



THE 1978 APA CONFERENCE ON THE CHRONIC MENTAL PATIENT: A DEFINING MOMENT

H. Richard Lamb, M.D.

Editor's Note: In the following commentary, H. Richard Lamb, M.D., discusses the work of the 1978 APA Conference on the Chronic Mental Patient, described in the conference report on page 869. The conference not only identified the problems and needs of persons with chronic mental illness but also made specific recommendations about the elements required to create an ideal community system of care. Dr. Lamb concludes that although some progress has been made in improving community care for persons with long-term and severe mental illness, much of the work lies ahead. (*Psychiatric Services* 51:874–878, 2000)

By the mid-1970s, there was already a considerable literature on the problems with community care of persons with long-term and severe mental illness (1–5). We knew that persons discharged from state hospitals were not necessarily “in the community,” but were often living in various kinds of mini-institutions where their lives were little different than they had been in the state hospitals (5–8). Many other persons with severe mental illness lived by themselves in deplorable circumstances. At the same time, there was a growing body of knowledge about what constituted good community treatment and rehabilitation. The principles of case management (5,10–12) and assertive community treatment (13,14) had been articulated. Both the essential concepts and the practical aspects of providing social and vocational rehabilitation as

well as an array of therapeutic housing alternatives had been set forth in the literature and put into practice in some jurisdictions (8,15).

There had also been two significant developments at the federal level in 1963. First, Aid to the Disabled (now called Supplemental Security Income) became available to persons with mental illness; for the first time, they were eligible for federal financial support in the community. Second, the community mental health centers legislation was passed.

Despite all this progress, the plight of most persons with long-term and severe mental illness had not appreciably improved. What was needed was leadership. Thus the stage was set for the APA Conference on the Chronic Mental Patient in 1978. John A. Talbott, M.D., and others who planned and participated in the conference stressed throughout that their aim was action and not merely to be “a study group to produce a document that might be put on a shelf and ignored.” In fact, Dr. Talbott lobbied vigorously and tirelessly after the conference to all who would listen. He spoke with persons at all levels of the American Psychiatric Association, including the assembly, the board of trustees, and the membership, by means of presentations at the annual meeting, the conference report published in *Hospital and Community Psychiatry* (16), and the widely distributed book, *The Chronic Mental Patient: Problems, Solutions, and Recommendations for a Public Policy* (17).

Dr. Talbott spoke to the President's Commission on Mental Health, and a copy of the recommendations of the conference was presented to that body. He testified before Congress and was active with the media. In my opinion, the conference, including the advocacy efforts that followed, was a defining moment in the initiation of effective action on behalf of persons with long-term and severe mental illness.

The third decade of deinstitutionalization

At the time of the conference, deinstitutionalization, which had begun in the mid-1950s, was a little over two decades old. The first generation of persons with long-term and severe mental illness to experience the new policies of fewer hospital beds and emphasis on living in the community was just coming of age.

Dr. Lamb is professor of psychiatry and director of the division of psychiatry, law, and public policy at the University of Southern California (USC) School of Medicine. Send correspondence to him at the USC Department of Psychiatry, 1937 Hospital Place, Los Angeles, California 90033 (e-mail, hlamb@hsc.usc.edu).

With the advantage of hindsight, we can see that the era of deinstitutionalization was ushered in with much naïveté and many simplistic notions about what would become of persons with long-term and severe mental illness in the community (18). The importance of antipsychotic medication and a stable source of financial support had been perceived, but, despite the considerable body of knowledge in the literature, the importance of developing such fundamental resources as supportive living arrangements was often not clearly seen—or at least policies to develop such resources were not implemented. “Community treatment” was much discussed, but there was no widely held philosophy as to what it should consist of, and the resistance of community mental health centers to providing services to persons with long-term and severe mental illness was not anticipated (19). It was not understood that some of this population would continue to need full-time sanctuary from the pressures of the world with which, in varying degrees, many were unable to cope (20,21). Nor had it been foreseen how reluctant many states would be to allocate funds for community-based services.

Other phenomena that had not been predicted were the advent of widespread homelessness among persons with severe mental illness and the large numbers of this population who would enter the criminal justice system. The problems of homelessness and criminalization were beginning to be observed in the 1970s (22,23) and were increasingly reported in the 1980s and 1990s (18,24–26).

The 1978 APA conference did much to dispel the early naïveté about deinstitutionalization by promoting a realistic assessment of the problems, drawing on the considerable body of knowledge already available and making a series of recommendations for a comprehensive and integrated system of care.

Community mental health in the late 1970s

Those working in community mental health today, especially those who have entered the field in the past 15 years or so, may find it difficult to imagine how persons with long-term and severe mental illness were regarded in the late 1970s. There was some recognition that persons coming out of state hospitals needed treatment, but such treatment was not high on the list of priorities of most community mental health centers. Professionals in these centers had been attracted to community mental health by what was then regarded as the glamorous activities of doing psychotherapy with less sick persons—the healthy but unhappy—as well as providing indirect services, mental health education, and consultation to non-mental-health agencies, such as teachers, welfare workers, and the police (19).

In the 1960s and early 1970s, it was often implied, and sometimes promised, by many in community mental health that techniques of primary prevention, such as consultation and mental health education, would result in a significant reduction of mental illness and eventually would drastically reduce the numbers of patients requiring conventional treatment (27,28). Although some of these techniques proved useful, there was no evidence that the

incidence of major mental illness had decreased. This did not stop some administrators from placing major emphasis on this approach. For instance, the mental health director of one of our major cities put most of his resources into mental health consultation. He was so convinced that he would thereby virtually eradicate mental illness that he funded very few direct treatment services. Of course mental illness did not disappear, nor was there any evidence that it even diminished, but it took that city many years to recover from these policies and develop adequate treatment services.

Attitudes toward families in the 1970s

Today the problems experienced by families of persons with severe mental illness are a cause for much concern in the field (29). Moreover, the important role that families generally and the National Alliance for the Mentally Ill (NAMI) in particular play in public mental health is taken for granted. This was not at all the case in the 1970s. Let me cite an example.

In 1975 I was running the psychiatric rehabilitation services of the San Mateo County, California, mental health services, and my budget was at the top of the list of items to be cut. At a meeting of the mental health advisory board, some people in the audience rose and very eloquently presented the case for not cutting the budget for services for persons with long-term and severe mental illness. They were listened to politely, but essentially ignored. The mental health advisory board included no known relatives of mentally ill persons.

After the meeting, I approached those who had spoken up and asked who they were. They turned out to be Anthony and Frances Hoffman and Eve Oliphant, parents of persons with schizophrenia, who had recently formed an organization called Parents of Adult Schizophrenics. Clearly this was a new and very important phenomenon. We arranged a meeting, and they were delighted to be taken seriously, at last, by a mental health professional.

We had a series of meetings, out of which came articles in *Psychiatric Annals* in 1976 (30) and *Hospital and Community Psychiatry* in 1978 (31), and presentations at the annual meeting of the American Psychiatric Association and the World Psychiatric Association. During this period we worked together on advocacy for services to persons with long-term and severe mental illness in San Mateo County. The local newspaper picked up the story of this new organization, which I believe was very helpful.

Being associated with an organization like Parents of Adult Schizophrenics in those days was very different from being associated with NAMI today. People who had been my friends in the San Mateo County administration became hostile. With sarcasm and even anger, they referred when talking with me to “your people.” Sometimes I was pressured and sometimes ignored. Clearly I had become very unpopular with the county mental health administration.

However, services for persons with chronic and severe mental illness were not cut as originally planned—and in fact they were increased.

The response to our 1978 report in *Hospital and Community Psychiatry* was heartening. The article brought an outpouring of letters and telephone calls from around the nation, which contributed to the founding of similar organizations elsewhere. NAMI itself was founded in 1979 and has since gone on to become a potent force in advocating for a heightened priority and increased services for persons with severe mental illness.

Unintended consequences of deinstitutionalization

A primary problem

At the time of the conference, we were just beginning to confront the effects of deinstitutionalization on persons with long-term and severe mental illness who had reached young adulthood in this new era when most persons with severe mental illness no longer lived out their lives in state hospitals. The effects of deinstitutionalization were not yet clearly understood and would be conceptualized and written about only in the two decades to follow.

Much of the concern about deinstitutionalization had focused on the fate of patients who were discharged into the community after many years of hospitalization. However, the problem that was to prove most vexing had been almost totally unforeseen by advocates of deinstitutionalization, namely, the treatment of the new generation that had grown up since deinstitutionalization (32–35). For instance, homeless persons with serious mental illness—schizophrenia, schizoaffective disorder, bipolar illness, and major depression with psychotic features—have tended to be largely from this new generation. How did this come to be?

Before deinstitutionalization, these “new long-term patients” would have been institutionalized for many years, often starting from the time of their first break in adolescence or early adulthood. Sometimes they reconstituted in the hospital and were discharged, but at the point of their next decompensation were rehospitalized, often never to return to the community. Thus after their initial failures in trying to cope with the vicissitudes of life and in living in the community, these persons were no longer exposed to the stresses of community living; they were given a permanent asylum from the demands of the world. Unfortunately, the ways in which state hospitals achieved this structure and asylum led to everyday abuses that left scars on the mental health professions as well as on the patients. Today, however, hospital stays tend to be brief.

Viewed in this context, the majority of the “new” generation of persons with long-term and severe mental illness are the product of deinstitutionalization. Arriving at such a view is not to suggest that we should turn the clock back and return to a system of total institutionalization for all persons with long-term and severe mental illness. In the community most of these patients can have something very precious—their liberty, to the extent that they can handle it. Further, if we provide the resources, they can realize their potential to successfully pass a number of life’s milestones. Nevertheless, it is the plight of this new generation of long-term, severely mentally ill persons that has been responsible for much of the concerns about deinstitutionalization. We have not pro-

vided adequate treatment and rehabilitation resources for them. Further, they have posed the most difficult clinical problems in treatment and have swollen the ranks of persons with mental illness who are homeless or in jail, creating serious social problems for the community.

Problems in treatment of the “new” long-term patients

Before deinstitutionalization, those who had been hospitalized for long periods had been institutionalized to passivity. For the most part, they had come to do what they were told. When, in the course of deinstitutionalization, those for whom discharge from the hospital was feasible and appropriate were placed in a community living situation with sufficient support and structure, most, though by no means all, tended to stay where they were placed and to accept treatment, including antipsychotic medications.

This sequence has not been the case for the new generation of persons with severe mental illness. They have not been institutionalized to passivity. Not only have they not spent years in hospitals, but also they have probably had difficulty just getting admitted to an acute care hospital (whether they wanted to be or not) and even greater difficulty staying there for more than a short period on any one admission.

Moreover, less than a half century ago there were no antipsychotic medications to bring these persons out of their world of autistic fantasy and help them return to the community. Even today many patients fail to take psychotropic medications because of disturbing side effects, fear of tardive dyskinesia, or denial of illness.

Many of “the new chronic patients” tend to deny a need for mental health treatment and to eschew the identity of chronic mental patient. Admitting mental illness seems to them to be admitting failure. To many of these persons, becoming part of the mental health system seems like joining an army of misfits. Many also have primary substance abuse disorders or medicate themselves with street drugs. Another factor contributing to their refusing treatment is the natural rebelliousness of youth.

In the late 1970s these problems were just beginning to manifest themselves and were not seen as clearly as we see them today. The 1978 APA conference recognized that there were serious problems with the very large numbers of persons with long-term and severe mental illness who had been discharged into the community, made these problems known to the field, and proposed solutions.

Out of the conference emerged a conceptualization of the elements of an ideal community system of care. It was perhaps the first clear exposition of the necessary components of such a system and is still valid more than two decades later. The following description of the system that emanated from the conference is based on the recommendations presented in the 1984 APA task force report, *The Homeless Mentally Ill* (36).

Conference recommendations

Clearly, a comprehensive and integrated system of care for persons with long-term and severe mental illness, with designated responsibility, accountability, and adequate fiscal

resources, must be established. The following are the components of such a system.

♦ Adequate, comprehensive, and accessible psychiatric and rehabilitative services should be available and, when necessary, be provided assertively through outreach services. First, there should be an adequate number of direct psychiatric services that provide outreach to severely mentally ill persons in the community; psychiatric assessment and evaluation; crisis intervention, including hospitalization; individualized treatment plans; psychotropic medication and other somatic therapies; and psychosocial treatment. Second, there needs to be an adequate number of rehabilitative services that provide socialization experiences, training in the skills of everyday living, and social and vocational rehabilitation. Third, an adequate number of professionals and paraprofessionals should be trained for community care of persons with long-term and severe mental illness. Fourth, the difficulty of working with some of these patients must not be underestimated.

♦ General medical assessment and care should be readily available, since we know that the long-term and severely mentally ill have a much higher morbidity and mortality than the general population.

♦ An adequate number and ample range of graded, stepwise, supervised community housing settings need to be established. Some persons with long-term and severe mental illness can graduate to independent living. However, housing settings that require people to manage entirely by themselves are beyond the capabilities of many in this population. Thus these settings should offer different levels of supervision, both more and less intensive, including quarterway and halfway houses, board-and-care homes, satellite housing, foster or family care, and crisis or temporary hostels.

♦ Clearly, the shift of psychiatric care from institutional to community settings does not in any way eliminate the need to continue to provide comprehensive services to mentally ill persons. Therefore, a system of responsibility for persons with long-term and severe mental illness who are living in the community needs to be established, with the goal of ensuring that each patient ultimately has one mental health professional or paraprofessional (that is, a case manager) who is responsible for his or her care. In such a case management system, each patient's case manager would ensure that the appropriate psychiatric and medical assessments are carried out; formulate, together with the patient, an individualized treatment and rehabilitation plan, including the proper pharmacotherapy; monitor the patient; and assist the patient in receiving services.

♦ For the more than 50 percent of persons with long-term and severe mental illness who are living at home and for those with positive ongoing relationships with their families, programs and respite care need to be provided to enhance the family's ability to provide support. The entire burden of deinstitutionalization must not be allowed to fall on families.

♦ Basic changes need to be made in legal and administrative procedures to ensure continuing community care for persons with long-term and severe mental illness. In the 1960s and 1970s, more stringent commitment laws and pa-

tients' rights advocacy remedied some very serious abuses in public hospital care. At the same time, however, these changes neglected patients' rights to high-quality, comprehensive community care as well as the rights of their families and society. New laws and procedures should be developed to ensure provision of psychiatric care in the community—that is, to guarantee a right to treatment in the community.

♦ For outpatients who are so gravely disabled or who have such impaired judgment that they cannot care for themselves in the community without legally sanctioned supervision, it needs to become easier to obtain conservatorship status as it is practiced in California. Involuntary commitment laws should be made more humane to permit prompt return to active inpatient treatment for patients when acute exacerbations of their illnesses make their lives in the community chaotic and unbearable. There also needs to be an adequate number of acute hospital beds for this purpose. Involuntary treatment laws should be revised to allow the option of outpatient civil commitment; in states that already have provisions for such treatment, that mechanism should be more widely used. Finally, advocacy efforts should be focused on making available competent care in the community, rather than simply focusing on liberty for mentally ill persons at any cost.

♦ A system of coordination among funding sources and implementation agencies needs to be established. Because the problems of long-term and severely mentally ill persons must be addressed by multiple public and private authorities, coordination, which was so lacking in the deinstitutionalization process, needs to become a primary goal. Territorial and turf issues have often been at the root of this problem, and different agencies serving the same mentally ill persons have often worked at cross-purposes. The ultimate objective must be a true system of care rather than a loose network of services, and an ease of communication among different types of agencies (for example, psychiatric, social, vocational, and housing).

♦ Ongoing structured 24-hour care should be available for that small proportion of persons with long-term and severe mental illness who do not respond to current methods of treatment and rehabilitation. Some persons, even with high-quality treatment and rehabilitation efforts, remain dangerous or gravely disabled. For these persons, there is a pressing need for ongoing structured 24-hour care in long-term settings, whether in hospitals, including state mental hospitals, or in high-quality intermediate care facilities.

♦ Research into the causes and treatment of chronic mental illness needs to be expanded, and more accurate epidemiological data need to be gathered and analyzed. Finally, additional monies must be expended to finance the system of care envisioned here.

The legacy of the 1978 conference

The recommendations that emerged from the conference could, with only minimal changes, be the recommendations we would make today for the community treatment of persons with long-term and severe mental illness. The idea of a policy in which public mental health would give high-

est priority to this population is no longer controversial. In 1978, on the other hand, such a proposal came as a shock to the majority of community mental health professionals, and it took about a decade for the idea to gain general acceptance. During this time, more and more people in the field recognized that it is our obligation to provide services to persons to whom we had formerly provided total care in state hospitals. Moreover, it became clear that if we did not provide this care to them, no one else would.

Unfortunately, the recommendations that came out of the conference have been only partially implemented. Only some jurisdictions have a comprehensive and integrated system of care for persons with long-term, severe mental illness. There is an appalling shortage of quality community treatment and rehabilitation services. There is insufficient support for the family members of these persons, many of whom have been called upon to take care of their mentally ill relatives. Although only a small proportion of persons with long-term and severe mental illness need highly structured, 24-hour care or involuntary treatment, strong forces, both within and outside the mental health professions, have opposed this; for many ideology has determined clinical practice rather than clinical experience determining ideology.

There is reason for optimism, however. The plight of many persons with long-term and severe mental illness has been dramatized by homelessness among mentally ill persons and by the large numbers of persons with severe mental illness in our jails and prisons (26). Thus awareness of the problems pointed out in the 1978 conference has grown since that time, which has led to a number of important developments. For instance, in some states funding for public mental health care has been significantly increased, and mental health professionals, family members, and legislators are taking a closer look at mental health laws. Those involved in the 1978 APA conference can take pride in a process that is at last beginning to bear fruit. ♦

References

1. Bachrach LL: A conceptual approach to deinstitutionalization. *Hospital and Community Psychiatry* 29:573-578, 1978
2. Granet RB, Talbott JA: The continuity agent: creating a new role to bridge the gaps in the mental health system. *Hospital and Community Psychiatry* 29:132-133, 1978
3. Lamb HR: *Community Survival for Long-Term Patients*. San Francisco, Jossey-Bass, 1976
4. Mesnikoff AM: Barriers to the delivery of mental health services: the New York City experience. *Hospital and Community Psychiatry* 29:373-378, 1978
5. Talbott JA: Deinstitutionalization: avoiding the disasters of the past. *Hospital and Community Psychiatry* 30:621-624, 1979
6. Lamb HR, Goertzel V: Discharged mental patients: are they really in the community? *Archives of General Psychiatry* 24:29-34, 1971
7. Weinberg J: The chronic patient: the stranger in our midst. *Hospital and Community Psychiatry* 29:25-28, 1978
8. Bachrach LL: Planning mental health services for chronic patients. *Hospital and Community Psychiatry* 30:387-393, 1979
9. Dancy RR: The broker: a new specialist for the community mental health center. *Hospital and Community Psychiatry* 23:221-223, 1972
10. Lamb HR: Therapist-case managers: more than brokers of services.

Hospital and Community Psychiatry 31:762-764, 1980

11. Schwartz SR, Goldman HH, Churgin S: Case management for the chronic mentally ill: models and dimensions. *Hospital and Community Psychiatry* 33:1006-1009, 1982
12. Kanter J: Clinical case management: definition, principles, components. *Hospital and Community Psychiatry* 40:361-368, 1989
13. A community treatment program: Mendota Mental Health Institute, Madison, Wisconsin. *Hospital and Community Psychiatry* 25:669-672, 1974
14. Test MA, Stein LI: Training in community living: a follow-up look at a Gold-Award program. *Hospital and Community Psychiatry* 27:193-194, 1976
15. Lamb HR (ed): *Rehabilitation in Community Mental Health*. San Francisco, Jossey-Bass, 1971
16. Conference report: the APA Conference on the Chronic Mental Patient. *Hospital and Community Psychiatry* 29:257-260, 1978
17. Talbott JA (ed): *The Chronic Mental Patient: Problems, Solutions, and Recommendations for a Public Policy*. Washington, DC, American Psychiatric Association, 1978
18. Lamb HR: Deinstitutionalization and the homeless mentally ill. *Hospital and Community Psychiatry* 35:899-907, 1984
19. Stern R, Minkoff K: Paradoxes in programming for chronic patients in a community clinic. *Hospital and Community Psychiatry* 30:613-617, 1979
20. Bachrach LL: Is the least restrictive environment always the best? Sociological and semantic implications. *Hospital and Community Psychiatry* 31:97-103, 1980
21. Zaleski J, Gale MS, Winget C: Extended hospital care as treatment of choice. *Hospital and Community Psychiatry* 30:399-401, 1979
22. Abramson MF: The criminalization of mentally disordered behavior: possible side effect of a new mental health law. *Hospital and Community Psychiatry* 23:101-105, 1972
23. Stelovich S: From the hospital to the prison: a step forward in deinstitutionalization? *Hospital and Community Psychiatry* 30:618-620, 1979
24. Baxter E, Hopper K: The new mendicancy: homeless in New York City. *American Journal of Orthopsychiatry* 52:393-408, 1982
25. Jemelka RP, Trupin EW, Chiles JA: The mentally ill in prisons: a review. *Hospital and Community Psychiatry* 40:481-491, 1989
26. Lamb HR, Weinberger LE: Persons with severe mental illness in jails and prisons: a review. *Psychiatric Services* 49:483-492, 1998
27. Becker A, Wylan L, McCourt W: Primary prevention: whose responsibility? *American Journal of Psychiatry* 128:412-417, 1971
28. Caplan G: *Principles of Preventive Psychiatry*. New York, Basic Books, 1964
29. Doll W: Family coping with the mentally ill: an unanticipated problem of deinstitutionalization. *Hospital and Community Psychiatry* 27:183-185, 1976
30. Lamb HR, Hoffman F, Hoffman A, et al: No place for schizophrenics: the unwelcome consumer speaks out. *Psychiatric Annals* 6:39-47, 1976
31. Lamb HR, Oliphant E: Schizophrenia through the eyes of families. *Hospital and Community Psychiatry* 29:803-806, 1978
32. Pepper B, Kirshner MC, Ryglewicz H: The young adult chronic patient: overview of a population. *Hospital and Community Psychiatry* 32:463-469, 1981
33. Schwartz SR, Goldfinger SM: The new chronic patient: clinical characteristics of an emerging subgroup. *Hospital and Community Psychiatry* 32:470-474, 1981
34. Sheets JL, Prevost JA, Reihman J: Young adult chronic patients: three hypothesized subgroups. *Hospital and Community Psychiatry* 33:197-203, 1982
35. Lamb HR: Lessons learned from deinstitutionalization in the US. *British Journal of Psychiatry* 162:587-592, 1993
36. Talbott JA, Lamb HR: Summary and recommendations, in *The Homeless Mentally Ill: A Task Force Report of the American Psychiatric Association*. Edited by Lamb HR. Washington, DC, American Psychiatric Association, 1984