

Defining 'Mental Illness' In Mental Health Policy

Diagnosis does not efficiently measure the need for treatment; we have better methods for managing scarce resources.

by **Howard H. Goldman and Gerald N. Grob**

ABSTRACT: Mental health policy is shaped fundamentally by the definition of *mental illness* associated with the policy. Changing policies reflect changing definitions. At various times, the definition may be narrow or broad with respect to the scope of conditions covered by a specific policy. The priority accorded to impairment severity is the most crucial and enduring policy issue related to the definition of *mental illness* and the scope of that definition. This paper explores the role of definitions in framing mental health policy, using examples from the history of policy making over the past half-century. [*Health Affairs* 25, no. 3 (2006): 737-749; 10.1377/hlthaff.25.3.737]

MENTAL HEALTH POLICY IS SHAPED by the definition of *mental illness* associated with the policy. At various times, the definition may be narrow or broad, depending on the scope of conditions covered by the specific policy. Some recent policies focus on the broad set of mental disorders in the diagnostic nomenclature; others focus on a narrow band of the most disabling conditions. Some policies deal with integrating mental illness into the mainstream of health and social policy; others focus on how mental disorders require special considerations or exceptions to mainstream policies.

The priority accorded to the severity of impairment is the most important and enduring policy issue related to the definition of *mental illness* and the scope of that definition. Although there has been a general trend toward placing a higher priority on providing treatment and services for people with the most severe and potentially disabling conditions, there has always been a counterpressure favoring a broader concern for people at all levels of impairment. Increasingly, people with a wide range of disorders are seeking mental health services, which puts pressure on resources and necessitates policies to allocate them.

This paper explores the role of definitions of mental health conditions in framing mental health policy, using examples from the history of policy making over the past half-century. Our main focus is the role of illness severity and the limita-

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tions of diagnosis for assessing need and shaping policy. Our secondary focus is on the tension between policies of inclusion of mental health concerns in mainstream health and social welfare programs and policies of exclusion, special financing, or exceptions for mental health disorders and mental health services.

Defining ‘Mental Illness’

Although explicitly not a policy document, the 1999 mental health report of the U.S. surgeon general reviewed the scientific basis of mental health and illness to inform mental health policy.¹ The report ended with a set of “courses of action”—broad policy recommendations that followed from its main findings that mental disorders are real health conditions, treatments are efficacious, and mental health is fundamental to health. These conclusions then served as the scientific basis for the 2002–2003 President’s New Freedom Commission on Mental Health.²

The surgeon general’s report begins with a set of definitions of *mental health* and *mental illness*:

Mental health is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and an ability to adapt to change and to cope with adversity. ...Mental illness is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning (pp. 4–5).

Further, the report followed convention in psychiatric epidemiology and mental health policy by defining subpopulations on the basis of degree of impairment.

■ **Incidence of mental illness.** *Serious mental illness* is a term used in federal regulations that defines some 5.4 percent of the U.S. adult population with a mental disorder that interferes with at least one area of social functioning. About half of these people (2.6 percent of adults) experience a severe and persistent mental illness. For children, federal regulations refer to a subpopulation with serious emotional disturbance (SED), involving some 5–9 percent of children, who have a mental disorder that imposes more limitations than experienced by the approximately 20 percent of children who experience some mental disorder during the course of a year.

These definitions are essential to understanding all of mental health policy. For example, the recent President’s New Freedom Commission focused specifically on services for adults with serious mental illnesses and for children with SED. The Executive Order charged the commission with keeping that narrow focus and maximizing “the utility of existing resources.”³ Key issues for this panel and previous mental health policy initiatives have been who constitutes the target population and what is the role of impairment severity in allocating resources.

■ **Epidemiology of mental disorders.** The epidemiology of mental disorders shows that most people who experience such a disorder live in community settings rather than in institutions.⁴ The service system is highly differentiated; mental health services have historically been separate from general health services, and public sectors, from private sectors. Different subpopulations are served in various

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organizations and agencies, subject to different policies, and affected by different programs. For example, adults with severe and persistent mental disorders are found most frequently in the public sector, using either categorical state and local mental health dollars or Medicaid, for those who qualify for Supplemental Security Income (SSI) (because they meet the criterion for disability and are poor). Those who have a work history might qualify for Social Security Disability Insurance (SSDI) benefits and also receive Medicare, which will fund their health service use. People with a serious mental illness might also be funded by Medicare, if they have retired, or by Medicaid, if they qualify for Temporary Assistance for Needy Families (TANF). Children with SED are eligible for special services in schools.

■ **Public and private sectors.** The public sector, with government employees providing services in government facilities, serves many disabled people who have limited resources but do not qualify for Medicaid or Medicare. Most of the services provided with the remaining public dollars are delivered under contract or with grants to private providers and agencies. In contrast, private insurance covers those who are employed and whose mental disorders are not persistently disabling, although their disabled dependents might also be covered by the family’s insurance. People with less severe mental disorders and with mental health problems might be treated in general medical settings, in the workplace or school, or just about anywhere in the community.

Definitions And Policies Intertwined—A Long History

There is a long history of interaction between mental health policies and definitions of *mental illness*.⁵ One of the most important examples dates to the late nineteenth century, when states passed a series of State Care Acts, which transferred responsibility for the care of people with severe mental disorders to the state. These acts still account for the public sector’s responsibility to provide care and treatment, particularly for those who are impaired and poor.

The first State Care Acts, in New York in 1890 and in Massachusetts in 1904, centralized financial responsibility for care of the indigent insane, a responsibility that had been divided between the state, which built asylums, and local governments, which often paid for the episodes of care. Local governments often preferred to keep people in local welfare institutions because of lower costs. Once the state accepted financial responsibility, local governments took the opportunity to redefine dementia and other disabling conditions of old age as “insanity” and transfer elderly people from almshouses to state institutions for lifelong care. This early example of cost shifting also illustrates the effect of definitions of *mental disorder* on policy. We now offer four contemporary examples of this phenomenon.

■ **Mental health or mental illness?** In the 1960s, tensions arose between policies for people with severe and persistent mental disorders and policies for those with the full range of conditions, including mental health problems.

A joint commission. The Joint Commission on Mental Illness and Health was created in 1955 by the American Psychiatric Association and the American Medical Association.⁶ As the name suggests, the commission had a broad mandate, and panel members had strong differences of opinion on basic matters, including the appropriate scope of its activities. Some commissioners favored a focus on individuals with disabling mental disorders; others wanted to focus on mental health problems and their prevention. The commission's agenda was elastic enough to cover the disagreements, and it set out to study mental illness and health and the various "medical, psychological, social, cultural and other factors that relate to etiology."⁷ The commission began with a concern for serious mental illness but over time shifted its emphasis to include mental health problems. Its final report, *Action for Mental Health*, published in 1961, favored a community-based system of integrated hospital and ambulatory services. But it also stipulated that no mental hospital be built with more than 1,000 beds and recommended that hospitals with more than that number of beds be transformed into long-term care institutions for chronic diseases, including mental disorders.⁸

The federal government extended the commission's service recommendations from a set of policies intended to assist disabled people and the state institutions that served them into a policy of support for a system of community mental health centers (CMHCs) that would serve people with all mental health conditions and work to promote mental health more broadly. *Action for Mental Health* made recommendations for improving services for people with severe mental disorders, but it also gave a strong impetus for expanding services for those who had not yet experienced a mental disorder or who had mental health problems tied to social inequities and other sources of environmental stress.

The NIMH's community programs. Ultimately, the National Institute of Mental Health (NIMH) launched two programs. The first was a small technical assistance program for state mental health authorities to develop new policies for mental hospitals. The other, a much larger and more ambitious program, came into existence when Congress passed the Community Mental Health Centers Act of 1963. The expectation was that eventually there would be a CMHC in each of the 2,000 U.S. catchment areas.

For a decade, the CMHC program grew, as did its scope. The NIMH argued for its expansion because it was advancing community care of people with severe and persistent mental disorders and assisting states in their policy of deinstitutionalization. It testified that the resident population of state mental hospitals was falling in relation to the increase in the number of CMHCs. In fact, however, there was little direct relationship.⁹ By the mid-1970s, the NIMH realized that it needed to improve CMHCs' role in caring for people with more-severe disorders. This re-

alization was spurred further by a U.S. General Accounting Office (GAO) study critical of the CMHC program for not doing more to improve the lives of people with “chronic mental illness.”¹⁰

The NIMH had created a work group to address the problem in 1974; in 1977 it made a series of grants to states and local communities under the Community Support Program (CSP). The grants encouraged states and communities to develop “community support systems,” which took a broader view of the needs of people with disabling mental illness.¹¹ This vision was to take hold across the country as public mental health systems began slowly to shift attention from the broad population served by CMHCs to those released from state hospitals. It was fitting that the NIMH funded the CSP with the resources from the small program of technical assistance to state hospitals initiated following the lead of *Action for Mental Health*.

The 1977 President's Commission. The critique of the NIMH and the CMHC program coincided with a change in presidential administrations. When Jimmy Carter came to Washington in 1977, he created a President's Commission on Mental Health, with his wife, Rosalynn, as its honorary cochair. The commission had a broad agenda, and like its predecessor, the Joint Commission on Mental Illness and Health, it encountered tension between those who favored a broad definition of *mental health* and those who favored a narrower focus on mental illness. Like *Action for Mental Health*, the commission's final report in 1978 covered a wide agenda to meet the needs of many different groups.¹² The legislation that followed in 1980, after almost two years of intense debate—the Mental Health Systems Act—was a smorgasbord. Although it had recommendations dealing with people with severe and persistent mental disorders, it also included service programs for children with SED and for members of ethnic minorities regardless of the severity of their conditions, and it outlined ways to target mental illness prevention. Authorizing legislation created a grant program for specific services for state mental health authorities in a forerunner of new federalism.¹³ The CMHC program had made grants directly to local service provider organizations.

Block grants instead of appropriations. No appropriations were ever made for the new programs, as almost every provision of the Mental Health Systems Act was repealed with the Omnibus Budget Reconciliation Act (OBRA) of 1981. Ronald Reagan had come to the White House with a new domestic policy agenda. A mental health and substance abuse services block grant replaced the proposed appropriations for the Mental Health Systems Act.

These mental health service programs were categorically funded. The CMHC program, the CSP, the proposed Mental Health Systems Act services, and the Reagan block grant were all grant programs. They did not provide mainstream health and social welfare resources; rather, these programs required specific and periodic authorization and appropriation from Congress.

The switch to mainstream insurance programs. All the while, the mental health system

was undergoing an important transformation. People with mental disabilities were living in community settings, and their incomes were being supported by Social Security disability programs. As a result, many of them qualified for Medicare and Medicaid—both mainstream health insurance programs created in 1965 at about the same time that the CMHC Act was passed. According to Richard Frank and Sherry Glied, these mainstream programs have made us better but not well.¹⁴

■ **A new focus on severe and persistent mental disorders.** Our second example explores the new way of looking at mental health care that emerged in the 1980s, when the focus of federal and state mental health policy shifted again toward concern for people with severe and persistent mental disorders. The shift paralleled a new focus on mainstream health and social welfare programs that could provide new resources for those living in their communities.

This period had its roots in the Carter Commission's 1978 charge to the Department of Health, Education, and Welfare (HEW, now Health and Human Services, or HHS) to develop a National Plan for the Chronically Mentally Ill. The National Plan was to make recommendations for improving care of people with "chronic mental illness" by altering policies of mainstream health and welfare programs, such as SSI and SSDI, as well as Medicaid and Medicare.¹⁵ The first step in the process and the first chapter in the National Plan involved defining the target population and estimating its size and other dimensions.¹⁶ The definition emphasized the duration of disability for people with the most severe disorders. When service users and advocates complained that the term "chronic mental illness" had negative connotations, the term was changed to "severe and persistent mental illness."

The National Plan renewed the priority on people with severe and persistent mental illnesses and underscored the importance of mainstream health and income support programs. In spite of Carter's defeat in 1980 and the arrival in Washington of an administration that was unfriendly to the provisions of the National Plan, most of those provisions were implemented during the 1980s. Interestingly enough, many of the changes were the result not of passage of legislation but, rather, of the actions of federal officials in such agencies as HHS and the Social Security Administration. Each of these mainstream programs altered their policies to accommodate the special needs of people with mental disorders. The criteria for disability attributable to mental impairment were changed, a variety of psychosocial rehabilitation services were added to Medicaid, and the annual limits on mental health benefits in Medicare were removed. These small, incremental changes reshaped the mental health system, expanding community programs and improving income supports for those with disabling mental disorders. SSI, SSDI, Medicaid, and Medicare became the financing backbone of public mental health services. They also expanded mental health services for Medicare beneficiaries and Medicaid recipients who did not have a disabling mental illness but qualified on other eligibility criteria.

■ **Improving mental health benefits in Medicare.** The third case provides two

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examples of the role of diagnosis in efforts to improve mental health benefits in Medicare. On the one hand, it illustrates how the special case of reimbursement for outpatient services for treating Alzheimer’s disease led to inclusion of all mental disorders in expanded insurance coverage. On the other, it shows how diagnostic considerations in Medicare’s prospective payment system (PPS), with its diagnosis-related groups (DRGs), took mental health care financing out of the mainstream of a major health program. An exception was made because DRGs were not appropriate case-mix adjusters for mental health care.

The drive to improve Medicare outpatient benefits for mental disorders began with a specific policy about one condition, Alzheimer’s disease, and then expanded to all mental disorders.¹⁷ In contrast, the limitations of diagnosis and DRGs in predicting inpatient costs led to the exemption of specialty psychiatric hospitalization from the PPS.¹⁸

Alzheimer’s disease task force. The first opportunity following the National Plan to expand the outpatient mental health benefit in Medicare came in 1984, when a Departmental Task Force on Alzheimer’s Disease considered a recommendation to reduce financial barriers to appropriate treatment for Alzheimer’s disease patients.¹⁹ One of the main barriers was Medicare’s \$250 annual limit and 50 percent copayment for mental health services, which were viewed as disincentives to receiving appropriate treatment for the many troubling behavioral complications of Alzheimer’s. Departmental leaders felt that a major statutory change affecting all mental disorders was infeasible and exceeded the mandate of the task force. Instead, they recommended a change in coverage for Alzheimer’s disease that could be accomplished using HCFA (now the Centers for Medicare and Medicaid Services, or CMS) guidelines without more elaborate regulatory or statutory change. Medicare directed its insurance carriers that the \$250 annual limit and the 50 percent copayment should not apply to any outpatient services for “medical management” of people with a diagnosis of Alzheimer’s disease. Medical management referred to care delivered in routine office visits. Psychotherapy would continue to fall under the \$250 limit and the 50 percent copayment rules.

This focused policy change for financing services for Alzheimer’s disease opened the door for a series of legislative changes to the mental health benefit in Medicare. OBRA 1987 (P.L. 100-203) increased the maximum annual Medicare reimbursement from \$250 to \$1,100. The 50 percent copayment remained in place. The law, however, also exempted from the annual limit “medication management visits” to a physician. It set the copayment at 20 percent for visits whose sole purpose was to prescribe or monitor the effects of psychotropic drugs. This provision built on the distinction made following the deliberations of the Alzheimer’s dis-

ease task force. By 1990, Congress removed the annual limit on outpatient mental health services, but the 50 percent copayment for psychotherapy remains.

Prospective payment system. In 1983 Congress enacted the Medicare PPS, which implemented a system of paying for each hospital stay at a rate determined prospectively. The amount was adjusted for differences in case-mix, according to a system of DRGs. In response to lobbying about concerns about adverse consequences of a PPS on psychiatric hospitals, Congress exempted freestanding psychiatric hospitals and psychiatric units in general hospitals until Medicare could study the situation.

A series of studies confirmed that there were too many problems in using DRGs as a case-mix measure for adjusting prospective payments to include specialty psychiatric inpatient facilities.²⁰ Too many hospitals would suffer large financial losses if they were to be included in the PPS, and too many other hospitals would come away with excessive profits from the payments. DRGs were too heterogeneous, combining many disorders in a single DRG. Even within a single diagnostic category, there was a wide variation in clinical need, so DRGs could not be used reliably to predict resource needs during a hospital stay. There was also concern that diagnoses could be altered or even falsified (through “upcoding”) in the face of financial incentives that favored payments for one condition over another.²¹

For the rest of the decade (and in fact until 2005), specialty psychiatric inpatient care would be exempt from the Medicare PPS.²² At the time, this policy of “exceptionalism” (that is, special rules for mental health services) was viewed as preferable to full participation in the mainstream PPS of Medicare. Not every policy for improving mental health services called for full participation in mainstream health and social welfare programs with identical policies and rules for inclusion.

■ **Parity in private insurance.** The final case example is of parity, the drive to integrate and equalize mental health coverage in the mainstream of private health insurance. Support for parity often has depended on what definition was used for *insurance benefits*.

Efforts to improve coverage of mental disorders in private insurance markets have encountered concerns about costs and whether spending on mental health treatment is worthwhile. These concerns have limited attempts to achieve “equal” coverage, but advocates of parity in the private sector have enjoyed newer successes as well. Lawmakers were concerned about cost increases as the definition of *mental disorders* expanded. Increasing diagnoses of newly recognized conditions, such as social anxiety disorder and sleep disorders, seemed to follow the introduction of new medications. New treatments for less severe conditions stimulated demand for services.²³ The definition of *mental illness* and the criteria for the specific disorders that would be covered by insurance parity continued as a central issue. Focusing expanded benefits only on people with specific diagnoses, such as those considered more severe and more “deserving,” countered some of the concerns

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about cost. Other cost concerns were handled by managing care.

The definition of *covered conditions* has played a role in three areas of policy supporting parity in private insurance markets: in state parity legislation, the federal parity act, and the Federal Employees Health Benefits (FEHB) Program.

State parity. Beginning in 1971 with Connecticut, as many as thirty-seven states had enacted legislation as of 2001 mandating some level of insurance coverage for mental health services.²⁴ The earliest efforts, such as those in Connecticut and Massachusetts, required all companies that offered insurance under the purview of state insurance regulation to offer some level of coverage for mental disorders. As time went on, these legislative initiatives fell under the rubric of “parity legislation,” although in fact few extended comprehensive parity for all conditions to all insured people of a particular state. Some restricted the parity coverage to a limited list of conditions that were considered more severe and thus less subject to moral hazard. Sometimes these mandates focused only on “brain diseases” or “biologically based” conditions. Limiting the scope of coverage to specific conditions was a means to focus resources on those with the most severe impairments, who were considered the most in need and the most deserving. Other legislative mandates expanded benefits to cover all conditions but retained some limitations in services, such as a specified number of outpatient visits or inpatient days or higher copayments for certain services.²⁵

As managed behavioral health care became more common and more effective at controlling utilization and costs, opposition to parity tended to lessen in state legislatures. If a parity initiative limited the expanded benefits to people who were receiving treatment within a managed care provider network, it was easier to control costs, and political opposition to parity initiatives eased as a result. Managed care arrangements permitted policymakers to widen the scope of insurance in terms of defining covered conditions and reimbursable services.

Taken together, the evaluations of state parity indicated that parity was associated with some expansion of care and treatment, particularly outpatient services, while inpatient care contracted. Total costs remained largely unchanged. Managed care made parity possible, but not always palatable for providers and some service users, because of hassles associated with utilization management and intrusion into the professional relationship by third-party managers.²⁶ Providers also resented the managed care companies’ successful efforts to negotiate lower fees for their clinical services. Some advocates also were concerned that managed care would restrict some private-sector services, forcing privately insured people into public services. Furthermore, parity initiatives in private, employer-based insurance markets had a more limited impact on people with severe and persistent

mental disorders, particularly those who were unable to work or who worked in jobs without health insurance benefits.

State parity initiatives would have been the only needed policy instrument in the private sector, if federal legislation, the Employee Retirement Income Security Act (ERISA) of 1974, had not given large employers who had employees in many states the right to self-insure and thus become exempt from state insurance regulations. Federal legislation was required to expand the effects of mental health parity to more people, particularly those in ERISA plans.

Federal parity act. Between 1994 and 1996 the main policy focus of federal mental health policy advocacy was on passage of a federal parity act. This effort paralleled the process of developing parity legislation in states across the country, as described above.²⁷ In 1992 Senators Pete Domenici (R-NM) and Paul Wellstone (D-MN) each proposed a federal mental health parity bill. Each had a somewhat different approach, however. Senator Domenici supported legislation that provided generous coverage for a limited number of the most severe mental disorders. Senator Wellstone, by contrast, sponsored a measure that would cover the full array of mental disorders, including substance abuse disorders. Neither bill was enacted, and health reform preempted the issue for about a year. Subsequently, the two senators cosponsored a bill that provided parity benefits for the treatment of all mental disorders except for those related to substance misuse. Their bill was debated in several sessions of Congress until 1996, when it was eventually scaled back.

What eventually became the Federal Mental Health Parity Act (P.L. 104-204) focused only on catastrophic insurance protection, in that it mandated parity with respect to annual and lifetime limits only. Managed care was encouraged to assess the “medical necessity” of each episode of treatment. The act went into effect in 1998 and had a sunset provision allowing it to expire unless it was renewed at the end of 2001.

Up until the untimely death in 2000 of Senator Wellstone, he and Senator Domenici worked to expand the scope of federal parity. In spite of almost annual efforts to expand it, the law has been extended without modification each time it was set to expire, beginning in 2001. Cost concerns remain; opponents continue to focus on the costs associated with imagined demand for trivial mental health problems, such as “jet lag.”²⁸

The FEHB Program. There had been earlier federal attempts to provide private health insurance parity benefits for the treatment of mental illnesses.²⁹ President John F. Kennedy directed the Civil Service Commission and its health insurance program to offer the same insurance benefits for treating mental illnesses as for any other covered conditions. For more than a decade, federal employees enjoyed generous mental health benefits. After 1975, most plans began to restrict benefits. The high-option plan of Blue Cross Blue Shield was the last federal plan to restrict mental health benefits, when in 1981 it was finally allowed to scale back its bene-

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fits after years of adverse selection. The FEHB Program had once been at the vanguard of progressive mental health benefits, but by the 1980s it reflected the insurance industry’s practice of placing limitations on mental health and substance abuse benefits.

At a White House Conference on Mental Health in June 1999, the FEHB Program again took center stage in federal mental health policy, when President Bill Clinton announced that he had directed the Office of Personnel Management (OPM), which operated the FEHB Program, to offer parity mental health and substance abuse benefits in its more than 200 participating plans. The parity policy was to apply to providers within networks of clinicians and to facilities that were associated with managed care organizations. The OPM encouraged the plans to manage the care in a way that controlled the cost increases that were expected to accompany the expansion of benefits. Parity in the FEHB Program was set to commence 1 January 2001.

President Clinton called for a study to evaluate this policy experiment to guide policy in other health insurance programs considering parity.³⁰ The evaluation demonstrated that comprehensive parity could be implemented as intended. The study of impact compared a set of FEHB plans with a group of plans that did not change behavioral health benefits during the study period. The evaluation found that the proportion of users of behavioral health services did not increase more in the studied FEHB plans than in the matched plans, except in the one plan that did not manage the parity benefit. Some advocates were disappointed that parity did not seem to improve access, although use and spending did increase in all of the plans—FEHB and matched plans alike. Total spending attributable to parity did not rise, but out-of-pocket payments did decline, reflecting improved insurance protection under parity. Concerns about quality deteriorating with the managed care associated with parity were unfounded for depression and substance abuse treatment, the tracer conditions studied.

The FEHB experience, like the recent experiences with state parity policies, demonstrates that it is no longer necessary to use limitations on the basis of diagnosis to control costs and allocate resources efficiently.³¹

Concluding Remarks

In spite of concerns about its intrusiveness and the risk that it limits access to needed care, managed care provides an alternative strategy to limitations based on diagnosis, which can be arbitrary and unnecessarily restrictive. Diagnosis does not efficiently measure impairment severity or need for treatment; thus, it is not a fair or effective way to control costs. It did not work very well with DRGs and the

Medicare PPS, and it left state mental health mandates without real parity.

Mainstream health and social programs have been critical to the health and well being of people with mental disorders who live in their communities. These programs have used diagnosis to allocate scarce resources on the basis of severity and need, but this approach has not been satisfactory. Newer methods of managing scarce resources hold the promise of dealing with an enduring tension in mental health policy—how to provide the right services to those “most in need,” to improve their quality of life and to support full participation in the community. These new methods also permit expanded insurance coverage to all who might experience a mental disorder without imposing arbitrary limits on the basis of diagnosis. Taken together, these mental health policies should promote recovery and full community participation for everyone.

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