

Dorothea Dix & Mental Health Care Reform

When was the last time you had a fever? How did you feel? You'd caught some bug, and your body reacted by increasing its temperature to fight the infection. You knew you were sick, didn't you? Well, we all get physically ill at one time or another. We know that our health is a fragile treasure that depends on genetics, environment and behavioral factors for its stability. But are we aware that our mental health is no different?

When was the last time you were really, really angry? How did you feel? I bet your emotional temperature was pretty high. You were probably quite sure that the object of your anger deserved your rage. Do you think you were mentally ill then? Most of us would say that we weren't sick; we had every right to be angry. But that's beside the point. When we have an infection, we have every right to run a fever, but we don't claim we're in good health.

We all have our ups and downs, and we're all out of our minds sometimes, a little or a lot. With grief or sadness, anger or fear, greed or lust. We're not quite ourselves for a while, and we might even make decisions or act in ways that are contrary to our long-term interests. Sometimes we're so confused that we're not sure what our interests are.

Karen is a 31-year-old woman with schizoaffective and borderline personality disorders. She's been cutting herself on her arms since she was 13 because it seems to make her feel better – she doesn't know why. She hears voices all the time. They tell her she is worthless, that doctors put microphones in her brain and liver, that she should kill herself. The voices never stop. She feels terrified all day and sleep brings only nightmares. Karen's tried to kill herself many times. She prays that God would let her die so she won't have to suffer any more. She thinks God's punishing her by keeping her alive. The only time she feels better is when she's high on crack. The only way she can earn the money for crack is prostitution. Sometimes she's arrested and sent to jail. Sometimes she's committed to a mental hospital. Either way, pretty soon she's back on the street turning tricks for crack and trying to figure out how to kill herself.

When was the last time you were depressed? Have you ever been incapacitated with grief? Like with colds and the flu, we usually get better. But some problems don't go away. And about five million Americans, including Karen, have a mental disorder that needs long-term care. Most of the severely mentally ill need some form of medication to help control their symptoms. They may also need counseling, housing, vocational rehabilitation, income assistance, and other community services to help provide the support necessary to focus on the most stable adjustment possible.

Despite our understanding of physical illness, it's often hard to be with the sick because they remind us of our vulnerability. The disturbing behavior of the mentally ill can touch a fearful place deep inside us. We can accept that our bodies are sometimes out of our control, but we seem to think we're supposed to keep our minds together by some kind of heroic act of will. So strongly do we cling to our ideal of mental stability that it casts a shadow on the vulnerability we share but don't want to see. We feel safer saying that the mentally ill are not like us. We may feel irritated, annoyed, we look away, and demand that others take care of them, keep us safe from them.

This unwillingness to behold the mentally ill is hardly a new phenomenon. Two hundred years ago, it was the basis for the average American community's response. They were confined out of the public eye, but not for treatment. The mentally impaired were considered subhuman, incapable not only of reason, but feelings of any type.

There was neither public will nor money for human accommodation, so they were either put in jails or kept by private citizens who were paid a few cents a month for their upkeep.

This was the situation that Dorothea Dix discovered around 1840. Dorothea Dix was a remarkable woman. She embodied the New England ideal of social responsibility. The eldest daughter of an ailing frontier mother and preacher father, she cared for her home and siblings from an early age. Eager to earn her keep, she opened her first private school when she was fourteen, her second in Boston six years later. In Boston she began going to the Unitarian church of William Ellery Channing, whose 1819 sermon on "Unitarian

Christianity” is generally regarded as the landmark event in the emergence of American Unitarianism. Dix took Channing’s sermons to heart.

Dorothea Dix struggled all her life from severe, chronic pulmonary hemorrhaging, and was able to work only intermittently. She opened and closed her successful schools several times before retiring altogether at the age of 34 to await her death. However, a period of convalescence brought her renewed strength, and she accepted Channing’s offer to serve as his children’s private tutor. As she regained her stamina, her commitment to Unitarian ideals led her to take on the charitable work of offering Sunday instruction to the women in the East Cambridge jail.

It was here that she discovered the wretched conditions under which the mentally ill were confined. They were kept in unheated cells during the coldest northern winters. When she asked why there were no stoves, the jailers explained that these people would only burn themselves.

Dorothea was appalled. Constrained from public speech by the limited role women of her time were permitted, she appealed to the courts in writing, calling for humane treatment and the construction of mental hospitals. When the installation of stoves was authorized, there was an uproar in the press where she was vilified as the “madhouse woman” who didn’t realize that the insane belonged in jail. What was called madness at that time was considered to be a moral problem, like crime, a regression to sub-humanity.

Dorothea Dix spent the next two years inspecting every jail and poorhouse in Massachusetts, looking for the mentally ill and documenting their treatment. She submitted her report to the state legislature where, amid powerful controversy, they authorized a modest improvement in care.

Dix didn’t stop there. She expanded her investigation to other states. She routinely found people locked in unheated sheds, their only sanitation an occasional hosing down. They would often be missing feet, hands and legs, lost to frostbite and infection. Forced to live with neither dignity nor hope, people tended to sink deeper and deeper into unresponsive despair.

Dorothea Dix resisted any temptations to either despair or rage. Patiently, relentlessly, she continued her inspections. Although her health problems forced

her to rest frequently, she returned to her work as soon as she could. She raised money to build mental institutions, found supporters for legislation, and eventually introduced the concept of humane treatment for the mentally ill into the national awareness.

She also opposed common beliefs about the chronic nature of mental illness. She argued for the efficacy of early treatment, saying that “insanity sensibly treated is as certainly curable as a cold or fever. Recovery is the rule; permanent disease is the exception.”

In her long career as a crusader for mental health reform, Dorothea Dix reported on conditions in each of the 26 states at that time and lobbied most of their legislatures as well as the federal government. When she started in 1840, there were 13 institutions for the mentally ill in America; by 1880 there were 125.

By the 1950’s, when Thomas Szasz came on the scene, institutionalization had long been the accepted form of treatment for the mentally ill. A Hungarian-born American psychiatrist, Szasz found that something had gone horribly wrong with Dorothea Dix’s ideal. Although conditions were far better than those she had found, success had produced new kinds of problems. Overcrowded and underfunded, mental hospitals had become warehouses where supposedly defective people were imprisoned with neither hope nor treatment.

Szasz was horrified to discover the lack of dignity accorded mental patients. They were considered incapable of exercising any meaningful judgment. Mere residency in an institution was considered proof of incompetence. Patients’ incapacity was believed to be chronic and incurable, so treatment was often considered irrelevant and patients were rarely, if ever, discharged.

The system was clearly in need of reform, and Thomas Szasz attacked it with a passion. He believed the mentally ill were confined against their will, and argued that institutionalization was immoral. Aided by the public shock at exposés of patient treatment and conditions, he crusaded for the closing of mental hospitals altogether.

Ken Kesey’s novel, *One Flew Over the Cuckoo’s Nest* provides a good example of Szasz’s position. It tells of a charming and highly capable but somewhat antisocial individual who fakes mental illness to avoid police trouble.

He's sent to a mental hospital, and as the result of a series of conflicts with those in charge, is eventually lobotomized, destroying his ability to think and to choose – effectively killing him as a person.

This characterization of mental illness as a social category based on society's need to repress its nonconforming members helped Szasz to spearhead the reform movement that eventually led to the mass deinstitutionalization of the 1970's. Legislators, administrators, and the general public alike were delighted that a troubling and confusing problem had been solved. It was a big relief to be able to say, "Great! We were wrong about the mentally ill. They don't really exist! We can close down the hospitals."

The alternative to hospitalization was to be community-based treatment. It was argued that people could be better served by local mental health centers and group homes. Unfortunately, Szasz's solution presupposed that people with genuinely and seriously impaired decision-making skills could participate proactively in their own treatment..

These reforms moved thousands and thousands of people out of mental hospitals into their communities. But the decades since have shown us where they ended up: in cardboard boxes and under freeway overpasses, in homeless shelters. Some are in the few hospitals still left, but at least five times as many are in our prisons and jails. Unsupported and unable to cope with what we call normal life, many turn to self-medication and are arrested for drug use, criminalized and punished for trying to cope as best they can. Others are homeless alcoholics who are rarely arrested, but live in conditions of squalid suffering. Many are dependent on their aging parents whose lives are as scarred by their adult children's suffering as are their children themselves. When these parents die or become disabled or simply unable to provide any more help, and the mentally ill are thrown into the mental health or criminal justice systems again.

In a perfect world, Szasz's reforms might have worked. Community mental health centers would be well-funded and staffed. Group homes would have community support, and offer treatment and occupational therapy. There would be no stigma attached to mental illness, and everyone would be as sympathetic

and understanding of it as they are of the flu or cancer. The criminal justice system wouldn't be burdened with the mentally ill because it would be as unthinkable to arrest them for the symptoms of their disability as it would be for someone lying on the ground with a heart attack to be arrested for loitering.

But we do not live in that perfect world. The institutions needed reforming, but Szasz, with all his idealism and zeal, actually increased the suffering he tried to reduce. The basic problem actually hadn't changed in 200 years: our eagerness to keep the mentally ill out of sight means that there will be suffering and abuse. Dorothea Dix brought the problem into the public eye and conscience and thereby improved the lives of many. But this is a situation that is never solved for once and for all. The illusion of success merely allows it to recede from our awareness again. Thomas Szasz also brought the problem of the treatment of the mentally ill into public awareness, and eliminated some serious problems but replaced them with others. At least centralized institutions, by virtue of their size, could be seen, publicized, and held accountable for their actions. By dispersing community responsibility for the mentally ill among many small programs with no centralized advocacy, we have failed them in a way unthinkable since Dorothea Dix's day.

We all get physically sick, whether mild or severe. Sometimes we stay at home in bed. Sometimes we need to go to a hospital. Virtually all of us also get mentally ill, whether mild or severe. What do we do then? Where do we go?

Our physical health care system is bogged down with our mixed priorities for excellent care and low expenses. Our mental health care system is currently burdened very little with mixed priorities: it has low visibility and even lower funding.

We need reform every bit as much today as we did in Dix's or Szasz's times. When we realize this, we often feel a strong urge to examine the system and try to come up with new ideas and programs. But Szasz's reforms demonstrated that well-meaning change is not necessarily the answer. There's something we need even more than new programs, and that's a feeling of public responsibility and compassion for those among us who are suffering from impaired mental functioning.

We need to stop looking away, stop characterizing the mentally ill as “other,” as a different kind of people.

When mental illness does make the headlines, it’s usually someone whose untreated mental illness led to some form of murder or mayhem. But this only reinforces the false notion that the mentally ill are significantly more violent than the rest of us. They are not.

Extreme forms of physical illness may also be scary, but we understand that physical health is a continuum that includes a range of conditions from normal to severely limited functioning. Just as we make a place in our community and our human family for people with different physical conditions and abilities, we need to welcome and support a continuum of mental impairments as well. Some may need institutions, some may need medication and therapy. We all need friendship and love.

Dorothea Dix and Thomas Szasz both worked to improve the condition of the mentally ill in America, one by building up, the other by tearing down. What they both did that made the most difference was they engaged our hearts and challenged our consciences. The light of public attention is one of the most potent medicines for reform. When we look away, abuse thrives in the darkness. We need to shine the light of our concern on the mentally ill and the system that fails them. We need to be able to look, to feel, to care. Not just because it *could be* one of us, but because it *is* us.