DEINSTITUTIONALIZATION: HEALTH CONSEQUENCES FOR THE MENTALLY ILL

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Introduction

Has deinstitutionalization of the mentally ill been a success or a failure? Have those who suffer from mental and emotional disorders benefited or been harmed by the move to depopulate state mental institutions and relocate patients in the community? Recently four prominent members of the American Psychiatric Association participated in a "great debate" on this issue (2). After both sides had presented their cases, the highly attentive audience decided to vote the debate a draw. Apparently they found the evidence and arguments in favor and opposed to deinstitutionalization equally compelling, convincing, and persuasive. Nevertheless, our view, though difficult to prove due to the lack of comparative data on health of patients before and after deinstitutionalization, is that the movement has done far more good than harm. Deinstitutionalization has had a positive influence on the health and welfare of patients, though it is far from reaching its ultimate goal of reversing the dehumanizing influences that have accompanied institutional care of the mentally ill for so many decades.

Treatment Prior to Deinstitutionalization

To understand this position, we must first have a clear picture of how disturbed persons were treated before President John Kennedy's call in 1963 for "a bold new approach" (37).

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Although the mandate for the old "institutional" system was to provide total care to mentally ill persons referred to the system by relatives, private physicians, social agencies, general hospitals, and the courts, in reality—says David Myerson, former Medical Superintendent of the Worcester State Hospital in Massachusetts—institutions primarily provided "security for the treatment of acute admissions and basic survival care for long-term institutionalized patients" (51). Put bluntly, many mental institutions, even as late as the 1960s, were functioning mainly as custodial facilities, warehousing patients who did not respond to treatment in the first few months of hospitalization.

When Myerson took over at Worcester State Hospital in 1969—in Massachusetts, a state known for its progressive approach to treatment—he described the hospital as a nineteenth century custodial facility where patients were easily admitted but not so easily discharged. The reason, he wrote, was "not necessarily for medical or psychiatric reasons, but because the Superintendent was expected to assume total and permanent care of the individuals *committed* to the hospital" (51; our italics).

Thus, even as late as 1969–1970, some institutions were serving as "dumping grounds" for society's unwanted. As Myerson points out, "All the demographic and psychiatric characteristics of admitted patients revealed that indigence, social helplessness, and isolation . . . determined admission to, and . . . residence at Worcester State Hospital" (51). The quality of care rendered to these patients during their hospitalization was of peripheral concern to the agents who committed them—police, sheriffs, social workers, and private physicians. "With few exceptions," Myerson reminds us, "affluent mentally ill from supportive families went elsewhere (to private facilities) for their psychiatric care" (51).

Obviously many of these institutions had not resolved the evils of custodial stagnation and neglect that had characterized mental institutions before the 1930s. As described by Greenblatt (32), facilities in that period were overcrowded, understaffed, and managed in a hierarchical, autocratic fashion. Treatment consisted primarily of seclusion, forced tube-feeding, chemical restraint, wet-sheet packs, and soaking for hours in tepid water, particularly if patients' behavior was disturbed and troublesome to the ward. Fortunate patients stayed for months, other inmates remained institutionalized for years (7). Almost all were committed involuntarily (35).

Due to the community's fear of the mentally ill and to the prevailing notion that treatment should be carried out in a quiet isolated environment far from the stresses and strains of society, facilities often were located in areas remote from family and friends. Inmates were frightened by their incarceration and felt banished by society. For the rest of their lives they carried with them the stigma of mental illness.

By the 1950s, however, many institutions had adopted a more therapeutic-egalitarian approach to care. They employed somatic treatments such as electric shock, insulin hypoglycemia, or lobotomy, and individual and group psychotherapies were tried with some success. Such interventions revolutionized attitudes concerning the prognosis of treatment, and ushered in enthusiasm about the potentialities of mentally ill patients formerly regarded as refractory. The successes of tranquilizers and later antidepressants added further to therapeutic optimism.

In the most enlightened facilities, the evils of custodial care and authoritarian management were greatly mitigated if not eliminated. Though still straining under the restrictions of lack of staff, poor buildings, and general environmental impoverishment, they tried valiantly to humanize operations and made concerted efforts to foster social, recreational, and work activities; to open institutional doors; to mingle men and women patients; and generally to reduce the barriers between hospital and community. They reduced the use of routinized, restrictive, punitive treatments. Nevertheless, a large percentage of poor persons continued to be hospitalized involuntarily, and back wards still held a large proportion of long-term, chronically ill patients with little hope for a better life "on the outside."

The most advanced of these institutions raised the hope that a modern mental hospital should and could function as a well rounded, intensive treatment, research, and training mental-health center with strong ties to the community. These exceptional places developed supportive ties and collaborations with the community, encouraged family members and friends to visit patients and to join actually in the therapeutic effort, and invited persons from the community to serve as hospital volunteers. Colleges and universities cemented cooperative relationships with these facilities, which soon became training grounds for budding social workers, psychologists, occupational therapists, nurses, rehabilitation specialists, and pastoral counselors.

Setting the Stage for Deinstitutionalization

Successes in improving the physical and social environments within hospitals, and lowering the barriers between hospital and community, encouraged officials to explore a number of transitional or community-based strategies for mental illness care and treatment. Outpatient and ambulatory care increased by leaps and bounds, serving both as aftercare of patients discharged from the hospital, and as preventative early care to obviate institutionalization of those who never had been hospitalized. Cooperative apartments for patients whose symptoms had been controlled in the hospital were developed (16, 28). Similarly, halfway houses (15), hospital daycare programs (41), home-care programs (72), and other community treatments

were explored. By keeping persons outside of the hospital, maintaining them on medications, and providing social support, patients were assisted toward health without losing community ties, connections to family and jobs, or suffering the debilitating dependency associated with long-term custodial care (9, 76).

Some workers went so far as to suggest that psychiatry should go public, so to speak—reach outside of mental institutions to organize a "Therapeutic Society" to balance the "Therapeutic Communities" that were being developed intramurally (30).

As professional and community attitudes began to change, the stage was set for deinstitutionalization—for shifting the primary burden of care to local communities.

The Joint Commission on Mental Illness and Health

The best publicized, most comprehensive statement concerning deinstitutionalization was published in 1961 as the final report of the Joint Commission on Mental Illness and Health, a national survey and analysis of the status of mental illness in our nation, organized by the American Psychiatric Association and supported by many community organizations and the Federal government. It issued a "call for action" outlining a philosophy and suggesting methods of transferring mental health care from state to local government. The intended approach was clearly stated (36):

> The objective of modern treatment of persons with mental illness is to enable the patient to maintain himself in the community in a normal manner. To do so, it is necessary 1. to save the patient from the debilitating effects of institutionalization, 2. to return him to home and community life as soon as possible, and 3. thereafter, to maintain him in the community as long as possible. Therefore, after care 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, among them day hospitals, night hospitals, aftercare clinics, public health nursing services, foster family care, convalescent nursing homes, rehabilitation centers, work services, and expatient groups.

To translate this vigorous new plan into action, the Commission made a number of urgent recommendations. They advocated the immediate phasing down of large mental hospitals to populations of under 1000, and called for a halt to construction of more hospitals. They called for vigorous research to improve our knowledge and techniques for care and treatment, asked for a doubling and tripling of Federal funds for innovative programs for the mentally ill, and urged establishment of small comprehensive mental health centers to serve all the individuals in a defined geographic area. The Commission also urged the mobilization of volunteers and paraprofessionals. Above all it called attention to the disgraceful system of care and

treatment of mentally ill persons that was tolerated by the richest nation on earth.

The publication of the Joint Commission report was followed a year later by two national conferences of state governors on the subject of mental health. The major result of these conferences was the passage of resolutions strongly urging more comprehensive state planning directed toward implementation of the recommendations of the Joint Commission.

Establishment of Comprehensive Community Mental Health Centers

The Federal mandate as stated in the Commission report and President John Kennedy's strong message to Congress calling for "a bold new approach" to mental health care led the 87th Congress to pass legislation in 1963 appropriating $4.2 million to finance comprehensive mental health planning in all the 50 states. More legislation quickly followed to formalize and legitimize the Comprehensive Community Mental Health Center (CCMHC) as the touchstone of the deinstitutionalization movement. According to this legislation, passed in 1963 and 1965 to provide monies to build and staff such centers, the centers were to have five essential services, namely, inpatient care, outpatient care, transitional care, twenty-four-hour emergency care, and community consultation and education (70, 71). States also appropriated funds from their own coffers to finance community programs and services.

By the end of fiscal year 1976, 649 of these comprehensive centers had been funded and 547 were in full operation (52). Later developments opened programs for children, drug dependent persons, elderly individuals, and the developmentally disabled, and provided for longer-term Federal support before phasing out state funding.

The greatest impact of this model of care was related to the government's requirement that these centers serve defined geographic regions designated as "catchment areas," whose individual populations embraced 75,000 to 200,000 citizens. Each area was to plan a comprehensive center for total care and treatment of mentally ill persons without regard to race, sex, age, ethnic makeup, or diagnostic category. The centers were to be developed either under one roof or as an affiliation of services carried on in several locations within a given catchment area that could link public and private providers under one administrative authority. Such authority was expected to assure continuity of services through a smooth flow of patients, records, and perhaps even therapeutic personnel from one system to another.

CITIZEN INVOLVEMENT The Federal legislators not only required states to designate catchment areas for each center, they also encouraged

citizens from these areas to become intimately involved in mental health planning and implementation. This prompted the formation of a new coalition between local citizens and the state hospital or mental health facility assigned to each district and renewed interest in public health psychiatry. It restimulated the sciences of epidemiology and preventive medicine, and deepened professional interest and concern in the various life styles and their effect on illness and treatment. It also encouraged research to identify and treat high risk groups, heightened concern for minorities and the disenfranchised, increased use of crisis and emergency intervention techniques, and mobilized paraprofessionals and volunteers to meet the multiple needs of patients in the community. Altogether, the movement signaled a major, even revolutionary, change in the country's view of the emotionally disabled.

Tying mental health centers to catchment areas and requiring strong community input to planning and implementation awakened the interest of the citizenry as never before. Citizen involvement in mental health issues reached its zenith during this period. Local volunteers were appointed to state planning boards, to boards of directors of state facilities, and especially to boards of the newly forming CCMHCs. Acting in these capacities, lay persons advised on mental health policy, consulted on budgets, and approved critical appointments.

This heightened interest and participation by a relatively small number of citizens had a ripple effect. They became local advocates and spokespersons for the mentally ill. They promoted much greater interest in the mentally ill by the community at large and educated their fellow citizens to greater understanding and sympathy for their plight. Citizens became more willing to expend human and financial resources to meet needs of ill persons locally. The stigma against mental illness eased (22, 34, 47), especially among the educated segments of society.

Judicial and Legislative Interventions

Motivation for these particular changes, and in fact for the entire deinstitutionalization movement, came not only from mental health professionals, Federal government intervention, and state legislation. Judicial decisions also significantly influenced the direction of mental health policy and practice.

A series of rulings, including the precedent-setting decision by Judge Frank M. Johnson, Jr. of the Fifth US District Court in *Wyatt v. Stickney* (74), made the issue of patients' rights an important consideration in mental-health care. Johnson's decision, handed down in response to a suit brought by Ricky Wyatt, an involuntarily committed patient, against Stonewall B. Stickney, the Mental Health Commissioner of the State of Alabama,

asserted that patients committed for treatment have a Constitutional right to adequate treatment. Johnson ordered an immediate upgrading of care in the state institution in which Wyatt was an inmate, and held the Alabama Mental Health Board responsible for implementation using its resources under the penalty of contempt. Moreover, he ruled that a shortage of state funds could not be used as an excuse to fail to carry out his orders.

In *Wyatt v. Stickney*, Johnson also established detailed, comprehensive standards for every phase of life and treatment for both mentally ill and retarded inmates, including physical plant standards, staff qualifications and ratios, and the requirement that treatment be individualized. An important principle incorporated into these standards was the right to be treated in the least restrictive setting appropriate to one's illness. This suit was followed by a deluge of lawsuits seeking to break new ground by creating additional patient rights. Thus, *Wyatt* and other landmark cases such as *Donaldson v. O'Connor*, which stipulated that nondangerous patients cannot be detained without treatment if they are capable of surviving in society (25), threw the spotlight on the issue of inappropriate or inadequate care.

Such rulings prompted mental health officials in all 50 states to sit up and take notice. Many responded by making sincere and concerted efforts to improve state institutions. Others opted to delay costly improvements until a specific suit was brought in their own state.

Many state legislatures responded by passing laws to insure that their facilities were in compliance with these court orders. By 1980, 45 of the 50 states had passed statutes on patients' rights, and 35 state departments of mental health had regulations regarding rights of patients. Thirty-nine states gave patients the right to refuse psychosurgery and a smaller number gave patients the right to refuse electroshock treatment and psychotropic medication. Thirty-five states by 1980 had established criteria for a safe, secure, and humane environment; 29 required patients to have a physical and mental examination before treatment was begun; 24 specified each patient's right to an individual treatment plan; 48 guaranteed confidentiality of patient records; 42 guaranteed the right to care in the least restrictive environment; and almost all states insured that patients were allowed to receive and send unopened mail, make and receive telephone calls, and possess private monies and personal property. Forty-three states regulated the use of restraints and seclusion, and 38 states had systems to enforce these laws and regulations (59).

Where actual progress was made, it consisted of actions on two fronts: first, persistent efforts were made to make the internal environment of the hospital more home-like and attractive and to humanize and normalize relationships between staff and patients. These efforts were intended to counteract patient dependency, feelings of helplessness and hopelessness,

and patient deterioration so often associated with long-term institutionalization. The quality of the patient's life came under more critical scrutiny, and a variety of social and occupational options were offered that patients could try at appropriate stages of their clinical careers. The goal was to prepare patients for discharge and return to the community (31).

The second and more dramatic action taken by state officials was the rapid reduction of public hospital populations. Some state institutions were shut down completely, while others drastically reduced their patient census over a period of only a few years. Although some thought the intent was to do away with public institutions altogether, this was never the case. The aim of deinstitutionalization was to close the worst of these public facilities and upgrade the remaining institutions for more selective use—for hospitalizing patients for shorter periods of time, and for more intensive treatment of long-term patients—the 2 to 5% of chronically disturbed individuals whose symptoms cannot be readily reversed (63). Monolithic inpatient facilities were to be phased down and converted into comprehensive community mental health centers that offered a full range of services to local catchment areas. In this manner it was hoped that eventually 95% or more of persons previously hospitalized could be treated in the community or hospitalized only briefly, while the severely disabled would receive vastly improved services in less crowded facilities with more favorable staff-to-patient ratios (1).

Expectations Versus Reality

Unfortunately, some of the high hopes, optimism, and idealistic zeal generated during the early years of deinstitutionalization could not be sustained, for they were based upon the belief that deinstitutionalization would finally lead to abandonment of state hospitals, would totally revolutionize patient care, and would reverse the social and occupational deficits accompanying mental illness.

A major weakness of the movement was that it was oversold to the public. Whatever success it had was to a large extent overshadowed by its failure to perform miracles. Critics began to attack the movement, the whole concept of community care, and made much of the faults of the CCMHCs in place at the time. The professional literature is full of complaints.

In her view of the literature on community treatment, anthropologist Sue Estroff (26) categorizes the most prevalent and forceful attacks as including the following:

1. Increased material and psychological costs to families of patients and community members (3, 69).
2. Lack of adequate supportive and psychiatric health-care services for patients living in the community (17, 45).

3. Poor quality of life, and social isolation and financial destitution of patients living in the community, particularly chronically disturbed persons (4, 43, 44, 56, 57, 67, 77).
4. The promising of more services and results than the system was prepared to deliver; and personnel problems within the health-care delivery system (23, 43, 50).

Although these charges have often been overstated and overdramatized, Estroff has noted, "Each claim has been substantiated to some degree and has been acknowledged as reasonable by treatment system personnel" (26). Continuing concerns were summarized as recently as 1978 in a report to the President's Commission on Mental Health (54). Most critics, however, are not calling for an end to deinstitutionalization; they simply want to make it work better. The balance sheet shows that the present situation and treatment of the mentally ill is a vast improvement over what prevailed during the previous period of "institutionalization."

How Well Has Deinstitutionalization Met the Problems of the Mentally Ill?

THE EXTENT OF THE PROBLEM   True progress in caring for persons suffering from mental illness often may be difficult to appreciate because of the vast improvements in hospitals and in patient care that have yet to be made. Statistics quoted by Darrel Regier, MD, Director of the Division of Biometry and Epidemiology of the National Institute of Mental Health, make clear the staggering numbers of persons with whom deinstitutionalization is expected to deal. Let us consider in particular the chronic patient, the most neglected individual in the spectrum of emotional disorder.

In 1977, approximately one in every 100 Americans (1.7 to 2.4 million persons) was considered to be chronically mentally ill. One in every thousand (more than 200,000 persons) had been hospitalized in a mental institution for more than one year, while another 750,000 mentally ill individuals were living in nursing homes. The other 800,000 to 1,500,000 chronically ill persons were in the community, 110,000 in short-term care units of psychiatric hospitals, and the remaining 690,000 to 1,390,000 in halfway houses, board and care facilities, single-room occupancy hotels, living with relatives, in their own homes, or surviving in the streets [unpublished draft report of the Workshop on Policy Issues Relating to Care of the Chronic Psychiatric Patient, Division of Health Policy Research and Education, Harvard University, 1982 (27)].

A small percentage of these persons is affluent enough to afford relatively high quality, individualized inpatient care in local, private psychiatric facilities, and upon release can pay for personalized psychiatric aftercare. Others

may be able to do well without relying on public supports if they have a well-functioning social support system, i.e. a suitable place to live and relatives who are willing and able to put up with and help resolve recurring bouts of illness and troublesome behavior.

However, a large percentage of mentally ill adults have suffered severe emotional problems with accompanying occupational and social deficits, leaving them bereft not only of adequate financial resources but also of the interest and support of relatives and friends sufficient to effect recovery. It is these hundreds of thousands of chronically ill persons who present the most severe test and challenge of the efficacy of the deinstitutionalization movement. How does their health and welfare compare with that of similar persons who in the past were treated only in mental institutions?

THE EFFECTS OF DEINSTITUTIONALIZATION   Deinstitutionalization has in fact occurred; many more of the mentally ill are now living and being treated in the community, and the nature of care has shifted from reliance on public inpatient care to ambulatory care and treatment by caregivers in the private sector (40). These shifts are highlighted by the fact that the resident population of state and county mental hospitals, which reached its peak of 559,000 in 1955 (8), by 1980 had been reduced to 138,000 (Survey and Research Branch, Division of Biometry and Epidemiology, National Institute of Mental Health, Personal Communication). In an earlier article, Klerman, during his tenure as administrator of the National Institute of Health's Alcohol, Drug Abuse, and Mental Health Administration explained, "As the population of institutions decreased, a correspondingly rapid expansion of [local] outpatient and ambulatory services of all kinds took place, including free-standing clinics, services affiliated with psychiatric and general hospitals, public and private facilities, and adult and child care" (39).

The dramatic decline of the inpatient census of public mental hospitals did not, however, necessarily signify a reduction in overall need for hospitalization; and the expansion of outpatient services did not mean that formerly hospitalized patients were the only beneficiaries.

SHIFTS IN INPATIENT CARE   Hospitals in the public sector were handling only about one in three inpatient-care episodes in 1971, whereas in 1955 they had handled almost two out of every three patients (63%) admitted to inpatient care. Nevertheless, comparative data also show that the national rate of inpatient-care episodes remained relatively stable between 1955 and 1975 at about 800 per 100,000 population (40).

Two trends help explain these seemingly confusing facts. First, while public institutions were reducing the numbers of patients residing therein,

their admission rates (the rate of inpatient-care episodes) increased. Second, more persons than ever before in need of hospitalization were being treated either in psychiatric wards of local general hospitals (21) (which handled 21% of the inpatient load in 1955 and 32% in 1975) or in CCMHCs, which did not exist in 1955 (but which were carrying 14% of the inpatient load by 1975) (40).

These facts suggest that whereas the number of persons hospitalized at any one time remained essentially unchanged, more inpatients were being treated closer to home, and average hospital stays were reduced. Klerman (40) cites unpublished data from the NIMH to make this point. In just four years, from 1971 to 1975, "there was a 41% decline in length of stay for admissions ... to state and county psychiatric hospitals." Patients now were being served near home by short-term hospitalization until disabling symptoms could be reversed, then they were being released to the community where far more aftercare services were available than ever before. This situation contrasts dramatically with the condition that existed before deinstitutionalization.

EXPANSION OF OUTPATIENT AND AMBULATORY CARE IN THE COMMUNITY   The dramatic expansion of outpatient and ambulatory services in the community signified that mental health services were becoming available and being used by a larger segment of the population.

Even though the rate of inpatient hospitalization remained roughly the same between 1955 and 1975, utilization of outpatient services skyrocketed in less than two decades, almost doubling from around 1100 episodes per 100,000 population in 1955 to around 2000 per 100,000 population in 1971 (40). While some of the increase can be accounted for by more frequent use of these services by more patients being released to the community, it is doubtful that aftercare services alone accounted for the increase. It is more likely that because of increased community awareness and concern about illness, the reduced stigma attached to seeking help, and the rapid expansion of local options for care, people were brought into treatment who before deinstitutionalization would neither have sought nor received such help.

In his earlier review of the situation Klerman concludes, "These trends have given us the advantage today of a more pluralistic and ambulatory system that includes both the public and private sector and that reaches out to many more people in the community than it was capable of before" (39).

CHRONICALLY ILL PERSONS AFFECTED BY DEINSTITUTIONALIZATION   A persistent question asked by many is, how well or poorly does this new system of care serve the chronically ill—those in need of intensive, long-term or intermittent, psychiatric, social, and occupational support?

Leona Bachrach (7) believes that five subgroups of this population have been affected by the movement out of public facilities into the community.

1. The first subgroup consists of those individuals who have been discharged from mental institutions after months of hospitalization. They include two smaller subgroups: First, there are persons who are hospitalized until symptoms are controlled, then released, and then rehospitalized when symptoms recur or when social role performance deteriorates to the point that caretakers are unwilling to maintain them in the community (8). These persons go through the revolving doors of the service-delivery system again and again. The other, smaller subgroup consists of those who are discharged, and then "fall through the cracks" of the service delivery system, never to be seen again.

2. The second chronic population includes those "never-hospitalized" individuals who probably would have been institutionalized several decades ago, but who, as the direct result of deinstitutionalization, now constitute an ever-increasing percentage of people in the community (7). In San Mateo, California, Lamb & Goertzel (46) found, for instance, that about two-fifths (39%) of chronically ill persons in that county never had been hospitalized; Pepper and colleagues (53) learned that approximately four out of five (79%) outpatients being treated in clinics in Rockland, New York never had been institutionalized.

3. A third subgroup of the chronically ill consists of patients who were admitted to state hospitals many years ago, and still are considered to be too ill and incapacitated to be discharged. In 1979, according to unpublished data from the NIMH's Division of Biometry, about 18% of patients in public facilities had been hospitalized for 20 years or more.

4. A fourth group is made up of patients who enter state hospitals, but are released within two weeks of admission. Some are rehospitalized chronic patients who need brief hospitalization to control recurrent symptoms, while others are acutely ill persons who are treated, then released after being "cured." Again, according to unpublished NIMH data, nearly one in four persons presently being admitted to state and county institutions is released within a week, and nearly 40% are discharged within two weeks.

5. The fifth and final group of chronically ill are those newly admitted patients who are likely to stay hospitalized for years. Smith & Hart (63) estimated that 2 to 5% of newly institutionalized patients will remain in state hospitals, too disturbed to be discharged.

Ideally, as sociologist Bachrach suggests, "programming for deinstitutionalization should accommodate all five of these patient subgroups ... [and] individuals in all of them must be regarded as legitimate beneficiaries of planning efforts that are intended to improve patient care in this era of deinstitutionalization." From this she concludes, "We are thus faced with

the task of arranging a multitude of services for a variety of patient groupings in numerous settings" (7).

Although planning of services for these subgroups is far from adequate, many individuals in them are better off today than prior to deinstitutionalization. The very division of the chronically ill population into subgroups suggests that their previous status as a relatively undifferentiated lot who spent the better part of their lives incarcerated on back wards of state hospitals has changed. Moreover, subgroup characteristics that some have viewed with alarm, may now be viewed with at least some optimism; for example, the "problem" of the much-talked about "revolving door" patients. As Klerman (39) and others (49) have pointed out, the availability of short-term, intermittent hospitalization to treat acute symptoms may be the key to community living for a significant percentage of these patients. We need to acknowledge and accept the fact that symptoms will flare up periodically that necessitate rehospitalization (61), but that these rehospitalizations may be of short duration, only briefly interrupting community adaptation.

Concerning patients who "fall through the cracks," we may surmise that at least some never come in contact with the institutional system again because they prefer freedom in the community to incarceration, or have been improved sufficiently by antipsychotic drugs to allow them to resume productive lives at home and at work (19).

How to assess the fate of "never hospitalized" chronically ill persons who are receiving no help is difficult. Before deinstitutionalization, would they have been allowed to remain in the community, or would they all have been committed to state institutions? If committed, would this have been a more desirable fate? Some overburdened family members would undoubtedly prefer hospitalization (3); but many patients would undoubtedly prefer "freedom" (24, 39). Also, "never-hospitalized" persons who are receiving help in the community may not necessarily place a heavy burden on others (68, 69). (Certainly for them, community living is preferable to incarceration.)

Many patients who have remained hospitalized in spite of deinstitutionalization may have benefited greatly from the movement. As hospitals have reduced their censuses, they have been able to direct an increased share of their resources to meet needs of these long-term patients (19). Moreover, Scheper-Hughes (58) reports that as "healthier" back ward patients are released, a phenomenon referred to as the "cream rising to the top" occurs—some of the more severely disturbed patients previously assumed to be hopelessly impaired, begin to appear more salvageable and are eventually regarded as new candidates for release.

The current practice of hospitalizing patients for short periods of time to

bring symptoms under control and then releasing them as "better-but-not-well" may have advantages over the older practice of hospitalizing such persons until they were truly greatly improved; this so often meant they stayed in institutions for very long periods, becoming so dependent that they were finally unable to resume life outside the hospital altogether. Newly released better-but-not-well patients, as a result of their earlier discharge, may be able to maintain whatever personal and social support systems in the community they had enjoyed. If they take their medications faithfully, because there is someone in the community to help them, there is a very good chance they can remain outside of the hospital; 50% of all patients who are readmitted are rehospitalized simply because they have stopped taking medications (18, 19, 62).

STATE HOSPITAL AS COMPREHENSIVE COMMUNITY MENTAL HEALTH CENTER   An often overlooked benefit of the reduction of state hospital populations has been the assumption of new roles by these hospitals in community outreach and treatment programs. An impressive example of how one hospital superintendent in New York altered his organization, its goals, and its treatment modalities to change a large custodial state institution into a modern comprehensive mental health center shows some of the unexpected gains that can result from deinstitutionalization.

In his book, *From State Hospital to Psychiatric Center,* Levine (48) tells the quite remarkable story of the transition that took place over several years, accomplished without budget additions. Despite a 25% inflation rate between 1974 and 1979, and a budget decrease of 25%, the number of patients served by the institution more than doubled. Three factors contributed to this increase:

1. patients in inpatient programs remained under the care of the institution,
2. all patients who left the inpatient hospital system were transferred into the outpatient system,
3. new patients were enrolled from the community.

The quality of care for inpatients improved tremendously as the staff-to-patient-ratio increased from 1:2 in 1974 to 1:1 in 1979. Because hospital staff often went into the community to see discharged patients in the center's community clinics, day programs, and sheltered workshops, continuity of care, usually difficult to achieve, was maintained. In four years, the organization was able to broaden its community support system to the extent that it was designated as a site for a Federal demonstration program. "We extended services to all members of the community," claimed the superintendent, "and made available, 24-hours-a-day, seven days a week, mobile crisis-intervention teams staffed with professionals, including psychiatrists" (48).

Under four successive superintendents, Boston State Hospital similarly reduced its inpatient census and vastly expanded its community treatment programs (19). In Canada, Lafave and his colleagues (42) shut down a large state institution, replacing it with comprehensive services in the community. Restructuring these outdated systems of public care has enabled thousands of patients and ill persons in the community to live freer, more normal lives.

SUCCESSFUL EXPERIMENTAL AND MODEL COMMUNITY PROGRAMS   A number of either experimental or model community programs also show that significant improvements in care have been made since deinstitutionalization without unrealistically high costs. As Bachrach suggests, many experiments with alternatives to hospitalization have been quite extraordinary and their successes provide hope for future service planning. She believes that "a search for commonalities in modern programs that are considered successful demonstrates that there are certain principles that characterize them" (6). These principles are similar to those Talbott (66) recommends as best suited to serving persons still housed in state institutions, reinforcing the idea that principles guiding effective planning for chronic patients can be applied in all settings. "These principles are structural and are not concerned with the substantive aspects of programming," says Bachrach, who adds, "they can be generalized" (6).

These model programs and experiments have contributed directly to the health and welfare of the persons who have been fortunate enough to participate in them. They have benefited all chronically ill persons by proving that community alternatives to hospital care can successfully reverse symptoms and treat associated complications of illness. This was the conclusion also reached by Braun and his colleagues in Massachusetts, based upon their review of studies assessing alternatives to hospital admission, modifications of conventional hospitalization, and alternatives to continued long-term hospitalization (10).

One of the most ambitious attempts at preventing hospitalization at the outset took place in Madison, Wisconsin in the 1970s. A team of researchers from the University of Wisconsin randomly assigned persons who sought admission to Mendota Mental Health Institute either for standard treatment, "inpatient hospitalization followed by aftercare in the community," or to "Training in Community Living," a treatment strategy in which patients remain in the community receiving intensive support, occupational counseling, and treatment from staff members. The program, conceived and operated by Leonard Stein and Mary Ann Test, served an unselected sample of adult patients who were experiencing severe symptoms of illness normally requiring hospitalization.

The following description of one patient's entrance into Training in Community Living illustrates how the program works (65).

> John, a 30-year old single man who had been hospitalized on six different occasions, was brought to the hospital by his parents. During the previous months he had become so irritable and irrational they no longer could endure his behavior. When they arrived at the admissions office, the hospital registrar picked up an envelope that randomly assigned John to the Training in Community Living Program. Immediately a call was placed to the program's headquarters in the community and a psychiatrist was sent to the hospital. After it was established that John, though in the midst of a schizophrenic episode, was not suicidal, homicidal, or in need of heavy doses of medication, the community treatment program was described to John and his parents who agreed to his participation. All three then were taken down to community headquarters where John's treatment strategy was worked out.

Stein & Test describe what followed (65):

> The immediate plan included increasing John's medication, arranging for him to stay at the YMCA at night until a more permanent community living arrangement could be worked out, and giving the family instructions that we would essentially "take over" with John, and requesting them to curtail all contact with him in order to prevent the continuation of the pathological relationship between John and his family.... The rest of the afternoon and evening John spent ... going to supper with a staff member, going to the YMCA to rent his room, and going to an evening activity with another staff member, as well as receiving a thorough physical examination.
>
> The next morning he was picked up by a staff member and taken to breakfast at a nearby coffee shop. Later that morning he met with the vocational rehabilitation counselor.... That afternoon he was taken over to one of the community's sheltered workshops and allowed to look the place over. Plans were then made for him to start work the next day.
>
> In a week, with intensive help on all fronts from staff, John's symptoms were much improved. Staff helped him locate and move into a rooming house, and then taught him how to keep his quarters, to plan menus, shop, and budget his money. They also helped him enter into recreational activities.

As his performance at the occuptional workshop improved, John became more independent and less in need of help in daily living. But there were set backs. An argument with the floor supervisor prompted John to walk off the job. Staff had to go to his room early the next morning and insist that he get out of bed and return to work. On another occasion John was evicted from the rooming house as a result of disruptive behavior. He landed on his parents' doorstep asking to move back in. All these episodes were handled firmly and consistently by parents and staff, who refused to allow him to reestablish dependency upon his parents, and most importantly, upon the availability of hospitalization when things got rough. Staff let him know that although they were there to help him adapt to living in the community independently, his acting out, disruptive, infantile behavior

would not buy him anything. They would not respond to his needs when he behaved as an "irresponsible child."

Several months later John was doing well on his own, seeing a staff person for only two hours a week. He had established ties with several community agencies, his medication was administered regularly by the Visiting Nurse Service, he was participating in an aftercare program sponsored by the Mental Health Center, and spent his recreational hours at a city center.

Stein & Test's follow-up of John and other patients who received Training in Community Living indicated to them that the success of the program derived from "assertively helping patients to: 1. acquire material resources, 2. learn necessary coping skills in vivo, 3. stay motivated and involved with treatment, and 4. help free themselves from pathological, dependent relationships (65)."

When these ingredients are incorporated into community treatment, the investigators conclude, "there is considerable hope for a solution" to treating chronically ill persons in the community without hospitalization.

The cost of this approach can be less burdensome on local and state purse strings than inpatient care. In an experimental program in Chicago based upon the Training in Community Living model (55), close to $400,000 were saved by treating 50 chronic recidivist patients in the community.

A second example of a community treatment program concerns a program designed to reach out to an even more regressed and impaired group of patients—those most disabled, long-term patients who upon release from state institutions often had to be reinstitutionalized on inpatient wards of local community mental health centers. These are the "unplaceable" persons who exhibit serious antisocial and asocial behavior and lack even minimal skills for daily living.

The Quarterway House, founded in December 1978 to help such patients, was established in Boston as one in an array of services designed to help patients originally released from state institutions (33). The objectives of the Quarterway House were to provide a less institutional, more therapeutic environment, to increase skills for independent living, and to develop communication skills and competency. The Quarterway House actually was a refurbished wing of the same building in which the patients had been hospitalized and in which "controls" continued to reside. Treatment for hospitalized patients emphasized intensive individual and group psychotherapy and occupational therapy, and was conducted by a team of staff members who also worked with relatives to help prepare them for patients' return to home. Much of the treatment was done by psychiatric residents and students of other mental health disciplines as part of their training.

Persons living in the Quarterway House had been offically discharged from inpatient care, paid monthly rent for their rooms, and supported

themselves on supplemental social security and disability payments. The house was staffed with about the same staff-to-patient ratio that existed on the ward, but the makeup differed significantly. The director was a master's level nurse. There were two recreational therapists, a registered occupational therapist, and 12 mental health assistants. Staff used a combination of rehabilitative, behavioral, psychopharmacological, and interpersonal approaches in their attempts to resocialize and rehabilitate these severely disabled patients (33).

> All eight males had a history of assault. One had been hospitalized in the state prison for the mentally ill, one had a history of rape . . . four were incontinent of urine, two were incontinent of feces, and one slapped his own ears so badly they were cauliflowered. Of the five females, all were occasionally assaultive, including one who recently had broken a cup on a medical student's face, producing a cut that required stitches. Two were quite autistic, one was incontinent of urine and three had very poor hygiene.

The researchers collected baseline data on the use of psychoactive medications, seclusion and restriction, general level of functioning, and inappropriate and antisocial behaviors on all 13 subjects and on the nine "controls" who remained hospitalized. A year later the same data were collected and additional information was gathered on the number of patients who had been discharged or placed in a less restrictive environment.

At the end of the first year, researchers found that Quarterway House residents were able to have their medication levels reduced, had been in isolation less frequently than inpatients, and were more free to move about in the outside community than ward residents. House residents also improved significantly over inpatients on a global measure of over-all functioning and on measures of socialization-survival skills such as personal hygiene, using the telephone, and dressing themselves. They regressed during the year, however, on the measures of social obstreperousness, whereas behavior of inpatients improved on this measure.

Unfortunately many of these model and experimental programs have been time-limited or have folded due to lack of long-term funding, and patients who improved dramatically while participating in them, lost those gains when the programs were shut down.

FOLLOW-UP AND OUTCOME STUDIES   More effective support for deinstitutionalization would be follow-up and outcome data showing conclusively that cohorts of patients who have been released from state hospitals are doing significantly better in the community than they were on hospital wards, that they are living more independent lives, are less symptomatic, less socially and occupationally handicapped. Unfortunately, "the question of what actually happens to patients who leave mental hospitals and reenter the community is largely unanswered" (5). Also a serious bias in interpretation often occurs because both the popular media, and at times

even the professional literature, tend to give more attention to negative aspects of deinstitutionalization than to its successes (67, 75). A brief summary of follow-up and outcome data, however, may be instructive.

One of the largest follow-up studies of patients released from inpatient care was conducted at Boston State Hospital (64). Of the estimated 2400 expatients still living since release during the late 1950s, 500 resided at home and were employed at least part-time; 600 were in foster care; 300 lived in cooperative apartments; 800 were in nursing homes; and 200 had been rehospitalized.

Results of another follow-up in Massachusetts, on patients transferred from Grafton State Hospital during its phasing out, showed that 252 of the 758 most elderly chronic patients who were discharged over the 18-month period were living a year later in community facilities—in family care, nursing homes, cooperative apartments—whereas 506 of the original group (who had been institutionalized for an average of 18 years each) were inpatients in other Department of Mental Health facilities. Interviews with those who achieved community residence showed that 90% preferred their new locations—whether nursing home, cooperative apartment, or home—to the hospital. "In contrast," reported the researchers, "less than half the patients transferred to other state hospitals rate their present situation better than Grafton, even though services [in the newer institutions] were supposedly superior" (38).

In their review of follow-up studies, the Group for the Advancement of Psychiatry (20) concluded that "72 percent of the discharged patients returned to households containing a member of the family, 13 percent to live alone, and the remainder to nursing or boarding homes." British studies arrive at similar findings: 71% of discharged patients live with relatives (11, 12–14, 29, 73), half of these with spouses.

In California and New York, where the largest exodus has occurred, researchers learned that "approximately one year after the sharp reduction in California hospital census . . . 11,000 former patients . . . [were] living in boarding homes and other residential facilities in Los Angeles" (60). In New York, 25,000 chronic mental patients were estimated to be living alone in one-room dwellings, Class B hotels, and rooming houses in Manhattan (57).

An optimistic view of deinstitutionalization might point out that almost three-quarters of released chronic patients end up at home with relatives or in foster care where it is likely they receive some personal, social, and financial support. However, both professionals and lay persons have described life in other community settings—board and care homes, nursing homes, single-room-occupancy hotels, and other "independent" living situations—as substandard, socially isolating, and lacking in necessary personal services. Yet there are several studies of persons who have been placed in

such community residences showing that these persons, compared to similarly impaired patients who remain in the hospital, have a better average mental status, and prefer their current living situations to life in the state hospital (24).

Much more careful research must be done to ascertain the relative status of comparable groups, the one remaining in hospitals, and the other served in deinstitutionalization programs, not only to clarify overall results, but to indicate how each group can be handled better in the future.

Summary and Conclusions

An adequate appraisal of the deinstitutionalization movement must cope with the fact that this movement was not simply an effort to treat a group of patients; it was in fact practically a total revolution in conceptualization, planning, and implementation of treatment systems throughout our nation. Never before had the national system of mental health care and treatment been so thoroughly studied. Never before had so many agencies been brought together to effect changes. Never before had a President of the United States asserted the great authority and strength of his office to convert a system commonly regarded as a disaster into a more humane and effective organization. Never before had the Federal government, the states, the American Psychiatric Association, and dozens of other interested groups joined hands to pursue common goals.

The goals were multiple: to increase research and to reduce ignorance about the causes and treatment of mental illness; to phase down the large state hospitals and to build no more large institutions; to shift the burden of care from hospital to community; to make hospitals more home-like and humane; and to depopulate them by transferring patients who were languishing without adequate treatment to community facilities where treatment could be more intensive, closer to home, family, friends, jobs, and community. The great program also aimed to mobilize community resources on behalf of the mentally ill, to multiply facilities appropriately structured and staffed to meet needs and treat discharged patients; to prevent hospitalization of early cases by intensive extramural therapy; and to train community volunteers, paraprofessionals, and indigenous workers to help the mentally ill.

This in itself is a very large sociocultural change in attitudes and approach, but it is by no means an adequate picture of what happened. Citizen groups were activated; legislative and judicial actions gave the mentally ill new rights, new dignities, and new services. The stigma of mental disability was considerably reduced, at least among the intelligentsia. Along with these vast sociocultural changes, new discoveries and techniques were introduced that dramatically changed the prognosis of nervous illnesses afflicting

the population. Traditional professionals were trained in larger numbers—especially psychiatrists, psychologists, nurses, and social workers. In addition, other professions paid more attention to the mentally ill than ever before, i.e. pastoral counselors, marriage and family counselors, rehabilitation workers. Self-help and mutual assistance groups expanded greatly in numbers and in activities.

One of the most significant efforts directly traceable to the deinstitutionalization movement was the attempt to provide care and treatment to all the people in the nation who had need, but were denied such because of poverty, lack of insurance, or lack of interest and desire to seek help. The plan promulgated by the national leadership to reach this end was to divide the nation into defined geographic zones, or "catchment areas," to plan a full panoply of services for all the individuals in each area, and to coordinate all facilities and care-givers to deliver services in a timely and effective manner. One specific instrumentality developed to advance on these multiple goals was the Comprehensive Community Mental Health Center, whose responsibility was to attend to the needs of all the sick in the given area, to provide transitional as well as inpatient care and treatment, to provide consultation and education, to stress continuity of services among the different facilities in the area, and especially to make available services to the needy without discrimination. The poor, the underserved, the members of minority groups, children, adolescents, drug dependent persons, and any other neglected elements of society were given more and more emphasis as time went on.

Many of the goals of the deinstitutionalization movement were achieved, some were only partially achieved, and some goals have escaped even partial fulfillment. What is more, with time, the movement began to creak and groan, as Federal and state funds began to dry up, as community facilities to accept discharged patients did not arise in proper synchronicity with the flow of patients out of the hospitals, and as the citizens began to recoil from the sight of homeless, deteriorated patients wandering the streets, living in flop houses, subject to abuse by the savage elements of society, and not infrequently acting out their bizarre, crude, and often frightening behavior in public. This produced a backlash by many citizens, community leaders, and professionals against the deinstitutionalization movement, a swelling of criticisms against the programs that had failed to solve problems, and a multiplication of anecdotes regarding inhumanities visited on patients prematurely released from mental hospitals.

Although deinstitutionalization is still very far from reaching the original goals espoused, it would be unfair to declare it a failure simply by overemphasizing its shortcomings and minimizing its extraordinary accomplishments. Indeed, rather few of its critics seem to want to jettison its major

ideological and humanistic goals; mainly they are repulsed by the hardships visited on those patients and families for whom deinstitutionalization admittedly has not worked. The many thousands of patients and families successfully reached and helped seem to be dwarfed by the cases, still too numerous, whose lot in life has clearly not been improved.

Nevertheless, in the main, the program so far has resulted in a dramatic and remarkably positive change in the nation's attitude, commitment, and identification with the needs of the mentally ill. Many believe that understanding by a large sector of the public of the nature and treatment of mental illness has advanced to a new height. Many more believe that the large number of progressive Federal and state statutes and decisions insure that never again will the nation return to the dehumanizing conditions that prevailed in that long dark period when institutional confinement was the only mode of care and treatment for the mentally ill.

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