Mental Health

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Mental illness is one of the most prevalent conditions affecting the U.S. population, yet the system is marked by fragmentation and dysfunction. Mental health is the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. The term mental illness refers collectively to all diagnosable mental disorders. A mental disorder is a health condition marked by alterations in mood, thinking, or behavior associated with distress and impaired functioning (HHS 1999).

Mental disorders are the leading cause of disability in the U.S. and Canada for people ages 15 to 44.

Mental disorders are among the most common of chronic diseases. Approximately one in four U.S. adults (57.7 million people) suffers from a diagnosable mental disorder in a given year (National Institute of Mental Health 2006). About 6 percent of the population has a serious mental illness, such as schizophrenia, bipolar disorder, or major depression, that limits their ability to function in many areas of life such as employment, self-care, and interpersonal relationships (National Institute of Mental Health 2006; HHS 1999). Mental disorders are the leading cause of disability in the U.S. and Canada for people ages 15 to 44 (National Institute of Mental Health 2006). In the U.S., mental disorders collectively account for more than 15 percent of the overall burden of disease from all causes and slightly more than the burden associated with all forms of cancer (HHS 1999). Approximately 45 percent of individuals with any mental disorder meet the criteria for at least one other mental health disorder (National Institute of Mental Health 2006).

While mental health is crucial to overall health, its importance has not always been recognized. Stigma surrounding mental illness persists with serious consequences. According to the Surgeon General's report on mental health, stigma is a product of fear and misinformation and can lead to isolation, discrimination, and outright abuse of affected individuals. Individuals with mental illness often avoid seeking treatment because they fear the stigma associated with their condition.

The evolution of the U.S. mental health care system over the past two decades can be characterized by several defining trends: an increased science and research base, increased advocacy, and the transformation of the financing and delivery system (HHS 1999).

Science and Research

As researchers have gathered new information about the brain, the treatment of mental disorders has evolved. Over the past few decades, scientists have gained the ability to study the activity of the brain through technologies such as positron emission tomography and functional magnetic resonance imaging. As the ability to learn how the brain functions increases, researchers will be able to see the effects of psychotherapy and medication.

Mental health services research has demonstrated the positive effects of a psychosocial approach to treating mental disorders. While specific effects vary depending on population, overall studies demonstrate that treatment is more effective than placebo (HHS 1999). Psychotherapy is often referred to as "talk therapy," because treatment is largely accomplished through verbal communication with a therapist. Different approaches include psychodynamic therapy, based on the theories of Freud, and behavior therapy, which focuses on changing current behavior patterns. Recent approaches combine behavior therapy with a cognitive approach, helping to promote adaptive behavior.

In the late 1980s, pharmaceutical companies focused on the development of medications to treat mental disorders. The result was a new wave of antidepressants—selective serotonin reuptake inhibitors—and antipsychotic medications that are as effective as the older medications, but with significantly fewer and less severe side effects. While many older pharmacotherapies were used primarily for serious mental illnesses, new drugs are also effective in treating those with relatively mild conditions (GIH 2003).

The adoption of evidence-based practices will help improve the quality of mental health services. For some conditions, such as depression, psychotherapy may be as effective as antidepressant medication. For others, such as schizophrenia or bipolar disorder, medication may be necessary for the individual to function, but psychosocial interventions can help improve outcomes. The infrastructure for assuring the delivery of these interventions, however, is weak. While medication is government regulated, its availability ample, and its administration generally straightforward, there are no training, licensure, or certification requirements obligating providers to have competency in evidence-based psychosocial treatments such as cognitive-behavioral therapy. In addition, it is difficult for consumers to identify which providers deliver such treatments (Patel et al. 2006).

Advocacy and the Consumer Movement

Over the past few decades, consumer groups have played a critical role in influencing changes within the mental health system.[1] Specific organizations representing patients and families have developed important goals of overcoming stigma and promoting recovery from mental illness (HHS 1999). Their work has drawn attention to the limitations of the mental health system with respect to financing, quality of care, and access to services. For example, Mental Health America (formerly the National Mental Health Association) has made significant progress in strengthening the child mental health movement and through its affiliate network, educates the public about mental health. The National Alliance on Mental Illness (NAMI), founded in 1979, is the nation's largest grassroots mental health organization and places a priority serving families of adults with chronic mental illness. NAMI has also been a strong force behind mental health parity legislation, which aims to provide coverage for mental health services that is equal to that of physical health services.

The work of these groups and others legitimized the empowerment model for individuals with mental illness, influenced legislation that created mental health planning councils in each state, and worked to expand the role of consumers as an integral part of the mental health care system. Because of their work, individuals with mental illness are more fully involved in the planning, delivery, and evaluation of their care.

Financing and Delivery System

Mental health policy over the past two decades has been a story of both progress and retreat. Fragmentation is a defining characteristic of the mental health service delivery system. With little coordination or information sharing, health care providers, schools, social service programs, prisons, and government agencies make critical decisions about the services people with mental health disorders receive (LeRoy et al. 2006).

The passage of the Mental Health Systems Act in 1980 called for a community-based system of treating mental illness and recommended that a substantial portion of the new resources be provided to support community mental health centers. The Reagan Administration, however, reversed the act a year later as part of its efforts to reduce taxes, federal spending, and the role of the federal government in addressing social issues. The new legislation, the Omnibus Budget Reconciliation Act of 1981, provided a block grant for states to provide mental health and substance abuse services, reversing the commitment of several decades of federal leadership

[1] Some users of mental health services refer to themselves as consumers. The term is not uniformly accepted, however, as some contend that users of the mental health system do not have the same power of choice and advantage as consumers in other markets (HHS 1999).

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in mental health policy (Grob 2001). Under fiscal pressures themselves, states looked to federal entitlement programs, such as Medicaid and Social Security Disability Insurance, to support individuals with mental health disorders.

The integration of people with mental illness into the community was supported by the American with Disabilities Act (ADA), signed into law in 1990. The act made it illegal to discriminate against an individual with a disability, defined as a physical or mental impairment that substantially limits one or more major life activities. Individuals with mental illness are using the ADA to challenge arrangements and programs that impede full community participation. In 1999, in *Olmstead v. L.C. ex. rel Zimring*, the U.S. Supreme Court found that the provisions of the ADA prohibiting discrimination in the administration of public programs prohibits states from unnecessarily institutionalizing people with disabilities if their needs can be met in a community setting. In 2001, an executive order required states to swiftly implement the decision (GIH 2003).

In 2002, the Bush Administration established the New Freedom Commission on Mental Health and tasked the group with conducting a comprehensive study of the gaps in the mental health care system and providing actionable recommendations to governments and mental health care providers (SAMHSA 2005). The commission concluded that "wholesale and fundamental transformation of the mental health service delivery system is required" (SAMHSA 2005). The commission also articulated an agenda for federal action in 2005, which includes specific steps towards public awareness and action, community-level treatment, cost effective treatment, improved research and its application, and funding for state-level transformation (SAMHSA 2005). Such profound recommendations will likely take years to implement.

Spending

During the 1990s, nominal spending on mental health services provided by both public and private providers grew dramatically, from $48.9 billion in 1991 to $85.4 billion in 2001 (Frank and Glied 2006). The rate of growth in mental health spending, however, was slightly lower than the increase in overall health spending over the same period. As a result, spending for mental health care has declined as a percentage of overall health spending, from 8.4 percent in 1991 to 5.9 percent in 2001 (Frank and Glied 2006).

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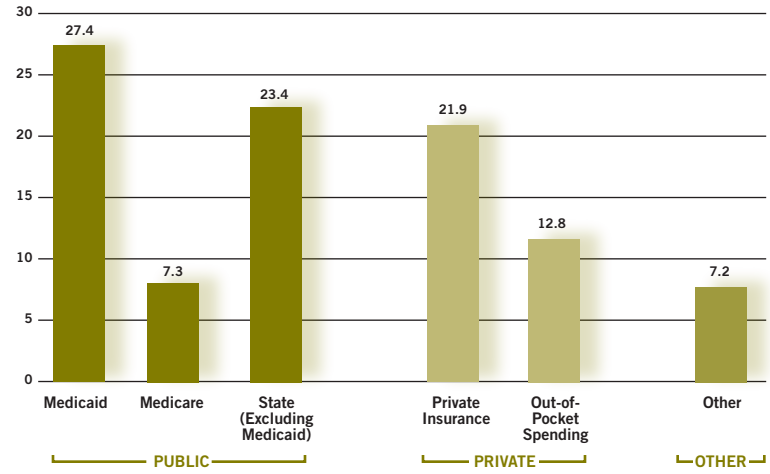
In 2001, mental health spending represented just under 6 percent of all health care spending, and the aggregate share that total mental health spending claims of national income has been stable over the past 35 years. Various payers contribute to mental health spending (Figure 1). Of the amount spent in 2001, approximately 58 percent came from federal, state, or local governments. The remainder of mental health spending in 2001 was supplied by private sector sources, including private insurance and out-of-pocket

Figure 1. Total Mental Health Expenditures by Funding Source, 2001 (percentage)



Source: Frank, Richard G. and Sherry Glied, "Changes in Mental Health Financing Since 1971," *Health Affairs* (25)3: 601-613, 2006.

spending. The share of mental health spending coming from all public sources has increased in recent years, rising from approximately 47 percent in 1971 to approximately 58 percent in 2001 (Frank and Glied 2006).

The early 1990s saw a push toward managed mental health care and behavioral health carveouts, which are separate contracts for managed mental health services. This trend has resulted in lower payments for services provided by both individual mental health providers and institutions (HHS 1999). In the private insurance market, the move to managed mental health care reduced spending on specialty mental health services, with observed reductions ranging from 20 percent to 50 percent depending on the study. In the public sector, a study of state Medicaid managed care programs showed that managed mental health care significantly reduced Medicaid payments to providers of inpatient mental health treatment. In states that use adequate capitation rates in their Medicaid managed care programs, managed behavioral health care can be implemented successfully, from the perspective of both Medicaid beneficiaries and mental health providers. A desire to achieve cost reductions, however, has led some states to set capitation rates that are too low. In turn, provider payments are decreased, making practice impossible for providers in some areas (GIH 2003).

Workforce Issues

Workforce shortages plague the mental health care system. Specific underserved populations include children and adolescents with serious mental disorders and older people. Geographically remote areas face critical workforce shortages as well. In certain areas in the east south central region of the U.S., there are 8.2 psychiatrists per 100,000 population, compared with 22.1 per 100,000 in the mid-Atlantic region (SAMHSA 2005). Moreover,

the mental health workforce does not reflect the growing diversity of the nation, nor of the population it treats (IOM 2005).

The mental health workforce shortage presents a barrier to access. Some providers have increasingly focused on those with the most severe mental illnesses, leaving those with less severe conditions without access to care. Those who can access care often find that services are limited; providers in the public mental health system often lack sufficient resources to provide evidence-based treatment such as assertive community treatment, psychiatric rehabilitation, and intensive case management. Individuals experiencing an acute mental health condition may languish in emergency rooms because psychiatric hospital beds are not available. Similarly, those ready for discharge from inpatient care may find that there are no appropriate residential or community services available.

Tracking the supply and distribution of mental health professionals and documenting workforce shortages is difficult. First, the mental health workforce is composed of many different types of providers offering a wide array of mental health and related services. For some mental health services, a shortage of one type of provider can be addressed if other appropriate providers are available. (For example, areas with shortages of mental health social workers may be able to rely on mental health nurses and psychiatric technicians to provide some of the services typically provided by social workers.) There are limits to substitution, however. For example, a shortage of psychiatrists, common in rural areas, may prevent individuals with mental disorders from receiving needed prescription medications. Second, licensing and certification requirements vary across states. Because each state makes its own decisions about which types of providers need to be licensed or certified, the cadre of licensed mental health professionals varies considerably. Third, not only are training requirements inconsistent among schools and professions, most often physicians with little or no mental health training, such as emergency room doctors or general practitioners, are expected to detect mental disorders and provide treatment. Despite the lack of consistent national data on the mental health workforce, there is consensus among experts that workforce shortages are reaching crisis proportions in many states and localities (GIH 2003).

In general, the workforce is not sufficiently equipped to supply service to all individuals who are in need. Reasons for the shortage include a smaller number of workers entering the field, a lack of sufficient training opportunities, and state variation in licensure requirements that limit the ability to practice across state lines. In addition, certain populations, such as residents of rural areas, have even less access to trained professionals.

In 2004, foundation giving for behavioral health was $204 million—approximately 6 percent of total health giving.

Philanthropic Opportunities

Over the past few decades, funders have supported a variety of programs to improve the mental health care system. Between 1991 and 2000, foundation funding for behavioral health increased significantly from $108 million to $218 million (Brousseau et al. 2003). Since 2000, this amount has decreased, however, despite the continued need for mental health services and system transformation. In 2004, foundation giving for behavioral health was $204 million—approximately 6 percent of total health giving (Foundation Center 2006). Efforts described below include providing services for children and youth, integrating mental health services, encouraging advocacy, improving the workforce, and increasing cultural competence. These examples are illustrative and only highlight a fraction of philanthropy's contribution to the field of mental health.

Services for Children

Robert Wood Johnson Foundation's (RWJF) Mental Health Services Program for Youth (MHSPY) began in 1988 with the intention of promoting coordinated community-based services, rather than institutional care, for children with mental health care needs. Roughly based on a federal initiative called Child and Adolescent Service System Program (CASSP) that sought to ensure coordination among child-serving agencies, MHSPY adopted the theory that community-based services would require fewer financial resources than institutionalization. Eight communities, geographi-

cally and demographically diverse, received funding to serve children with the most serious mental disorders, such as major depression, bipolar disorder, and conduct disorder. Further complicating the plan of care, many children had more than one diagnosis, and some were involved in the child welfare or juvenile justice systems. The grantees focused on a number of strategies to avoid institutionalization: providing comprehensive case management, changing the financing system, and promoting interagency coordination.

The evaluation of the program found that the grantee sites did expand services to children and that case management became universal practice. Low hospitalization rates were noted in each of the sites—mostly 5 percent or less—despite previous histories of high hospital or residential treatment (Saxe and Cross 1998). The evaluation could not, however, objectively measure the effectiveness of the treatments. Anecdotal evidence suggested that sites were successful in providing holistic treatment services for the children and their families and that this method of patient-focused care was critical to the success of coordinated care. Respite services were another factor in easing the burden on families.

MHSPY was replicated in 12 states, building on the lessons learned from the original program. The goal for the new program was to assist states with local initiatives that provide child-centered care with a focus on the family. Despite the challenges of integrating funding streams, a lack of involvement of education officials, and changes in the political environment, the replication program achieved measurable outcomes, such as a reduction of 1,000 children in residential treatment centers in Illinois, yielding taxpayer savings of $36 million; a 95 percent reduction in institutional placements in Mississippi; and a decrease in hospital utilization in San Francisco by about one third (RWJF 2000).

Systems Integration

In 2003, a group of eight Colorado foundations—Caring for Colorado Foundation, The Colorado Health Foundation, The Colorado Trust, Daniels Fund, The Denver Foundation, First Data Western Union Foundation, Rose Community Foundation, and Rose Women's Organization—formed a collaborative to study the mental health needs of the state. The study revealed a crisis within the state's fragmented mental health care system. Specifically, it found that, of the 900,000 Coloradans who need mental health services each year, fewer than one-third receive them. It also exposed a statewide shortage of mental health providers, particularly for children, older adults, and residents of rural areas (TriWest Group 2003). Evaluators offered several recommendations: improve awareness among decisionmakers, promote integrated funding and service provision, implement evidence-based treatment, and examine strategies to boost access for underserved groups.

In response to the study's findings, several members of the collaborative, including Caring for Colorado Foundation, The Colorado Health Foundation, The Colorado Trust, and the Denver Foundation launched Advancing Colorado's Mental Health Care in 2005. The goal of the project is to improve the coordination of mental health services across agencies and facilitate patient navigation of the system. The grantees include:

- Denver Public Schools, which is using school-based resource teams to coordinate services with community agencies;
- Prowers County Behavioral Health Integration Project, which is taking a proactive approach to addressing mental health by supporting new mothers and developing a jail diversion program;
- El Paso County Co-Occurring Disorders Collaboration and Health District of Northern Larimer County, which are both developing new services for individuals with co-occurring mental and substance abuse disorders;
- Mesa County Consortium on Health, which is working with other agencies to reduce cultural and language barriers to care; and
- Summit County Collaborative, which focuses on children with severe emotional disturbances.

Advocacy

Since its conception in 1978, The John D. and Catherine T. MacArthur Foundation has been a strong champion of mental health advocacy. Through its research networks, the foundation has brought knowledge to practice and helped shape the mental health policy landscape (MacArthur Foundation 2005). In particular, through the MacArthur Research Network on Mental Health

Policy Research, the foundation has worked to encourage evidence-based practice, improve mental health financing, and ensure fairness and equity in the management of mental health benefits. The foundation has also supported the Judge David L. Bazelon Center for Mental Health Law in Washington, DC. Founded in 1972 by a group of committed lawyers and professionals in mental health, the center has succeeded in securing legal rights for individuals with mental disabilities. Such landmarks include outlawing abuse of patients in an institutionalized setting and guaranteeing the rights of individuals with mental disabilities to education, to live in the community, and to receive federal entitlements.

In 2001, The California Endowment launched its Special Mental Health Initiative with $24 million to identify effective mental health practices and programs in the state. A group of 46 grant recipients created projects to work independently or collaboratively over four years in underserved communities to provide direct services, training, community education, or other services. A learning community of these grantees convened periodically to share information and lessons learned. Specific projects related to improving the workforce include developing and implementing a promotores model of mental health support; offering cultural competence training to mental health providers; recruiting and training community health workers to facilitate peer support groups; and supporting an infant mental health specialist training program.

Through the learning community, grantees shared ideas about addressing the workforce shortages in the state. With limited resources, nonprofits must find innovative ways to recruit and retain qualified providers. One program was able to recruit a master's level, bilingual therapist only after raising the salary by 30 percent. Other programs have worked to develop the paraprofessional workforce, including promotores, teachers, and child care providers, but have met resistance in terms of scheduling, funding, and unexpected demands. Some program directors have worked tirelessly to overcome resistance on the part of counties to hire paraprofessionals.

The foundation explored the evidence base for treating mental illness and determined that many evidence-based practices, once adapted for cultural differences, would indeed be appropriate for many minority groups.

Grantees found that these workforce strategies led to better outcomes in their programs. Many of the training programs resulted in more integrated service delivery models, and dissemination of mental health knowledge throughout agencies helped agency staff be better prepared to detect mental disorders. Other grantees were able to achieve the ultimate goal of increasing the workforce capacity. One program reported an overall increase of 186 percent over 17 months in Latino lay mental health workers employed in key agencies (The California Endowment 2006).

Cultural Competence

During a 2005 strategic planning process, The Hogg Foundation for Mental Health in Texas created new funding priority areas, one of which is cultural competence. According to population estimates, just over half of the Texas population consists of racial and ethnic minorities. To serve this growing group, the foundation seeks to address not only disparities within the health care system but also care that is incongruent with certain cultures. The foundation explored the evidence base for treating mental illness and determined that many evidence-based practices, once adapted for cultural differences, would indeed be appropriate for many minority groups. With goals of increasing the availability of mental health services for people of color and generating knowledge about the cultural adaptations of evidence-based practice, the foundation released a request for proposals. In July 2006, the foundation announced awards of more than $2.9 million over three years to five organizations to adapt the delivery of evidence-based practices to be compatible with the cultures of their populations of color. Grantees are working on a variety of cultural adaptation projects, including therapy for Latino adolescents with depressive disorders and treatment for African-American children with attention-deficit hyperactivity disorder. During the first year, the grantees will develop proficiency in a specific evidence-based practice. By the second year of the initiative, grantees will have implemented a cultural adaptation of the evidence-based practice by modifying the provision of services, changing provider relationships with clients, or altering the evidence-based practice itself. Finally, an independent evaluator will use program evaluation results throughout the process to provide feedback to the foundation and grantees on the impact of their efforts.

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Fast Facts

Prevalence

Approximately one in four adults suffers from a mental disorder in a given year (National Institute for Mental Health 2006).

Approximately one in five children and adolescents experiences a mental disorder in a given year (HHS 1999).

The Costs of Mental Illness

In the U.S., mental disorders account for more than 15 percent of the overall disease burden and slightly more than the burden associated with all forms of cancer (HHS 1999).

In 1996, direct treatment of mental disorders cost the U.S. $69 billion (HHS 1999).

The direct and indirect costs of untreated mental disorders exceed $300 billion annually (GIH 2003).

In 2004, 31,647 people committed suicide (Minino et al. 2006).

The Mental Health Care System

More than 33 million Americans seek mental health services each year (IOM 2005).

Nearly two-thirds of all people with diagnosable mental disorders do not seek treatment (HHS 1999).

Close to two thirds (62 percent) of mental health expenditures are government-funded (Frank and Glied 2006).

Vulnerable Populations

An estimated 40 percent of homeless individuals have substance use disorders; 20 percent have serious mental illnesses (SAMHSA 2003).

Roughly two-thirds of children with major depression also exhibit symptoms of another mental disorder (HHS 1999).

Older adults have the highest rates of suicide (HHS 1999).

The prevalence rate of suicide for American Indians and Alaskan Natives is 1.5 times the national rate (HHS 2001).

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Recommended Reading

Frank, Richard G. and Sherry A. Glied, *Better But Not Well: Mental Health Policy in the United States Since 1950* (Baltimore, MD: The Johns Hopkins University Press, 2006).

This book provides insight into the past half-century of mental health care in the U.S., covering important advances in understanding mental illnesses, increases in spending on mental health care and support of people with mental illnesses, and the availability of new medications that are easier for the patient to tolerate. The authors argue that although these changes have made things better for those who have mental illness, they are not quite enough.

Garduque, Laurie, "Putting Knowledge to Work for Mental Health," Views from the Field, *GIH Bulletin*, October 22, 2001.

In this article, Laurie Garduque of The John D. and Catherine T. MacArthur Foundation challenges the philanthropic community to do better when it comes to funding for mental health. She describes how grantmakers can—and should—play a key role in charting new territory, challenging service systems to do better, and promoting the adoption of evidence-based practices.

Grantmakers In Health, "Addressing Maternal Depression," Issue Focus, *GIH Bulletin*, October 18, 2004.

This article outlines the prevalence of and treatment opportunities for maternal depression. It also discusses the effects of maternal depression on children and families and provides examples of philanthropic activity.

Grantmakers In Health, *In Harm's Way: Aiding Children Exposed to Trauma* (Washington, DC: 2005).

Exposure to violence, abuse, or natural disasters can have both immediate and long-term effects on children's health and their ability to function fully in their families, schools, and communities. This Issue Brief focuses on the needs of children exposed to trauma, strategies for early identification and intervention, and ensuring the provision of timely and appropriate services.

Grantmakers In Health, *Turning the Tide: Preserving Community Mental Health Services* (Washington, DC: 2003).

This Issue Brief highlights the crisis in community mental health programs, citing inadequate financing and a shortage of appropriately trained providers as two major problems. The authors explore how health grantmakers can support community programs that provide critical mental health intervention and treatment services to children and adults.

Institute of Medicine, *Improving the Quality of Health Care for Mental and Substance-Use Conditions* (Washington, DC: The National Academies Press, 2005).

This report, part of the IOM's Quality Chasm Series, examines the mental health care delivery system and addresses issues pertaining to health care for both mental and substance-use conditions. It provides system improvement strategies for clinicians, health insurance providers, policymakers, and other stakeholders.

Jamison, Kay Redfield, *An Unquiet Mind: A Memoir of Moods and Madness* (New York: Alfred A. Knopf, Inc., 1995).

This memoir examines bipolar disorder from the perspectives of both the healer and the healed. Dr. Jamison, a psychologist and professor of psychiatry at Johns Hopkins University, tells the story of her struggle with bipolar disorder.

Saxe, Leonard and Theodore P. Cross, "The Mental Health Services Program for Youth" in Stephen L. Isaacs and James R. Knickman, eds., *To Improve Health and Health Care: 1998—1999* (San Francisco, CA: Jossey-Bass, 1998).

This essay chronicles Robert Wood Johnson Foundation's involvement in providing community-based services for children and youth with mental illness. The authors describe the challenges encountered in implementing, financing, and coordinating services in the Mental Health Services Program for Youth.

U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General* (Rockville, MD: 1999).

This seminal report enforced the message that mental health is fundamental to overall health. Calling for increased understanding of mental disorders, the report explains the neuroscience of mental health, calls for the use of evidence-based practice, and outlines the disparities in access to mental health services.

U.S. Department of Health and Human Services, *Mental Health: Culture Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General* (Rockville, MD: 2001).

This supplement to *Mental Health: A Report of the Surgeon General* outlines the extent to which racial and ethnic disparities exist in the prevalence of mental disorders and in mental health treatment. The report pays special attention to vulnerable, high-need populations, such as the homeless and the incarcerated, in which minorities are overrepresented.