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Health Affairs 2, no.4 (1983):96-127
doi: 10.1377/hlthaff.2.4.96
To Subscribe: https://fulfillment.healthaffairs.org
THE LONG VOYAGE: POLICIES FOR PROGRESS IN MENTAL HEALTH

by Mary R. Merwin and Frank M. Ochberg

Prologue: Two decades ago, the enactment of the Mental Retardation Facilities and Community Mental Health Centers Construction Act signaled the federal entry into the deinstitutionalization movement, which started in 1955. During the years 1963 to 1980, the census of public mental hospitals declined from 504,000 to only 138,000. Deinstitutionalization has proven a misnomer, though; for many patients it merely shifted the site of hospitalization to general hospitals. A significant portion of those individuals who have been greatly affected by the shortcomings of the movement toward deinstitutionalization are the nation’s chronically mentally ill. Mary Merwin, who holds a doctorate in clinical psychology (University of Illinois), and Frank Ochberg, a psychiatrist trained at Johns Hopkins and Stanford, trace the evolution of the long struggle of the nation’s chronically mentally ill from a period of absolute neglect toward a spectrum of community-based, comprehensive services. They applaud the concept of deinstitutionalization, but fault its failure to provide the needed range of services to replace an institutionalized environment. Merwin and Ochberg bring a variety of perspectives to this task. Merwin, who formerly directed adult treatment services for Grand Traverse County (Michigan), developed a reputation as among the best of front-line providers of mental health care who offer a significant share of power to the consumer of care—a concept both authors advocate strongly. Ochberg’s experience spans federal, state, and local government service and now the private sector, as medical director of St. Lawrence Hospital in Lansing, Michigan. Ochberg was associate director (1978-1979) of the National Institute of Mental Health. He also is a recognized expert on the subjects of terrorism and stress management. From their perspectives, Merwin and Ochberg argue for continued improvement in the treatment of the chronically mentally ill and a new orientation for psychiatric professionals away from traditional approaches.
What are the critical mental health policies of federal, state, and local governments, and what should they be? This is the question we ask ourselves at a time when dreams are dying, and bold, new approaches seem old and wanting. The national agenda has little room for comprehensive solutions to enduring social problems. We are tempted to trim our ideals as we trim our national economic sails.

The critical policy questions involve defining and describing those consumers who will receive public benefits and then determining the scope and shape of benefit options. But public policy is not simply a package of public supports for various categories in need. It is a set of values that guides selection from a set of choices. In our case, the values underlying the selection process derive from our identification with the consumer and our frustration with the hegemony of competing professional interests in American mental health politics. Throughout the following treatise, we deliberately emphasize choices and approaches that, within pragmatic limits, offer a fair share of power and dignity to the consumer rather than the provider of services. The consumer group that concerns us most consists of people who have been institutionalized, or would have been institutionalized thirty years ago, before the emptying of state hospitals. Today, these people endure chronic and remittent mental illnesses, drift to the lower rungs of the socioeconomic ladder, and exhaust family ties and professional patience. Thirty years ago, these people occupied half the hospital beds in America. Today, they move from back wards to back alleys, through the revolving doors of public mental hospitals, and through the dockets of judicial review as proponents of treatment debate proponents of liberty.

To us, the current climate is no cause for radical redefinition of purpose. The pace of progress may slacken, but efforts to replace inhumane, ineffectual institutions with comprehensive community-based supports for those who can benefit from such services must continue. Efforts to educate the taxpayer and the elected official also must continue. Ultimately, consumers of public mental health services must play a leading role in the formulation of public mental health policy in America.

Consumers Of Mental Health Services

For the purposes of this discussion, people who use mental health services can be divided into three broad groups according to the range and types of services they need and to their degree of disability or dysfunctional behavior.

1. Consumers and potential users of public and private outpatient psychotherapy services. At any given time, up to 25 percent of the country’s population may suffer from mild to moderate depression, anxiety, psychophysiological disorders, and other emotional problems. Additional distress is
caused by marital and family problems, less than optimal self-esteem and role performance, and alcoholism or drug abuse. This quarter of our population is not considered “mentally ill” and seldom obtains care from the public or private mental health system. A 1977 study by Mechanic found that 33 percent of those surveyed reported seeking help from a friend, and 28 percent from a relative. People also seek mental health services from primary health care providers, particularly physicians. In 1975, an estimated 54 percent of all persons treated for mental disorders received their services in the primary medical sector and primary care physicians were cited as serving the largest number of psychiatric service consumers. But people also receive assistance from the clergy, child guidance and family services clinics, crisis intervention centers, telephone help lines, women’s centers, Community Mental Health Centers, and clinicians from a variety of professional disciplines in private practice. Funds for these services come from health insurance, government grants, and fees paid by the consumer. Most consumers in this group have at least minimally adequate financial resources, social supports, and independent living skills. Their disability and personal distress are often mild or moderate, although these conditions sometimes become acute, particularly if the individual does not seek or receive help.

2. Persons “at risk” of developing problems requiring professional intervention. This group consists of people who, because of physical or environmental factors, experience extremely high stress and who, without assistance, may begin to experience problems of a more serious nature. People with chronic physical illness, people in high stress occupations, persons who have been victimized, teenage parents and their children, and the growing numbers of long-term unemployed fall into this category. The services that could benefit these people are often more educational than therapeutic in nature and may involve learning stress management and coping techniques. Community Mental Health Centers (CMHCs) provide services for this group in the form of consultation and education or primary prevention programs. Local colleges also provide these services to the general public through community education classes; women’s centers and crisis centers hold workshops and seminars that serve the same purpose. Private firms offer these services in some locations, but are likely to consult with groups, such as police departments, rather than the general public. The funding sources are as varied as the consumers and providers and may be public or private but seldom involve a third-party carrier.

3. People known as chronic mentally ill. The third group of consumers consists of diverse persons with widely ranging needs; what most of these people have in common is a marginal lifestyle at or below the poverty line, a paucity of social supports, dependence upon public mental health organizations, and minimal coping and independent living skills. These
consumers usually carry a diagnosis of a major mental disorder such as schizophrenia, manic depressive illness, or, increasingly, borderline personality. Directly affected by the policy, practice, and partial failures of deinstitutionalization, their lives lend themselves to both sensational newspaper exposes and heartwarming accounts of personal struggle and success in escaping institutional degradation and dehumanization.

Deinstitutionalization: Philosophy, Policy, And Practice

Background and history of deinstitutionalization. In the nearly thirty years that deinstitutionalization has been with us in the mental health field, initial optimism has given way to more sober appreciation of the complexity of the issues. Ideally, deinstitutionalization means more than returning to the community those persons who have been long-term residents of state institutions. Rather, deinstitutionalization consists of: (1) the prevention of inappropriate and unnecessary mental hospital admissions by provision of treatment in the community; (2) release to the community of institutionalized persons who have been prepared for such release (or who will not benefit from further hospital treatment); and (3) establishment and maintenance of community support systems for noninstitutionalized persons (both those released from hospitals and those whose admissions were diverted). Too often in practice, deinstitutionalization has meant simply discharging people from mental institutions without providing the originally intended array of community supports and alternative treatments.

The concept of community care represented an innovation in “treatment” of the mentally ill in the United States. In colonial America, the mentally ill who were not persecuted for demonic possession or witchcraft were simply locked up and ignored in jails and poorhouses. In the late eighteenth century, the first hospitals for mental patients were opened, although treatment within their walls was far from humane, and many of the impoverished mentally ill remained in poorhouses and jails. In the mid-1800s, Dorothea Dix convinced many state legislators that care of the mentally ill was a public responsibility. The state mental hospital system that resulted from these efforts is still with us today. Conditions in the state hospitals declined during the next one hundred years due to overcrowding and insufficient funding. In 1946, Congress passed the National Mental Health Act, which involved the federal government in support of mental health services and research, and the training of mental health professionals.

In 1955, state hospital populations reached their peak census of approximately 559,000 people. At this point, mental health professionals began to advocate community care, in part because the introduction of psychotropic medications contributed significantly to symptomatic man-
agement of many severely psychotic patients and made discharging them back to the community possible. The availability of Social Security payments also influenced the deinstitutionalization movement by giving otherwise indigent people some financial protection.

In the early 1960s President Kennedy called for a bold, new approach to the care and treatment of the mentally ill and mentally retarded. At the same time, the Joint Commission on Mental Illness and Health released the findings of its six-year study, *Action for Mental Health*, citing humanitarian, clinical, and economic reasons for a move to community treatment.\(^7\) The report described deplorable conditions in overcrowded institutions offering only custodial care, found long-term institutionalization debilitating and without therapeutic effectiveness, and pointed out the high costs of institutional treatment. The passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164) signaled the opening of the deinstitutionalization movement. The advent of Medicare and Medicaid programs in 1965 showed state fiscal planners a way to shift a significant portion of state costs to the federal government by moving persons out of state mental hospitals. During the years from 1963 to 1976, the census of public mental hospitals declined from 504,000 to 2,16,000.

That era was one of social and political reform emphasizing the right of persons to self-determination; it produced a number of landmark legal decisions that furthered the deinstitutionalization movement. The decisions made it difficult to commit people to mental institutions against their will and affirmed the rights of individuals to treatment in the least restrictive setting appropriate to their needs. The court’s endorsement of each individual’s right to treatment also directed the institutions away from custodial care and toward more active therapeutic efforts.

**Impacts of deinstitutionalization.** In 1955, when the state mental hospital census peaked at 559,000, that figure represented approximately half of all hospital beds in the United States. In 1963, the figure had declined to 504,000, but by 1973 it was lower than 200,000\(^8\) and by 1980 only 138,000.\(^9\) In short, the census of state mental hospitals has declined by slightly over 75 percent since 1955.

Deinstitutionalization was a misnomer because for many patients it merely shifted the site of hospitalization to the general hospitals.\(^10\) In recent years, 60 percent of all inpatient episodes have occurred in general hospitals, 40 percent of those in general hospitals without psychiatric units.\(^11\)

Today, CMHCs account for a significant percentage of inpatient care, although the exact figure is difficult to determine because the general hospital figures overlap the CMHCs which often use general hospitals for their inpatient care. The figure is probably between 10 and 20 percent, not including residential care offered as alternatives to hospitalization.
From 1955 to 1975, inpatient care declined from 77 percent to 27 percent of all episodes of care. During the same period, total episodes of care increased dramatically from 1.7 million to 6.9 million. As most observers believe the overall rate of hospitalization has remained fairly stable, outpatient services have clearly become the major type of mental health care; outpatient care increased from 379,000 in 1955 (when CMHCs did not exist) to 4.6 million in 1975, a twelve-fold expansion.\(^\text{12}\)

It is generally believed that mental hospital stays have decreased considerably since 1955. However, average length-of-stay appears to vary with type of institution—from 11.6 days in general hospitals to six months for state/county hospitals. At only two types—VA psychiatric hospitals and state/county hospitals—have stays become shorter in the last decade. At the others, which account for 80 percent of inpatient episodes, stays have been stable and relatively short throughout this period.\(^\text{13}\) It is not uncommon for people originally admitted to general hospitals to be transferred to state/county hospitals if they do not respond fairly quickly to treatment. This practice may reflect the unavailability of continued payment in the general hospital, the high premium placed on beds in the general hospital, or the orientation of treatment in the general hospital to brief, acute episodes.

It is generally believed that the rate of hospitalization (number of hospitalizations per 100,000 population) has remained stable over the past fifteen years.\(^\text{14}\) However, analyses that include data based on primary diagnoses in general hospitals without psychiatric units indicate that from 1965 to 1969, admissions have increased from approximately 950 per 100,000 to almost 1,400 per 100,000.\(^\text{15}\) During this period, the number of episodes in general hospitals without psychiatric units rose more than 600 percent—from 184,000 to 1.2 million. This dramatic increase in admissions to general hospitals without psychiatric units may reflect increases in the incidence of mental illness, the number of people being treated by primary health providers, awareness on the part of primary health providers of mental disorders, availability of coverage for psychiatric hospitalization, a reduction in the stigma attached to mental illness, or any combination of the above.

Deinstitutionalization is generally believed to have greatly increased the rate of readmission, placing patients in a “revolving door” into and out of the hospital. To calculate readmission rates, one must follow individuals, rather than aggregate numbers over long periods of time. National data do not exist, but a few geographic- and time-limited studies have been completed.\(^\text{16}\) These surprisingly sparse data seem neither to substantiate nor to refute the “revolving door” hypothesis.\(^\text{17}\) An increase in readmissions would not in itself represent a failure of deinstitutionalization but might simply reflect the chronic nature of mental illness. Just as people with chronic physical illnesses are hospitalized only during
acute phases and discharged during remissions, so too, people with chronic mental disorders need hospitalization only during episodes of acute disturbance.

In spite of substantial decreases, psychiatric hospitalization remains a significant proportion of total hospitalization. Today, 25 percent of hospital days are psychiatric; hence, efforts to develop alternatives to hospitalization may have a significant effect on hospital cost containment.

Many of the persons discharged from state mental hospitals in the name of deinstitutionalization were, in fact, merely moved to nursing homes. From 1969 to 1974, the number of nursing home residents with mental disorders increased dramatically—by 48 percent according to one source or 100 percent according to another. Nursing homes were the single largest type of placement from state hospitals. The most widely accepted reason for this shift is financial. During the time of vast movements of people out of state institutions, federal funding through Medicaid was available for nursing home care but not for noninstitutional community placements. Alternate community placements were few, ironically, because of a lack of funding.

**People Termed Chronic Mentally Ill**

The term chronic mentally ill carries the negative connotations of continuous illness and low potential for improvement. Applying any term to this population obscures the diversity and heterogeneity of the individuals who comprise it. Nevertheless, most mental health professionals use the term chronic mentally ill for this group, and we are unaware of a less stigmatizing or more accurate and generally understood designation. We have avoided the use of the word patient because it puts undue emphasis on a medical approach and implies passivity and dependence on medical professionals.

Defining and identifying the chronic mentally ill are difficult tasks. Mental health professionals do not entirely agree among themselves, let alone with others, such as community residents, legislators, law enforcement personnel, and, most important, mental health care consumers and their families. The definition involves medical and social judgments that vary with time and context. Policymakers dealing with chronic mentally ill people need insight into their lives. For a variety of reasons, policymakers seldom take the opportunity to listen to these people. This lack of communication is detrimental to the total mental health system and the services it provides to consumers and providers alike.

**The deinstitutionalized.** Chronic mentally ill people exhibit behavior that interferes profoundly with their ability to live life as most of us do. They may be unable or unwilling to perform traditional roles, such as worker, student, parent, or spouse. They find it difficult to maintain strong
or lasting supportive interpersonal relationships. They are extremely vulnerable to stress and tend to lack coping mechanisms. Many do not appear able to perform daily living tasks, such as grooming, shopping, cooking, and management of money. In many cases, these disabilities are less a result of the mental illness per se than of “treatment”: particularly institutionalization, long-term use of phenothiazines, and other services that promote dependency.

The chronic mentally ill experience poverty, dependency, discrimination, and isolation. The results are poor nutrition, substandard housing, and inadequate access to work, transportation, and medical services. Although these latter characteristics are shared by many in this country who are not among the chronic mentally ill, the Task Panel on Deinstitutionalization, Rehabilitation, and Long Term Care described the chronic mentally ill as:

A minority within minorities. They are the most stigmatized of the mentally ill. They are politically and economically powerless and rarely speak for themselves. Their stigma is multiplied, since disproportionate numbers among them are people who are also elderly, poor, or members of racial or ethnic minority groups. They are the totally disenfranchised among us.20

This population is variously defined by diagnosis (usually including schizophrenia; severe affective disorders such as manic depressive illness; organic brain syndrome; certain personality disorders, especially borderline personality; and alcoholism); by functional disability (most notably inability to function successfully in a vocational or homemaking role); and by duration (length or numbers of institutionalizations or other twenty-four-hour residential care). Using these criteria, the Department of Health and Human Services Steering Committee on the Chronic Mentally Ill estimates the number of people with a diagnosis of severe mental disorder at 3 million; those who have, as a result, moderate or severe disability at 2.4 million; and those whose disability is prolonged and severe at 1.7 million. The committee views these latter 1.7 million as the chronic mentally ill.21 Other estimates range as high as 4 million.22 Of the 1.7 million, 900,000 are institutionalized (750,000 in nursing homes, 150,000 in hospitals for more than one year) and 800,000 (including 110,000 hospitalized at any given time for a period of more than three months but less than one year) are in the community.

The uninstitutionalized. Of those people who used to be in state institutions, some were discharged to supportive environments, escaped chronicity, and disappeared from the system. A second group, “dumped” without adequate planning or services back to an unwelcoming and unsupportive environment, became the unserved chronic mentally ill. Today they live on the streets or in single room occupancy hotels and boarding homes. This group has become the fuel for public and professional outcries against deinstitutionalization.
A third group, possibly the majority, was discharged to a community where at least minimally adequate follow-up and other services were delivered. Deinstitutionalization has made the quality of their lives at least equal, if not superior, to life in the institution. The mental health and social services system can take little credit for the success of the first group and must bear responsibility for the failure with the second. The third group, by and large, has not received the intense and comprehensive services needed to foster their rehabilitation and to maximize their potential. But neither have they suffered the exploitation and degradation of those who “fell through the cracks.” This group is now middle-aged and older, fairly comfortable with their lives, and content to use the social and recreational opportunities offered through mental health “drop in” programs and the services of “medication clinics.” They may have substantial secondary disabilities, such as reluctance to pursue rehabilitation and make major life changes.

Still another group affected by deinstitutionalization has received little attention from the mental health and social services system. This group poses the greatest challenge to mental health providers. It consists of the young chronic mentally ill, the people who in the past would have entered and probably stayed in state institutions, but who now are either not hospitalized or hospitalized for only brief periods. These uninstitutionalized young adults, roughly eighteen to thirty-five years of age are the first group of seriously dysfunctional people to spend little time in institutions as a result of policies favoring admission diversion and short-term hospitalization. They typically experience recurrent crises and only intermittently choose to participate in mental health-provided programs. This group has: (1) a low rate of hospitalization; (2) a high incidence of the use of alcohol and other drugs; (3) a high incidence of suicide attempts as well as of successful suicides; (4) a high incidence of conception of children, who become our next high-risk generation; (5) a sizable incidence of law violations involving violence; (6) for the majority, a history of mental health treatment before age eighteen; and (7) for the majority, a high or total degree of financial dependence on public assistance programs or on families.

These are some of the characteristics that make this new, uninstitutionalized generation a high-risk, high-priority, and high-anxiety group both for professionals and for the public.

For some years, these young adults have been evident to those direct service providers dealing with the chronic mentally ill, but only very recently have they become a focus of administrative planners and a topic in the professional literature. Like others of their age group, these young adults are extremely mobile and change residences frequently within and between cities, in and out of rural areas. They often appeal to the human services system in urgent need of food and shelter. The heterogeneous
population appears to contain three subgroups. One consists of individuals roughly similar to older deinstitutionalized persons in that they are passive, apathetic, poorly motivated, and dependent on the mental health system. They are “well ensconced in the role of patients.” Those in the second subgroup are highly motivated and function quite well when psychotic symptoms are in remission, but they have few lasting social supports and experience repeated failures and psychotic episodes. Those in the third subgroup—the most visible and most disturbing to providers and the community—tend to be relatively aggressive and easily frustrated; their impulsive behavior often brings them into contact with the criminal justice system.

These young adults generally have few social supports; they tend to alienate family and friends as well as mental health service providers. They are pervasive users of public services, but they generally do not follow through with treatment plans, dropping out of sight until the next crisis. Providers respond to this behavior by becoming frustrated, angry, and “burned out.”

**Needs for community living.** In the headlong rush to discharge long-term residents of institutions, state government planners were shortsighted and local mental health services were shortchanged. We had recognized the debilitating and dependency-producing aspects of the total care that institutions had provided. But we somehow assumed that, suddenly placed on their own, the human products of these institutions would be capable of meeting their own needs. Community Mental Health Services were minimal, often consisting only of five- to fifteen-minute “med checks” every one to twelve months, with CMHC psychiatrists. What “aftercare” services existed were totally unprepared and unable to meet basic needs for food and shelter, let alone all the other nonmental health needs of the chronic mentally ill. Nor was anyone else prepared and willing to do so. Indeed, one of the primary failures of the deinstitutionalization movement has been that it did not designate a point of authority and ultimate responsibility for the coordination of services to this population.

Today, the needs of most deinstitutionalized and uninstitutionalized people are not being met in the communities. However, the need for comprehensive services for the chronic mentally ill population has been recognized and several attempts have been made to enumerate the services needed. One list includes: (1) housing, whether independent or supervised; (2) transportation to services, recreation, shopping; (3) work and leisure activities, sheltered or not; (4) a support network, particularly self-help groups of chronic consumers; (5) income support, usually Supplemental Security Income (SSI); (6) casework to aid consumers in negotiating the bureaucratic maze to obtain services; (7) medical follow-up for monitoring and prescribing medication; (8) crisis management help during the frequent crises around housing, financing, and relationships;
(9) training in independent living skills, such as shopping, food preparation, money management; (10) family support services for those families trying to provide care; (11) community education to increase public understanding and tolerance; (12) access to hospitals for acute psychoses, particularly if alternatives do not exist; and (13) a focus of coordination, a case manager to assure that needed services are received.

Similarly, the Community Support Program of the National Institute of Mental Health (NIMH) calls for a comprehensive service system for adults with long-term psychiatric disabilities to assure that the following functions are performed by service agencies, self-help groups, or through links with natural support systems in the community: (1) identification of clients in the hospital or community and outreach to offer services; (2) assistance in applying for income, medical, and other benefits; (3) twenty-four-hour crisis stabilization services in the least restrictive setting, with hospitalization available when alternatives are insufficient; (4) psychosocial rehabilitation services, including, but not limited to, training in independent living skills, vocational rehabilitation, transitional living arrangements which encourage improvement in functioning, and opportunities to develop and improve social skills, interests, and leisure activities; (5) supportive services of indefinite duration, including living and work arrangements and appropriate day and evening activities; (6) medical and mental health care; (7) backup support to families, friends, and community members; (8) involvement of concerned community members; (9) protection of client rights; and (10) case management services, to ensure continuous availability of appropriate forms of assistance.

Voices of the consumers. These lists of needs were assembled by professionals. Seldom are consumers asked what they need. Most professionals devise individual treatment plans for the chronic mentally ill (and perhaps for other consumers of mental health services) without seeking the advice of the individual concerned or giving more than lip service to the belief that the consumer has something of value to say and the right to say it. Chronic mentally ill people are a diverse and heterogeneous group with views that range across a wide spectrum from the few who believe they have received or are receiving precisely what they need from the mental health community, who believe the medical model is appropriate, and who willingly seek hospitalization at times and take their medication regularly, to the few who feel mental health professionals have nothing to offer, that the mental health system is merely an instrument of social control, and that hospitalization and psychotropic medications are primarily methods to exert that control. The vast majority of views lie somewhere between these extremes.

The author of the following remarks is a young man who spent ten years of his life in mental institutions between the ages of eight and nineteen. Upon release, he became involved with Fountain House, a
very large program in New York City that is based upon a psychosocial rehabilitation model (rather than a medical model). Fountain House stresses work and vocational skill building, provides some opportunities for member self-direction and decisionmaking, and is touted as one of the model programs in the country. Although clearly not the program for all, it receives high marks from many it serves.

One of the most important things you first have to think about is where you’re going to live when you leave the hospital. I hope that younger patients like myself and also the older ones, have more of a choice and a chance when they leave the hospital. Many of us, with just a little help, could live with each other in a real apartment of our own. I hope in the future we don’t just put all the people coming out of hospitals in places like group homes and residences, not unless they really need to be there. I just think we don’t know what a patient needs for sure unless we have more than one way of doing it. What we need are choices, some different opportunities. Then we can find out what’s really best for each individual.

It means a lot to have a chance to work in a regular place of business where your illness, number of hospitalizations, time in the hospital, luck of vocational history, and all those things, do not stand in the way, or keep you from having a chance.

But it’s not all success. We need the chance to fail as long as we still want to keep trying. Many of us have had many hospitalizations or spent many years in mental institutions. Our lives have been influenced by these experiences, aside from whatever our illness has done to us.

One way to help us continue to fail is to expect a kind of miracle, an almost instant change, in a very short period of time. Or to believe that we cannot change, are forever chronic, always dependent, to be taken care of, to be officially segregated from our society by being evenly distributed so that we don’t “overload” any one neighborhood or place.

I’m thinking about a family and what seems to go on there, at least I think so, and how this could really help a lot of chronic patients in the community. A family is a place where I think a lot of things go on. You really don’t feel you’re being raised, that people are doing things to you to raise you. You don’t get discharged or terminated; and even when you grow up and get a job of your own and move away, it’s a place you keep in touch with and visit. There’s always an interest and that’s what makes the difference.

I think this is what we need for the chronic patient. We don’t have such places in our lives; and while we can’t be little again and go back to small families, we ought to have, wherever there are enough of us around, a kind of bigger family where you don’t feel you’re a patient, that someone is doing something to you for your own good, where no one would say, ‘that’s not my department, that’s not my job, that’s not my problem.’
place where you do things together, where there’s a common interest in almost anything that’s happening to you. . . .

People will behave according to their surroundings. In other words, if you go to another country you will adapt to that country. Now you take anybody, put them in an institution, call them a patient, put them on meds. They do everything to make him feel sick. After awhile he’s going to start believing it, whether it’s true or not.

Even if you’re well, you can get sick in a hospital. And you’re sick, you can get sicker. And when you come out of the hospital into Fountain House, there are really no technical brilliances at Fountain House. There’s no complex Freudian theory or anything like that. It’s just a common sense approach. . . Here they treat you as a person not a patient. . . .

To finish up, I have tried to say lots of things about what we need as chronic patients in the community. Most important is to stop looking at us as chronic. We can be helpful to each other. We can learn from each other. We can set examples for each other and we can encourage and support each other. Somehow, we know that each of us can do better. When we get this across to each other we can change and do more with our lives.  

Judy Chamberlin speaks for a group of people who feel they have suffered greatly at the hands of mental health professionals and the system, and who argue for alternative helping services outside of the system. Her story (and those of thousands of other mental patients) shows the mental health system at its worst. She writes:

Mental hospitals have been called “total institutions” in which even such ordinary decisions as when to eat, go to the toilet, and go to bed are made by others. A natural consequence of being subjected to such a regimen is a feeling of depersonalization. Feelings of depersonalization are frequently considered primary symptoms of mental illness. To complete the circle, psychiatrists usually attribute their patients’ feelings of depersonalization to their internal state and not to conditions within mental institutions.

The whole experience of mental hospitalization promotes weakness and dependency. Not only are the lives of patients controlled, but patients are constantly told that such control is for their own good, which they are unable to see because of their mental illness. Patients become unable to trust their own judgment, become indecisive, overly submissive to authority, frightened of the outside world. The antitherapeutic nature of mental hospitalization has long been recognized.

A tremendous gulf exists between patients and staff in mental institutions. Patients are seen as sick, untrustworthy, and needing constant supervision. Staff members are seen as competent, knowledgeable, natural leaders. These stereotypes are believed by large numbers of patients and staff members. Communication is difficult among the gulf. Staff members don’t believe what patients tell them. Patients don’t believe what other patients say.
Patients begin to question their own perceptions of situations, including their very accurate perceptions that they are looked down on and spied on by the staff. These observations are corroborated by so-called “normal” people who have posed as mentally ill and have admitted themselves to mental hospitals. Moreover, these criticisms are often accurately applied to community programs where providers exercise power over consumers.

Chamberlin argues the case for truly consumer-run alternatives, in which professionals serve at most a supportive role, and the traditional distinctions between helper and helped cease to exist. Although consumers may create these alternatives out of anger and frustration with conventional treatment, they must go beyond anger, Chamberlin states, and relearn their sense of their own worth and confidence in their own abilities. Mutual support or self-help groups are a natural, perhaps essential, starting point. In these groups, the individual can begin to experience distress as a response to the frustrations of real life, to recognize that this effect is not a sign of getting “sick” again, but a legitimate expression of emotion.

She argues that mental health professionals feel threatened by the expression of negative emotions on the part of consumers. All too often, professionals interpret such expression as justifying further treatment. Chamberlin describes professionals as “skeptical of true alternatives because they cannot see patients as competent people. . . . True alternatives are threatening because they do away with the need for professionals.” Self-help alone cannot remedy severe mental illness, but we see consumer support groups as an essential part of a comprehensive mental health program.

Mental health consumerism in Michigan. In 1979, the Michigan Department of Mental Health established a consumer initiative as explicit policy. This initiative included a budget request for $200,000 to support consumer-run self-help groups, appoint consumers to statutory advisory bodies, designate a staff liaison to consumer organizations (an employee who was a leader in Recovery, Inc., and a self-identified consumer), and sponsor statewide conferences for consumers. The legislature appropriated half the requested amount, and the executive impounded half of that, as Michigan’s economy collapsed and programs without political support vanished. One vocal consumer advocate on the Mental Health Appropriations Committee of the Michigan House of Representatives saved the program from budgetary extinction and maintained the precedent of state support for consumer-run self-help groups.

From 1979 to 1983, between ten and twenty support groups for expatients or family members operated in Michigan. These included the highly structured, well-established Recovery, Inc., fellowships of family members who met weekly to discuss their mutual concerns about severely mentally handicapped relatives, and organizations of consumers of pub-
lic mental health services. These groups managed to coalesce and form a
statewide alliance, Citizens for Action in Mental Health (CAMH), that
still endures. The coalition invariably focuses on practical issues: finding
jobs, surviving on food stamps, basic nutrition, Social Security regulations.
Although CAMH cannot rival the public employee unions in influen-
cing mental health legislation, it participates with growing strength and
maturing sophistication in public policy determination. The future of a
statewide consumer movement is not secure. All the forces that militate
against progress in the public sector have intensified with the harsh eco-
nomic climate and the cruel stereotyping and scapegoating that invari-
bly surface in hard times. However, CAMH’s survival proves that it can
be done—that hundreds of expatients and hundreds of family members
can develop local self-help groups and organize a statewide coalition.

Model service programs. The available studies of the efficacy of vari-
ous community-based programs for these consumers have research de-
sign problems, but their findings all point in positive directions. This
literature reveals that the severely disturbed can be served and main-
tained in the community, with very limited use of hospitalization, and
that community care is consistently equal to or better than hospital care
in outcome, namely, functioning level of the consumers. It also suggests
that over time, people who leave the programs function less well than
those who do not, that is, many of the most severely impaired appear to
need continuous support and treatment to maintain themselves in the
community. The literature also contains evidence that hospitalization is
self-perpetuating, a finding that calls for a strong effort to divert those
crucial first admissions. Moreover, consumer satisfaction with services is
higher in community programs. Although most examinations of cost bene-
fit or cost effectiveness are narrowly quantitative, their findings suggest
that community alternatives are no more expensive and may be less ex-
pensive than hospitalization,

The most successful new mental health developments appear to share
the following principles: 1. Top priority in these programs is placed on the most severely
disturbed.
2. Treatment programs are extremely individualized, and program for-
mats have maximum flexibility, varying over time in intensity, de-
pending upon the need and motivation of the consumer.
3. There is open access to the program, with easy entry and reentry, and
a bare minimum of the usual bureaucratic red tape and paperwork,
4. The programs provide for the full range of comprehensive services
and functions that institutional care provides.
5. They have strong links with other human resources, and include some
form of client services management.
6. The programs provide strong, immediate response capabilities to
crises, including liaison and access to hospital beds, if necessary.
7. They use assertive outreach efforts to help keep people in programs or at least to maintain effective consumer monitoring.
8. They engage in strong advocacy on behalf of consumers.
9. The programs are culturally relevant to consumers, including being “streetwise” and integrated into the consumer subculture.
10. Many services are available on the consumer “turf,” that is, the office-based model is minimized.
11. The staff is specially trained, attuned to the unique survival strategies of chronic mentally ill people, dedicated to this population, and able to appreciate even small progress made by consumers.
12. The programs are responsive to staff concerns, including feelings of frustration, anger, or helplessness; they strive to build interstaff support and to prevent burnout.

Programs differ as to who (what kind of professional or paraprofessional) does what (precise treatment approaches) to whom (characteristics of consumers). To the extent that they follow any theoretical model, it would be a broadly defined psychosocial rehabilitation model, which provides “certain basic opportunities and services—socialization, living arrangements, educational and work opportunities, training in community living skills, advocacy—in the context of a supportive, normalizing group in the community.” They focus on creating circumstances that encourage and enable people to do things for themselves and for others; opportunities—not just services—with an emphasis on mutual and self-help. This hybrid model is neither purely mental health nor rehabilitation, neither purely professional nor self-help.

The Role Of Community Mental Health

Passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act in 1963 marked the official birth of Community Mental Health Centers (CMHCs), but it took several years for Community Mental Health (CMH) programs to become established in any significant number. In the first six years of the program, the total amount appropriated was only $277 million, slightly less than 2 percent of total dollars expended on mental health in 1974 alone. Since then, CMHC funding has remained an insignificant portion—never more than 5 percent—of federal mental health dollars.

Almost from the beginning, CMH was criticized. It was expected to be all things to all people. At one extreme, CMH was to be of the community and for the community, when often no community existed. The federal catchment areas were artificial populations of 50,000 to 200,000, statistical groupings of people that were not necessarily social, cultural, or ethnic units. Community Mental Health was to serve and empower the
poor, and bring about social and political change with innovative new “treatment” techniques. These techniques involved more sociology and community organization than the type of work most mental health professionals had been trained to do. Community Mental Health was to eradicate mental illness through primary prevention programs, which at that point were ideas on paper, untried and untested. Community Mental Health was to spread mental health techniques to other “caregivers” (everyone from bartenders to police), so that mental health aid would permeate the community. The proponents of these notions showed little recognition of the resistance they were to encounter among those “caregivers,” who saw their roles very differently and who simply wanted CMH workers to “do their job.”

At the opposite extreme, CMH was expected to replace state hospitals and to provide for the needs for those returning to the community from the state institutions. Unfortunately, “aftercare” services for this population were not among the original five mandated services for federally funded CMHCs, and the communities supposedly directing and prioritizing services did not want former state hospital patients in their midst. A further obstacle to serving the chronic mentally ill was the competitive rather than cooperative relationships between CMHCs and state institutions. The birth of the CMHCs announced the demise of the latter. State institutions, literally fighting for their lives, had the support of the communities in which they were located and for which they provided a major source of employment, the unions representing hospital employees, and state legislators responding to their constituencies back home. Legislators who serve on mental health committees come disproportionately from districts with large hospitals and represent the employees and the status quo rather than the consumer and the promise of a better future. “Given this strong opposing political force and given their inherently shaky fiscal base, there was never a viable chance for community mental health centers to fulfill their mandates. In effect the dragons they were to slay were supposed to finance the slaying!”

CMHCs therefore remain in a vulnerable political position. The original eight-year federal staffing grants have expired, and local governments are unable or unwilling to pick up the burden of support, despite the finding that state hospital utilization is lower in areas with, than in areas without, CMHCs. Although the census in state hospitals is decreasing, the costs of hospitalization are skyrocketing. As a result, state mental health dollars do not follow discharged patients into the communities. To make ends meet, the CMHCs are turning to activities, such as outpatient counseling for the middle class, which at least, in part, pays for itself through insurance and client fees. Not only professionals but funding sources support the medical model. For financial reasons, the CMHCs are unable to provide adequate programs of outreach to the poor and chronic mentally
ill, prevention services, and consultation and education. As long as state government operates mental hospitals with their large populations of unionized employees, the politics of mental health will discriminate against community mental health programs.

Providers Of Mental Health Services

The primary providers of mental health services are psychologists, psychiatrists, social workers, psychiatric nurses, and paraprofessionals (generally defined as persons with a bachelor’s degree or less). Various types of allied mental health professionals have entered the field, providing occupational, vocational, recreational, and art therapies, especially for the chronic mentally ill. These additional professionals now make up 12 percent of the full-time-equivalent staff positions in mental health facilities. Between 1968 and 1976, the pool of “core” mental health professionals increased by over 50 percent: psychiatrists by 55 percent, nurses by 65 percent, social workers by 165 percent, and psychologists by 193 percent. In 1976, mental health facilities employed more than 15,000 full-time-equivalent (FTE) psychiatrists, over 15,000 FTE psychologists, over 39,000 FTE psychiatric RNs (6,000 to 7,000 with master’s degrees), and almost 26,000 master-level social workers.

In 1955, professionals in these four categories, plus aides and attendants, delivered most of the mental health services. Most mental health services were delivered in hospitals, which maintained a traditional power and status hierarchy with roles and functions strictly defined by discipline. Since 1955, the separation of disciplines has diminished and roles have increasingly blurred and overlapped. For one thing, all professional disciplines have adopted and used the many new therapy techniques (behavior, family, and reality therapy, for example). Today, all groups perform individual and group therapy and are involved in other activities, such as consultations, administration and management, education, prevention, and crisis intervention. Except in psychopharmacology, most new developments in mental health care in recent years have come from nonmedical disciplines and have become available as techniques for all disciplines. As a result, “although psychiatrists still dominated the field in 1975—especially in prestige, power, and financial reward—one barely noticed clear separation of tasks, except that psychiatrists were largely responsible for physical examinations and prescribing drugs.” In the CMH setting between 1970 and 1976, the number of psychiatrist staff positions per center dropped from 6.8 full-time equivalents to 4.3, while the number of psychologists doubled and social workers increased 35 percent. The proportion of trainees in centers who are psychiatric residents also dropped from 29 percent to 14 percent. How much of this shift is due to a move away from the medical model, the unavailability or
difficulty of recruiting psychiatrists, cost containment measurements, or other factors is unclear. Certainly, CMHCs themselves represent a move away from the medical model. Moreover, community mental health is not a medical specialty, and many of the issues of community mental health concern health rather than illness. Physicians are basically trained to treat illness, but not to promote health or to perform such other community mental health functions as consultation, education, and community organization. The psychosocial rehabilitation model with the chronic mentally ill, and other psychotherapies with outpatient consumers, may be supplanting the medical model, which places the physician at the head of the team.

Although no conclusive data are available on the subject, as dollars become more scarce, utilizing the most costly professionals for anything other than their medical expertise may appear to be poor fiscal management. Indeed, psychiatrists may have priced themselves out of all the roles and functions that other disciplines can and do perform. The policies of third-party reimbursement, whether by private insurance carriers or public programs such as Medicare and Medicaid, also have influenced the shift in personnel. Until recently, only services provided by physicians or under the supervision of a physician were reimbursable. Despite the opposition of the medical profession, licensed psychologists and certified social workers are gradually receiving appropriate recognition as qualified and independent mental health service providers. Although employing those providers may reduce costs somewhat, and partially reduce “on paper” supervision, it also will provide incentives for these professionals to leave organized and, especially, public care settings where pay tends to be lower.

Although psychiatrists are by far the most highly paid of the mental health professionals, they are among the lowest paid of medical doctors; their increased average net income between 1970 and 1977 (21 percent) was the lowest of seven medical specialties and their real income actually dropped by 23 percent. The number of medical graduates entering psychiatric residencies has been dropping since 1970, and the 1976 act limiting the number of foreign medical graduates admitted to the United States resulted in a 25 percent drop in psychiatric residents between 1976 and 1978. The supply of psychiatrists seems likely to diminish in future years, and shortages are already reported in rural areas and in subspecialties such as child and geriatric psychiatry.

Given the overlapping of roles and possibilities of substitution among disciplines, one must ask whether this is affecting the quality and cost of mental health care. Although these expanded, overlapping roles provide more opportunity for mental health workers, resentment and bitterness follow the perception that any discipline has higher pay, privileges, and status for doing essentially the same work as another. Research has be-
gun to examine, the efficacy and cost effectiveness of services provided by various mental health professionals and paraprofessionals. One study compared the cost effectiveness of psychologists and psychiatrists serving a small number of consumers diagnosed as schizophrenics. Primarily because their patients had lower hospitalization rates, lower recidivism, and less drug use, psychologists appeared to provide substantially less expensive treatment. These findings serve only to raise more questions, which cannot be answered without further study.

**Services to the chronic mentally ill.** Mental health professionals are often reluctant to work with the chronic mentally ill. The work lacks prestige and status, and it is seen as unattractive and unrewarding, both professionally and financially. As in the primary health field, caregivers tend to focus on less severely impaired consumers who are more manageable, treatable, and able to pay their own way. One writer attributes professionals’ avoidance of the chronic mentally ill to dissatisfaction with the burden of meeting these consumers’ chronic dependence needs, moral disapproval of that dependency; distaste for the lower social classes, and—in common with the rest of the community—an inclination to exclude the mentally ill. Professionals are too often unrealistically pessimistic, arguing that chronic mentally ill people are not treatable, that their disabilities are not amenable to improvement, and that they primarily need custodial care.

Thus, programs serving the chronic mentally ill are staffed predominantly by paraprofessionals, whether in supervised living arrangements, psychosocial rehabilitation programs, social recreational drop-in programs, or by the provision of case management. It is reported that generalists and paraprofessionals provide as much as 80 percent of the direct care received by the chronic mentally ill. This arrangement may be conducive to efficacy of service, but it also indicates the low status and perceived unattractiveness of this group. Young paraprofessionals, just beginning in the mental health field, often bring great enthusiasm, idealism, and energy to their jobs. Often they show a degree of respect for the chronic mentally ill that has long since eroded with the professionals. Young paraprofessionals have not yet resigned themselves to these consumers’ lower prospects of improvement and growth. In the absence of specific knowledge about how to help the chronic mentally ill (other than by prescribing medications), the attitudes of these paraprofessionals may be as helpful as anything the professionals have to offer. Unfortunately, lack of respect on the part of the professionals, lack of progress on the part of the consumers, and relatively small financial reimbursement for what comes to be seen as the most difficult work eventually takes its toll. Paraprofessionals begin to “burn out,” evincing negative attitudinal changes toward consumers, a loss of creativity and enthusiasm, and a high staff turnover rate.
Special initiatives are needed to create and maintain a quality work force delivering services to this group. The difficulty and high stress of working with these consumers must be acknowledged, and the work must be reimbursed accordingly, as well as structured to provide opportunities for career advancement and include measures to prevent burnout.

The role of consumers as volunteers and employees. Although staff members may oppose the hiring of consumers, such hiring is conducive to quality services and the improvement of attitudes toward the chronic mentally ill especially. In programs serving the chronic mentally ill, consumer-employees provide hope and role models for others served by the program. They also serve as liaison or even as interpreters between consumers and other staff. They alert other staff to such issues as subtle condescension and patronization of consumers, and to ways in which programs promote chronicity and dependency rather than growth, rehabilitation, and independence.

Within the larger community, by publicizing its “affirmative action” policy of hiring consumers, the agency serves as a role model to other employers. And if the agency also provides vocational training and placement services and works with employers in the community, it can sustain a dialogue and share information with these potential employers about the difficulties of hiring the chronic mentally ill. Hiring consumers moves agencies out of the position of asking employers to do what they have not themselves been willing to do.

The use of consumers as volunteers within an agency provides some of the same benefits, although not to the same degree. Also, given the financial need of most chronic mentally ill people, the agency must avoid exploiting them. Although excluding consumers’ volunteer opportunities is a form of discrimination, agencies must exercise caution in recruiting consumers as volunteers.

Financing Of Mental Health Services

Costs of mental health services. In 1971, 35 percent of all mental health expenditures were out-of-pocket from the consumer, 31 percent were state and local dollars, 21 percent federal dollars, and 11 percent private insurance. State and local governments pay a significantly larger share and private insurance carriers a significantly smaller share of mental health costs than of total health care spending. Between 1974 and 1980, the costs of all direct care for mental health services rose steadily from $14 billion to $20 billion. If these calculations include estimates of indirect costs, such as lost productivity and income maintenance payments, annual totals at least double. Mental health has represented 11 to 15 percent of total health expenditures and accounts for approximately 1 percent of the Gross National Product. Most of this money still goes for institu-
tional care (60 percent in 1980). Nursing homes are consistently the site of the largest expenditures; they account for approximately 30 percent of total dollars spent, followed by public mental hospitals at 23 percent, psychiatrists in private practice at about 9 percent, and CMHCs at only 4 to 5 percent.

These figures are difficult to interpret. Given the rate of inflation during the 1970s, mental health costs probably have increased only slightly in real dollars. The disproportionate amount spent on institutional care is especially difficult to interpret. In part, it reflects the total care of institutions, which is not included in outpatient costs. However, it also reflects the institutional bias of the funding programs, especially Medicaid, which has been the primary source of funding for the reinstitutionalization of people from state hospitals to nursing homes. The shockingly low percent of expenditures for CMHCs accounts in part for the lack of comprehensive services for the deinstitutionalized and noninstitutionalized population.

**Current financing framework.** In the 1950s private insurance coverage for mental health outpatient services was at parity with medical treatment for physical illness. Psychoanalysis was the predominant form of psychotherapy, and insurance carriers found that significant portions of total benefit payments were going to a few individuals who were not disabled and who were performing their usual roles, including employment. The private carriers quickly stopped offering such benefits. In the mid-1960s, the federal government entered the field with its Medicare and Medicaid programs, but it followed the lead of private carriers, and severely limited outpatient benefits.

The reimbursement limits in mental health services involved higher deductibles, copayment requirements, caps on maximum benefits, and limitations on providers eligible for reimbursement. Eligible providers are physicians or, in some cases, certain other professionals under the direct supervision of a physician. Reimbursing only the most expensive professional is not necessarily cost-effective in terms of outcomes, and it limits the consumer’s supply to the available 28,000 psychiatric providers by excluding the 121,000 psychologists, social workers, and psychiatric nurses. This reimbursement policy favors the medical model over community alternatives, education, and rehabilitation; discriminates against other mental health service providers; and supports the dominance of medical professionals. Limiting reimbursement inhibits innovation and results in neglect of the poor and the chronic mentally ill.

High deductibles and copayments keep all but the affluent from utilizing outpatient benefits because the needy cannot afford to copay or to meet deductible requirements. These limits, as well as unrealistically low caps on maximum benefits, lead to overuse of inpatient services, which, of course, are far more expensive.
The chronic mentally ill receive public financing for mental health services through several programs that are part of Social Security legislation. These include: Supplemental Security Income for the aged, blind, and disabled (SSI); Disability Insurance Program (SSDI); Medicare; Medicaid; and the Title XX Social Services Program, which provides a variety of social services. Specific eligibility, service, and payment criteria vary widely.

In addition, application procedures are generally complex and difficult, especially for the chronic mentally ill. Waiting periods for benefits can be long, causing great stress and hardship for those in need. Disability determination is a slow (SSI usually takes three to six months), complex, and subjective process that often results in denial of benefits to severely disabled people. Mental health workers in certain areas work on the assumption that benefits will be denied initially but granted upon appeal. This practice, of course, discriminates against those who do not know the system and do not have assistance from those who do. Certain regulations discourage use of less restrictive alternatives: for example, people living with their families or in another’s household receive reduced SSI payments; efforts to avoid the reduction sometimes result in unnecessary or inappropriate placements in group homes and other supervised living arrangements. Benefits under SSI are much too low to meet people’s needs. People living in a supervised board and care setting have only $52 a month for all personal needs, including clothing, personal care items, transportation, and recreation. A person living independently receives only $284, with which he or she must meet all living expenses.

Today, funding is designed not to meet needs but to satisfy special interest groups, among which the chronic mentally ill have low priority. The Report of the Deinstitutionalization Task Force of the President’s Commission on Mental Health states: “We would stress as strongly as we possibly can that there will never be any real hope of adequate community mental health services so long as over half the American mental health dollar is spent on state institutional and mental-health-related nursing home care.”

**Recommendations**

**Divisions of responsibility.** As noted above, most people with mild to moderate emotional problems receive help outside the specialized mental health sector. There is little to be gained from attempting to change this practice, and it is probably quite appropriate. Specialized mental health services are often unnecessary, particularly when services outside the specialized sector carry no stigma and therefore encounter less resistance. Natural support networks (the “first line of defense”) could, however, be strengthened and extended, and the mental health sector
may aid in promoting them. Community Mental Health and the primary health care system (the “second line of defense”) could foster the growth and acceptance of specialized mutual-help groups, such as widow-to-widow, cancer victims support groups, Alcoholics Anonymous, and Recovery, Inc.

When people seek more formal assistance, it is most often from the primary health providers. Mental health professionals have a role to play here as consultants and educators. Many general physicians need education regarding the proper use and the misuse of psychoactive drugs, especially tranquilizers, sedatives, and antidepressants. They also need to be better trained in the recognition of problems such as alcoholism, depression, and potential suicide. Studies show that 71 to 91 percent of people who committed suicide had been recently in the care of a physician. Over two-thirds of these people had histories of suicide threats or attempts, but only 40 percent of the physicians were aware of them. Although three-quarters of the people were depressed, that diagnosis was rarely made, nor was the depression treated. More than half of those who died by overdose had received an unlimited prescription within one week of the suicide. It is important that general physicians recognize when specialized mental health treatment is appropriate.

The growing popularity of family practice groups, health maintenance organizations, and other such collections of professionals from both medical and mental health fields should be fostered. These group practices serve to integrate the medical and mental health fields, leading to a more holistic approach, oriented toward promoting health rather than curing illness. They facilitate coordination of care, treatment of psychosomatic illnesses, early intervention, and prevention through education.

Office-based psychotherapy by mental health professionals may be useful to those whose problems are more prolonged or too severe for primary health providers to serve. These services can be provided through public organized care systems, or private practitioners, including those in group practices.

We recommend that public policy: (1) foster the use of natural support systems for the emotional problems of living; (2) foster the development of mutual-help groups around shared problem areas; (3) foster the use of mental health professionals as consultants and educators to the primary health providers, to enhance their responsiveness to patients’ needs; (4) foster group practices of mental health and medical professionals, which focus on health promotion; and (5) maintain specialized outpatient psychotherapy services for those more acutely in need.

In addition, even in a time of fiscal restraint, primary prevention needs and deserves public support. Data confirm the efficacy of certain primary prevention programs, especially those that deal with mothers’ prenatal care and infants’ health, mother-infant bonding, and the teaching of in-
terpersonal cognitive problem-solving skills to children, and coping and stress-reduction techniques to adults. The success of primary prevention programs in averting costly medical and mental health problems makes them an appropriate public health concern. Public or private non-profit mental health organizations should work with universities to develop programs and further knowledge through research. We recommend that public policy foster primary prevention programs and encourage joint efforts of service delivery organizations and the research capabilities of universities.

The confusion and conflicts of interest of the various levels of government involved in mental health have been obstacles to the efficient and effective delivery of mental health services. A clear division of responsibility among the federal, state, and local levels of government would aid in the delivery of all mental health services. The federal responsibility in mental health should be promotion of the delivery of services, training of the work force, and research. The federal government must give top priority to serving the chronic mentally ill and take a public position of advocacy for this population.

The states should serve as a conduit for federal funds, do statewide planning, supplement federal funding, provide technical assistance as necessary, and, most important, relinquish their role in the direct delivery of services. State government has a conflict of interest when it operates state hospitals while advocating community alternatives. When states are employers of thousands of mental health workers, state government must deal more with provider concerns and less with consumer issues. The local public mental health authorities (in most cases the CMH board) should become responsible for their use of the hospital and for the people from their areas who are patients in it. We recommend carefully written performance contracts between the federal and state governments and between the State Departments of Mental Health and the Community Mental Health boards.

The CMH boards, who best know the service needs of their areas, should deliver, either directly or through contract, the most appropriate mix of services. They could choose either to continue to use the state facilities through direct contract, or to use those dollars for alternative hospitalization or residential programs. They would be required, however, to provide comprehensive, integrated services for the chronic mentally ill of their catchment area, including those people who entered a state institution from there.

We also recommend joint efforts between CMHCs and universities, with a clear division of responsibility. Universities would be responsible for teaching and research; CMH would deliver the services. This arrangement would result in better training of professionals, especially for work with the chronic mentally ill, which most medical and graduate schools
do not provide; more relevant and applicable research; and better evaluation of services.

In short, we recommend that: (1) federal policy place top priority on services to the chronic mentally ill, while also promoting other services, professional training, and research; (2) the states distribute federal funds, do statewide planning, supplement funding, and provide technical assistance; (3) CMHCs be responsible for the delivery of all public mental health services, including those provided in state institutions; and (4) universities form partnerships with CMHCs through which they could provide teaching and training of professionals and complete research.

Services to persons known as chronic mentally ill. The report of the Task Panel on Deinstitutionalization, Rehabilitation, and Long Term Care to the President's Commission on Mental Health stated:

There can be no adequate system of mental health care in the Nation if the special services required by this subpopulation of the mentally ill are not provided.\textsuperscript{59}

We agree. The lack of cooperation in continuity of care between state-operated mental hospitals and local CMHCs, the lack of assistance through the maze of bureaucracy leading to financial and service benefits, and the lack of a center of responsibility have been severely detrimental to the population most in need of mental health service. To fill these gaps we recommend that: (1) a local mental health authority (in most cases the CMH board) be designated in each geographical area as the entity (referred to by some as a core services agency) responsible for meeting the needs of the chronic mentally ill, either directly or through contract with other service delivery agencies, or through accessing services and benefits provided by other systems; (2) this agency control the full range of mental health services available to and needed by this population, including (by contract or direct operation) inpatient beds in state facilities; (3) an adequate system of client services management be available to assure on an individual basis that all needs (mental health and other) are considered and all benefits to which the person is entitled are obtained; and (4) the smallest local entity capable provide services to assure a personalized, rather than large, impersonalized bureaucratic service delivery system.

We do not support a total integration of the social services and welfare system within the mental health system for this population. Rather than consolidating all services under a mental health authority, we favor the mainstreaming of chronic mentally ill into services provided to the general public, and a collaborative approach, particularly with the general medical sector.

No service system can be said to be truly comprehensive if it gives the consumer no choice as to the provider or the services to be obtained.
People termed chronic mentally ill have and deserve the right to make choices about their lives, to take risks, to make mistakes, in short, the right to fail, as well as to succeed. The choice of services and provider is an essential aspect of providing opportunities, rather than mandatory services deemed appropriate by the professionals. Collaborative as well as truly consumer-run efforts are extremely important. Therefore, we recommend that public policy foster the development of a variety of smaller alternative providers and services so that consumers can choose that assistance most helpful and comfortable to them as individuals, and that these alternatives include consumer-run services, as well as other professional, paraprofessional, and collaborative services.

The Deinstitutionalization Task Panel Report to the President’s Commission on Mental Health pointed out that mental health policymaking typically draws on the judgment of professionals and not that of consumers as to how their needs should be met:

They are frequently discriminated against by the very system that was designed to help them, for this system tends to focus on their disabilities rather than on their strengths. Like others who suffer from unjust exclusion, they need help of an affirmative nature to promote their responsible involvement, to assure that (they) are perceived as persons of worth and as partners in the helping process.

We recommend that public policy: provide for significant consumer representation at all levels of policymaking, planning, and delivery of service; and foster the development of organized consumer and parent groups and coalitions of groups, for the purposes not only of mutual support but also of advocacy on their own behalf.

The chronic mentally ill suffer general discrimination and violation of their civil rights in our society, limiting their opportunities in housing, employment, education, and even access to certain services, such as vocational rehabilitation programs and treatment in the least restrictive setting. We recommend that public policy actively support federal, state, and local legislation and ordinances to bar unjustified discrimination based upon chronic mental illness and disability in housing, employment, education, and service programs.

The stigma of mental illness, disapproval of deinstitutionalization, and distrust of the mentally ill themselves remain strong in our society. The “visibly” chronic mentally ill are often actively shunned, avoided, and excluded. They cannot exercise full rights and opportunities of citizenship under these conditions. An intense effort on the national level, as well as the local level involving, for example, the media, community service organizations, church groups, and the schools, to educate the public regarding mental illness and the needs of the chronic mentally ill is needed. Therefore, we recommend that public policy support a major educa-
tional effort at the national level, involving consumers themselves, to reduce the stigma surrounding mental illness, the deinstitutional movement, and the existence of the chronic mentally ill in communities; and strong local efforts toward the same ends, also involving consumers and stressing face-to-face efforts.

The role of CMH. Public policy must recognize the impossibility of the original mandates to CMH, the inherent conflict between CMH and state institutions, and the terrible void created by the lack of clear responsibility for the chronic mentally ill. We recommend that public policy should: (1) recognize CMH as the party responsible for providing or obtaining the full range of services needed by the chronic mentally ill; (2) encourage CMH to compete in the marketplace, with other outpatient mental health service providers; (3) provide incentives for CMH to increase its consultant role in the community, particularly with the general medical sector; (4) encourage CMH to join in partnership with universities for the purposes of professional training and research; and (5) provide incentives for these partnerships to focus on primary prevention and the chronic mentally ill.

The workforce. Public policy affects the workforce by designating the providers deemed eligible for reimbursement and by determining the type of professionals who are trained and the type of training received. We recommend that public reimbursement policy: (1) provide greater equity among disciplines, particularly when the services rendered are the same (equal pay for equal work); (2) promote the use of paraprofessionals, especially former consumers; (3) promote professionals as consultants according to specialized skills; and (4) recognize the value and difficulty of working with the chronic mentally ill by increasing the status and reimbursement for these services. Public policy should support training and retraining that include preparation for work with the chronic mentally ill, and include an emphasis on the community psychosocial rehabilitation mode.

Funding services for the chronic mentally ill. Building a financing framework to meet the needs of the chronic mentally ill involves more than just listing services and the dollars needed to pay for them. The framework must be carefully devised to avoid the problems of current financing, such as incentives for institutional care, and must be based upon support of a variety of values and principles.

The most basic of these values is that of equity. In 1966, Congress stated equity to be a major objective for the federal CMHC movement. However, the underlying principles of equity never were elucidated. Equity in social policy involves distributing scarce resources fairly to those who seek help. According to at least one analysis, equity does not imply the same amount of services for everyone; rather, distribution is equita-
ble when it is based on need—not demographics or income. We recommend equity as the underlying value to guiding the restructuring of mental health and social services financing, and assigning priority to the needs of the chronic mentally ill.

To guide financing and structuring of services, we recommend: (1) innovation, variation, and alternatives in services, which provide choices to consumers; (2) the delivery of services in the least restrictive setting; (3) programs that move consumers away from the passivity and dependence of the patient role; (4) coordinated services and continuity of care among all services; (5) a psychosocial rehabilitation and, more broadly, a holistic and health-promoting rather than a medical model; (6) the promotion and growth of mutual help and advocacy groups, and consumer-run programs; (7) great expansion of the role and numbers of consumers in policymaking positions; (8) affirmative action on the hiring of consumers within mental health service delivery agencies; and (9) the desegregation and mainstreaming of consumers into the services and social institutions of the larger society.

Community programs are still unavailable or insufficient to meet needs in many parts of the country. Consumers remain in institutions, even now longer than necessary, and in some cases indefinitely, because the beds and services in the community do not exist at all, or exist in insufficient numbers. The number of beds needed in institutions cannot be decreased until beds in the community increase. Therefore, some double funding of institutions and community alternatives is needed while institutions are still phasing down. We recommend that funding must be made available to local mental health authorities to meet the needs of the chronic mentally ill through development of community services, allowing continuing decrease in numbers of hospital beds.

Discrimination based on disability operates against those who cannot easily speak on their own behalf or find their way through the bureaucratic maze. This discrimination has become flagrantly apparent in the current federal administration’s crackdown on SSI recipients. The redetermination of eligibility for continued receipt of this income support has resulted in termination of benefits to many severely mentally disabled persons. It has resulted in crises of serious proportions, including numerous rehospitalizations. We recommend that: (1) eligibility and reimbursement practices that discriminate against the chronic mentally ill not be perpetuated; (2) eligibility criteria be based upon more objective measures of functioning level and adequately distinguish between mental and physical disabilities; (3) trial work periods and periods of reentitlement be expanded to avoid disincentives for vocational rehabilitation; and (4) income support be sufficient to allow a standard of living above that of abject poverty.
Conclusion

An appreciation of the historic struggle of persons severely afflicted with mental and emotional disorders and an understanding of the twentieth century discoveries in psychology and psychiatry suggest that we are on a long voyage that will take decades to complete. Successfully concluding this journey will require thorough public understanding of certain complex forms of human suffering. Ultimately, those who suffer in these ways must achieve a sense of equity instead of injustice, pride instead of stigma, participation instead of patronization in their capacity as consumers of mental health services.

NOTES

1. The authors wish to thank Vee Bjornson for greatly appreciated assistance in the preparation of the manuscript, and Jayne Claytor, librarian of St. Lawrence Hospital, Lansing, Michigan. We also acknowledge the valuable editorial assistance of Bruce Vladeck and colleagues at The Robert Wood Johnson Foundation.


4. President’s Commission on Mental Health.

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