DEINSTITUTIONALIZATION: AVOIDING THE DISASTERS OF THE PAST

John A. Talbott, M.D.

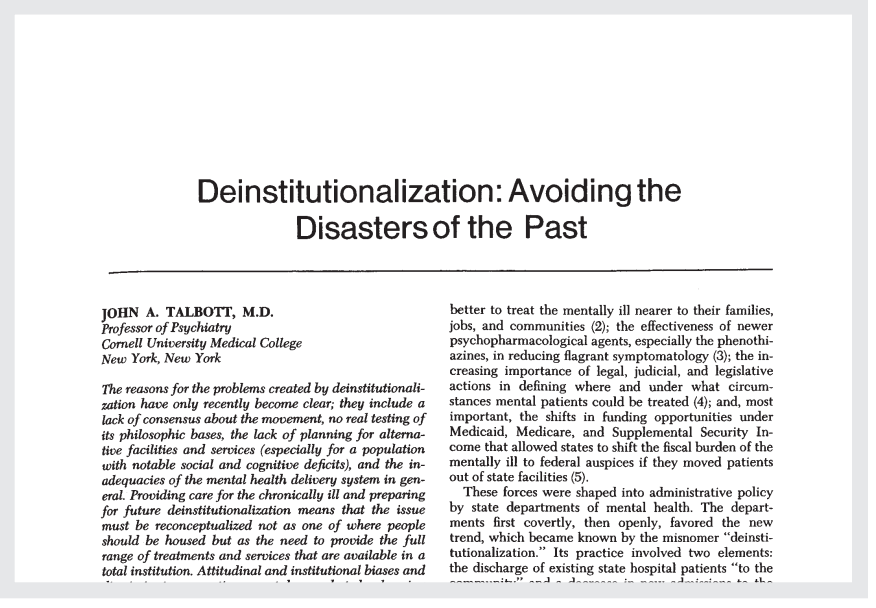
The reasons for the problems created by deinstitutionalization have only recently become clear; they include a lack of consensus about the movement, no real testing of its philosophic bases, the lack of planning for alternative facilities and services (especially for a population with notable social and cognitive deficits), and the inadequacies of the mental health delivery system in general. Providing care for the chronically ill and preparing for future deinstitutionalization means that the issue must be reconceptualized not as one of where people should be housed but as the need to provide the full range of treatments and services that are available in a total institution. Attitudinal and institutional biases and discriminatory practices must be combated, planning for community facilities and services must be improved, and funding for both institutional and community services must be provided during the phasing down of institutional services. The author proposes a set of ten commandments or basic rules to guide future deinstitutionalization activities.

Traditionally, America's sickest psychiatric patients, those suffering from severe or chronic mental illnesses, have been cared for in state psychiatric facilities. Since the birth of the state hospital in the 1800s, it has cared for increasing numbers of seriously ill persons and, until relatively recently, was the locus for the bulk of psychiatric treatment in this country.

In 1955 the census of the nation's state hospitals reached its peak of 560,000, and since then there has been a steady and dramatic decline to its current level of under 170,000—a decrease of more than 60 per cent (1). The reasons for this decline are several: the impact of the community mental health philosophy that it is better to treat the mentally ill nearer to their families, jobs, and communities (2); the effectiveness of newer psychopharmacological agents, especially the phenothiazines, in reducing flagrant symptomatology (3); the increasing importance of legal, judicial, and legislative actions in defining where and under what circumstances mental patients could be treated (4); and, most important, the shifts in funding opportunities under Medicaid, Medicare, and Supplemental Security Income that allowed states to shift the fiscal burden of the mentally ill to federal auspices if they moved patients out of state facilities (5).

These forces were shaped into administrative policy by state departments of mental health. The departments first covertly, then openly, favored the new trend, which became known by the misnomer "deinstitutionalization." Its practice involved two elements: the discharge of existing state hospital patients "to the community" and a decrease in new admissions to the state facilities.

Early in the history of deinstitutionalization, general hospitals and other agencies in the community attempted to cope with the discharge of large numbers of state hospital patients through expansion and innovative programs (6). By 1971, however, it became clear that without additional services and funding, such efforts would become increasingly ineffective because they were diluting the resources of local facilities and overtaxing their staffs. Rumblings of



Deinstitutionalization: Avoiding the Disasters of the Past

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discontent became evident both in psychiatry and in government (7–9). Within a few years, this murmur became a roar as local communities (inundated by hundreds of discharged patients), national and local media leaders, and representatives from the broader field of medicine voiced their concern (10,11).

Despite this outcry, and the increased attention paid to the problems created by deinstitutionalization, it has been only recently that individuals, professional organizations, and governmental agencies have begun to analyze the problem in a systematic manner and attempt to determine what went wrong (12–14). In this critique, I will attempt to build on the existing analyses and propose solutions to prevent what happened before from happening again. To do so, I will briefly describe what did occur and why, suggest what should be done next, and propose ten commandments that should govern further deinstitutionalization efforts.

What happened?

When lay people or psychiatric professionals refer to the mess or disaster created by deinstitutionalization, they are usually referring to several events. Most striking was the dramatic appearance of large numbers of obviously mentally ill people on city streets, people who were dirty, who wore torn or inappropriate clothing, who hallucinated and talked to themselves or shouted to others, and who in general acted in a strange or bizarre way. In many places, huge ghettos of discharged patients were created in areas of low-cost housing, proprietary homes, or deteriorating neighborhoods.

Thousands more patients were transferred to nursing homes. While the percentage of Americans living in institutions of all types has remained steady at 1 per cent, from 1950 to 1970 the proportion of this number residing in nursing homes rose from 19 to 44 per cent, while the proportion in state hospitals fell from 39 to 20 per cent (15). Conditions in nursing homes became as scandalous as those for the wanderers on city streets. Especially affected were the elderly who received short shrift not only by being denied admission to custodial institutions but also by being forced to remain in acute care facilities for months, awaiting placement in less expensive and more appropriate institutions. All acute care facilities, especially general hospital emergency rooms, began to be used more to handle the social problems or the exacerbations of the chronically ill than to deal with acute mental conditions, and the populations seen in what formerly were acute and chronic care facilities began to approximate each other.

Two new syndromes were described: "falling between the cracks" and the "revolving door," the former indicating a total lack of follow-up and aftercare for discharged patients, and the latter their continued readmissions. That is, patients spent fewer total days in hospitals but accounted for many more admissions and readmissions to a larger number of hospitals, with shorter lengths of stay for each admission (16,17). Meanwhile, back at the state hospital, where planners had expected that the decreased population would result in better patient treatment and care, there was increasing demoralization, demedicalization, and deterioration.

The net result of the movement was that what had been achieved was not deinstitutionalization but transinstitutionalization. The chronic mentally ill patient had his locus of living and care transferred from a single lousy institution to multiple wretched ones.

How did this disaster occur?

It has taken years to realize why what happened did happen, but the reasons now seem fairly clear. First and most basic, as Scherl and Macht have pointed out, there was no consensus about the idea of deinstitutionalizing the chronic mental patient population (18). Subsequently then, when citizens, legislators, labor representatives, small-business men, mental health professionals, and governmental executives observed the results of the movement, there was a predictable hue and cry.

Second, since there was no single reason to explain why the state hospital population began to drop in 1955, there was no true testing of the tenets later given as the philosophic underpinnings of deinstitutionalization: for example, community care is better than institutional care, community care costs less than institutional care, and care in the least restrictive setting is of higher quality.

Third, there was no planning before or during deinstitutionalization. For instance, in 1968 in New York State, a commissioner of mental hygiene promulgated a memorandum outlining the rules of deinstitutionalization. Rationales were advanced that a reduction in new admissions to state hospitals would force localities to develop alternatives—13 years after the shift had begun (19). Today, more than ten additional years later, conditions are still unchanged, for the state's newly issued five-year plan calls for a new process of "admission diversion" and a further decrease in the state hospital census of 5000, still in the absence of additional community facilities or supports (20).

Fourth, although experts such as Bertram Brown insisted that deinstitutionalization must consist not only of increased discharges and decreased admissions, but of a greater number of community facilities (21), the community facilities did not develop apace. There remains, 25 years after the initiation of deinstitutionalization, an absolute and relative paucity in both the number and the range of graded community facilities for the treatment of patients with chronic mental illness. With the knowledge that state hospitals required 100 years to achieve their maximum size, the precipitous attempt to move large numbers of their charges into settings that in fact did not exist must be seen as incompetent at best and criminal at worst.

Fifth, in addition to the nonexistence of community facilities for the chronically ill, there was no provision for supplying the patients with all the services available in the state hospital, such as medical and psychiatric care, social services, housing and nutriment, income maintenance or appropriate employment, and vocational and social rehabilitation. To expect patients with major ego

deficits and residual dysfunctioning, without families and social networks, to suddenly be able to obtain for themselves the professional and custodial services they formerly took for granted in a total institution seems the stuff of sheer fantasy.

Sixth, although the vast array of needs of chronic patients is intensified by social and cognitive deficits, there was no provision for any glue to stick the needed services and supports together. Not only was the patient expected to find all the services he had previously been given at the state facility, but he was expected to put them into some sort of comprehensive package of reasonable, cost-effective treatment and care, a task that the professional establishment has been unable to accomplish.

Seventh, while mental illness is becoming more fully accepted and destigmatized, American society has not progressed to the point that it is totally comfortable with naked men dancing on Broadway or bag-ladies wandering up Park Avenue.

And, lastly, the disaster occurred because our mental health delivery system is not a system but a nonsystem. One beneficial result of deinstitutionalization was that it revealed, as has no other event in history, the inadequacies of mental health delivery and laid bare most of the flaws of our nonsystem. It became clear that our services are totally fragmented, with different levels of government responsible for similar kinds of planning, funding, implementation, and monitoring of services; with all levels of government (federal, state, and local) both contracting for services and directly providing their own competing services; and with no one seeming to be in charge.

Deinstitutionalization also revealed the rank discrimination against long-term care and chronic illness by governmental and private third-party reimbursers, by housing agencies, under labor laws, and so forth. It revealed how inflexible our funding structure is, and how vested are the interests that constitute the mental health structure—so that, try as one might, it was impossible to have money follow patients from state to community settings. It also pointed up the intolerable lack of cooperation both between hospitals and agencies in the community and between agencies up the administrative ladders to Washington.

What do we do now?

While almost every error imaginable has been made in deinstitutionalization, it is unthinkable to suggest a return to pre-1955 days. We have proceeded too far to turn back, and there is sufficient evidence that deinstitutionalization's failures were not due to ideological or philosophical deficiencies. Failures were due to implementation of the underlying ideas. But if we are to, first, provide care for the estimated one to seven million chronically mentally ill patients with whose health we are charged and, second, prepare for further deinstitutionalization, we must learn from the past and not repeat our errors.

There must be a reconceptualization of the problem of the treatment and care of the severely and chronically mentally ill. Instead of considering the issue as one of where people should be housed, we must assess the needs of chronic patients and design or revise our services to meet those needs. And this means first and foremost that we must realize that we're not talking merely about psychotherapeutic needs but about medication, resistance to ongoing treatment, medical needs, housing, income, rehabilitation, social services, and what, for want of a better term, has become known as a community support system—that is, a system of supports that enables the chronically mentally ill person to receive the treatments and services he would receive if he were housed in a total institution.

There must also be a reassessment of the attitudes of all segments of society toward the chronically ill. The lack of consensus about deinstitutionalization, plus the continuing stigmatization of the mentally ill combined with the lack of a visible effective constituency for the chronically ill, contributes to the problem. We cannot continue business as usual so long as we are faced with these overwhelming odds. A broad coalition of health professionals, consumers, government officials, business leaders, and others must be forced to combat the widespread attitudinal and institutional biases and discriminatory practices that now exist, or the issue of scandalous care of the chronically mentally ill will be with us forever.

Adequate planning must be undertaken not only to catch up to where we are in reality but also to prepare for future deinstitutionalization. The National Institute of Mental Health's community support program is a commendable step in the right direction. But it occurs at the same time that individual states are trying to bolster their state hospital programs to stave off loss of accreditation and are continuing to husband resources, sequestered for inpatient care, both centrally in their bureaucracies and among their own facilities. Twenty-five years after the beginnings of deinstitutionalization, we continue to need an adequate number and range of graded community facilities and services. We continue to need adequate programs to prepare patients, through teaching them the skills of everyday living, to resume community living. And, for those patients living in less than total institutions, we require active rehabilitation programs that are funded to support both transitional and discharge activities.

If we are to avoid the errors of the past, future attempts to deinstitutionalize patients and close state hospitals must have built-in funding for both institutional and community services during the phasing-down process. While this approach requires double funding, planners, administrators, and legislators cannot expect, as they did in 1955, that when patients are shoved out of state hospitals and such facilities are closed down, adequate community services will spring up.

And lastly, to avoid the errors of the past, there must be an administrative structure to handle future changes, wherever patients are and whatever services are delivered. So long as funding and administrative responsibility

for planning, implementation, monitoring, and evaluating services remain fragmented and unclear, and so long as the conflict of interest between contracting for and providing services exists in all layers of government, we will perpetuate the mental health nonsystem.

The ten commandments

To implement the lessons learned from our past quarter century of failure at deinstitutionalization, I propose ten commandments or basic rules to govern our future actions.

♦ Before patients are discharged, there must be an adequate number and range of community services and facilities to provide patients with treatment, care, and community support.

♦ Barriers to full participation in health and mental health delivery systems must be removed so that existing eligibility and reimbursement practices that discriminate against the chronically mentally ill are not perpetuated.

♦ Chronically mentally ill patients must have full civil rights and opportunities, including equal access to housing, education, vocational rehabilitation, income maintenance, and adequate care in the community.

♦ Money must follow patients. That is, funding must be as flexible as patient populations, and if there are further shifts in the locations of care or treatment, monies must accompany the patients to meet their needs.

♦ Medical-psychiatric money should be separate from but coordinated with funding for community support (for example, housing, food, income support, social services, and vocational and social rehabilitation). It is especially critical to keep this requirement in mind when considering what benefits are to be included under national health insurance.

♦ A system that ensures continuity of care must be developed. To date, the degree of achievement of this truism is inversely related to its utterance.

♦ A case management system must be established. Such a system should not create a whole new profession or paraprofession but should make use of existing manpower and resources.

♦ Services should be provided by the smallest local entity that is capable of delivering such services. Such entities must designate a specific person or facility as the core service agency of the service delivery system.

♦ Federal, state, and local governments should divest themselves of the conflict of interest inherent in both contracting for services and operating services themselves. If local entities operate services, city and county governments can monitor and plan them on their level, states can coordinate a statewide plan, and the federal government can oversee a national effort.

♦ There must be a concerted national effort that would increase and continue existing research into the causes of chronicity, its prevention, effective treatment, and model service systems for the chronically ill.

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