Correcting Misconceptions in Mental Health Policy: Strategies for Improved Care of the Seriously Mentally Ill

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In the decades following World War II, a strong coalition emerged emphasizing environmental factors as prominent contributors to mental illness and championing the importance of substituting new patterns of community care for the traditional reliance on public mental hospitals for the seriously mentally ill. In the period from approximately 1955 to 1975, this coalition vastly influenced public policy toward the mentally ill and shaped the federal role in mental health policy (Mechanic 1980; Grob 1987).

Those associated with this movement often assumed that mental illness was a simple continuum from mild to severe dysfunction in contrast to a heterogeneous collection of unrelated disorders, that early intervention could prevent serious mental disorder, that population dynamics and the populations at risk were unchanging, and that use of mental health resources for outpatient psychiatric care was always more cost effective than hospital care. These were all testable assumptions, but they were mostly accepted on faith (Mechanic 1980). In the 1960s the rhetoric of community care developed a momentum of its own, importantly shaping agendas and debates on mental health policy, and broadly influencing the thinking of intellectual elites, public policy makers, and the general public (Grob 1987). In the process many dedicated professionals and reformers lost touch with the heterogeneity of mental health problems, and the tough realities of
designing and implementing effective programs appropriate for the most seriously mentally ill.

Mental health policy, particularly as it pertains to serious and chronic mental illness, represents an arena badly served by much of the social and preventive care ideology that attained dominance and is still commonly espoused. The excesses of ideology, and particularly naive notions about labeling and normalization processes, provided a target for critics of deinstitutionalization who focus on exaggerated claims and obvious failures of community care, proclaim the intent of deinstitutionalization as naive and counterproductive, and argue for the reestablishment of an enlarged mental-hospital sector. Neither type of advocacy serves the needs of the mentally ill well nor contributes to a well-informed public. By identifying some of the dominant misconceptions, and defining issues more carefully, we can hopefully develop targeted and efficacious strategies that offer potential for bringing improved care to this most needy population.

Transformation of the Mental Health Sector

Mental health professionals have the impression that service systems are relatively impervious to change, that traditional institutions resist innovations, and that the entire mental health sector is exceedingly slow in responding to obvious need. At a gut level most professionals and concerned lay persons readily endorse these sentiments despite the lack of any reference point or criterion. What they mean, perhaps, is that the services fall short of what they deem desirable, or that the priorities for allocation are inequitable, but by any criterion the mental health sector has experienced an extraordinary degree of ferment, an enormous growth in size, and a virtual revolution in structure in a period of only 30 years (Mechanic 1980).

In 1955 the number of episodes treated in mental health facilities was 1.7 million, and the vast majority occurred in public mental hospitals. Inpatients in public mental hospitals peaked at 560,000 at this time, and services available in outpatient settings were limited severely by the ability to pay. By the middle 1980s inpatients in public mental hospitals fell to 115,000 and general hospitals became the major site of acute psychiatric care. In 1984 there were almost 1.7 million discharges from short-stay hospitals with a primary mental
illness diagnosis, and an average length of stay of approximately 12 days (Dennison 1985). The elderly demented as well as many elderly mentally ill are now in nursing homes; estimates made on the basis of the "1977 Nursing Home Survey" total some 668,000 patients with mental illness or dementia (Goldman, Feder, and Scanlon 1986). In short, there was a dramatic reorganization of inpatient psychiatric care, a major change in the distribution of patients among sites of care, and a transformation of the pattern of hospitalization for acute psychiatric illness. None of these changes suggests the elimination of important disparities by socioeconomic status, race, and ethnicity, although public programs significantly improved access among disadvantaged groups.

As a consequence of reductions in the populations of public mental hospitals, and the transfer of many hopeless chronic patients to nursing homes, the public mental hospital was in many instances transformed from a custodial institution to an active treatment unit. The professional-patient and staff-patient ratios improved enormously, and active treatment and rehabilitation programs were developed to a point where in many instances there was little resemblance between the hospital as it had once been and as it is now. It is, of course, difficult to describe conditions in the United States because each state maintains its own mental health system and there is great diversity in the availability of facilities, funding patterns, and relative emphasis put on different aspects of care. But, by 1982, the typical state mental hospital had 529 inpatients and 807 employees, with average expenses per patient of more than $31,000 per year. Between 1970 and 1982 the average number of patients per employee was reduced from 1.7 to .7, and the average expenditure per patient increased from $4,359 to $31,000 ($12,500 after controlling for inflation) (Dolan 1986).

Even more impressive has been the overall growth of the mental health sector. In 1980 mental illness was the third most expensive category of disorder, accounting for more than $20 billion of health care expenditures (U.S. Department of Health and Human Services 1983). This level of expenditure has been made possible by the growth of mental health coverage in both public and private health insurance programs. The Bureau of Labor Statistics "Level of Benefits Survey" shows considerable depth of inpatient mental health coverage among employees studied in firms above a minimum size (Brady, Sharfstein, and Muszynski 1986). In 1984 almost all (99 percent) had inpatient
psychiatric coverage, and about half had it on the same basis as any other illness. Ninety-six percent had outpatient coverage, but only 7 percent on the same basis as other illnesses. Most common restrictions were on dollar limits and coinsurance levels (typically 50 percent). Increased coverage has contributed to the purchase of millions in additional services. The Institute of Social Research at the University of Michigan surveyed the United States population in 1957 and 1976 using many of the same questions. Over the 20-year period, use of professional help for psychological problems increased from 14 to 26 percent, although the levels of well-being in the population were approximately the same (Kulka, Veroff, and Douvan 1979).

As one would expect, the greatly increased capacity to pay for services and their provision are linked to a dramatic increase in mental health manpower of every type. In 1947 there were only 4,700 psychiatrists in the United States, and only 23,000 mental health professionals in psychiatry, clinical psychology, social work, and psychiatric nursing; by 1977 their numbers had increased to 121,000, with large increases continuing to the present in clinical psychology, social work, and other disciplines oriented to psychotherapy (Mechanic 1980). The "National Medical Care Utilization and Expenditure Survey" (NMCUES) found that psychiatrists and psychologists each had approximately one-quarter of mental health visits, approximately 40 percent were to other providers in office settings (social workers, nurses, counselors, etc.), and about one-tenth occurred in mental health clinics, outpatient departments, and emergency rooms (Taube, Kessler, and Feuerberg 1984). Mental health has become a large and diversified sector.

Even using conservative measures, unmet mental health needs persist and they are enormous (Shapiro et al. 1985; Leaf et al. 1985). If one accepts broad definitions of such needs, then it is evident that no conceivable society is likely to meet them. But the evidence shows that a majority of individuals even with major mental illness have received no mental health care of any kind during the prior six months. The policy challenge is to define clearly the most critical needs and priorities, and to devise systems of organization and reimbursement that respond effectively. The problems seem to be less issues of mental health personnel and more questions concerning the availability of reimbursement, the definition of reimbursable providers, and public attitudes and stigma. Beyond the 37 million Americans who have no health insurance at all, mental health coverage for many Americans
employed outside of large firms is greatly inadequate. Also, many persons continue to resist care for mental illness. The individual facts reviewed here are well known. It is remarkable, however, how few mental health professionals appreciate the receptivity of mental health services to incentives, and how deeply the system of services has been transformed in a relatively short period. Growth, of course, is not an end in itself. Equally important is the issue of allocation of care relative to need and public priorities.

Contrary to the common-sense view, it may be less instructive to ask why change proceeds slowly and, more pertinently, to inquire why in the absence of a truly efficacious technology, could such changes have taken place? If we understand this, we can better appreciate points of leverage in the system.

Deinstitutionalization of the Mentally Ill

In the period up to and following World War II, the mental health sector was dominated by state systems of inpatient mental health care. Between January 1942 and June 1945 an estimated 1,875,000 among the 15 million men screened for the military were rejected for service because of alleged psychiatric problems. Of those inducted, a large proportion of those later separated from the armed forces due to disability were discharged specifically for neuropsychiatric reasons. These facts created much concern and, in conjunction with the successes of psychiatrists in the armed services in dealing with pressing psychiatric problems, encouraged interest in improving basic preventive and treatment services and research in the psychiatric area (Mechanic 1980).

This is not the context in which to trace the complex history of the federal government's involvement in mental health, or the development leading to the Mental Health Study Act of 1955. My colleague, Gerald Grob, is at work on a history of mental health policy during these years that will illuminate how various important influences came together during the postwar era. Psychiatric writers commonly focus on the widespread introduction of neuroleptic drugs in the mid-1950s but generally neglect the critical state of psychiatric hospitals in the decade after the war. Federal aid to the states for mental health services decreased during the Korean war, and the Hoover Commission in 1955 criticized the abruptness of the reduction
of such federal support. States were acutely aware of their financial and personnel limitations, and were seeking a way of joining the then optimistic spirit emerging in the mental health field.

The widespread introduction of neuroleptic drugs in the 1950s was an important tool, but not the cause of deinstitutionalization. Experience in the United States and Europe showed that in some instances deinstitutionalization began before their introduction (Scull 1977). Drugs were as important for their effects on attitudes and administrative behavior as they were for their specific effects on psychotic symptoms. In large institutions, drugs gave treatment personnel hope and a greater sense of efficacy, and facilitated administrative change. The ability of drugs to blunt the most disturbing of psychotic symptoms also gave families greater confidence that patients could return to the community and be managed. But many problems remained, including issues of suitable housing, subsistence, and the need to change community attitudes. It is widely assumed that deinstitutionalization began with a vengeance in 1955, the point at which inpatients in public mental hospitals reached their peak. In fact, the timing of deinstitutionalization varied greatly by state and, for the nation as a whole, the pace was relatively slow, only 1.5 percent a year between 1955 and 1965 (Gronfein 1985).

Large-scale deinstitutionalization did not come until the mid-1960s, in combination with a number of changes that addressed issues of community attitudes and subsistence. Attitude change involved three strong ideological thrusts. The 1960s were a period of civil rights activity and advocacy. The young lawyers and activists for the civil liberties of the mentally ill came out of the civil rights movement and involvement with public interest law. Civil commitment was characterized by substantial abuses and was a visible target for their efforts (Ennis 1972; Miller 1976). In these initiatives they were influenced by the social science literature on the adverse effects of custodial mental hospitals and the abuses of psychiatry (Goffman 1961; Wing and Brown 1970; Szasz 1963). This work provided both the ideology, and much of the substance, to justify an attack on involuntary hospitalization. A third aspect was psychodynamic conceptions of mental illness that were increasingly accepted in the scientific literature, the mass media, and public conceptions (Mechanic 1980). Mental illness was portrayed commonly as a single continuum from mild to severe, a product substantially of sociocultural and psychosocial factors (Leighton
Within this dominant ideology of environmental causation, it followed that bringing more benign influence to bear on the mentally ill would ameliorate their level of disturbance. That major mental disorders might be fundamentally different from common distress syndromes, or that poor community environments could have the same negative effects as poor hospital environments, were not considered seriously. The result was a strong antihospital ideology.

To remove disabled people from hospitals successfully required places for relocation, and it was not until the rapid expansion of welfare programs in the 1960s that the means became widely available. Medicaid stimulated a dramatic growth of nursing home beds, and the program financed the cost of nursing home residence. This not only provided the states an opportunity to transfer elderly mentally ill and demented patients receiving custodial care in hospitals to an alternative institution, but also allowed the transfer of significant state costs to the federal budget. The expansion of Social Security Disability Insurance (SSDI) in those years, and the introduction of supplemental security income (SSI) for those without the required work history for disability eligibility, provided much of the financial support necessary to return impaired patients to a variety of community settings, including families, board and care facilities, and single occupancy housing. Between 1966 and 1980 the yearly rate of deinstitutionalization averaged 6 percent. It could not have been achieved without the expansion of welfare programs.

The Composition of the Seriously Mentally Ill Population

Deinstitutionalization has been a rallying cry for those advocating community care and a target of their critics. Because the term is used imprecisely and is not clearly tied to particular patient populations or relocation sites (Bachrach 1976), it has little empirical utility. Deinstitutionalization is viewed as a source of many current problems and has a certain currency in the ideological debate, but the debate is more a source of heat than light.

Even prior to 1955, most inpatients in public mental hospitals returned to the community. In any given year the net releases and deaths—the typical way of tracking inpatient occupancy—almost equaled the rate of new admissions. In 1950, for example, there were 152,000 admissions, 100,000 releases, and 41,000 deaths. The longer a patient
remained in the hospital, the less the likelihood of release, but a significant proportion of new admissions returned to the community within a few months. Beginning in 1956 net releases and deaths exceeded new admissions but only by 7,952 individuals. It wasn't until 1970 that net releases (excluding deaths) actually exceeded the number of new admissions during the year (President's Commission on Mental Health 1978, 94). Moreover, in any given year the vast majority of patients leaving were those who were admitted relatively recently.

These simple data indicate that the deinstitutionalized population is a heterogeneous collection of varying patient cohorts. Many would have returned to the community in the absence of policy change, and common references to the deinstitutionalized seem to refer to clients who have never been part of the long-term mental hospital population at all. While, in theory, these population processes can be explicated, much of the relevant empirical work has not been attempted. It is not fully clear who among the "deinstitutionalized population" would have been the long-stay patients in earlier eras.

Public mental hospital populations were reduced by deaths, return of a residual group of long-term care patients to nursing homes or other community settings, substantial reduction of the average length of stay among newly admitted patients (median, 23 days in 1980), and by more stringent admission criteria. Of public hospital patients resident in 1955, a large proportion either have since died or have been relocated to nursing homes. Goldman, Feder, and Scanlon (1986) estimate that some 668,000 nursing home patients in 1977 had diagnoses of mental illness or dementia. This population includes transfers from mental hospitals but probably most came to nursing homes directly from the community. Kiesler and Sibulkin (1987) estimate that as many as half of the elderly discharged from mental hospitals in the post-1964 years came to nursing homes. Nursing homes played a significant role for relocation of the elderly mentally ill, but a small role for younger patients. In 1977 only about 5,500 patients under age 45 and primarily with mental illness were residing in nursing homes (Goldman, Feder, and Scanlon 1986).

The general discussion appears often to refer to the original hospitalized cohorts, but, in fact, the populations that alarm the community are later cohorts most of whom have never been long-stay inpatients and some who have never had a psychiatric admission at all. As mental
health services organization has changed, acute psychoses are treated typically with short inpatient admissions in community general hospitals and in reconstituted public mental hospitals. Most such patients have had entirely different histories with the mental health services system than earlier cohorts, relying less on inpatient care and more on community services. Some proportion of these patients would have been long-term residents of mental hospitals in an earlier era.

The amount of serious mental illness in the population, with schizophrenia as the prototype, depends on both the rate of incidence and the size of the population at risk. Much of the increasingly evident problem of serious mental illness in the community is not due to deinstitutionalization, or even to changes in the way psychiatric hospitalization is used, but more to shifts in the demography of the population with large subgroups at ages with highest risk of incidence. Morton Kramer (1977) predicted these problems more than a decade ago simply by projecting demographic trends. The misattribution of the source of changes to deinstitutionalization, vaguely defined, encourages serious errors in policy making. Unless the society was prepared to maintain a massive public hospital system, or alternative institutions, for new occurrences of mental illness, the problem would have been evident in communities regardless of what we did.

Long-term care in aging provides an analogy. The demand for services is substantially a product of the growth of the elderly population, the increased prevalence of the oldest-old subgroup with high risks of functional disability, and the delay of mortality. Despite having enormously increased nursing home beds at large national expense, providing for 1 1/2 million residents, the numbers of disabled elderly in the community far outnumber those in nursing homes. Except for those most incapacitated, there is no real alternative to community care. A similar logic pertains to the criminal justice system. As the subgroups of youth at high risk of criminal activity and arrest in the population swelled, we substantially increased prison capacity. Such capacity, however, could not keep up with the increase in offenders, and in many localities only the most serious and persistent offenders are jailed, and many convicts are released early because of prison overcrowding.

A population of major concern to the mental health system, and to the community, are young schizophrenics and other seriously disturbed youth, who are aware of their civil liberties and hostile or indifferent
to psychiatric ideologies. They frequently are uncooperative with the types of treatment made available to them and their mental illnesses are commonly complicated by abuse of drugs and alcohol. They mix with other street people, constitute a significant minority of the homeless population, and at various points in their life trajectories are hospitalized, jailed, or live on the streets (Lamb and Grant 1982; Lamb 1984). The problems are compounded by the fact that the age groups at highest risk have increasing numbers of minority and disadvantaged youth that connect the stigma of mental illness with the social difficulties associated with color and disadvantage. This population poses difficult problems of appropriate treatment and requires approaches for establishing contact and trust that are very different from the conventional office-based mental health services. Blaming deinstitutionalization for these problems is wrong-headed since most of these patients are not appropriate clients for long-term institutional care. The barriers to designing acceptable care are not constructively addressed by simple distinctions between hospital versus community services. In contrast, they will depend on carefully developed strategies of community care.

Necessary Functions of Community Mental Health Systems

Viable systems of community mental health services for the seriously mentally ill must take three important facts into account. First, the population is diverse, encompassing individuals with different disorders and needs, varying types of disabilities and capacities, and at different points in their illness trajectories. Second, service planning must take place in a context where it is difficult to predict the prognosis of patients over a long period of time. In the case of schizophrenia, for example, a significant proportion of patients do reasonably well over the long term, while others have frequent exacerbations and increasing chronicity and disability. It is clear from a number of studies, however, that schizophrenia does not result in inevitable deterioration and incapacity (Harding et al. 1986; Bleuler 1978; Ciompi 1980; Clausen et al. 1982; Huber et al. 1979). Third, the problems associated with illness are often significantly compounded by the disadvantages of poverty and racism.

Hospitals have certain advantages in treating the most seriously disabled mental patients needing a high intensity of service, just as
the nursing home serves a comparable advantage for the most incapacitated elderly, who may be disoriented, incontinent, and difficult to control. Many of the difficulties in the care of highly disabled clients relates to loss of control in community care relative to the control that hospitals typically have in performing treatment and custodial functions. The community is deficient in supplying many needs we take for granted in hospitals: housing, basic medical care, and opportunities for social participation. Also, maintaining contact over time, monitoring medication compliance, and encouraging regular routines, typical of hospital care, are no small tasks in the decentralized settings of present community care. And opportunities for persuasion to achieve conformity to reasonable bounds of behavior, what sociologists refer to as social control, is more difficult to exercise in community care, particularly for many young patients who reject the legitimacy of psychiatric concepts and treatment, than in the more coercive context of a total institution, however benevolent it may be.

In the process of deinstitutionalization the psychiatric hospital was devalued, and little effort was made to differentiate good from poor inpatient programs. There is some segment of the patient population for whom a refuge is the most practical and humane solution (Gudeman and Shore 1984) and perhaps necessary to protect the community as well. But community care for most patients is the desired approach, not only because it is impractical and expensive to hospitalize most of the seriously mentally ill for a lengthy period, but also because it is more consistent with patients' preferences and important values relevant to personal autonomy, independence, and minimal restriction. The vigorous civil liberties activities of the 1960s that reformed civil commitment procedures and created a variety of new patient rights increased sensitivity to the implications of restricting personal choice and introduced significant improvements in the use of coercive interventions. Criteria for involuntary hospitalization, use of isolation and other punishments, and the opportunity to impose unwanted treatments have been narrowed, consistent with modern concepts of civil liberties. Moreover, the vast majority of seriously mentally ill prefer deprivations in the community to coercion, however well-intentioned. Whenever patients are asked about their preferences, the vast majority prefer treatment in the community. Appropriate models can be developed to provide care and rehabilitation, superior to most hospitals (Kiesler 1982; Stein and Test 1978), but the necessary tasks
are neither easy nor as inexpensive as some advocates suggest (Weisbrod, Test, and Stein 1980). If we are to avoid recreating large mental hospital systems, an alternative increasingly advocated by observers frustrated with the failures of community care, much developmental effort in communities is essential. We will examine these developmental strategies later.

The expansion of the mental health sector obscures the important issue of the equitable distribution of mental health dollars. Hard data on resources spent on those most seriously ill and incapacitated are almost impossible to obtain, but the indications are that some subgroups of the most seriously mentally ill may have less access to essential services than ever before. These deficiencies result from underfunding of chronic care, the failure to shift funding from traditional to new types of programs, and the limited insurance coverage among the most needy population. The homeless mentally ill, now found in significant numbers in every large city of our nation, convey both the magnitude of the challenge and the diversity of needs that must be met to suitably respond to the multifaceted character of long-term mental illness (Lamb 1984). The homeless are but the tip of the iceberg. The severely mentally ill remain a substantially neglected population.

Points of Leverage in Mental Health Policy

Understanding clearly how deinstitutionalization occurred provides clues to the types of social policies that shape the services system and provide possible points of leverage. Most mental health professionals are insular in their concerns and have focused on relatively small categorical federal programs and their conversion to block grants, neglecting the much larger state and federal arenas that drive the system: state mental health budgeting and financing mechanisms, and federal programs such as Medicaid and Social Security. This failure to focus on the major point of leverage has resulted in neglect of the most likely possibilities for reform.

Refunding State Mental Health Budget Priorities

Mental illness traditionally has been a state responsibility and constitutes a major part of each of the 50 state budgets. States have invested
heavily in their mental institutions, and with reduction of public inpatients many states significantly have improved their hospitals and treatment and rehabilitation programs. The vast majority of seriously mentally ill are in the community, but most states continue to be focused institutionally because of their commitments to maintain hospital improvements in a context of increased court scrutiny, because of the pressures of hospital employees and communities that depend on the financing of hospitals, and because states are reluctant to take on large, new community obligations within a context of fiscal constraint. In 1981 two-thirds of state expenditures continued to support state hospitals although the proportion varied from more than 90 percent in such states as Georgia, Iowa, and Mississippi, to a minority of expenditures in California and Wisconsin (National Institute of Mental Health 1985). In the latter instances, there are strong state incentives for local government to seek alternatives to inpatient care. In Wisconsin, mental health financing encourages managed care and tradeoffs between community and inpatient care (Stein and Ganser 1983).

The problem of getting services to follow the patient is inherently more difficult in states having well-established hospital systems, communities economically dependent on hospitals, and well-organized and unionized employees. Such systems require transition strategies that allow funds to follow the patient on a graduated basis, that guarantee the stability of the hospital system over some period of time, and that facilitate working closely with unions and employees in programs of scheduled attrition and retraining to the extent that is feasible. Concomitantly, structures need to be developed for diversion of inappropriate admissions to community programs and for intensive discharge planning commencing soon after a patient is admitted to a state hospital.

Because of the barriers in many states to a community-based system, phasing-in such programs may initially require enhanced funding to build community care structures while maintaining some redundant hospital support. To the extent that such financing allows the initiation of a more rational financial process, it is a wise long-term investment, although it may require considerable persuasion before state legislatures, facing resource constraints, see the wisdom of this course.

At the federal level, the two major welfare changes that affected mental health were the Medicaid program and the expansion of Social Security Disability coverage. The disability programs had the dual function of providing community subsistence but also automatically
including recipients under public health insurance programs. These programs are vital to the future of the public mental health system. Unfortunately, those who make policy in these areas have little awareness or knowledge of serious mental illness, and the impact of these programs on the mentally ill is a by-product of other health policy concerns. The mental health sector has not related meaningfully to the formulation of many of these important policies and their administrative implementation.

**Improving Disability Determination**

The disability program, as it affects the mentally ill, is instructive. Based on a concept of permanent and total disability, eligibility criteria are believed to reinforce a sense of personal defeat and to be a disincentive to rehabilitation. Many mental health professionals feel ambivalent in encouraging clients to enter the disability system. Viable community care, however, depends on such support since many severely mentally ill cannot maintain employment, are too disoriented, or behave too bizarrely to be acceptable to employers. By the mid-1970s there had been a major expansion of numbers of disabled persons receiving disability insurance, among whom the mentally ill were a major subgroup. The growth in these costs led to the 1980 amendments to the Social Security Act in which Congress required that states review all awards at least every three years. These reviews resulted in the loss of benefits among large numbers of the severely mentally ill, and subsequently, to much litigation in the federal courts. It became apparent that the application of existing disability criteria seriously underestimated the incapacities of many chronic patients to work in a sustained way, and stripped significant numbers of their benefits. Subsequently, new psychiatric criteria based on an integrated functional assessment were developed that have supported the reinstatement of many patients excised from the disability rolls.

Disability determinations require considerable discretion on the part of the Social Security Administration (SSA), and success in gaining eligibility depends in no small way on how the claim is constructed, how appropriate medical and psychiatric information is obtained, and the persistence of the potential recipient. There are several levels of review, and administrative law judges (ALJs) who hear appeals for the SSA reverse denials in approximately half of the cases they review
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(Mashaw 1983). Seriously mentally ill persons often have difficulty making an appropriate application for disability, presenting their needs in a way that increases probable success, or understanding their options when faced with denial. Because of the large numbers of mentally ill denied benefits in recent years, mental health workers and other advocates have taken an aggressive role in pursuing appeals at both the ALJ level and in the federal courts.

Expeditious attainment of disability benefits is important in order to stabilize the chronic patients' life situations and plan appropriate care. Barriers include the common delays in awarding benefits and the contradictory eligibility criteria for such benefits and access to vocational rehabilitation services. We need a better way of providing the chronic patient essential subsistence so as not to discourage rehabilitation. In some localities, mental health personnel and state agencies administering disability determinations have government workers located in mental health service facilities to make the disability filing process more simple and accessible. But if the potential of this system is to be better realized, the disability system must be linked to stronger incentives for rehabilitation. This requires reconciling contradictory assumptions and eligibility requirements in these program areas.

The Need for Medicaid Reform

The key to effective community care systems is reimbursement and the financial incentives that shape service provision. The Medicaid program is vital to the long-term mentally ill, the vast majority of whom are poor and depend on the public system. It constitutes the largest potential source of federal funding for reconstituting our system of public mental health care. Medicaid accounted for expenditures of $991 million in state and county mental hospitals in 1983 (Redick et al. 1986), primarily for the population under the age of 21 and over the age of 64. In 1980 Medicaid was the expected principal source of payment for 1.9 million inpatient days in nonfederal general hospitals and private psychiatric hospitals (estimated from National Institute of Mental Health 1985, 46). Because of the fragmentation of service organizations, in the typical system of community services there is little ability to track mentally ill clients. The chronic patients having an exacerbation of symptoms come in or are brought to emergency
rooms where they are seen by physicians unfamiliar with them, and who choose hospitalization because of the insecurities that uncertainty provokes. In a well-organized community program, many of these admissions could be prevented and the patient referred to more appropriate care. About two-thirds of Medicaid mental-illness bed days relate to the chronic population; more effective use of these expenditures could contribute much to revitalizing public mental health services.

Reforming Medicaid in this context is particularly complex in light of the wide range of mental health benefits across states. Several short-term options can be pursued, however. Demonstrations are now being planned that facilitate the pooling of expected inpatient and outpatient Medicaid contributions under the control of a single public entity that establishes systems of managed care for a defined population of public patients. Waivers will not only permit the responsible entity to balance community and outpatient care, and psychiatric and social services, but, even more important, could allow a sufficient resource base to construct the necessary components of service into a system. There are technical barriers involving assessing and sharing risk, and arriving at a realistic basis for estimating federal contributions, particularly in the present context where many patients are not receiving even minimal services. Such an approach, however, offers a strategy for a coherent way of managing one of the most difficult and disorganized arenas of care for seriously impaired persons.

Managing Care for the Severely Mentally Ill

Effective community care for the most seriously disabled patients requires performance of many of the same functions as the mental hospital, ranging from assuring appropriate shelter to managing serious medical and psychiatric problems. To do so in the community context requires some influence over areas of responsibility involving different sectors (housing, medical care, social services, welfare) and varying levels of government. To recreate these functions outside the hospital without the control over resources that hospitals typically have is a formidable challenge and one that has to be assessed in relation to the political culture and legal and professional environments of varying localities. Performance of the task requires a sense of mission, clear definition of responsibility, and an understanding of the longitudinal
The system is overwhelmed by difficult patients who need long-term management and persistent efforts for modest results. The responsible organization must have the financial and organizational capacity to provide the necessary services directly or through contract. Especially difficult areas include housing and case management. Each deserves some discussion.

The Problem of Housing

The homeless have become a growing problem in our nation's large cities. Estimates of the size of this population vary a great deal, with a range from a quarter of a million to 3 million. Among the explanations suggested for the increased homeless population are a changing employment market and increased joblessness, the loss of low rent housing in cities with conversion of housing stock, redevelopment and gentrification of inner city neighborhoods, the erosion of the "safety net" for the poverty population, and the deinstitutionalization of the mentally ill. Many of the homeless have profound mental health needs, but the notion that deinstitutionalization caused homelessness is a gross misconception. Individual studies differ in criteria for judging mental illness among the homeless, but existing evidence suggests that as many as one-third to two-fifths of the homeless suffer from significant mental impairments, and that this is a population of immense medical and mental health need (Lamb 1984; Rossi et al. 1987). These problems are exacerbated and, in some cases, may be in consequence of lack of adequate shelter. The homeless mentally ill are simply the most visible of much larger populations that are not only inadequately housed but are not receiving the medical and mental health services they need (Lamb and Grant 1982). In every large city, local mental health services lack access to housing they require to organize care effectively for the patients they serve. Mental health agencies in large cities control limited housing placements, have only superficial relations with public housing authorities, and almost all report housing needs for the severely mentally ill that substantially exceed availability. In many instances, housing placements constitute as little as 5 to 10 percent of estimated need.

In recent years many cities have encountered vigorous resistance to the siting of group facilities for the chronic mental population as well as other stigmatized groups. This has seriously limited the neighborhoods
in which group homes can be located, often resulting in concentration of such facilities in marginal and transitional neighborhoods. Many cities have come to see scattered site housing as a pragmatic response to community concern. They justify this strategy in terms of promoting patient independence, which may be appropriate for some but not many others. Communities need viable plans for developing a range of housing from group homes and supervised apartments to independent living. There is room for different views on the appropriate mix, but it is unlikely that any limited option could serve a population as heterogeneous as this one.

Housing for the mentally ill, as one component of a much larger housing problem, exemplifies the gap between needs and reality. Housing is an integral part of a coherent community care approach, but while many chronically mentally ill are eligible for housing assistance they get little attention from city and county housing authorities, who have little understanding of their special needs, and, in any case, face profound problems of identifying available housing stock to meet pressing demands from many groups. Progress in this area depends on enlarging appropriate housing sites and collaboration between the mental health services and public housing authorities. Cooperation makes possible joint ventures and relationships with nonprofit developers to stimulate housing opportunities appropriate to the severely mentally ill. These arrangements can be made more acceptable if the responsible mental health entity provides support services and emergency response systems for landlords. Initiatives for developing housing opportunities within organized mental health systems, as in the recent program by the Robert Wood Johnson Foundation and the U.S. Department of Housing and Urban Development are a critical need (Aiken, Somers, and Shore 1986). But in the final analysis, while improvements are possible within current constraints, effective solutions will depend on the willingness of government at all levels to face the crisis in low-income housing and take meaningful steps to remedy the displacement of the poor from housing opportunities in many of our large cities.

**Case Management**

As communities view the challenge of developing appropriate care for the most disabled, they embrace the case-management concept. The concept has varied meanings in different contexts, but case management
has a long tradition in social work, where the case worker helped identify and mobilize a variety of community services on behalf of a client. Many of the case-management approaches used in social work for decades, such as street teams, crisis intervention, and brokering community services, are being adopted particularly in relation to the new young chronic patients and the homeless mentally ill who are less inclined toward traditional service approaches.

Case management is loosely thought of as a solution to a wide variety of difficult problems. But the responsibilities it is expected to bear are alarming in the context of the realities of system disorganization and the types of personnel given these tasks. Thinking about case management in the more restricted medical context, the case manager is the primary care physician who serves as the doctor of first contact, provides the necessary continuing care and supervision, and makes appropriate referral for specialized medical and other services. The integrity of this role requires high-level and broad-scope clinical judgment, linkage with the needed specialized services, and authority with other doctors and professionals and with the patient. What is more important, it requires the authority under reimbursement programs or existing financial arrangements to provide or prescribe necessary services (Lewis, Fein, and Mechanic 1976).

Case management with the chronically mentally ill population is inherently more complex. It not only requires appreciation of general medical and psychiatric needs and care, but sophistication about such varied issues as housing, disability and welfare benefits, psychosocial rehabilitation, sheltered and competitive work programs, and issues relating to the legal and criminal justice systems. In some systems of care, the case manager functions as a therapist as well as a broker of services; in others the case manager helps define and marshall the necessary services but has no direct therapeutic relation to the client. The scope of case-management functions, the typical caseload, the level of expected training and experience, and the authority of the case manager vary enormously both within and among systems of care. Indeed, the concept is used so broadly as to have no specific meaning at all.

While the concept of the case manager has intuitive appeal, it remains unclear whether it is appropriate or realistic to assign such varied and complex functions to individuals in contrast to more complex teams or subsystems of care. First, there must be a clear definition
of continuing responsibility; few professionals other than physicians have traditionally taken such roles. Second, given the diverse and complex functions necessary, specialization is more likely to lead to effective service. Third, case management of these patients is clearly a longitudinal process, but the "half life" of case managers is short, and attrition is high. Case managers typically have neither the training and experience, control over resources, or professional standing to command resources from other organizations or even to be persuasive with them. Thus, case management to be effective must be embedded in an organizational plan that defines clearly who is responsible and accountable for the care of the most highly disabled patients, that has in place the necessary service elements to provide the full spectrum of needed services, and that can coordinate and control diverse resources that flow into the system so that balanced decisions can be made about the expenditure of limited resources.

Organizational Barriers

In the hospital we take shelter, activity, and basic medical supervision for granted, but each poses serious challenges for community programs of care. The closed character of hospitals allows staff to monitor patient activities carefully, to ensure medication regulation and compliance, and to induce appropriate behavior through a system of rewards. In the community, each of these areas becomes problematic and presents organizational challenges. Even approximations of these responsibilities require a level of organization and coordination absent in most community mental health service programs. Scarce resources, fragmentation of funding and service elements, lack of clear definitions of responsibility, and poorly developed career structures for the mental health professions in community care pose significant obstacles.

The Absence of a Clear Focus of Responsibility and Authority

In most of the nation's urban areas, responsibility for serving the mentally ill is fragmented among varying levels of government and categorical service agencies. There is typically little coordination among governmental sectors and providers of service, resulting in inefficiencies, duplication, poor use of resources, and failure to serve clients in need.
Public mental hospital units, funded and administered by the state or county, may be poorly or not at all linked with outpatient psychiatric care or psychosocial services. Admission to and discharge from inpatient units often occurs without relation to an ongoing system of community services, or careful long-term planning of patients' needs. Agencies serving the homeless, the substance abuser, or the retarded maintain separate service systems, making it particularly difficult to help patients with multiple problems, and inpatient care under Medicaid and local medical assistance programs often function independently of outpatient care or psychosocial rehabilitation services in the community.

The precise shape of the necessary administrative structures remains unclear; different structures will fit varying political, legal, and service delivery environments. While establishment of mental health authorities implies centralization, an administrative authority could promote local diversity and program innovation. Concentration, however, can lead to less flexibility, innovation, and public support. In one city, for example, the director of a functioning authority for most of the chronic patients in that community made the strategic decision not to take over a number of smaller agencies serving some of these patients. The rationale was that each of these agencies had an enthusiastic board who served as advocate for improved care and such advocacy outweighed the advantages of his taking direct control over these agencies.

There are a variety of models for nonprofit and public authorities in such areas as transit systems, freeways, and redevelopment efforts (Walsh and Leigland 1986). Unlike authorities that can raise capital through income-producing potential, the ideal of a mental health authority comes closer to state educational authorities intended to operate with more flexibility than typical government bureaucracies. The ideal is not always realized, and these agencies do develop their own bureaucratic cultures.

The relative merits of organizing mental health services through government agencies, special boards designated by statute, nonprofit voluntary groups, or some hybrid of these forms remain unclear. Nor is it obvious to what degree such entities should be direct-service providers as well as planning, financing, and administrative bodies, or whether they should restrict themselves to limited administrative and regulatory functions in relation to contracting agencies. These assessments cannot be made in the abstract but must be weighed in relation to the organization and effectiveness of existing service providers,
statutory requirements, and the political culture of the locality. In theory, performance contracting and the competition it implies seem advantageous to publicly organized services, but in practice the funders often become dependent on their contractees and may have few real options (Dorwart et al. 1986).

The specific strategy for governance is perhaps less crucial than the message that the mental health public sector is being revitalized. Public mental health services are in low repute among professionals, many patients, and the general public. They have typically become excessively bureaucratic, self-protective, risk-aversive, and have provided little incentive for innovation. Yet, there is little likelihood that the complex needs of the chronic mental patient will be met by the private sector. Public mental health services require greater control over resources and flexibility in operation if they are to engage the attention and energies of outstanding administrators, psychiatrists, and other mental health personnel. By engaging the interest of professional communities, university training programs, and the larger public, the isolation of public-sector services can be reduced. Reasonable career structures for mental health professionals in the public sector can be developed with more opportunity to enhance the professional training and continuing education of those who work in public mental health. But achieving this will require the development of a strong and more independent entity than is now evident in most state mental health systems.

Mental Health Advocacy

The increased involvement of families of the severely mentally ill through the National Alliance for the Mentally Ill and other organizations is leading to a forceful constituency. Severe mental illness constitutes one of the nation’s most serious health care problems, but support for appropriate services and research is substantially less than in the case of other categorical disease entities that have had strong, persistent, and effective political constituencies. Mental illness interests have been less persuasive politically for many reasons, but inability to unite their advocacy groups and the reluctance of influential family members to speak openly about the devastating impact of these problems and lobby have been major deficiencies. With the organization of the
alliance and coalition building among varying interest groups, prominent persons more commonly acknowledge mental illness in their families and lobby aggressively for greater government investment in services and mental health research. Health care financing is in substantial part a political activity, and the mentally ill will only get their share when they can use the political process as effectively as those representing cancer, heart disease, and Alzheimer's disease.

Mental illness continues to suffer from discriminatory treatment in public as well as private health insurance. Such programs as Medicare, affecting not only the elderly but also the younger disabled population, have coinsurance and maximum benefit limitations that ration mental health services more than any other care for diseases of comparable magnitude. Medicaid, in many state programs, provides little or no mental health coverage and, even in the most generous states, benefits are relatively limited. Similarly, private health insurance, even in the largest firms, has more limits on coverage for mental conditions than others and often outpatient benefits involve extremely high coinsurance (Brady, Sharfstein, and Muszynski 1986). Under nonprofit insurance programs, mentally disabled dependent children may fail to receive coverage comparable to that available to physically disabled dependent children (Rubin 1987).

An important motive for limits on mental health coverage is cost containment, but this does not explain the special status of mental health benefits. The traditional responsibility of state government, and the deep prejudice toward disorders of the mind, probably play some role, but it is also apparent that major health policy makers know less and care less about mental illness than many other major morbidities. Gaining equity in the current cost-conscious context is difficult, but this area could be a continuing point of pressure for mental health advocacy groups.

Insurance reform remains a long-term objective, but a more focused and acute problem is the underfinancing of the public mental health sector. Most chronic mental patients inevitably end up in the public sector when personal resources are depleted and limited insurance coverage, if there is any, is exhausted. These patients depend, thus, on the generosity of state and local mental health funding, and the quality of Medicaid coverage. The federal government has removed itself from the mental health services arena, arguing it is a state responsibility. Perhaps the most likely route to federal assistance will
come as greater pressures build to seek federal relief for the growing uninsured population that now numbers 37 million people. Addressing needs of the chronic patient thus inevitably requires forceful advocacy, close attention to the organization of public-sector services and public financing, more generally, and opportunities to build coalitions with other interested constituencies.

In sum, the problems commonly attributed to deinstitutionalization are more complex than the debate suggests, reflecting important changes in the nation’s demography, concepts of civil liberties, social welfare, and in the financing and provision of medical services more generally. Ample evidence exists that structures can be developed to provide appropriate community care for most mental patients (Stein and Test 1980a, 1980b; Falloon et al. 1984, 1985; New South Wales, Department of Health 1983; Kiesler and Sibulkin 1987; Leff et al. 1982). Success of important components of essential programs has been demonstrated in many settings (Fairweather et al. 1969; Stein and Test 1978; Tessler and Goldman 1982) but they rarely all come together in a single community. An effectively constituted public entity with the ability to direct substantial resources would allow linking components essential for maintenance of function and rehabilitation into a responsible alternative to long-term or episodic hospital care. The course is not fully clear and there is much uncertainty about the future. Existing evidence and experience suggests, however, that we have the capacity to do far more than at present, even within the limited means available.

References


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