Virtual Mentor
American Medical Association Journal of Ethics
October 2013, Volume 15, Number 10: 886-891.

HISTORY OF MEDICINE

Deinstitutionalization of People with Mental Illness: Causes and Consequences

Daniel Yohanna, MD

In ancient Greece and Rome, asylum was a place where those who were persecuted could seek sanctuary and refuge. Those persons included debtors, criminals, mistreated slaves, and inhabitants of other states [1].

Is there a group of American citizens more deserving of safety and refuge than people with severe mental illness (SMI) who have traded one level of confinement in state mental hospitals for another in our nursing homes, intermediate care facilities, jails, and prisons—or, worse, become homeless? This paper reviews trends in the transinstitutionalization of people with SMI and proposes that it is time we offer asylum, in the best sense of the word, to the most vulnerable of the people with severe mental illness.

According to the National Institute of Mental Health (NIMH), 6.3 percent of the population suffers from severe mental illness [2], defined as longstanding mental illnesses, typically psychosis, that cause moderate-to-severe disability of prolonged duration [3]. Given that the number of adults 18 and over in the United States in 2010 was estimated to be roughly 234,564,000 [4], approximately 14.8 million people have severe mental illness. Experts polled by the Treatment Advocacy Center estimated that about 50 beds per 100,000 people would meet needs for acute and long-term care, but in some states the number of available beds is as low as 5 per 100,000 people [5]. Thus, many who need residential treatment cannot obtain it.

The changes that led to this lack of space, as well as changes to the institutionalization process, have made it impossible for people with severe mental illness to find appropriate care and shelter, resulting in homelessness or "housing" in the criminal justice system's jails and prisons [6]. The percentage of people with severe mental illness in prisons and jails is generally estimated to be 16 percent of the total population [6]. Given that the population in U.S. prisons and jails totaled 2,361,123 in 2010 [7], it would appear that nearly 378,000 incarcerated persons have severe mental illness [7].

How Did We Get Here?

Deinstitutionalization as a policy for state hospitals began in the period of the civil rights movement when many groups were being incorporated into mainstream society. Three forces drove the movement of people with severe mental illness from hospitals into the community: the belief that mental hospitals were cruel and inhumane; the hope that new antipsychotic medications offered a cure; and the desire

to save money [8]. It has not worked out as well as expected on any of the three fronts. People with severe mental illness can still be found in deplorable environments, medications have not successfully improved function in all patients even when they improve symptoms, and the institutional closings have deluged underfunded community services with new populations they were ill-equipped to handle.

Historically, state hospitals fulfilled many needs for people with severe mental illness which included therapy, medication, medical treatment, work and vocational training, and a sense of community. Prior to 1950s, it was not uncommon for state hospitals to provide a work environment. There were often workshops and farms to make or grow some of their own needs. This was particularly true at the end of the nineteenth century [9] before entrepreneurs realized there was a profit to be made in the state hospital system and slowly began selling goods and services to the hospitals, reducing "the amount of work and increasing the amount of idleness in the system" [9].

Legal limits on institutionalization. As patients were being discharged into the community, a series of legal decisions also had an impact on whether one could be readmitted or stay in a hospital setting. As early as 1866, after E.P.W. Packard was committed by her husband to an Illinois state mental institution, efforts to "reform" the system were under way. In her account of the episode, two physicians came to her home, took her pulse, and declared her insane [9]. She was confined for 3 years and, upon her release, led a successful campaign across the country to change the laws to safeguard people's rights in the hospitalization process [9, 10]. Today every state has civil commitment laws outlining the requirements necessary to hospitalize someone with SMI.

Over time, several court cases have further defined the legal requirements for admission to or retention in a hospital setting. In *Lake v. Cameron*, a 1966 D.C. Court of Appeals case, the concept of "least restrictive setting" was introduced, requiring hospitals to discharge patients to an environment less restrictive than a hospital if at all possible [11]. In the 1975 case of *O'Connor .v Donaldson*, the U.S. Supreme Court declared that a person had to be a danger to him- or herself or to others for confinement to be constitutional [12]. The 1999 U.S. Supreme Court decision in *Olmstead v. L.C.* stated that mental illness was a disability and covered under the Americans with Disabilities Act. All governmental agencies, not just the state hospitals, were be required thereafter to make "reasonable accommodations" to move people with mental illness into community-based treatment to end unnecessary institutionalization [13].

These court decisions have certainly limited the ability of state facilities to confine people in hospitals against their will and created conflict between laws that are intended to preserve liberty and prevent wrongful hospitalization, on the one hand, and the need to identify and treat people early in their diseases, on the other. Although preserving the rights of people with severe mental illness to be treated in

the least restrictive settings is noble, it has allowed many people with SMI to "fall through the cracks" in the system or be rehospitalized in what has been termed the "revolving door" of acute hospital admissions [8]. An even more egregious situation occurs when difficulty being admitted to a hospital leads to the homelessness of people with severe mental illness, who wander the streets in major cities, being arrested or dying. The term "dying with one's rights on" was coined by Darold Treffert in 1973 to describe how the laws have gone too far in protecting the rights of individuals at the expense of their safety and well-being [14].

Reduced beds in state facilities. Changing federal laws have also contributed significantly to reducing the number of available beds in state facilities. The passage of the 1963 Community Mental Health Construction Act, which made federal grants available to states for establishing local community mental health centers, was intended to provide treatment in the community in anticipation of the release of patients from state hospitals [9]. Laws providing income subsidies through the Aid to the Disabled Program (latter called Supplemental Security Income or SSI), food stamps, and housing subsidies has made it ostensibly possible for people with SMI to live in the community, although many still cannot survive in any dignified or independent manner given that the subsidies are below the poverty level of $11,490 for an individual [15] (current 2013 federal SSI payment is $8,529.32 per year for an individual [16]).

Perhaps the most important change in federal law was the introduction of Medicaid, which shifted funding for people with SMI in state hospitals from the states' responsibility to a shared partnership with the federal government [17]. This created an incentive for states to close the facilities they funded on their own and move patients into community hospitals and nursing homes partially paid for by Medicaid and the federal government. With the Omnibus Budget Reconciliation Act of 1981, the federal government ended direct federal funding for community-based nursing homes that primarily treated patients with mental health problems and required the screening of patients entering nursing homes to assure they had legitimate medical illness [18]. It required states to return to funding non-nursing homes for the long-term care of people with SMI in the community [18], basically segregating many people with SMI into large, underfunded facilities. These facilities were often for profit and privately owned, creating an incentive to reduce costs and care in the name of profits. The perils of this were aptly illustrated in a series of articles by Clifford Levy in the *New York Times* in 2002 [19].

Structural social and economic factors. Why are so many people with severe mental illness placed inappropriately in our jails and prisons? Davis argues that the current decentralized mental health system has benefited middle-class people with less severe disorders preferentially [20], leaving the majority of people with SMI who are either poor or have more severe illness with inadequate services and a more difficult time integrating into a community. Factors such as high arrest rates for drug offenders, lack of affordable housing, and underfunded community treatments might better explain the high rate of arrests of people with severe mental illness [21].

Emergency rooms are crowded with the acutely ill patients with long psychiatric histories but no plausible dispositions. Patients who are violent, have criminal histories, are chronically suicidal, have history of damage to property, or are dependent on drugs cannot be easily placed. They are often discharged back to the streets where they started.

In many states, state hospitals will not even consider admitting patients on Medicaid, expecting the private sector to care for them. But private hospitals have difficulty using the court system to commit people with SMI to the hospital because of the cost of transportation to the court, which is usually off-site, use of personnel, and the lack of reimbursement for psychiatrists who testify in court. It is a time-consuming process that often takes up to half a day.

What Is Needed?

State hospitals must return to their traditional role of the hospital of last resort. They must function as entry points to the mental health system for most people with severe mental illness who otherwise will wind up in a jail or prison. State hospitals are also necessary for involuntary commitment. As a nation, we are working through a series of tragedies involving weapons in the hands of people with severe mental illness—in Colorado, where James Holmes killed or wounded 70 people, Arizona, where Jared Loughner killed or wounded 19 people, and Connecticut, where Adam Lanza killed 28 including children as young as 6 years old. All are thought to have had severe mental illness at the time of their crimes. After we finish the debate about the availability of guns, particularly to those with mental illness, we will certainly have to address the mental health system and lack of services, especially for those in need of treatment but unwilling or unable to seek it. With proper services, including involuntary commitment, many who have the potential for violence can be treated. Just where will those services be initiated, and what will be needed?

Nearly 30 years ago, Gudeman and Shore published an estimate of the number of people who would need long-term care—defined as secure, supportive, indefinite care in specialized facilities—in Massachusetts [22]. Although a rather small study, it is still instructive today. They estimated that 15 persons out of 100,000 in the general population would need long-term care. Trudel and colleagues confirmed this approximation with a study of the long-term need for care among people with the most severe and persistent mental illness in a semi-rural area in Canada, where they estimated a need of 12.4 beds per 100,000 [23]. A consensus of other experts estimates that the total number of state beds required for acute and long-term care would be more like 50 beds per 100,000 in the population [5]. At the peak of availability in 1955, there were 340 beds per 100,000 [5]. In 2010, the number of state beds was 43,318 or 14.1 beds per 100,000 [7].

After the initial treatment in state hospitals, many people will still be in need of long-term treatment, as noted above, in a real asylum such as the ancients imagined. (The exact numbers will need to be reviewed; current studies are too small or not from sufficiently urban areas to be applicable across the country and for every population.)

We cannot depend on our current outpatient facilities to provide the support that is needed to prevent unnecessary homelessness or admissions to jails and prisons among the most vulnerable people with SMI. More housing with various degrees of supervision and facilities with a full-range of services must be brought back into the mental health system, along with revised laws for access to those services, to appropriately care for this population.

New hospitals today look more like luxury hotels then hospitals. They are designed to give a resort-like atmosphere with all its amenities. Certainly we can design facilities that are safe, provide refuge from a difficult world, and offer meaningful activities to improve the lives of the most severely mentally ill. For those who need respite, care, and rehabilitation, the idea of an asylum as idealized by the ancients might be a welcomed alternative.

References

1. Phillipson C. *The International Law and Custom of Ancient Greece and Rome*, Volume 1. London: MacMillan and Company; 1911:355-357.
2. Kessler RC, Chiu WT, Demler O, Walters EE. Prevalence, severity, and comorbidity of twelve-month DSM-IV disorders in the National Comorbidity Survey Replication (NCS-R). *Arch Gen Psychiatry*. 2005;62(6):617-627.
3. Goldman HH, Gattozzi AA, Taube CA. Defining and counting the chronically mentally ill. *Hosp Community Psychiatry*. 1981;32(1):21-27.
4. US Census Bureau, Population Division. Table 1: Intercensal estimates of the resident population by sex and age for the United States: April 1, 2000 to July 1, 2010. http://www.census.gov/popest/data/intercensal/national/tables/US-EST00INT-01.csv. Accessed September 4, 2013.
5. Torrey EF, Entsminger K, Geller J, Stanley J, Jaffe DJ. The shortage of public beds for mentally ill persons: a report of the Treatment Advocacy Center, 2008. http://www.treatmentadvocacycenter.org/storage/documents/the_shortage_of_publichospital_beds.pdf. Accessed September 3, 2013.
6. Lamb RH, Weinberger LE. The shift of psychiatric inpatient care from hospitals to jails and prisons. *J Am Acad Psychiatry Law*. 2005;33(4):529-534.
7. Lamb RH, Weinberger LE. Some perspectives on criminalization. *J Am Acad Psychiatry Law*. 2013;41(2):287-293.
8. Talbott JA. Deinstitutionalization: avoiding the disasters of the past. *Psychiatr Serv*. 2004;55(10):1112-1115.
9. Slovenko R. The transinstitutionalization of the mentally ill. *Ohio Northern University Law Rev*. 2003;29:641-660.
10. Packard EPW. *Marital power exemplified in Mrs. Packard's trials and self-defense from the charge of insanity or three years' imprisonment for religious belief, by the arbitrary will of a husband, with an appeal to the government to so change the laws as to protect the rights of married women*. Hartford: Case, Lockwood and Company; 1866.
11. *Lake v Cameron*, 364 F 2nd 657 (DC Cir 1966).

12. *O'Conner v Donaldson*, 422 US 563, 95 S Ct 2486 (1975).
13. *Olmstead v L.C.*, 119 S Ct 2176 (1999).
14. Treffert DA. Dying with one's rights on. *JAMA*. 1973;224(12):1649.
15. Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services. 2013 poverty guidelines. http://aspe.hhs.gov/poverty/13poverty.cfm. Accessed September 4, 2013.
16. US Social Security Administration. SSI federal payment amounts for 2013. http://www.ssa.gov/OACT/cola/SSI.html. Accessed September 4, 2013.
17. Gronfein W. Incentives and intentions in the mental health policy: a comparison of the Medicaid and community mental health programs. *J Health Soc Behav*. 1985;26(3):192-206.
18. Eichman MA, Griffin BP, Lyons JS, Larson DB, Finkel S. An estimation of the impact of OBRA-87 on nursing home care in the United States. *Hosp Community Psychiatry*. 1992;43(8):781-789.
19. Levy C. Voiceless, defenseless and a source of cash. *New York Times*. April 30, 2002. http://www.nytimes.com/2002/04/30/nyregion/30HOME.html. Accessed September 4, 2013.
20. Davis L, Fulginiti A, Kriegel L, Brekke JS. Deinstitutionalization? Where have all the people gone? *Curr Psychiatry Rep*. 2012;14(3):259-269.
21. Osher FC, Han YL. Jails as housing for persons with serious mental illnesses. *American Jails Magazine*. 2002;16(1):36-41.
22. Gudeman JE, Shore MF. Beyond deinstitutionalization: a new class of facilities for the mentally ill. *N Engl J Med*. 1984;311(13):832-836.
23. Trudel JF, Lesage A. Care of patients with the most severe and persistent mental illness in an area without a psychiatric hospital. *Psychiatr Serv*. 2006;57(12):1765-1770.

Daniel Yohanna, MD, is the vice chair and an associate professor in the Department of Psychiatry and Behavioral Neuroscience at the University of Chicago Pritzker School of Medicine. His interests are in community psychiatry and forensic psychiatry, as well as the development of systems of care for people with mental illness.

Related in VM

The "Army of Lost Souls," January 2009

Outpatient Commitment: A Treatment Tool for the Mentally Ill? January 2009

Pro/Con: Outpatient Commitment for the Severely Mentally Ill, October 2003