

POSITION STATEMENT: A CALL TO ACTION FOR THE CHRONIC MENTAL PATIENT

Ad Hoc Committee on the Chronic Mental Patient
John A. Talbott, Chair

This statement was approved by the Assembly at its October 1978 meeting and by the Board of Trustees at its December 1978 meeting upon recommendation of the Ad Hoc Committee on the Chronic Mental Patient. It was prepared by the Ad Hoc Committee on the Chronic Mental Patient.

There is no more urgent concern than the needs of the chronic mentally ill who suffer from severe, persistent, or recurrent mental illnesses with residual social and vocational disabilities. As a result of the deinstitutionalization programs of the past decade and the continuing growth of high-risk populations that generate chronic illness, the problems associated with the care of these patients constitute a national crisis. The Conference on the Chronic Mental Patient, sponsored by the American Psychiatric Association in collaboration with the President's Commission on Mental Health, was held in Washington, D.C., January 11–14, 1978, and addressed the striking inadequacy of care, treatment, and rehabilitation of this group, estimated to number over one million Americans.

The chronic mentally ill are of all ages, including children, and have a variety of diagnoses. They may reside in community or institutional

settings. Such patients must be distinguished from those individuals who may be receiving various forms of psychotherapy for mental disorders without attendant long-term disabilities. The chronically ill have a host of special and unique problems including extreme dependency needs, high vulnerability to stress, and difficulty coping with the demands of everyday living, resulting in difficulty securing adequate income and housing and holding down a job.

The term “chronic mentally ill patient” stigmatizes persons so designated and obscures their diversity and potential for improvement. It is not a desirable appellation because of its implication of hopelessness and progressive deterioration but has been used in this report because of its historical and current use in the literature and by the profession and because of its descriptive clarity. While these people have a chronic illness that requires medical and psychiatric attention over a long period of time and are, therefore, appropriately called patients, it is equally important to recognize them as persons with continuing disability. This disability concept carries the positive implication that a psychosocial rehabilitation approach should complement any treatment provided.

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Successful programs for helping the chronically ill patient offer a continuum of residential and nonresidential services to ensure that care is tailored to meet individual needs and to provide easy access and reentry to services and responsiveness to crises. Such programs use the skills of persons with an interest in and knowledge about chronic mentally ill patients. They provide thorough monitoring and balance active outreach with the encouragement of self-sufficiency and independence. They also encourage interagency cooperation and referral and serve as patient advocates. They have effective vertical (e.g., up higher governmental levels) and horizontal (e.g., across to other community agencies) structures. Sensitivity to incremental degrees of progress, eco-

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Obstacles to effective delivery of services to the chronically mentally ill are monumental. They include the attitudes of patients, families, communities, community leaders, and professionals; the lack of an integrated community support system; fragmentation of federal programs; the absence of unified funding; the failure to designate responsibility for treatment, care, and rehabilitation of the chronically ill patient; widespread discrimination in employment, ambulatory care funding, zoning, etc.; and conflicting and/or limiting federal and state regulations.

POLICY STATEMENT

To address the needs of the chronic mentally ill, a national public policy must be adopted. This policy must include the following:

1. *Public sensitivity and financial commitment to a system of opportunities and services.* A systematic approach to caring for the chronic mentally ill must include at a minimum active case-finding and outreach; 24-hour emergency and crisis stabilization services; functional evaluation; medical and psychiatric care; training in skills of everyday living; socialization; an array of specialized living arrangements; subsistence, prevocational evaluation, clinical work adjustment programs, and subsidized transitional and permanent full and part-time work opportunities that are meaningful and feasible; and assistance to families—all of which are monitored and managed in accordance with individual needs. In addition, provision should be made for indirect services such as community consultation, community education, community organization, and interagency collaboration. The system should recognize that some patients, while chronically disabled, are only partially disabled and can function in supportive situations. The system should be designed to promote growth and sustain functioning to the maximum degree feasible for each individual and should be directed toward patients who voluntarily request assistance.

2. *Designation of clear responsibility for providing services at appropriate levels of government.* The assurance of care, treatment, and rehabilitation of the chronically mentally ill is a national public health responsibility. Thus, every level of government bears some responsibility to assure adequate services to this population.

The federal government should have the responsibility for defining eligibility; identifying and assuring levels of benefits; funding services under national health insurance or categorical programs; establishing regulations ensuring access to services, quality care, and cost effectiveness; and monitoring program implementation. The state government should assume responsibility for statewide planning, approval of local plans consistent with that statewide plan, supplementary funding and benefits, standards, and program monitoring within the state. At the local level; appropriate organizational entities should be responsible for local planning and integration of services for the chronic mental patient, administering and/or managing those services either directly or by contract, and evaluating programs.

3. *Full civil rights for the chronically mentally ill.* There should be no discrimination against the mentally ill. The right to adequate treatment in the community and to confidentiality must be guaranteed. Chronic mentally ill patients should have full access to medical, legal, educational, vocational, occupational, and housing services and opportunities. These services and opportunities to the mentally ill should be provided in settings that allow the maximum independence consistent with the patient's needs.

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

5. *The same policy and implementation requirements* for classes of service, levels of care, and accountability that are required of public and private, state and local health systems and facilities should be applied to programs run directly by the federal government (i.e., the Veterans Administration and Public Health Service systems).

6. *Social and cultural factors.* There should be an equitable allocation of mental health resources in the community to citizens from all social, economic, and racial (ethnic) backgrounds and population densities. All services delivered must be adapted to meet the cultural values and perceptions or needs of various ethnic, minority, and subcultural groups.

7. *Utilization of families.* Wherever possible, patients' families should be involved in their treatment and care rather than depending on more expensive and less caring substitutes. While women in the home have traditionally assumed the caretaking responsibility, changing roles suggest that their presence can no longer be taken for granted; there must be adequate financial, social, and mental health supports available when families assume such responsibility.

RECOMMENDATIONS

Psychiatry's Role in the Care of Chronic Mentally Ill Patients

Since care of the chronic mentally ill patient is a major health concern to the public, 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 mentally ill require vigilant monitoring. In addition, psychiatrists have a responsibility in the development of comprehensive services for the chronic mentally ill and should be involved at all levels of program planning, public education, training, and research related to preventive care and rehabilitative services.

The American Psychiatric Association should take the lead in undertaking programs to elevate the prestige and value of work with chronic mentally ill patients. Portions of the scientific programs of annual meetings, regional meetings, and district branch scientific meetings should be devoted to this population. Research should be sponsored and groups working with this population should be encouraged. APA should also take steps to encourage psychiatrists and others to monitor the quality of care administered to the chronic mentally ill patient population by their peers.

The prestige and status of psychiatrists who work in programs with chronic mentally ill patients will be enhanced by affiliation with medical school departments of psychiatry; teaching and/or clinical assignments at medical schools by psychiatrists who work with the chronic mentally ill; clinical and supervisory assignments by faculty of academic departments to programs for chronic mentally ill patients; continuing medical education programs held at the site of programs for chronic patients by medical schools and APA district branches; academic appointments for psychiatrists working in programs for the chronic mentally ill patient; and a referral system involving private psychiatrists, which will ensure continuity of care.

Community Education

1. All involved consumer, professional, paraprofessional, and governmental bodies should mount a coordinated education and lobbying program, using professional communication expertise (lobbying, marketing, community education) to inform the public about the chronic mentally ill and how to meet their needs.

2. Community education must be oriented toward increasing the visibility and status of programs directed to chronic mental patients.

3. A major effort should be undertaken to develop a constituency for the chronic mentally ill patient population.

4. District branches should make an effort to include the subject of care and treatment of the chronic mentally ill in both their community and scientific programs.

Research

There must be a continuing emphasis on research in the area of chronic mental illness, including epidemiology, etiology, therapy, outcome, and effective service delivery. In

addition, new efforts should be undertaken to clarify the conditions under which family care is helpful or harmful; to ascertain the rate and nature of problems faced by the (current) deinstitutionalized population as compared with the (formerly) institutionalized chronically ill population; to study the criteria for deinstitutionalization and for various types of group maintenance, including continued hospitalization; to define and refine the tasks, skills, and process of case management; and to reexamine the issues relating to confidentiality. Uniform data collection regarding the size, composition, and service needs of the chronic population at the local level is needed to help identify special problems and needs and to improve program planning and monitoring. Another fruitful area for research is the prevention of chronicity, especially in children and adolescents as well as in the aging.

Training

1. Training programs should be expanded or established for persons, including family members, in the skills appropriate to the needs of the chronic mentally ill.

2. Current professional training programs, including psychiatric residency programs, should be modified and reoriented toward an interdisciplinary focus to enhance the capacity of professionals to treat and care for the chronic mentally ill patient. Persons who have been working in chronic care settings should be retrained to be able to function within a community/rehabilitation model, nursing homes, and geriatric facilities, as well as in programs that help patients in strength assessment and the acquisition of the skills of everyday living.

3. Funding is required to implement the above retraining provisions and provide incentives for state governments to carry out this statutory responsibility where necessary. Consideration should be given to mechanisms whereby psychiatric residents could "pay back" the money spent on their training by serving in shortage areas (e.g., state hospitals).

4. Psychiatric residency training programs should be encouraged to include training for more chronic mentally ill patients than the 10 specified in the residency training guidelines, as well as to include training in administration and planning. Consideration should also be given to a new subspecialty—rehabilitation psychiatry.

5. A program for volunteer case aides should be established to promote local volunteer mobilization around the chronic mentally ill patient.

6. Training programs should be established for medical students and primary care physicians, especially those working in emergency settings, to focus on the special treatment needs of patients with chronic mental illness, since these patients have a higher incidence of medical illness and are often resistant to medical care due to their mental disability. Such programs should include experience with ambulatory chronically mentally ill patients, with particular emphasis on appropriate and inappropriate psychopharmacological medications, the concomitant social and vocational disabilities, and the full array of am-

bulatory treatment programs necessary for chronically ill patients.

7. The establishment of guidelines for training and career development of psychiatrists involved with program planning for and treatment of chronic mentally ill patients should be encouraged. A study of psychiatrists currently working in this area may offer data relevant to the development of successful educational experiences and career pathways.

Continuity and Provision of Services

1. Barriers should be removed to assure chronic mentally ill patients access to a full range of medical, psychiatric, rehabilitative, income maintenance, social, employment, and related opportunities and services appropriate to their needs in the least restrictive setting.

2. The system of care should be continuous between institutions and local programs, and there should be well developed systems for interservice program referral. It is necessary to establish and support case management to enable the chronically ill patient to use and benefit from community resources and programs. Such management should be based on a comprehensive treatment and management plan; the patient, and if possible the family, should be involved in the planning and delineation of responsibilities. Before extensive programs of case management are undertaken, however, there is a need to define the role, responsibility, and function of care, fixing of responsibility, and linking of hospitals with community services. Interagency linkage should be encouraged through inducements and sanctions written into legislation, regulations, and procedures. Adequate resources should be provided for case management functions, and funding should allow for an adequate period of time for training staff and establishing information systems, etc., to phase in such a system.

Financial Needs

The financial recommendations that follow include consideration of cost savings resulting from the shift of chronically ill patients from higher cost institutional programs to lower cost community alternatives. Attention to the ways in which financing mechanisms perpetuate higher cost care can prevent escalating and outrageous costs for programs serving chronic mentally ill patients. Some evidence exists that high quality integrated programs based on a least restrictive but full service model are no more costly than state hospital incarceration.

1. Programmatic funds should, as a long-term goal, flow from the federal to the state level and be earmarked for the chronic mentally ill patient where possible. This includes monies currently administered in the Departments of Health, Education, and Welfare, Housing and Urban Development, Labor, etc. Thus, a specified share of welfare, housing, rehabilitation, health, and mental health dollars would be directed to this population either on a capitation or index of need basis. These monies would be allocated to local communities or agencies only if programs were ac-

countable in relation to the chronic mentally ill patients' needs for service.

2. On the federal level, structures should be created to provide oversight, both by Congress and the executive branch, of legislation and regulations affecting the needs of chronic mentally ill patients. A comparable structure should be established on the state and local levels.

3. The Department of Health, Education, and Welfare should perform a national survey of Medicare and Medicaid eligibility requirements, benefit services, and reimbursement schedules. This survey would elucidate current inequities and help establish national parity.

4. Chronic mentally ill patients are entitled to full participation in the health care system. Medicare, Medicaid, and future national health insurance should not single out the chronic mentally ill as a class or discriminate against them in any way. This is especially important regarding private psychiatric care, which is often less costly than that provided by institutions.

5. 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. In all future funding, there should be differentiation between health services (e.g., evaluation, diagnosis, medical, and psychiatric treatment) and social and supportive services (e.g., escort services, housing, etc.).

6. Any future national health insurance should also include cost effective but positive financial incentives to encourage professionals to care for the chronic mentally ill patient, so that the existing disincentives to providing long-term care are reversed.

7. Financing of psychiatric and human services should be modified to remove fiscal disincentives (e.g., Medicare restrictions on ambulatory care) and unnecessarily restrictive or debilitating settings or forms of care, such as inpatient hospitals or nursing homes.

8. 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.

9. A federal technical assistance program, along the model of the agricultural extension program, should be developed to help localities develop appropriate programs for chronic mentally ill patients.

10. Funding mechanisms should encourage states and localities to move individuals out of the human services system into mainstream community life through rehabilitative programs.

11. Priority should be given to proposed systems ensuring that money follows chronic mentally ill patients, either through a voucher system that would enable patients to buy any or all necessary services or by some other mechanism.

12. There is agreement on the following points regarding recommendation 13 in the Preliminary Report of the President's Commission on Mental Health (advocating establishment of a class of intermediate care facilities for

mental patients under Medicaid): there is a current shortage of federal and state funding for community living arrangements for the mentally disabled; there is a need for a continuum of types of living arrangements, offering varying degrees of supervision and support; funding policies should promote a planned, accountable system of living arrangements within each state and local planning area; there is a critical need for improved methods to link special living arrangements with nonresidential treatment, rehabilitation, and support services; and it is vital to recognize that appropriate living arrangements are necessary but not sufficient in meeting the needs of the mentally disabled.

Based on these areas of agreement, it is recommended that additional resources for community living arrangements for the mentally disabled be made available through earmarking federal and state housing and social service funds.

With respect to the advisability of specific federal funds for intermediate care facilities for the mentally ill, while we support the intent of the proposal, we believe that no such facilities should be established, because specific federal funding for a particular class of facilities will result in overdevelopment of one type of residential arrangement at the expense of other types, it will detract from the availability of adequate resources for essential nonresidential rehabilitation and support services, it will interfere with developing flexible local systems based on community needs, and it will 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.

13. Provisions of Supplemental Security Income legislation and procedures should be modified to replace the current disincentives against patients' returning to productive employment with positive incentives; e.g., allowances should be made for patients' rehabilitation potential.

Administrative Issues

As a long-term goal, the federal government should take responsibility for leadership and advocacy of care for the chronic mentally ill patient; establish policy and ensure consistency in all relevant agency policies; set basic programmatic guidelines and regulations; establish minimal care and accountability standards; issue guidelines setting forth broad parameters for the utilization of funds; provide strong incentives and bonuses for care of the chronic mentally ill patient in the community; stimulate collaboration among agencies involved in policy planning and program implementation; develop technical assistance and disseminate information concerning the chronic mentally ill patient; develop criteria for determination of local government's ability to assume planning, management, and service operation responsibility and to establish programs for those localities without sufficient capacity to provide training, assistance, and funding to attain an acceptable level; and provide assurances that any jurisdictional level that has oversight/coordination responsibilities (and has reduced or

eliminated its service operations) maintains the necessary staff expertise to carry out its responsibilities in the areas of planning, licensure, etc.

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 programmatic responsibility. They should also establish and provide assurances that coordination mechanisms are in place and operating to ensure chronically ill patients' access to appropriate support programs, develop appropriate standards for programs on a state level, establish regulatory/guideline appeals mechanisms, provide services for specific populations when it is not feasible for any other entity to assume this function, and monitor local service operations.

Local authorities should designate specific local entities to perform program activities; coordinate the planning and provision of services; hold local entities accountable for these services; establish entitlement for chronic mentally ill patients to relevant support systems; ensure nondiscrimination; ensure maximum consumer (public and nonprofit) participation; and provide local entities with formal authority over support-system resources such as welfare, rehabilitation, etc., applicable to this population.

Local entities should be the final common pathway for program funding directed toward providing the chronic mentally ill with a holistic integrated program based on the least restrictive, rehabilitative model with appropriate medical-psychiatric input. Local entities eligible for designation as the authority responsible for chronic mentally ill patients should include both public and nonprofit facilities.

The immediate goals should include the following:

1. Oversight mechanisms should be established at the federal level; examples are a select committee in Congress comparable to the Select Committee on Aging, and an executive branch equivalent, which would oversee federal legislation and regulations applying to chronic mentally ill patients.

2. Each state mental health authority should designate a single person/office to assume primary responsibility for acting in behalf of, planning, and supporting services for chronic mentally ill patients. Such person/office should develop knowledge about all potential federal and state programs that may provide funding and/or services for chronic mentally ill patients and transmit that knowledge to appropriate mental health service providers. Further, that person/office should review legislation, appropriations, and rules and regulations and should serve as an advocate for policies that will enhance services for chronic mentally ill patients.

3. Each state should produce a plan which guarantees that the needs of the chronically ill population will be provided for. Such plans should fix responsibility within each local planning area with a single community agency that assumes the role of convener, catalyst, coordinator, community organizer, and advocate for meeting the full range of needs of chronic mentally ill patients. The type of agency

that can best assume this role may vary from community to community, depending on what is available. In all cases, it is essential that such responsibility be clearly assigned and recognized.

4. Clinical integration should be done by the local area health or mental health planning body independent of any care delivery system of its own that might represent a competitive interest. This also applies on the state level.

5. Accountability is a critical element to assure that the services promised are actually delivered. Evaluation of these services must be consistent and equally applicable to all service providers. Efforts should be made to limit the costs and bureaucracy of the evaluation process—possibly by utilizing the Health Systems Agency structure or an equivalent—and to encourage a positive attitude in enforcing accountability; i.e., evaluators should be oriented toward helping recipients satisfy not only regulatory requirements but also toward improving services, in addition to identifying service deficiencies and threatening penalties. Affirmative approaches to quality of life and social and vocational disabilities should be a primary objective.

6. Rather than building a whole new network of programs and services, the emphasis should be on the development of staff and facilities for the chronic mentally ill patient, making use of existing functions and resources, including the family whenever possible, and restructuring and reordering such programs in ways that better meet the needs of the chronic mentally ill patient. The development of new approaches and capacity should be encouraged at the local level, and technical assistance should be provided to enable this.

7. States should be discouraged from developing new state-operated facilities for chronic mentally ill patients and should phase down present facilities over time. While states must assure an adequate supply of facilities to meet the needs of chronic mentally ill patients, in order to encourage the local development of programs these facilities should not be state operated.

8. The federal government should eliminate any state or regional options in the utilization of essential federal funds, e.g., Section 8 of the Housing Law of 1975, and establish mechanisms whereby states and localities may appeal restrictive regulations.

Civil Rights

There should be federal legislation or regulations to accomplish the following:

1. *Prohibit discrimination against chronic mentally ill patients in vocational rehabilitation, employment, and education.* Specifically, Title VII of the Civil Rights Act of 1964 should be amended to prohibit “unjustified” discrimination in employment on the basis of handicap. In addition, there should be vigorous enforcement of Sections 503 and 504 of the Rehabilitation Act of 1973, federal legislation to encourage the hiring of the mentally handicapped

(either through bonuses or tax incentives), and assurance that the severely and chronically mentally disabled are served by vocational rehabilitation agencies. Also, the concept of equal job opportunity should be applied to women in both institutional and community rehabilitative and vocational programs.

2. *Prohibit discrimination against chronic mentally ill patients in housing.* Specifically, Title VIII, Fair Housing, of the Civil Rights Act of 1968, should be amended to prohibit discrimination in housing on the basis of handicap. The Department of Housing and Urban Development should promulgate regulations to encourage states and localities to allocate additional Section 196 funds to develop more group care facilities, and to make additional Section 8 rental assistance funds available to mentally disabled persons living in group homes.

Federal legislation should be enacted encouraging the private market to provide housing to the mentally handicapped and conditioning receipt of federal revenue sharing or other funds to states having a plan for the development of community care and community residencies for the mentally disabled.

3. *Endorse the right to adequate treatment for both voluntary and involuntary patients in the hospital and the community, in the least restrictive setting consistent with individual treatment needs.* This includes the establishment of a mechanism whereby the patient may object to any aspect of his/her treatment plan, including transfer to another facility or to the community.

4. *Protect confidentiality, while allowing access to relevant information for legitimate treatment, planning, and research needs.* Centralized records should contain the minimum amount of information needed to meet the patient's future treatment needs, with access to records limited to a “need to know” basis, and patients should have the right to consent to the release of particular items of information from their records for time-limited periods, revocable by the patient. Stringent protection should govern access to treatment records, and stringent criminal penalties should be mandated for misuse of information included in records. Insurance claims (private and governmental) should be reviewed by a claims review system in which physicians would review patients' records without their names attached.

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

6. *Prohibit zoning discrimination against the mentally ill by requiring that receipt of revenue sharing, housing, and other federal funds be predicated on the absence of exclusionary zoning laws or regulations in an area.*

7. *Enact a “Bill of Rights” for mentally disabled persons residing in the community.*