

Community Mental Health Care: New Services from Old Systems

EDWARD M. KENNEDY

United States Senate

Chairman, Subcommittee on Health and Scientific Research

HE WAS BORN OUT OF WEDLOCK TO YOUNG PARENTS who never lived together. R.W.'s birth record reflects virtually no prenatal care. At six months of age, when his mother gave up caring for him, R.W. was shifted from one relative to another. Although he was never diagnosed as retarded, it was clear that he was a slow learner with poor physical coordination and poorly developing social skills. Finally, at age eleven, when he could neither adjust to school nor to life with an aunt, he was institutionalized in the children's unit of a state hospital. Shortly after being diagnosed as "borderline schizophrenic," his behavior began to deteriorate even further, and he was placed in a locked ward with other hopeless patients. Here, out of sight, he received minimal custodial care.

Although R.W. had been institutionalized over most of his life, in 1972, at age twenty-three, the hospital staff decided he had become tractable enough to live outside the hospital if he would take his Thorazine as prescribed and report back to the hospital for follow-up care every two weeks. Tragically, the combination of his sporadic and tenuous familial and other social relationships, and the superficial and perfunctory preparation for independent living, led predictably to failure. Since that discharge seven years ago, R.W. has served eighteen months in prison, lived in at least thirty different places, held countless jobs for one- or two-month periods, and has been rehospitalized at least six times. Yes, all the specters of the neglected mental health patient haunt him, whether R.W. is institutionalized or deinstitutionalized.

Deinstitutionalization—simply defined as moving patients away from the dehumanizing experiences in state institutions into stimulating, caring, and smaller community-based settings—was part of the social policy contained in the 1963 Community Mental Health Centers Act. Pursuit of this policy has been controversial at best, or, as in the case of R.W., a colossal failure at worst. It has been the subject of intensive scrutiny by government, clinicians, social planners, and the public.

For decades, social and medical policy had been one of placing our long-term, chronically disturbed mental patients in large state-owned and -operated hospitals, remote from populated residential areas. It had been a one-way street. The movement of the patients back to their communities began tentatively in the early 1950s, and was abetted by the discovery of the miracle psychoactive drugs later in the decade. Because these drugs made it possible to control the more alarming symptoms of several forms of mental illness, it soon became clear that they could be used in a program to maintain more patients outside of state hospitals. Even some severely regressed patients, who were receiving only custodial care in the hospitals, have benefited from such programs. Unfortunately, these drugs have had little long-term curative effect.

This movement rode the wave of social experimentation in the 1960s, and Massachusetts, along with New York and California, led the nation in implementing a policy that was hailed as progressive, enlightened, and humanitarian. Early in the 1970s, pockets of uncertainty and disaffection with deinstitutionalization began to surface. Community resistance began to stiffen, especially in inner-city areas where most of these patients were being placed without adequate discharge planning and follow-up care. Public outcry about property depreciation, risk of injury caused by assaultive patients, and even the unsightliness of the more passive, became increasingly strident. There continue to be calls for a halt to this process and in several states the process of moving patients out of the mental institutions has slowed dramatically.

The original Community Mental Health Centers Act of 1963 was premised on a redefinition of the federal role in providing mental health care. The vision was that of an integrated system of services utilizing federal, state, public, and private resources. It called for substantial local community input in the planning and delivery of services to targeted geographic populations. Not only was the goal to

assist patients like R.W. in moving out of state hospitals, but also to treat them in community-based facilities using short-term therapy and crisis intervention techniques. The act was intended to respond to the total person's needs—not just the behavioral symptoms—in the most appropriate setting.

But the vision of an integrated service system under an integrated support system has been elusive for sixteen years. We continue to wrestle with two independent and uncoordinated service systems: one with federally supported community mental health centers, and another with state-supported mental hospitals.

To be sure, perhaps millions of mentally disabled Americans have achieved some measure of help despite the systemic shortcomings. But the greater number have fallen victim to our failure to make deinstitutionalization an inherent part of an integrated service-support system. Too many patients released from institutions have been suddenly assaulted by the most elemental human problems: where to live, how to maintain themselves, how to survive. They are often not prepared prior to discharge for the kinds of decisions that need to be made. Some never learned fundamental survival protection techniques or self-maintenance habits. Others, because of illness or medication, forgot them. Yet, precisely at a time when the individual experiences the severe shock of sudden removal from a system that has provided custody and asylum, there are no substitute supports to assist in the transition. Almost all need financial assistance upon release from an institution, and some need it continually, or at least during periods of dysfunction.

While an initial aim was to close or scale down as many hospitals as possible, experience has dramatized the limits of the possible; there will always be a residual population requiring ongoing hospital care. Care in the remaining institutions, however, must be upgraded. An attempt to do so with mere rhetorical reform will not succeed. The severe inflationary pressures in the present Proposition 13 atmosphere, the shift in the composition of the state hospital toward a more chronically disabled population, and the wave of "right-to-treatment" litigation all contribute significant additional pressures to devise new approaches to the needs of the institutionalized.

It was within the context of the debate over the future direction of the community mental health centers, the plight of the deinstitutionalized patient, and a more austere budgetary process

that the President's Commission on Mental Health was established. The commission was charged to review the mental health needs of the nation and to make recommendations as to how the nation might best meet these needs. The report was thorough and incisive. It further documented the very desperate need for the federal and state governments to assume real responsibility for these patients and undertake appropriate new programs. What we have seen since the release of the report has been a rather modest legislative proposal of community support programs based on more coordination, continuity, and collaboration. Although a first step, these services alone will not go very far toward dealing with the basic problem.

The debate in Congress and elsewhere invariably settles on the need to define the appropriate federal role in the planning and delivery of mental health services, especially to deinstitutionalized patients who have been part of a state service system. Certainly, the federal government must go beyond simply providing incentive to states to expand their efforts or funding short-term demonstration projects which have little impact on entrenched systems. The federal role must be much more active, with strong commitments to fund certain core services on an ongoing basis. The emerging question is whether or not, left to their own devices, the states will expand their resource commitment to serve the mentally ill. History has taught us that this has not happened on any broad scale and that the federal government must fill the void. The current mental health legislation before the Congress begs the question of expanding services and focuses instead on better management of existing meager resources. It backs away from the federal role as defined in the 1963 legislation and the need for effective financial and program partnership at all levels of government.

Although the commission's proposed community support program does take a step toward assigning responsibility and coordinating social services to chronic patients through the use of case managers assigned to each discharged patient, the overriding need remains for strong, federally financed support for programs in housing, income maintenance, and other rehabilitation services. Fiscal and administrative implementation of these programs should precede the patient's discharge. For years, we labored under the misunderstanding that deinstitutionalization was not only humane, but that it was also cheaper. This may not be the case, as experience has taught us that the rationality of reallocating money from state

hospital systems to community support is not always politically feasible. Often, state hospital "constituencies" are a persuasive political force in state governments.

Without making significant changes in our relevant financial entitlement programs—Titles XVIII (Medicare), XIX (Medicaid), and XX (flexible social service appropriations)—our nation's progress toward caring for the chronic mentally ill will be limited. Our federal health care insurance coverage for the mentally ill must be improved. The need for more entitlement support for intermediate care facilities for the mentally ill goes unmet. Too many patients, eligible for Supplementary Security Income, are discharged from state mental hospitals with their paperwork in process and without eligibility firmly established. Without this financial support, the likelihood of rehospitalization is great. Expanded outpatient mental health coverage under Medicare is a necessity, to assure that the elderly deinstitutionalized and the never-institutionalized patients can receive continuous care. Until these and other changes are made, with active participation from the states, we have avoided coming to grips with the issues.

Finally, we must energetically approach and change the public's perception of those with mental illness. As stated in the report of the President's Commission, "the shift from non-community to community-based care, while solving certain problems, has brought in its wake a number of new problems. Mentally ill and mentally retarded persons discharged from hospitals face difficulty in being accepted by people in their home communities. Too often, they return to find ignorance, prejudice, and fear of mental illness, discrimination, and social ostracism." The community mental health centers must play a vital role in erasing this unfortunate stigma, but it will take the collective efforts of us all in changing these misunderstandings about mental illness.

The decision of the *Milbank Memorial Fund Quarterly* to focus on the needs of the deinstitutionalized patient is both appropriate and timely. If we as a society are to achieve our goals of social sanity for all our citizens, we must continue to focus on the most vulnerable of our population. That is where history will measure our success or failure.

Address correspondence to: Senator Edward M. Kennedy, Room 2241, Dirksen Senate Office Building, Washington, D.C. 20510.