Lake stretches for an uninterrupted 38 miles. East of town stands an abandoned military depot that once contained nuclear weapons. To the south, a high cyclone fence topped with razor wire marks the boundary of the old asylum, which closed in 1995 and was reopened as a prison. And just north of the fence is an exceptionally beautiful field—30 acres of mown grass that slope down to the lakeshore, with a view of farms beyond the shifting surface of the lake’s deep waters. The field is Willard’s cemetery. The buried stretch away in every direction, their remains filed in orderly rows like seeds and marked only by small, numbered aluminum discs set in the ground. Each of the 5,776 burials that took place at Willard is described in a logbook. In all of those entries, the presence of a mourner is noted exactly once.

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LUNATIC ASYLUMS in the 19th century were typically presented as great humanitarian achievements. But they also created a culture that encouraged patients to stay sick. Advocates say that this culture has not gone away. It’s why the system is broken today.

“Adult homes are like roach motels,” said Cliff Zucker, executive director of Disability Advocates, Inc., the plaintiff in the 2003 lawsuit against New York State. “You can go in, but you can’t come out.” If you want to see this problem for yourself, volunteer at a psychiatric day program. “Most day programs still assume that people will continue to relapse,” said Harvey Rosenthal, the executive director of the New York Association of Psychiatric Rehabilitation Services. “This attitude is reinforced by a system that links a provider’s pay to how often a patient shows up, whether they need to or not, and regardless of the outcome. The good news is that a lot of health reform is paying for good outcomes, so it won’t support the old mindset.”

One of the big ideas in the Affordable Care Act is to reduce costs by improving the coordination of services. Everyone with a health insurance policy will be assigned a case manager who will keep track of how that person uses services, while looking for duplication and overuse. The case managers working through networks of providers called “health homes” will coordinate medical services, housing, and rehabilitation. And the law will sign up people who use the most health care first—people who bounce in and out of emergency rooms—because that is where the biggest savings are to be found. “Peer advocates have a new, powerful ally now,” said Rosenthal, who was hospitalized for depression in college, then later worked at a state hospital and a clubhouse. “Many state budget directors hate avoidable hospital visits as much as we do.”

Many doctors are not happy with this development. They tend to rely on evidence-based research, but only a few randomized trial studies of peer counseling have been

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conducted, and the results are inconclusive. Medicaid programs, which are designed and run by the states, are going ahead anyway. Twenty-four states have expanded the role of managed care in their Medicaid programs for fiscal year 2012, according to the Kaiser Foundation. Behavioral health organizations, which are like HMOs for psychiatric and substance abuse services, are hiring large numbers of peer counselors. (“It could be great,” said Sara Goodman, one of the directors at Baltic Street. “Most of us don’t earn enough to save for retirement or take vacations. It would be great if we did.”) New York’s health-home system is rolling out this year, and every high-use Medicaid patient in the state—about one million people, including everyone who bills Medicaid for psychiatric services—will be assigned a case manager. California is doing roughly the same thing but delegating more of the decisions to county officials. And while the governor of Florida and the attorney general of Virginia pursue last-ditch efforts to repeal the Affordable Care Act, bureaucrats in those states are quietly making plans for health homes.

According to Rosenthal, the changes being driven by President Barack Obama’s health care legislation are the most significant and hopeful developments he has seen in 35 years in the field. “But success is not guaranteed,” he said. “I worry that a lot of labels and language will change, but the mindset and practices may not. A lot of traditional groups like hospitals want to run the new health homes. They don’t realize what kinds of fundamental changes are needed. I also worry that consumers will need a lot of help to grab control of their own care, because they have been discouraged for so long. Years of daycare programs have trained them to be passive. Health care reforms are forcing these people to change, and a lot of them are going to need a lot of encouragement.”

It may take a while to prove that peer services save money while improving care. After all, the services constitute a form of education, and it’s difficult to put a dollar value on that. Perhaps the cost savings won’t ever be proven. Some people won’t get better, either, and peers are probably just as susceptible as anyone else to corruption. The new plan could fail in many ways. But it also stands out from its predecessors precisely because its proponents and counselors began their training as consumers. Isaac Brown, the CEO of Baltic Street, spends every day juggling the demands of a small not-for-profit that manages hundreds of peer relationships, job training programs, and housing services throughout Brooklyn. And every month, he goes to the doctor to get an injection that keeps his schizophrenia in check. Brown brought Anthony Sgarlato along, and now Sgarlato works with dozens of people such as Terry Thompson. They are members of a guild that was founded in 1790. With the help of good medical care and a strong social network, they are pushing past their own problems while reaching back to help others do the same thing. The healing, it seems, depends on a mystery: not the mystery of causes and cures, but the mystery of what happens when two people make a connection that promises to endure. ●