



## CONFERENCE REPORT: THE APA CONFERENCE ON THE CHRONIC MENTAL PATIENT

**Editor's Note:** The report of the American Psychiatric Association's Conference on the Chronic Mental Patient reprinted below was first published in the April 1978 issue of *Hospital and Community Psychiatry*. Former APA president John P. Spiegel, M.D., who became increasingly concerned about the plight of deinstitutionalized patients, used the money in his president's fund to sponsor the conference and persuaded John A. Talbott, M.D. (now the editor of *Psychiatric Services*) to chair it. The report, written by *H&CP* senior assistant editor Karen Huey, outlines the recommendations developed by the conferees, which were later submitted to the President's Commission on Mental Health. H. Richard Lamb, M.D., describes the impact of the conference in a commentary beginning on page 874. (*Psychiatric Services* 51:869-873, 2000)

It is estimated that more than one million Americans suffer from severe, persistent, or recurrent mental illnesses. They are labeled chronic mental patients, and as a result of the deinstitutionalization programs of the last ten years and the continuing rapid increase in the size of the high-risk population, the problems associated with their care constitute a national crisis. In order to offer some concrete recommendations for dealing with that crisis, the American Psychiatric Association, in collaboration with the President's Commission on Mental Health, sponsored a conference on the chronic mental patient. It was held January 11-14 in Washington, D.C.

The chairman of the conference, John Talbott, M.D., chief of comprehensive clin-

ical services at the Payne Whitney Psychiatric Clinic in New York City, charged the 80 participants with formulating a statement of national public policy that addressed the needs of the chronic mental patient. In addition, he asked them to compile a list of specific recommendations for dealing with that population to submit to the President's Commission on Mental Health for its consideration when writing the final report to President Carter, which is due April 1.

The seed for the conference was planted in 1973-74 while John P. Spiegel, M.D., professor of social psychiatry at the Florence Heller Graduate School for Advanced Studies in Social Welfare at Brandeis University in Waltham, Massachusetts, was president of the American Psychiatric Association. In his talks to APA district branches during his year in the presidency, Dr. Spiegel became increasingly aware that while deinstitutionalization and long-term care were significant problems, there was very little research in those areas, and he could say little beyond the fact that they were problems. Thus he made two decisions: to use the money in his presidential fund to initiate a conference on those topics, and to ask Dr. Talbott, whom he described as "a wizard at pulling off miracles," to run the conference.

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local program director; two psychiatrists; a chairman; and a recorder. There were also ten consultants who were available to the groups during their discussions. The consultants were experts in such fields as deinstitutionalization, state legislation, medical sociology, psychopharmacology, epidemiology, employee unions, research, medical economics, and funding.

There were seven questions for discussion, and for each question a background paper written by an expert in the area had been circulated to all conferees before the conference began. The seven questions were:

- Who are the chronic mental patients, where are they, and what are their needs?
- What programs work and what programs do not work to meet the needs of chronic mental patients?
- What are the obstacles to implementing effective programs, and what are some ways to surmount those obstacles?

discussants, including a planner or legislative aide involved with mental health; an expert in a particular mental health area; a patient, parent, or patient advocate; a nonpsychiatrist clinician; a federal, state, or local program director; two psychiatrists; a chairman; and a recorder. There were also ten consultants who were available to the groups during their discussions. The consultants were experts in such fields as deinstitutionalization, state legislation, medical sociology, psychopharmacology, epidemiology, employee unions, research, medical economics, and funding.

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- ♦ Who are the chronic mental patients, where are they, and what are their needs?
- ♦ What programs work and what programs do not work to meet the needs of chronic mental patients?
- ♦ What are the obstacles to implementing effective programs, and what are some ways to surmount those obstacles?
- ♦ What are the economic issues involved in providing effective care for the chronic mental patient?
- ♦ What are the pros and cons of case-client-patient assessment and management?
- ♦ Who has and who should have responsibility for coordinating, implementing, and monitoring services for chronic mental patients?
- ♦ How does the right to privacy clash with the need for information exchange, teaching, and determination of what programs have not worked for specific patients?

Each task group discussed three questions. The result of the group's discussion on each question was a brief document, prepared by the recorder, specifying policy points and recommendations. The document each group prepared on a question was used by subsequent groups discussing the same question. After two days of discussion, the conferees convened in one group and hammered out a policy statement and a list of recommendations for submission to the President's Commission.

The conferees agreed that a national public policy addressing the needs of the chronic mental patient must include several elements.

*Public sensitivity and financial commitment to a system of opportunities and services.* A systematic approach to caring for the chronic mental patient must include, at a minimum, active outreach, medical and mental health care, functional evaluation, subsistence, an array of special living arrangements, crisis stabilization, assistance to families, socialization, meaningful and feasible work opportunities, training in skills of daily living, monitoring, and case management. There should be allowances in the system for patients who, while chronically disabled, are only partially disabled and can function in supportive situations. The system should be designed to promote maximum growth and sustain the functioning of each individual in the least restrictive and most appropriate setting.

*Designation of clear responsibility for providing services at appropriate levels of government.* Because the assurance of care, treatment, and rehabilitation of the chronically mentally ill is a national public health responsibility, every level of government has some responsibility for ensuring that adequate services are available to that population.

The federal government should define eligibility; identify and ensure levels of benefits; provide funds under national health insurance or categorical programs; establish regulations ensuring access, quality, and cost-effectiveness; and monitor program implementation.

The state governments should assume responsibility for statewide planning, approval of local plans consistent with the statewide plan, supplementary levels of benefits and funds, and program monitoring within the state.

At the local level, appropriate organizations should be responsible for planning and integrating services, administering or managing those services either directly or by contract, and evaluating programs.

*Civil rights.* There should be no discrimination against the mentally ill. They should have full access to housing and to medical, legal, educational, vocational, and occupational services. The services should be provided in settings that allow the patient to be as independent as possible. In addition, the patients' right to adequate treatment in the community and to confidentiality must be guaranteed.

*Reform of funding mechanisms.* Funding mechanisms should be designed to remove incentives toward more restrictive forms of care; to prevent discrimination against the chronically mentally ill; and to ensure their access to health, human-service, rehabilitation, and housing programs. There should also be sufficient funding to increase the availability of services such as active outreach, crisis stabilization in the normal environment, remediation of functional skills, and case management; and the provision of meaningful daytime activities and long-term supportive work opportunities.

*Application of the same requirements to all programs.* The same policy and implementation requirements for classes of service, levels of care, and accountability that

are required of public, private, state, and local health systems and facilities should apply to Veterans Administration and Public Health Service programs run directly by the federal government.

*Social and cultural factors.* There should be equitable allocation of resources in the community according to social class, to economic and ethnic background, and to population density. Service delivery must be in accordance with the cultural values and perceptions of various ethnic, minority, and subcultural groups.

### Recommendations to the commission

After the conferees agreed on the policy statement, they began to make their recommendations, based on their discussions and reports prepared during the conference, to submit to the President's Commission. The recommendations fell into several categories, including those dealing with financial issues, administrative issues, continuity and provision of services, community education, training, research, civil rights, and psychiatry's role in the care of the chronic mental patient.

The conferees had several recommendations concerning financial issues. The first was that funds for programs should flow from the federal level—including monies currently administered under the Department of Health, Education, and Welfare, the Department of Housing and Urban Development, and the Department of Labor—to the state level, and should be earmarked for the chronic mental patient where possible. The monies should be allocated to local communities or agencies only if programs are accountable in relation to the chronic mental patients' needs for service. Other recommendations regarding financial issues follow.

♦ On the federal level, structures should be created to provide oversight, both by the Congress and by the executive branch, of legislation and regulations that have an impact on the needs of chronic mental patients. On the state and local levels, a comparable structure should be established.

♦ The Department of Health, Education, and Welfare should survey Medicare and Medicaid eligibility requirements, benefit services, and reimbursement schedules. Such a survey would point out current inequities and would help establish national parity.

♦ Medicare, Medicaid, and any national health insurance program of the future should not single out the chronically mentally ill as a class and should not discriminate against them. Chronic mental patients are entitled to full participation in the health care system.

♦ Medicare, Medicaid, and future national health insurance benefits should include a full range of inpatient, day treatment, and outpatient services encompassing periodic medical and psychological evaluation and treatment, resocialization, and rehabilitation.

♦ National health insurance should include cost-effective financial incentives to encourage professionals to care for chronic mental patients.

♦ Financing of mental health and human services

should be modified so that the least restrictive form of treatment is the most advantageous financially.

♦ All federally funded comprehensive community mental health centers should be required to provide comprehensive services to the chronically ill mental patient as one of the mandated essential services.

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In a discussion of recommendation 13 in the Preliminary Report of the President's Commission on Mental Health—advocating the establishment, under Medicaid, of a class of intermediate-care facilities designed specifically to meet the conditions and needs of mental patients—the conferees agreed on several points: there is a shortage of federal and state funding for community living arrangements for the mentally disabled; there is a need for a continuum of living arrangements offering varying degrees of supervision and support; and funding policies should promote a planned, accountable system of living arrangements within each state and local planning area. They also agreed that there is a need for improved methods to link special living arrangements with nonresidential treatment, rehabilitation, and support services, and that while appropriate living arrangements are necessary in meeting the needs of the mentally disabled, they are not an end in themselves.

The conferees recommended that additional resources for community living arrangements for the mentally disabled be made available through designation of federal and state housing and social service funds.

They expressed two different points of view, however, with respect to the advisability of allocating specific federal funds for intermediate-care facilities. Some of the conferees supported the establishment of such facilities subject to two provisos. The first is that there be strong requirements preventing indiscriminate discharge of institutionalized patients into a new type of facility. The second is that a mechanism be established to ensure that intermediate-care facilities would be developed only in the context of a planned, integrated service system providing

a full spectrum of living arrangements and nonresidential services for the mentally disabled.

Some of the conferees, while supporting the intent of the proposal to establish intermediate-care facilities, cautioned against it on the grounds that specified federal funding for a particular class of facilities might result in overdevelopment of one type of residential arrangement at the expense of other types. They also felt that it might detract from the availability of adequate resources for essential nonresidential rehabilitation and support services, might interfere with developing flexible local systems based on community needs, and might be more expensive than a policy that would limit use of medical funds to more narrowly defined medical needs and would support housing arrangements from nonmedical resources.

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### **Administrative issues**

The conferees recommended that, as a long-term goal, the federal government should take responsibility for leadership and advocacy of care for the chronic mental patient, establish policy and ensure consistency in all relevant agency policies, and set basic program guidelines and regulations. State governments should carry out the leadership, patient advocacy, and planning functions on a statewide basis for distribution of federal monies; supplement federal funds with state monies; and designate local authorities to have responsibility for programs.

Local authorities should designate specific local entities to coordinate the planning and provision of services, be accountable for the services, ensure that there is no discrimination against the chronic mental patient, and have authority over support system resources, such as welfare and rehabilitation, applicable to that population.

The immediate goals recommended by the conferees include the establishment of oversight mechanisms at the federal level, such as a select committee in Congress comparable to the Select Committee on Aging, and an

equivalent in the executive branch that would oversee federal legislation and regulations that apply to chronic mental patients.

Conferees also felt that each state mental health authority should designate a single person or office to assume primary responsibility for acting on behalf of, and planning and supporting services for chronic mental patients. Additional recommendations include the following:

- ♦ State mental health plans should assign responsibility to a single agency within each local planning area. That agency will assume the role of convenor, catalyst, coordinator, community organizer, and advocate for meeting the full range of needs of chronic patients. The type of agency that can best assume that role may vary from community to community. In all cases, however, it is essential that the responsibility be clearly assigned and recognized.

- ♦ Clinical integration should be done by the local area health or mental health planning body, but independent (at both state and local levels) of any care delivery system that might represent a competitive interest.

- ♦ Accountability is a critical element for ensuring that the services promised are actually delivered. Evaluation of the services must be consistent and apply equally to all service providers. Attempts should be made to limit the costs and bureaucracy of the evaluation process—possibly by using the Health Systems Agency structure or an equivalent—and to encourage a positive attitude in enforcing accountability. In addition to identifying service deficiencies, evaluators should help recipients satisfy regulatory requirements and improve services.

- ♦ When developing facilities and staff for the care of the chronic mental patient, one should use existing resources, whenever possible, and restructure them to better meet the needs of the population rather than try to build a new network of programs and services. The development of new approaches should be encouraged at the local level, and technical assistance in carrying them out should be provided.

- ♦ The state should be discouraged from developing new state-owned and -operated facilities for chronic mental patients and should phase out present facilities over a period of time. While states must ensure that there are facilities to meet the needs of chronic mental patients, the states should not own and operate them.

### **Continuity of services**

The conferees recommended that barriers be removed so that chronic mental patients have access to a full range of health, mental health, rehabilitation, income-maintenance, social, employment, and related opportunities and services in the least restrictive setting. They also recommended that the system of care be continuous between institutions and local programs and that there be well-developed systems for interservice program referral.

In addition, they felt that it is necessary to establish

and support case management to enable the chronic patient to use and benefit from community resources and programs. Such management should be based on a comprehensive treatment and management plan that involves the patient and, if possible, the family in the planning and delineation of responsibilities.

The conferees had two recommendations in the area of community education. The first was that consumer, professional, paraprofessional, and governmental bodies should participate in a coordinated education and lobbying program, using the expertise of professionals in the area of communications, to inform the public about the needs of the chronic mental patient and ways to meet those needs. The second recommendation was that community education be oriented toward increasing the visibility and status of programs for chronic mental patients.

There were three recommendations under the training category. The first was to expand current and establish new training programs in the skills appropriate to the needs of chronic mental patients. The second was to modify and re-orient current professional training programs so that they are more interdisciplinary. The third was to provide funding to implement retraining provisions and, where necessary, provide incentives for state governments to carry out their statutory responsibility for training.

The conferees also agreed that there must be a continuing emphasis on research in the area of chronic mental illness. They felt the research should include etiological, therapeutic, outcome, and effective service delivery issues.

In the area of civil rights for chronic mental patients, the conferees recommended that there should be federal legislation or regulations to accomplish several aims:

- ♦ Prohibit discrimination against chronic mental patients in employment and housing.
- ♦ Endorse a right to adequate treatment in the community.
- ♦ Endorse a right to treatment in the least restrictive setting consistent with each patient's treatment needs.
- ♦ Protect confidentiality while allowing access to relevant information for legitimate treatment, planning, and research needs.
- ♦ Support the amendment of Title 7 of the Civil Rights Act of 1964 to prohibit discrimination in employment on the basis of handicap.
- ♦ Create tax incentives to encourage hiring of the partially disabled.
- ♦ Support the amendment of Title 8 of the Civil

Rights Act of 1968 to prohibit discrimination in housing on the basis of handicap.

♦ Encourage states and localities receiving HUD funds to allocate additional monies to develop group-care facilities and to provide rental assistance to the mentally disabled living in group homes.

♦ Develop and fund an advocacy system independent of service providers to help ensure the implementation of patients' rights. The system should either be part of the protection and advocacy system created by the Developmental Disabilities Act or be modeled on that system.

The conference ended with a statement of psychiatry's role in the care of the chronic mental patient: "Since care of the chronic mental patient is a public health responsibility, it is incumbent on psychiatrists and other physicians to take an active role in attending to the needs of this population. Even though psychosocial problems may predominate, the medical and psychiatric needs of the chronic mental patient require vigilant monitoring. In addition, psychiatrists have a responsibility in the development of comprehensive services for the chronically mentally ill, and should be involved at all levels of program planning, public education, training, and research related to preventive care and rehabilitative services."

Dr. Talbott and others who planned and participated in the conference stressed throughout the proceedings that it was aimed at action; it was not merely a study group to produce a document that might be put on a shelf and ignored. The week after the conference, Dr. Talbott presented the preliminary draft of the report to a conference in Racine, Wisconsin, attended by the chairmen of the President's Commission's task panels and special study groups related to service. He reported that the recommendations drawn up at the APA conference were well received by the group in Racine. In late January a copy of the recommendations was submitted to the President's Commission.

In addition, the proposed policy and recommendations have been presented to the APA assembly and will be presented to the board of trustees. APA will be discussing and working on implementing recommendations as policy during the course of the year. At the APA annual meeting in May in Atlanta, the recorders from the conference will make presentations at several sessions. Finally, there are plans to prepare a book containing the background papers, proceedings, summary papers, proposed policy, and specific recommendations.

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