Some Perspectives on Deinstitutionalization

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The authors discuss what can be learned from our experience with deinstitutionalization. The deinstitutionalization of mentally ill persons has three components: the release of these individuals from hospitals into the community, their diversion from hospital admission, and the development of alternative community services. The greatest problems have been in creating adequate and accessible community resources. Where community services have been available and comprehensive, most persons with severe mental illness have significantly benefited. On the other hand, there have been unintended consequences of deinstitutionalization—a new generation of uninstitutionalized persons who have severe mental illness, who are homeless, or who have been criminalized and who present significant challenges to service systems. Among the lessons learned from deinstitutionalization are that successful deinstitutionalization involves more than simply changing the locus of care; that service planning must be tailored to the needs of each individual; that hospital care must be available for those who need it; that services must be culturally relevant; that severely mentally ill persons must be involved in their service planning; that service systems must not be restricted by preconceived ideology; and that continuity of care must be achieved. (*Psychiatric Services* 52:1039–1045, 2001)

What has been learned from the successes and failures of deinstitutionalization? Over the past five decades many things have been done well, but many mistakes have been made. The purpose of this article is to examine, from our perspective of more than three decades of study of this subject, both the positive and the negative aspects of this revolution in mental health care.

Deinstitutionalization can be defined as the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based alternatives for the care of mentally ill people (1). According to this definition, deinstitutionalization is not limited to the reduction of psychiatric hospital censuses, even though this is a common understanding of the term (2,3). Rather, the definition extends beyond hospital depopulation to include the provision of alternative services. Thus, although downsizing or closing long-stay psychiatric hospitals is a critical part of deinstitutionalization, it is only a part of that process—it is not all of what deinstitutionalization encompasses (4).

Accordingly, in theory deinstitutionalization consists of three component processes: the release of persons residing in psychiatric hospitals to alternative facilities in the community, the diversion of potential new admissions to alternative facilities, and the development of special services for the care of a noninstitutionalized mentally ill population (5). The last of these processes is particularly important, because it assumes that the altered life circumstances of these persons will inevitably result in new configurations of service needs and a better quality of life.

The dimensions of deinstitutionalization in the United States are impressive. In 1955, when numbers of patients in state hospitals in the United States reached their highest point, 559,000 persons out of a total national population of 165 million were institutionalized in state mental hospitals. As of December 1998, there were 57,151 occupied state hospital beds for a population of about 275 million (personal communication, Manderscheid R, 2000). Thus in a little more than 40 years the number of occupied state hospital beds in the United States was reduced from 339 per 100,000 population to 21 per 100,000 on any given day. Some individual states have gone even further. In California, for example, there are fewer than three state hospital beds per 100,000 population, excluding forensic patients (personal communication, Mone R, California State Department of Mental Health, 2001).

It must be noted that the first two processes of deinstitutionalization that we have mentioned have proceeded far more rapidly than the third. That is to say, hospital censuses throughout the country have been drastically reduced, and many would-be admissions to those hospitals have been blocked, but the critical third

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process of supplying adequate and accessible community alternatives to hospitalization has frequently lagged far behind (6).

The rationale for pursuing deinstitutionalization, which combined elements of idealism and pragmatism, reflected justifiable concern for the well-being of mentally ill persons, many of whom were living miserable lives inside the state hospitals (7). This rationale encompasses several critically important assumptions. First, it was widely, even passionately, assumed that community-based care would be intrinsically more humane than hospital-based care. Second, it was similarly assumed that community-based care would be more therapeutic than hospital-based care. Third, it was further assumed that community-based care would be more cost-effective than hospital-based care (5,8,9).

However, these assumptions had not been tested empirically, and there has been cause over the years to question their validity. For example, we have begun to realize that community care may indeed hold the potential to be more humane and more therapeutic than hospital care; however, this promise cannot be realized unless comprehensive services for the most severely mentally disabled persons have been mandated and adequate resources have been provided to ensure the implementation of these services (4). We have also begun to understand that if all the hidden costs associated with responsible programming are considered, it is generally not accurate to conclude that community services will result in substantial savings over hospital care (10–13).

We have also learned that we are not ready to close all our state psychiatric hospitals, although their imminent demise was often predicted amid the optimism of the 1960s and 1970s (14). Many planners who continue to harbor the hope that we will some day eliminate these facilities increasingly acknowledge the difficulty of establishing alternative sites where patients can be admitted for intensive, structured observation or comprehensive care in a hospital-like setting.

Nonetheless, we may conclude that the basic idea of community care appears to be valid for most persons who would formerly have resided in psychiatric hospitals. Our outcome research has revealed that in communities where all three elements of deinstitutionalization have been concurrently implemented, the result has most often benefited persons who suffer from mental illness. The quality of care for these persons has improved substantially, and many individuals express much greater satisfaction with their life circumstances as contrasted with conditions inside psychiatric hospitals (15). In fact, some persons, despite their illnesses, have realized a certain degree of "normalization" in their daily activities. Some live independently, and some are productively employed—achievements that were relatively rare in the days before deinstitutionalization. For these people deinstitutionalization must be regarded as a positive development.

However, these generalizations do not apply to all mentally ill individuals. Even in places where community care has been thoughtfully conceived and adequately funded, some individuals have fared poorly. And given that there has been such a great investment of hope, effort, and clinical competence, we must ask ourselves why we have not witnessed more consistently positive outcomes in our community-based programs for mentally ill people.

Some portion of the answer to this vexing question undoubtedly lies in the fact that, over the years, the service needs of mentally ill persons have changed, often in ways that were not anticipated. For example, some "new" long-term severely mentally ill persons have found it extremely difficult to sustain themselves in the community. Among other problems, their easy access to alcohol and other chemical substances has greatly exacerbated their symptoms and has interfered with any progress they might have made, a fact that was largely overlooked in the early years of deinstitutionalization. Moreover, community resistance, severe fragmentation of services, and insufficient and inadequate housing opportunities (16,17) have often conspired to create barriers to appropriate residential placement for these severely mentally ill persons.

The new generation of severely mentally ill persons

Initially, concerns about deinstitutionalization tended to focus on those severely mentally ill persons who had been discharged into the community after many years of living in state hospitals. However, treating the new generation that has grown up since the implementation of deinstitutionalization policies has proved to be even more difficult. Such difficulties were almost totally unforeseen by those, including the authors, who were advocating deinstitutionalization.

For example, the large number of homeless persons who have severe mental illness—that is, schizophrenia, schizoaffective disorder, bipolar illness, or major depression with psychotic features—has tended to come from this new generation (18,19). To understand this phenomenon, we need to look at how this new generation differs from its predecessors.

People who have been hospitalized for long periods tend to become institutionalized to the point of passivity (20). Generally, they have learned to follow orders. When they are placed in a community living situation that has sufficient support and structure to meet their needs, most tend to remain there and to accept treatment. However, this has not been the case for the new generation of severely mentally ill persons. They have not been institutionalized to passivity. They have not lived large parts of their lives in hospitals, and for the most part they have spent only brief periods in acute care hospitals.

In the days of the very large "asylums," these "new long-term patients" would have been institutionalized, often permanently and usually starting from the early phases of their illnesses in adolescence or early adulthood. Thus these persons, after their initial difficulties in trying to cope with the problems of life and of living in the community, were no longer exposed to these stresses: they were given a permanent place of sanctuary from the demands of the world. Unfortunately, the ways in which state hospitals provided this sanctuary often led to serious abuses.

Today, the great majority of severely mentally ill persons live in the com-

munity, not in state hospitals. However, this new generation of long-term, severely mentally ill persons has often posed difficult clinical problems in treatment and rehabilitation, and many of these individuals have suffered from homelessness and inappropriate incarceration. These problems have caused many of the concerns about deinstitutionalization (21–23). However, we believe that if adequate community resources are provided, most of these persons can realize their potential for social and vocational functioning and also enjoy their freedom.

However, these patients present new challenges for service planners and clinicians. For example, disturbing side effects, fear of tardive dyskinesia, or denial of illness may discourage many severely ill persons from taking psychoactive medications. Outside of the hospital it is difficult for clinicians to prescribe and monitor the very medications that bring these patients into remission and enable them to function in the community.

Moreover, for many in the new generation of mentally ill persons, the label of "mental patient" is anathema (24), and denial of their illness and their need for treatment is common. For many of these persons, becoming part of the mental health system is tantamount to admitting failure and some basic defect (25). In addition, substantial numbers of these persons also have substance use disorders or medicate themselves with street drugs (26–28), circumstances that generally serve to exacerbate their symptoms.

Some new service priorities

In our opinion, there is nevertheless reason to be optimistic in the midst of this apparent chaos, because a new understanding of the complexities of community-based care for long-term severely mentally ill persons has emerged. This understanding is reflected in our support of some critical new service priorities. For example, we have learned to focus on providing a variety of outreach interventions that enable providers to treat patients where they are, not where we might wish or expect them to be (29,30).

In addition, we are now emphasizing the need for intensive case management efforts in which mental health professionals and paraprofessionals are charged with assisting patients in overcoming barriers to care (31,32). We are also striving to develop a wide variety of specialized programs—for example, vocational and psychosocial rehabilitation programs, psychoeducational efforts, and diversified housing programs—that respond to the new realities of deinstitutionalization (15,29,33). The increasing prevalence of homelessness and criminalization among mentally ill persons tells us unequivocally how important it is that we consider such factors in planning services for long-term severely mentally ill persons (23,34).

Homeless mentally ill persons

Caring for homeless mentally ill persons has become one of the greatest challenges to public mental health and to society in general. This problem has taken on greater importance because of evidence that a third to a half of all homeless adults in the United States have major mental illness—schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder—and up to 75 percent have major mental illness, severe substance use disorders, or both (35).

The two American Psychiatric Association task forces on the homeless mentally ill (22,34) concluded that this problem is the result not of deinstitutionalization per se, but of the way it has been implemented. Homelessness among long-term severely mentally ill persons is symptomatic of the grave problems that generally face them in this country. Thus the problem of homelessness will not be resolved until the basic underlying problems of the long-term severely mentally ill population generally are addressed and a comprehensive and integrated system of care is established for them.

The solutions for homelessness in the mentally ill population are the same solutions to emerge from the lessons learned from deinstitutionalization, which we discuss in a subsequent section. These lessons address the basic needs of long-term severely mentally ill persons in the community. Of special importance is the nation's critical shortage of affordable housing in which many subsidized units of housing for people with disabilities, including people with mental illness, have been lost as a result of changes in federal housing policy (36).

How do individuals who are chronically and severely mentally ill become homeless? Obviously there are many pathways to living on the streets, and it is useful to look briefly at some of them. Long-term severely mentally ill persons are vulnerable to eviction from their living arrangements, sometimes because of their inability to deal with difficult or even ordinary landlord-tenant situations (37). In the absence of an adequate case management system, these individuals end up on the streets and on their own. Many, especially the young, have a tendency to drift away from their families or from board-and-care homes. They may be trying to escape the pull of dependency and may not be ready to come to terms with living in a sheltered, low-pressure environment. They may find an inactive lifestyle extremely depressing. Or they may want more freedom to drink or to use street drugs (38).

Some long-term severely mentally ill persons may regard leaving their comparatively static milieu as a necessary part of the process of realizing their life's goals, but this process can exact its price in terms of homelessness, crises, decompensation, and hospitalization. Once mentally ill persons are out on their own, they may stop taking their medications. The state of disarray associated with their illness may cause them to fail to notify the Social Security Administration of a change of address or to fail to appear for a redetermination hearing. Thus they may no longer be able to receive their Supplemental Security Income checks. The lack of medical care on the streets and the effects of abuse of alcohol or other drugs are additional serious complications. These persons may now be too disorganized to extricate themselves from living on the streets except by exhibiting blatantly bizarre or disruptive behavior that leads to their being taken to a hospital or jail.

There is still another factor. Evidence has emerged that homeless mentally ill persons have a greater severity of illness than do mentally ill persons in general. At Bellevue Hos-

pital in New York City, approximately 50 percent of formerly homeless inpatients are transferred to state hospitals for long-term care, compared with 8 percent of other Bellevue psychiatric inpatients (39).

Severely mentally ill persons in the criminal justice system

There has been much concern since the 1970s about the numbers of mentally ill persons in our jails and prisons (40–44). The extent to which incarceration rates of mentally ill persons are related to deinstitutionalization has been the subject of considerable research (45–47). Although there has been some evidence to support the premise that an increase in incarceration rates has in fact taken place, this premise is difficult to prove scientifically because of a lack of good studies of the numbers of mentally ill persons who were incarcerated before deinstitutionalization with which our postdeinstitutionalization data can be compared. Nevertheless, several factors enable us to conclude that an increase since deinstitutionalization has indeed occurred.

First, very large numbers of mentally ill persons currently reside in our jails and prisons. Second, long-term hospitalization in state hospitals is no longer an option for long-term severely mentally ill persons, because of drastically reduced numbers of state hospital beds. Finally, both clinicians and researchers have observed that a large proportion of mentally ill persons in our criminal justice system today in most respects resemble the persons who used to be long-term patients in state hospitals (23).

As a result of deinstitutionalization, large numbers of mentally ill persons are now in the community. At the same time, limited community psychiatric resources are available, including hospital beds. Society has a limited tolerance for mentally disordered behavior, and the result is pressure to institutionalize persons who need 24-hour care wherever there is room, including jail. Indeed, a criminalization of mentally disordered behavior—that is, a shunting of mentally ill persons who need treatment into the criminal justice system instead of the mental health system—has been described (43,47). Rather than hospitalization and psychiatric treatment, mentally ill persons who have committed minor crimes often are subjected to inappropriate arrest and incarceration. In addition, many severely mentally ill persons who formerly would have lived out their lives in state hospitals are now in the community, where there are more opportunities for them to come to the attention of the police for what is perceived to be criminal behavior (48–51). Such behavior is often a manifestation of their illness.

Other factors cited as contributing to the very large numbers of severely mentally ill persons in prison include the more formal and rigid criteria for civil commitment and the lack of adequate support systems for mentally ill persons in the community. Still another factor is the difficulty faced by mentally ill persons coming from the criminal justice system in gaining access to both community mental health treatment in general and to treatment that is appropriate to their needs (52). For example, many individuals may need outreach services or an agency that can provide the degree of control and structure required to treat many mentally ill offenders successfully. We can only conclude that, in this era of deinstitutionalization, the criminal justice system has largely taken the place of the state hospitals in becoming the system that can't say no (53).

A range of effective strategies to prevent severely mentally ill persons from entering the criminal justice system or, once there, to divert them to mental health treatment has been developed (23,54–56). These strategies include mental health consultations to police officers in the field, formal training of police officers, careful screening of incoming jail detainees, and diversion to the mental health system of mentally ill persons who have committed minor offenses. Many other preventive strategies are among the needs of severely mentally ill persons in the community—assertive case management, adequate and appropriate mental health treatment, involvement of and support for families, and, not infrequently, various social control interventions, such as outpatient commitment, court-ordered treatment, psychiatric conservatorship, and 24-hour structured care.

Lessons learned from deinstitutionalization

Deinstitutionalization has left us with a heightened awareness of the humanity and needs of mentally ill persons. It has left us with a biopsychosocial point of view that implies the interaction of biological, psychological, and sociological events as they affect the lives of mentally ill persons (57). Such a biopsychosocial view demands that we consider not only the biology of mental illness but also the sociological context of care and particularly the special circumstances, needs, and hopes of individual patients as we plan mental health services with them and for them (58–60).

A social process with secondary consequences

Deinstitutionalization involves more than changing the locus of care; it is a social process with secondary consequences. In addition to its being an important geographical event, deinstitutionalization is an ongoing process that has subtle implications. More specifically, it is a vital process of ongoing social change—of movement away from one orientation in treatment and toward another that is radically different—that has had a profound influence on the lives of mentally ill people. Today, deinstitutionalization affects those individuals who continue to use psychiatric hospitals by shortening their stays in such facilities and often by making discharge an end in itself that sometimes overrides clinical concerns. Deinstitutionalization also affects persons who do not use psychiatric hospitals but who might have done so in another era: the persons whose admissions have been prevented or diverted altogether.

We can no longer measure the success of deinstitutionalization in terms of reduced hospital populations, because when we do so we can easily lose sight of those mentally ill people who never enter hospitals in the first place (8). We can also lose sight of the many mentally ill persons who end up back on the streets or in jails and prisons. There are now said to be more people residing in state prisons and jails than there are in public psychiatric hospitals (61).

Tailoring service planning to individual needs

Deinstitutionalization has clearly demonstrated the importance of individualized care for mentally ill persons, who constitute a diverse and heterogeneous group of people. Service planning must be tailored to the needs of specific individuals (62).

Mentally ill individuals further vary in the degree to which they are able to tolerate stress and unpredictability. They vary as well in the kinds of programs that will best serve their needs—for example, whether they can live alone or would be better suited to congregate residential plans; whether they need intensive psychiatric interventions or would be better served by less invasive psychiatric care; and whether they are able to work, and, if so, whether they need sheltered or supported work or competitive employment opportunities.

In the days before deinstitutionalization, service planners had a strong tendency to group all mentally ill persons together and to ask, in effect, "What ought we to do with the 'mentally ill'?" However, deinstitutionalization has generated a focus on rehabilitation and individual need, and we are more likely today to rephrase this question as, "What may we do for this particular person who suffers from mental illness?"—a conceptual shift of major proportions.

Facilitating access to hospital care

It is essential to facilitate access to hospital care for patients who need it, for as long as they need it. In the early years of deinstitutionalization many believed that if we could only eliminate the countertherapeutic practices that had been exposed in some of our psychiatric hospitals, we would simultaneously eliminate the need for hospitals altogether. Unfortunately, much of our early community service planning proceeded on the assumption that we would never again require extensive resources for inpatient care. However, experience has shown that just as is the case for people who suffer from somatic illnesses, some mentally ill persons sometimes require hospitalization (63). Precisely how many must be hospitalized and under what circumstances depend largely on what alternative services are available in any given community, because trade-offs are possible. Obviously, fewer people will require hospital care in places that offer a complete array of excellent and integrated community-based services.

In any case, we know today that the community is not necessarily the most benign treatment site for all mentally ill people at all times and that access to hospital care for those who need it, for as long as they need it, is absolutely essential to the success of deinstitutionalization.

Cultural relevance of services

We have often seen that mental health programs that meet with success in one time and place will encounter problems in another place or time unless specific efforts have been made to adapt the program to local cultural realities (64). Thus services must be culturally relevant. For example, it makes good sense to plan services somewhat differently in urban and rural communities. Not only may there be major variations among these places in the array and quality of facilities, but also there are often differences in the effectiveness of social support networks. Often there are marked discrepancies in attitude toward the use of mental health facilities as well (65).

However, cultural concerns are not defined exclusively by urban or rural residence or ethnicity; additional social factors must be considered in service planning. For example, people who have spent long periods in psychiatric hospitals may have learned to relate to caregivers in stereotypical ways—for example, passivity, as we have discussed—that will affect the manner in which they approach and use the mental health system in the community (66). This possibility also holds for individuals who have spent extended periods living in homeless shelters or on the streets (34).

This lesson thus underscores the fact that one-size-fits-all approaches are not appropriate for people who need mental health care, not only because each mentally ill person is different from every other as an individual, but also because each person must be considered within a specific cultural context.

Involving severely mentally ill persons in service planning

Severely mentally ill persons must be involved in service planning to the fullest extent possible. The experiences, values, and personal goals of individual patients must be acknowledged in the planning process (62,67). And this in turn requires that the person be informed about the nature of his or her illness and about its symptoms, course, and possible consequences. Even when a person is severely mentally ill, there is always an intact portion of the ego that the clinician should engage in order for care to be effective (68); this intact portion must be tapped and rewarded in treatment planning. "Ask the patient" is not an unreasonable guideline for service planning.

An extension of this lesson involves consulting with families of mentally ill persons as well, whenever that is feasible. Relatives often have expert knowledge that is otherwise unavailable to service providers. Before deinstitutionalization the concept that mentally ill persons or their relatives could—or should—participate in service planning was not widely held. Deinstitutionalization has given us an opportunity to explore the benefits of such involvement, and there is now widespread acknowledgment of its efficacy (69).

Flexibility of service systems

Service systems must be flexible, open to change, and not restricted by preconceived ideology. This requirement is exemplified in the matter of planning housing for mentally ill persons. Ideally all mentally ill persons should be able to live independently, but in reality no single type of housing equally suits all of these individuals. Some need highly structured residential settings, whereas others can live quite successfully in independent residences; most fall somewhere along a continuum between these two extremes. Service systems must respond to clinical needs rather than allow preconceived ideology to determine the kinds of services they provide. To do otherwise results in many mentally ill persons' not having their essential needs met and jeopardizes their ability to adjust to life in the community.

Continuity of care in the community

We must achieve continuity of care in the community. The importance of continuity of care tended to be overlooked in the early years of deinstitutionalization, when many proponents believed that in the absence of the negative effects of institutional residence, chronicity would disappear (70,71). Thus program planning today frequently focuses on patients' immediate requirements and ignores the future, even though patients' service needs tend to endure. It is crucial that persons who have severe and long-term mental illness be able to receive services over a long period, perhaps indefinitely, and preferably from the same agencies and clinicians (70).

Unfortunately, too little knowledge about the complex and continuing needs of severely mentally ill persons has found its way into practice (72). When applied, however, such knowledge has led to a much richer life experience and a higher quality of life for mentally ill individuals (73).

Conclusions

We have observed that community mental health care is potentially more humane and more therapeutic than hospital care, but that this potential is realized only when certain preconditions have been met. The lessons of deinstitutionalization discussed here reflect those preconditions. It is worth noting once again that although these lessons are now widely—if not universally—accepted, they were virtually unknown in the days before deinstitutionalization. In this regard, deinstitutionalization may indeed be viewed as fostering progress in the care of mentally ill persons.

At the same time, however, it is clear that there have been serious disjunctions in the pursuit of the three component processes of deinstitutionalization—hospital depopulation, admission diversion, and development of comprehensive community-based services. We have taken away from mentally ill persons the asylum from the pressures of the world and the care and treatment, however imperfect, that they received in state hospitals. The central problem that now needs to be addressed is society's obligation to provide adequate care and treatment—and, when necessary, asylum—to these individuals in the community. With the advent of the modern antipsychotic medications and psychosocial treatments, the great majority are able to live in a range of open settings in the community—with family, in their own apartments, in board-and-care homes, and in halfway houses.

Nevertheless, there remains a minority of persons who have chronic and severe mental illness who need highly structured 24-hour care, often in locked facilities, and these individuals must not be overlooked. The fact that a significant proportion of this minority are not receiving sufficient care but are instead living in jails, on the streets, or in other unacceptable situations (74) is evidence that adequate community care has not been provided for some of the most severely ill persons.

The lives of most chronically and severely mentally ill persons have now changed permanently from institutionalized living to community living. With adequate treatment and support, this change greatly improves their lot and leads to a much richer life experience. We have learned what must be done to bring about this change. What is needed now is the will and the funding to realize the potential of deinstitutionalization to improve the lives of all severely mentally ill persons, whether they reside in the community or in hospitals. ♦

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