Deinstitutionalization

Understanding the mental health care system as it works today requires a certain amount of historical background. The system was not always one of community counseling services and atypical psychotropic medications. State mental institutions were once the norm. In 1955, 559,000 people were institutionalized. However, as recently as twenty years ago, there were only 132,000 people in state hospitals. (Redick & Witkin, 1983.) In the last 40 years, drastic funding cuts have resulted in a loss of 93 percent of state psychiatric hospital beds. This report provides links to inpatient state facilities still serving the severely mentally ill.

A number of factors influenced both the concept and the implementation of deinstitutionalization, or the discharging of institutionalized psychiatric patients into community settings. Advocacy efforts and innovative medications contributed to a promising climate. But the effects of discharging the mentally ill without community recovery plans in place, and without the money necessary to fund such initiatives, allowed a misguided, albeit well-intentioned effort, to create and contribute to a fragmented system.

This report first highlights state plans for transitioning patients from inpatient psychiatric institutions, and then explores the reasons behind such rightsizing of these facilities.

State Innovations, “Rightsizing”, and Community Reinvestment

“Rightsizing” is the term given to downsizing an organization most efficiently and effectively. As used here, it refers to the process of downsizing a psychiatric hospital only to the extent that its patients continue to receive proper care—those who require inpatient care continue to receive it, while others are readied for a return to society and then integrated into a community-based care setting.

Ohio and Pennsylvania are two states that are addressing deinstitutionalization by rightsizing and reinvesting mental health funds in community care. The Ohio Department of Mental Health (ODMH) created the Integrated Behavioral HealthCare System (IBHS) in 1997. Today, it provides inpatient treatment to an estimated 1,100 people. Fifteen hospitals were either closed or consolidated into nine sites that were then organized into five Behavioral Healthcare Organizations (BHO). These BHO’s provide adult inpatient services across the state. Outpatient Community Support Network (CSN) services are also provided in 39 counties and offer case management, medication/somatic, residential, crisis intervention, education, forensic monitoring and non-clinical support services to approximately 1,600 patients a year. All of the programs are accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO).

A system known as “product lines” implements the IBHS. According to ODMH, “The goals of each product line are to ensure a consistent quality of services throughout the state, maximize resources, and provide an integrated level of leadership for mental health services statewide.” IBHS’ product lines are: Intensive and Specialized Services (ISS), Forensic and Risk Management, Community Support Network (CSN), and Child and Family Services.

More information on IBHS is available at http://www.mh.state.oh.us/offices/ibhs/website.ibhs.home.html.

1 Hospital Closures and the Medicaid IMD Exclusion; Treatment Advocacy Center; http://www.psychlaws.org.
Pennsylvania’s Office of Mental Health and Substance Abuse Services created the Community Hospital Integration Projects Program (CHIPP) in 1991. To date, it has placed more than 1,500 people in the community. The goal of the program is to prepare patients for their discharge from an inpatient facility while coordinating with counties in an effort to ensure a successful transition. In fiscal year 1998 – 1999, the Department of Public Welfare spent more on community-based services than on state inpatient hospital services, for the first time ever.

More information on CHIPP is available at [http://www.dpw.state.pa.us/omhsas/omhchipps.asp](http://www.dpw.state.pa.us/omhsas/omhchipps.asp).

**Historical Context**

Viewed from today’s perspective, the kind of treatment patients in the mental institutions of the fifties received might be considered dubious, but at the time the “state of the art” was much different. These were days when lifelong institutionalization was the norm for a vast majority.

While there were certainly a number of people housed in institutions that needed to be treated in a safe, secure environment, state hospitals were also often used as alternatives of last resort for mentally ill people whose families could no longer cope, and for people whose conditions were grossly misunderstood. Those suffering from epilepsy, mild forms of depression, and what would come to be known as Alzheimer’s disease were shut off from the world with the seriously mentally ill and with the developmentally disabled, like children with Down Syndrome who, in those days, were not expected to live to adulthood.

In the late 1950s and early 1960s, studies of the system painted a grim picture. Then, a burgeoning consumer/survivor/ex-patients movement gave a voice and a face to those that would once have lived out their lives in an institution. Advocates began to push for reform; for better living conditions and “more humane” treatments. But what eventually happened may have tipped the scale too far in the other direction.

**Factors for Reform**

**I. A Call to Action**

In 1955, the Mental Health Study Act directed the Joint Commission on Mental Illness and Health to study the needs and resources of the mentally ill and to make recommendations for a national program on mental health. In 1961, the Commission published its final report, *Action for Mental Health*. The report stated that, at “the typical state hospital... there are three patients for every employee, physicians and nurses seldom attend the patient, he loses his rights as an individual and acquires none as a patient, he is encouraged to fade into the herdlike background, and his illness attracts attention only as it may create a disturbance and require his further restriction. The system effectively deprives him of all hope.”

The Commission found that any progress was dependant on solving three problems— those of manpower, facilities and costs. *Action for Mental Health* offered three solutions, outlined as pursuit of new knowledge, better use of present knowledge and experience, and cost.

In terms of the first solution, pursuit of new knowledge, the Commission offered the following recommendations:

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1. “A much larger proportion of total funds for mental health research should be invested in basic research as contrasted with applied research.

2. Congress and the State legislatures should increasingly favor long-term research in mental health and mental illness as contrasted with short-term projects.

3. Increased emphasis should be placed on, and greater allocations of money be made for venture, or risk, capital in the support both of persons and of ideas…

4. The National Institute of Mental Health (NIMH) should make new efforts to invest in, provide for, and hold the young scientist in his career choice.

5. Support of program research in established scientific and educational institutions… should be continued as considerably expanded…

6. The Federal government should support the establishment of mental health research centers, or research institutes.

7. Some reasonable portion of total mental health research support should be designated as capital investment in building up facilities for research in States or regions where scientific institutions are lacking or less well developed.

8. Diversification should be recognized as the guiding principle in the distribution of Federal research project, program, or institute grants…”

Ironically, these recommendations are still valid today, more than forty years after they were made by the Commission.

The second solution, better use of present knowledge and experience, was characterized by a willingness to “adopt and practice a broad, liberal philosophy of what constitutes [mental illness] and who can do treatment.” The Commission believed that certain therapies, generally those for persons with severe disorders, should be carried out by highly trained professionals, but that nonmedical mental health workers (counselors, clergy, volunteers and the like) could be just as helpful and could provide highly effective support. The Commission encouraged recruitment of persons into the mental health professions, as well as recruitment of qualified volunteers. The Commission also stated that community involvement was imperative to secondary prevention, or early detection/intervention. Part of this recommendation centered around the Commission’s conviction that community mental health clinics should be utilized as an alternative to hospitalization for persons with less severe illnesses, and that “it is implicit that treatment need not be confined to a hospital.”

Action for Mental Health foreshadowed future problems with another recommendation— that “aftercare and rehabilitation are essential parts of all service to mental patients, and the various methods of achieving rehabilitation should be integrated in all forms of services.” The third solution, addressing cost, was that “expenditures for public mental patient services should be doubled in the next five years— and tripled in the next ten.” The Commission said that federal aid was necessary, since states lacked the resources necessary to make appropriate changes. The Commission also suggested “that the States and the Federal government work toward a time when a share of the cost of State and local mental patient services will be borne by the Federal government.”

The Commission also touched on an idea that was revolutionary at the time and is still one of much debate— that of parity. The report noted that private insurance, when it did cover mental disorders, did not usually offer beneficiaries mental illness coverage equal to physical illness coverage, but that voluntary insurance was “valuable and merits further expansion.” Another NGA report addresses state parity initiatives.
Action for Mental Health ends with the following sentence: “It remains to be determined whether the nation does, in fact, wish to make the effort and expenditure to catch up.” With the President’s New Freedom Commission on Mental Health currently investigating the mental health care delivery system, this commentary is still timely and serves as an example of how far we still have, as a nation, to go in terms of effectively addressing mental health care needs.

II. Federal Reform

The Commission’s report did spur change. “Deinstitutionalization” initially discharged two-thirds of all patients from state mental hospitals to their families. (Redick & Witkin, 1983.)

In 1963, President Kennedy signed Aid to the Disabled (ATD), which allowed the mentally ill access to federal grants-in-aid that, in turn, allowed them to maintain a low standard of living out in the community. Also in 1963, the Mental Retardation Facilities and Community Mental Health Centers Construction Act was adopted, providing grants to staff new community care centers. But from the outset, these centers were notoriously underfunded and some of the patients who were returned to community settings had difficulty adjusting to “normal” life.

In 1965, Congress enacted Medicaid. In an effort at reform that included a plan to dismantle state psychiatric hospitals and implement a community care system, Congress included as one of Medicaid’s provisions language stating that reimbursement was prohibited for any nonelderly resident of an institution for mental disease (IMD). An IMD is defined as “a hospital, nursing facility, or other institution of more than 16 beds, that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases…”³ The IMD Exclusion, as it is commonly called, resulted in the thousands of people housed in psychiatric institutions becoming unavailable for Medicaid reimbursement. While the intent may have been to deinstitutionalize, those patients were simply transinstitutionalized, or relocated to nursing homes and public hospitals where federal funds would pay for their care.

In 1979, President Carter convened the President’s Commission on Mental Health. The Commission’s findings, that community treatment of mental illness was grossly underfunded, resulted in the adoption of the Mental Health Systems Act of 1980. The legislation dramatically increased funding for community mental health treatment services.

In 1999, the Olmstead decision ruled that it was discriminatory to place disabled persons in an institutional environment if they could be better treated in a community-based setting. Background on and the ramifications of the Olmstead decision are discussed in accompanying NGA documents.

III. Innovations in Medication

The 1950’s saw the introduction of tranquilizing drugs into the treatment of the mentally ill. Tranquilizers, capable of calming even the most unmanageable patients, revolutionized care within the institutional setting. These drugs widely replaced shock therapy and lobotomies as standard methods of treatment and allowed a large number of patients to return to society. In New York State, for example, the mental hospital population dropped to 89,000 in 1959, down from approximately 93,000 in 1955, the first year that tranquilizers were used to treat.⁴

³ 42 U.S.C. 1396d(i)
Treatment for mental illness took another turn in the 1970s with the advent of atypical psychotropic drugs for conditions such as schizophrenia. Illnesses that many had considered untreatable were now, while still chronic, controllable. However, in certain patients there is a reluctance to take prescribed medication and, out of an institutional setting, no way to require them to do so. For some of these people, adhering to treatment would be an admission of illness. Others are reluctant to alter a mental state they are accustomed to; drugs dull their creativity, their emotions, their sex drive. They would rather “function” as they always have—with manic highs and desperate lows that feel more real than the day-to-day routine of life on medication.

For those who do choose to take medication, life is often livable. Recent pharmacological innovations have produced selective serotonin reuptake inhibitors (SSRIs) that treat disorders such as depression and anxiety. These drugs have proven greatly beneficial to the elderly, in particular. Seniors who may once have been misdiagnosed with senility or dementia and gone untreated or been confined to nursing homes are now able to live out their later years more comfortably.

However, prescription drugs, in general, are costly, and medications to treat mental illnesses are often prohibitively expensive, since they usually lack less expensive generic counterparts. It is also an unfortunate sidebar of treatment that the mentally ill often need to prove their failure on certain older drugs before doctors will prescribe them newer meds. This system can be frustrating and even dangerous.

**Funding**

And who pays for these medications? When state institutions closed, state governments cost-shifted. State and local governments fund a fair share; in 1997, they paid 28 percent of mental health and substance abuse treatment expenditures, compared to only 13 percent of general health care costs. Federal programs such as Medicaid, Medicare, Supplemental Security Income (SSI), and federal block grants accounted for 30 percent of funding in 1997. Medicaid spending alone accounts for a third of all public spending on mental health and substance abuse treatment. According to a report by the U.S. Department of Health and Human Services (HHS), Medicaid spending increased 11 percent in 2001, partly because of a 19 percent increase in drug spending. The future of Medicaid funding of mental health services is currently unclear, and the question of who will end up paying for counseling and treatment through atypical psychotropic drugs hangs in the balance.

Privately funded mental health and substance abuse treatment accounts for the remainder of money spent on services. In 1997, patients paid 44 percent of the money spent on psychiatric services out of their own pockets. They paid 41 percent of expenditures on psychologists, counselors, social workers and nurse practitioners out of their own pockets. Patients who visited non-psychiatric physicians for psychiatric problems only paid 18 percent of expenses out-of-pocket.

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5 *Forgotten Policy: An Examination of Mental Health in the U.S.; Ro and Shum for the W.K. Kellogg Foundation; May 2001.*

6 *National Expenditures for Mental Health and Substance Abuse Treatment, 1997; HHS, SAMHSA, CMHS, and CSAT; July 2000.*

7 *ibid*

8 *Spending on Mental Health and Substance Abuse Treatment, 1987 – 1997; Mark et al for Health Affairs; 2000.*

9 *National Expenditures for Mental Health and Substance Abuse Treatment, 1997; HHS, SAMHSA, CMHS, and CSAT; July 2000.*
Effects of Deinstitutionalization and the Mentally Ill Homeless Population

The long-term effects of deinstitutionalization are staggering. Proponents argue that community treatment is more humane; unfortunately, it does not work for everyone.

Some of the released patients desperately needed structure and control, but were unable to function in an unaccommodating society. Once out in the “real world”, they found that the community was not ready or equipped to meet their needs. They needed safe places to stay, which were unavailable, so they found themselves on the streets. This “treatment refractory group” found that, once homeless, seeking and securing treatment was often virtually impossible. Food and shelter became priorities, as opposed to psychiatric counseling and medication.

According to the Center for Mental Health Services (CMHS), one-third of today’s homeless are seriously mentally ill, while more than half also suffer from alcoholism or drug addiction. Contrary to a common stereotype, they are not “too lazy” to find jobs; their illnesses prevent them from holding jobs. The system has failed them, and for those who have spent decades on the street, deinstitutionalization is the admirable idea that only worked in theory.

The harsh reality is that people continue to fall through the cracks in a society that has never quite known what to do with them. Meanwhile, states are struggling with solutions.