Commentary

Closing Gaps in Mental Health Care for Persons with Serious Mental Illness

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Ronald Kessler and colleagues, using data from the National Comorbidity Survey (NCS), estimate that in the period from 1990 to 1992, 5.4 million people in the U.S. household population between the ages of 18 and 54 years with a serious mental illness received no treatment in the prior year (4.7 million) or dropped out of treatment (0.7 million). Extrapolating to those not covered by the survey, this estimate rises above six million. The magnitude of unmet need for persons with even the most serious mental illnesses is not surprising news but reveals again the extraordinary failures of our mental health services system despite significant improvements in psychiatric drugs and other technologies and improved knowledge. This important survey report joins other studies in carefully documenting the magnitude of lack of care and neglect and the failure of much treatment to meet even minimal standards of evidence-based medicine (Lehman and Steinwachs 1998; Young et al. 1998; Wells et al. 1996).

CRITERIA FOR CASE DEFINITION AND HELP SEEKING

Good numbers are important for formulating coherent social policies. In mental health, both policymakers and the public have become inured to large estimates of persons with mental illness and unmet need. The expansive and overinclusive use of mental health concepts and estimates of psychopathology (Wakefield 1996; Regier, Kaelber, Rae, et al. 1998) probably contribute to public skepticism and may undermine public commitment to those who are at highest risk. Thus, it is important to examine carefully how Kessler and colleagues assess serious mental illness and define treatment.

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To their credit, Kessler and colleagues focus on disorders associated with functional impairments. Their disorder definition includes some diagnoses, such as common simple phobias, whose seriousness may be doubted and thus may be too inclusive. This is tempered by the required functional impairment associated with the disorder including vocational incapacity, serious interpersonal difficulties, a suicide attempt or plan within the past 12 months, or, alternatively, presence of the most severe disorders including bipolar disorder, major depression, nonaffective psychoses, and panic disorder. These impairment criteria are for the most part rigorous, with the possible exception of including as serious any person with a 12-month DSM-III-R disorder who reported his or her social relationships "devoid of intimacy, the ability to confide, or the sense of being cared for or supported" (Kessler, Berglund, Zhao, et al. 1996). Nevertheless, however one looks at it, millions of people with serious mental illnesses do not receive treatment, much less appropriate care.

Respondents in the NCS were said to have received treatment if in the prior 12 months they saw a psychiatrist, a psychologist, a social worker, a mental health counselor, a medical doctor other than a psychiatrist, or an ancillary health professional such as a nurse. This is a generous definition of treatment. It is well established that general physicians are important mental health providers because many people resist specialty mental health care or lack appropriate insurance coverage for mental health services. Thus, primary medical care especially is part of our hidden mental health system. However, an extensive literature over decades demonstrates that primary care doctors do poorly at recognizing mental illness, and when they do recognize it they often treat such conditions inappropriately (Wells et al. 1996; Wells, Sherbourne, Schoenbaum, et al. 2000; Mechanic 1990, 1997).

By using a generous definition of treatment, Kessler and colleagues may be underestimating the magnitude of the treatment gap. For example, McAlpine and Mechanic (2000) examined whether persons defined as seriously mentally ill received specialty outpatient care from a psychiatrist, psychologist, social worker, psychiatric nurse, or counselor in the prior 12 months or were admitted to a hospital or visited an emergency room for an emotional or substance abuse problem. This narrower definition of treatment use found, not surprisingly, that three-fifths of persons with severe mental illness in this sample did not utilize such specialty services over a 12-month period (McAlpine and Mechanic 2000). This definition of specialty care arguably represents those better-trained specialists for persons with serious and complex disorders.

INSURANCE GAP

Kessler and colleagues are correct technically in their conclusion that financing of services is unlikely by itself to eliminate unmet need for treatment. It is well established that the stigma of mental illness remains high (Link, Phelan, Bresnahan, et al. 1998), much of the public still regards mental illness as discrediting, and incorrect and poor information about psychiatric illness and psychiatric treatment abound. But in confirming that insurance alone cannot solve the problem, serious danger of misinterpretation arises. As the authors acknowledge, their measure of insurance coverage is deficient in that they simply asked respondents whether they had any mental health insurance coverage. What is needed is specification of coverage, coinsurance, and deductibles; limits on visits; and maximum benefits. Survey respondents cannot provide such data accurately, and obtaining reliable measures requires additional surveys of employers or other purchasers and sometimes the insurer. Nevertheless, others have found that persons with serious mental illness compared to those with no mental disorder are more likely to be uninsured (20 percent vs. 11 percent), less likely to have private insurance (34 percent vs. 63 percent), and more likely to be covered by Medicaid (16 percent vs. 2 percent) (McAlpine and Mechanic 2000). Persons with various types of insurance had odds ratios of using mental health specialty care from 2.5 to 7.1 as compared with persons with no insurance. Medicaid and Medicare were important safety nets; persons having such coverage had an odds ratio for use of specialty services of 5.8 relative to the uninsured (McAlpine and Mechanic 2000). I suspect that even these data significantly underestimate the importance of appropriate insurance coverage.

SOCIODEMOGRAPHIC PREDICTORS

Kessler and colleagues report relatively few sociodemographic differences in seeking help among persons with serious mental illness in multivariate analyses. This is consistent with findings from other studies, but it is nevertheless important to understand that persons with less education and income and minorities are more likely to be uninsured. Kessler and colleagues report that those aged 18 to 34 with serious mental illnesses are less likely to receive treatment and more likely to drop out of treatment than members of other age groups. They also found, surprisingly, that persons in the most rural areas with serious mental illnesses are more likely to receive treatment than persons in more populated areas. The rural finding is provocative but based

on a small sample, and it needs further confirmation. The age differences have to be understood in the context of the truncated age distribution in the NCS, which excluded persons over age 54. Had the survey included a more complete range of ages, the researchers probably would have found that both younger and older respondents with serious mental illness are less likely to receive treatment, especially from the specialty mental health sector.

There are different explanations for greater undertreatment among young adults and the elderly. Adults early in their life trajectories are resistant to diagnosis and treatment that implies a possible lifelong disorder that may impede achieving their aspirations and keeping up with their peers. Young persons with schizophrenia are particularly difficult to engage in treatment and often struggle against being incorporated into the mental health services system (Schwartz and Goldfinger 1981; Sheets, Prevost, and Reihman 1982). They not uncommonly join street cultures, abuse substances, and are jailed for minor offenses. Reaching this population requires targeted strategies that probably do better by focusing attention on potential for recovery and future function than on the disorder itself. Older cohorts, in contrast, probably have entrenched views of the stigmatizing implications of mental illness. When they receive treatment they are more likely to do so in a somatic context and in the general medical care sector, and there may be particular value for this population in downplaying psychiatric attributions. Much is yet to be learned in these areas of intervention, and they are promising areas for continued research (Mechanic 1997).

NEEDED PUBLIC POLICY RESPONSES

The problem of gaps in mental health care, particularly for persons with serious mental illness, is multifaceted and requires a long-term perspective and strategy. Parts of the problem are inherent in the disorganization of the American health care system; large numbers of people who are uninsured and even much larger groups who are underinsured for mental health services; stigmatization of persons with serious mental illness; difficulty in coordinating among various public sectors that affect this population and particularly our criminal justice system; challenges in organizing coherent and appropriate long-term care services for this population in the community; limits of our knowledge of efficacy and effectiveness in providing treatment to these populations; and character of some mental illnesses that impairs insight about the need for treatment and treatment adherence. The fact that we have made less

progress in care than anticipated over recent decades and that the problem of effective treatment for this population is a worldwide problem should make us cautious about any suggestion of a quick fix.

Despite Kessler et al.'s message that the problem transcends financial coverage, no single initiative would do more to close the gap than to provide appropriate insurance coverage for this population. It is no accident that persons with serious mental illness who are covered under Medicaid and Medicare do almost six times better in access to specialty care than those who are uninsured (McAlpine and Mechanic 2000). Medicaid coverage of course varies substantially by state; persons covered by Medicaid in states that have expanded long-term-care benefits have more access to appropriate care. Such insurance should ideally cover services and drugs administered in jails and prisons, our newest "public mental hospitals," and for those on probation. A 1999 Justice Department study reported that more than 280,000 persons with mental illness are in jails and prisons and more than a half million more are on probation (Ditton 1999). Strong coordination between payers, the mental health system, and the criminal justice system is a fundamental aspect of the picture, but it is not easy to achieve.

Many people seek to avoid services for mental illness because stigma remains and treatment is commonly seen as discrediting. Efforts have been made to reduce stigma, but much in our media and culture continues to reinforce it. Progress has been made as evidenced by the growth in acceptance of mental health services throughout the population. Various strategies to reduce stigma—among them admired cultural icons speaking publicly about their illnesses and treatment and strategies reinforcing the message that mental illnesses are disorders like other medical conditions and effective treatments are available—seem promising. The credibility of the disease argument is diminished, however, by the expansive definitions encouraged by the DSM and the medicalization of personal and social problems.

The practice of telling the public that more than one-third of us at any time have a mental illness and a majority of the population will have a mental disorder sometime in their lifetime, although correct in some sense, is also probably bad strategy. No epidemiologist would make pronouncements that most Americans have a physical illness in a 12-month period, although that too is correct. Such a statement would seem trivial and beside the point. The global concept of mental illness is dysfunctional and probably harmful (Mechanic et al. 1994; Baker and Menken 2001) although it is difficult to extricate it from our vocabulary. We would do much better to focus on specific conditions, their etiologies, natural histories, and treatments. The term

"mental illness" continues to evoke in the public's mind the disorganized and seemingly irrational behavior characterized by psychoses and unpredictable dangerousness. We know that as a class persons with psychiatric disorders are not dangerous but that florid psychotic symptoms, especially in conjunction with substance use, increase such risks (Link, Andrews, and Cullen 1992; Steadman, Mulvey, Monahan, et al. 1998). An important way to achieve credibility and fight stigma is to encourage the public to have a much more contextualized view of specific psychiatric conditions and avoid global characterizations.

I have already noted the challenges of developing an appropriate alliance with the criminal justice sector, and this is needed at the local, state, and federal levels. But organizing community care for persons with the most serious and persistent disorders also involves alliances with other sectors vital to the lives of these clients, including housing, social services, rehabilitation, and social security. After almost three decades, the intensive case management pioneered by the Program in Assertive Case Management and found to be superior in many studies as compared with conventional treatment approaches is now recognized and implemented as a useful model in many localities. But even here implementation remains slow. Managed behavioral health care providers that are taking on increased responsibility for public clients have to be inclusive of such effective approaches. Good managed behavioral health care strategies offer potential for needed coordination and integration, but managed behavioral health organizations have not yet demonstrated that they can provide the needed pattern of services for persons with serious and persistent disorders (Mechanic and McAlpine 1999).

As Kessler and colleagues make clear, many problems remain at the individual level in having clients accept a need for treatment and understand how good treatment can help them. Persons with schizophrenia and other serious illnesses may lack the insight required to understand that they are ill and need appropriate care and adherence to treatment plans. But responsibility for treatment is not only theirs. Many medications have unpleasant side effects and other risks, and patients need sensitive management and guidance with treatment regimens that minimize undesirable features. Clinician-patient communication needs to be strong so patients understand their illnesses and medications and so their treatments and problems can be addressed. Efforts to improve responsiveness to psychiatric morbidity in primary care have been advocated for decades but have only achieved modest improvements. Recent initiatives show more promise (Wells, Sherbourne, Schoenbaum, et al. 2000), but it probably is a mistake to believe that primary care physicians can be

reasonable substitutes for specialty care, especially for the more seriously ill (Mechanic 1990, 1997).

In our enthusiasm to welcome advances we still have to attend to our ignorance. New antipsychotic and antidepressant medications appear to have fewer side effects and can be tolerated more readily. We have now also demonstrated some very useful and effective management and rehabilitation strategies that improve patient function and quality of life and help reduce family burden (Lehman and Steinwachs 1998). But many patients still have difficulty tolerating treatment, go from one medication to another with little relief, and continue to live difficult and impoverished lives. Improvements in the long run will depend substantially on improving our knowledge base, establishing what is effective, and making it more possible for those who need services to reach them without undue barriers.

I have now been engaged in mental health activities for 45 years. I began my work in large, locked mental hospitals just after the introduction of Thorazine, manufactured by GlaxoSmithKline. I have been an observer, researcher, and participant in the dismantling of the old institutional system. In this process many promises were made but not kept (Grob 1994; Mechanic 1999), concern about the costs often trumped concerns about developing realistic systems of community care, and rhetoric often was substituted for good science and serious description. Yet no reasonable person could wish to go back to the earlier system of care. The majority of persons with these disorders, even in our current, dysfunctional system, are much better off than they were. Whatever deficiencies we recognize today—and there are many—any fair judgment must recognize substantial improvements. Progress has come through better science, improved drugs and other technologies, and, most importantly, the growth of health insurance and mental health coverage. The Medicaid program, with all of its deficiencies, has been the godsend of many persons with serious and persistent mental illness as well as many elderly citizens and people with disabilities. The challenge is to disseminate what we know to those who need it most; that will require improved insurance, enhancements of eligibility and coverage in the Medicaid program in many states, a stronger safety net, and more effective service linkages across sectors at local, state, and federal levels.

REFERENCES

Baker, M., and M. Menken. 2001. "Time to Abandon the Term Mental Illness." *British Medical Journal* 322 (7291): 937.

Ditton, P. M. 1999. *Mental Health and Treatment of Inmates and Probationers (NCJ 174463).* Washington, DC: Bureau of Justice Statistics.

Grob, G. N. 1994. *The Mad Among Us: A History of the Care of America's Mentally Ill.* New York: Free Press.

Kessler, R. C., P. A. Berglund, M. L. Bruce, J. R. Koch, E. M. Laska, P. J. Leaf, R. W. Manderscheid, R. A. Rosenheck, E. E. Walters, and P. S. Wang. 2001. "The Prevalence and Correlates of Untreated Serious Mental Illness." *Health Services Research* 36 (6): 987–1008.

Kessler, R. C., P. A. Berglund, S. Zhao, P. J. Leaf, A. C. Kouzis, M. L. Bruce, R. M. Friedman, R. C. Grosser, C. Kennedy, W. E. Narrow, T. G. Kuehnel, E. M. Laska, R. W. Manderscheid, R. A. Rosenheck, T. W. Santoni, and M. Schneier. 1996. "The 12-month Prevalence and Correlates of Serious Mental Illness (SMI)." In *Mental Health, United States, 1996 DHHS Pub. No. (SMA) 96-3098,* edited by R. W. Manderscheid and M. A. Sonnenschein, pp. 59–70. Washington, DC: U.S. Government Printing Office.

Lehman, A. F., and D. M. Steinwachs. 1998. "Patterns of Usual Care for Schizophrenia: Initial Results from the Schizophrenia Patient Outcomes Research Team (PORT) Client Survey." *Schizophrenia Bulletin* 24 (1): 11–20.

Link, B. G., H. Andrews, and F. T. Cullen. 1992. "The Violent and Illegal Behavior of Mental Patients Reconsidered." *American Sociological Review* 57 (3): 275–92.

Link, B. G., J. C. Phelan, M. Bresnahan, A. Stueve, and B. A. Pescosolido. 1998. "Public Conceptions of Mental Illness: Labels, Causes, Dangerousness, and Social Distance." *American Journal of Public Health* 89 (9): 1328–33.

McAlpine, D. D., and D. Mechanic. 2000. "Utilization of Specialty Mental Health Care Among Persons with Severe Mental Illness: The Roles of Demographics, Need, Insurance, and Risk." *Health Services Research* 35 (1, Part II): 277–92.

Mechanic, D. 1990. "Treating Mental Illness: Generalist vs. Specialist." *Health Affairs* 9 (4): 61–75.

Mechanic, D. 1997. "Approaches for Coordinating Primary and Specialty Care for Persons with Mental Illness." *General Hospital Psychiatry* 19 (6): 395–402.

Mechanic, D. 1999. *Mental Health and Social Policy: The Emergence of Managed Care, 4th Edition.* Boston: Allyn & Bacon.

Mechanic, D., and D. D. McAlpine. 1999. "Mission Unfulfilled: Potholes on the Road to Mental Health Parity." *Health Affairs* 18 (5): 7–21.

Mechanic, D., D. D. McAlpine, S. Rosenfield, and D. Davis. 1994. "Effects of Illness Attribution and Depression on the Quality of Life Among Persons with Serious Mental Illness." *Social Science and Medicine* 39 (2): 155–64.

Regier, D. A., C. T. Kaelber, D. S. Rae, M. E. Farmer, B. Knauper, R. C. Kessler, and G. S. Norquist. 1998. "Limitations of Diagnostic Criteria and Assessment Instruments for Mental Disorders." *Archives of General Psychiatry* 55 (2): 109–15.

Schwartz, S. R., and S. M. Goldfinger. 1981. "The New Chronic Patient: Clinical Characteristics of an Emerging Subgroup." *Hospital and Community Psychiatry* 32 (7): 470–74.

Sheets, J. L., J. A. Prevost, and J. Reihman. 1982. "Young Adult Chronic Patients: Three Hypothesized Subgroups." *Hospital and Community Psychiatry* 33 (3): 197–203.

Steadman, H. J., E. P. Mulvey, J. Monahan, P. C. Robbins, P. S. Appelbaum, T. Grisso, L. H. Roth, and E. Silver. 1998. "Violence by People Discharged from Acute Psychiatric Inpatient Facilities and by Others in the Same Neighborhoods." *Archives of General Psychiatry* 55 (5): 393–401.

Wakefield, J. C. 1996. "DSM-IV: Are We Making Diagnostic Progress?" *Contemporary Psychology* 41 (7): 646–52.

Wells, K. B., C. Sherbourne, M. Schoenbaum, N. Duan, L. Meredith, J. Unützer, J. Miranda, M. F. Carney, and L. V. Rubenstein. 2000. "Impact of Disseminating Quality Improvement Programs for Depression in Managed Primary Care: A Randomized Controlled Trial." *Journal of the American Medical Association* 283 (2): 212–20.

Wells, K. B., R. Sturm, C. D. Sherbourne, and L. S. Meredith. 1996. *Caring for Depression.* Cambridge, MA: Harvard University Press.

Young, A. S., G. Sullivan, M. A. Burnam, and R. H. Brook. 1998. "Measuring the Quality of Outpatient Treatment for Schizophrenia." *Archives of General Psychiatry* 55 (7): 611–17.