GIH

TURNING THE TIDE:
Preserving Community Mental Health Services

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Foreword

As part of its continuing mission to serve trustees and staff of health foundations and corporate giving programs, Grantmakers In Health (GIH) convened a group of experts from the fields of philanthropy, research, government, and health care on September 19, 2002 to examine the status of community-based services for people with mental disorders. This Issue Dialogue, "Turning the Tide: Preserving Community Mental Health Services," explored how health grantmakers can support community programs that provide critical mental health intervention and treatment services to children and adults.

This Issue Brief synthesizes key points from the day's discussion with a background paper previously prepared for Issue Dialogue participants. It includes quantitative and qualitative information on mental health, as well as profiles of public sector, private sector, and grantmaker strategies for promoting improvements.

Special thanks are due to those who partici-pated in the Issue Dialogue, but especially to the moderators, presenters, and discussants: Janice Bogner, program officer at The Health Foundation for Greater Cincinnati; Carol Breslau, senior program officer at The Colorado Trust; Ruth Brousseau, program director at The California Wellness Foundation; Charles Curie, administrator of the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Administration; Michael Hogan, director of the Ohio Department of Mental Health; Constance M. Pechura, senior program officer at The Robert Wood Johnson Foundation; and Mary Rainwater, former program officer at The California Endowment.

About GIH

Grantmakers In Health (GIH) is a nonprofit, educational organization dedicated to helping foundations and corporate giving programs improve the nation's health. Its mission is to foster communication and collaboration among grantmakers and others and to help strengthen the grantmaking community's knowledge, skills, and effectiveness. GIH is known today as the professional home for health grantmakers and a resource for grantmakers and others seeking expertise and information on the field of health philanthropy.

GIH generates and disseminates information about health issues and grantmaking strategies that work in health by offering issue-focused forums, workshops, and large annual meetings; publications; continuing education and training; technical assistance; consultation on programmatic and operational issues; and by conducting studies of health philanthropy. Additionally, the organization brokers professional relationships and connects health grantmakers with each other as well as with others whose work has important implications for health. It also develops targeted programs and activities, and provides customized services on request to individual funders. Core programs include:

- **Resource Center on Health Philanthropy.** The Resource Center monitors the activities of health grantmakers and synthesizes lessons learned from their work. At its heart are staff with backgrounds in philanthropy and health whose expertise can help grantmakers get the information they need and an electronic database that assists them in this effort.

- **The Support Center for Health Foundations.** Established in 1997 to respond to the needs of the growing number of foundations formed from conversions of nonprofit hospitals and health plans, the Support Center now provides hands-on training, strategic guidance, and customized programs on foundation operations to organizations at any stage of development.

- **Building Bridges with Policymakers.** GIH helps grantmakers understand the importance of policy to their work and the roles they can play in informing and shaping public policy. It also works to enhance policymakers' understanding of health philanthropy and identifies opportunities for collaboration between philanthropy and government.

GIH is a 501(c)(3) organization, receiving core and program support from more than 200 foundations and corporate giving programs each year.

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Introduction

Across the country, the demand for community mental health services is growing due to increased awareness of mental health disorders across the lifespan, the availability of new and effective treatments for mental disorders, and other factors. At the same time, community mental health programs are in crisis as a result of inadequate financing and a shortage of appropriately-trained providers. Nationwide, the imbalance between the supply of and demand for community mental health services is causing unnecessary personal suffering and imposing avoidable societal costs.

An Issue Dialogue convened by Grantmakers In Health on September 19, 2002 provided health grantmakers with a timely opportunity to talk with their colleagues and with public officials, researchers, and other experts about strategies for addressing current mental health needs in states and communities. This Issue Brief synthesizes information from the background paper written in preparation for the meeting with the presentations and discussions that took place at the session. It is organized into seven sections that:

• provide background on the prevalence, impact, treatment, and cost of mental disorders;

• describe the demand for mental health services delivered in community settings;
• review the existing supply of community mental health services;
• explain how mental health services are financed;
• describe coverage for mental health services in private insurance plans and public health coverage programs;
• discuss why so many community mental health systems are in crisis; and
• identify strategies that health grantmakers can use to strengthen community mental health services.

This Issue Brief covers issues facing individuals with a range of mental health needs, but devotes more attention to the needs of and services for those with serious mental illnesses. It focuses only on mental health issues and mental health treatment services and does not discuss in detail the other services often needed by those with mental disorders, such as income support, housing, employment and training services, and social and recreational opportunities. A full discussion of these services is beyond its scope. For the same reason, the report does not cover the many types of programs and services that can help prevent mental health problems in children and youth.

Background: Prevalence, Impact, Treatment, and Costs of Mental Disorders

Mental disorders are among the most common of the chronic diseases affecting the U.S. population. A landmark report issued by the Surgeon General of the United States in 1999 put the prevalence of diagnosable mental disorders among adults at one in five, or 40 million adults nationwide (HHS 1999). Other estimates indicate that over the course of their lifetimes to date, close to 50 percent of the population has experienced a mental disorder (Manderscheid and Henderson 2001). About 5 percent of the population (or 5.5 million individuals) is considered to have 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 (HHS 1999).

According to a definition from the American Psychiatric Association, mental illnesses are biopsychosocial disorders. They are biological in that they arise, in part, from disturbances in brain or other body system chemistry; they are psychological, manifesting in disturbances in thought and/or emotion; and they are social, arising, in part, from patients' social and cultural environments (how they are raised, the norms of their community, what sorts of stress they face in their everyday lives) (American Psychiatric Association 2002).

Individuals with mental disorders experience a range of emotional, cognitive, and physical symptoms. Some of the more common emotional and cognitive symptoms are: anxiety; psychosis (defined as a disturbance of perception and thought process); mood disturbances; impaired ability to organize, process, and recall information; and impairment of impulse control. The physical symptoms that may be experienced by those with mental disorders include elevated breathing and heart rate, sweating, muscle tension or trembling, fatigue, pain, and changes in appetite.

In contrast to many physical disorders, the causes of most mental disorders are not well understood. Factors that potentially contribute to the development of mental disorders include: biological factors, such as low birthweight, genetic predisposition, and developmental disabilities; environmental factors, such as exposure to trauma, infectious agents, or chemicals; social and cultural factors, such as socioeconomic status, the presence or absence of supportive relationships, and exposure to stressful life experiences; and the timing, intensity, and duration of exposure to various environmental stressors and risks (Manderscheid and Henderson 2001). There is general agreement that, like many physical disorders, mental disorders are generally the product of interactions among biological, psychological, and social and cultural factors.

The Prevalence and Impact of Mental Disorders Across the Lifespan

Worldwide, four mental disorders — unipolar major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder — rank among the 10 leading causes of disability, with unipolar depression leading the entire ranking (National Advisory Mental Health Council 2000). In the United States, 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).[1] For those with serious and persistent mental illness, research has shown that their illness profoundly affects their ability to hold a job and maintain relationships. By itself, major depression accounts for more bed days than any impairment except cardiovascular disorders (National Council for Community Behavioral Health Care 2002).

Mental disorders typically have an earlier age of onset than other chronic diseases, with a median age of onset in the early to late teens for anxiety disorders and early to mid-twenties for mood disorders (Manderscheid and Henderson 2001). Evidence from studies of both adults and children show that the first symptoms of disabling adult psychiatric conditions can appear very early in life, manifesting as emotional or behavioral disorders in childhood. For example, overactivity and restlessness at age three is associated with antisocial behavior five years later.

Mental disorders affect people of all ages, although vulnerability for particular forms of mental and behavioral disorders changes across the lifespan. In addition, the manifestations and functional impact of particular mental disorders may vary across age groups. What follows is a brief discussion of the prevalence and characteristics of mental disorders for individuals in three age groups: children and adolescents, adults, and older adults.

Children and Adolescents

The prevalence of mental disorders among children and adolescents is not as well documented as is the prevalence among adults. Approximately one in five children and adolescents experiences the signs and symptoms of a diagnosable mental disorder during the course of a year, a prevalence similar to that seen in adults (HHS 1999). An estimated 5 percent to 9 percent of these children and youth (between the ages of 9 and 17) will experience severe impairments in their ability to function in school, in their families, and in their communities; these children are considered to have serious emotional disturbance.

The most common mental disorders affecting children are disorders of anxiety and mood, attention-deficit disorder, and autism and other pervasive developmental disorders (HHS 1999). Children with disorders of anxiety and mood may

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[1] Burden of disease is a measure developed by health policy researchers to provide a common indicator that captures the impact of premature death and disability on populations. Premature mortality (measured using Years of Life Lost, or YLLs) and morbidity (measured using Years Lived with Disability, or YLDs) are combined into a single measure of burden known as Disability Adjusted Life Years (DALYs). One DALY can be thought of as one lost year of healthy life and the burden of disease as a measurement of the gap between current health status and an ideal situation where everyone lives into old age free of disease and disability (Murray et al. 2001).

experience intense distress over a period of months or years and experience feelings such as unreasonable fear and anxiety, depression, low self-esteem, and worthlessness. Children with attention-deficit disorder and other disruptive behavior disorders may be inattentive, hyperactive, aggressive, or defiant, while those with autism and other pervasive developmental disorders often have cognitive difficulties, difficulty understanding and using language, and difficulty understanding the feelings of others.

Other mental disorders affect significant numbers of children and youth or have a typical age of onset in childhood or adolescence. Among these are eating disorders, learning and communication disorders, schizophrenia, and tic disorders.

There are some differences in the prevalence of specific mental disorders between boys and girls. In children, emotional disorders, such as anxiety and depression, are more persistent in girls than in boys, while the reverse is true for behavioral disorders, such as conduct and oppositional disorders (Manderscheid and Henderson 2001).

Adults

The annual prevalence of mental disorders in adults is approximately 20 percent. For adults, the most common mental disorders include anxiety disorders, mood disorders, and schizophrenia (HHS 1999).

Anxiety disorders are the most common mental disorders among adults. Anxiety disorders include panic disorder, phobias, obsessive-compulsive disorder, post-traumatic stress disorder, and generalized anxiety disorder. Individuals with anxiety disorders experience a state of heightened fear or arousal in relation to stressful events or feelings. Anxiety disorders affect twice as many women as men (HHS 1999).

Mood disorders also affect significant numbers of adults. Major depression and bipolar disorder are the most familiar mood disorders, but there are other forms as well, such as dysthymia (a milder form of chronic depression) and seasonal affective disorder.

Schizophrenia affects about 1 percent of the adult population and is marked by profound alterations in cognition and emotion. People with schizophrenia may experience hallucinations (hearing internal voices or experiencing sensations not tied to an obvious source) or delusions, which are characterized by false beliefs or by the assignment of unusual significance or meaning to normal events. Most people with schizophrenia experience periods of exacerbation, alternating with periods of remission.

Adults with mental disorders often have other co-occurring conditions. Up to 10 million people have co-occurring mental health and substance abuse disorders, while many others have co-occurring medical conditions, such as heart disease, diabetes, cancer, and obesity. Mental health and medical conditions co-occur for a variety of reasons. Medical disorders may contribute biologically to depression, for example. People with medical illnesses may also become depressed in reaction to the prognosis, pain, or incapacity they experience as a result of their medical condition (National Mental Health Association 2002a).

Older Adults

Estimates indicate that 19.8 percent of older adults (those age 55 and older) have a diagnosable mental disorder, with 4 percent having a serious mental illness (HHS 1999). From 8 percent to 15 percent of adults over age 65 have Alzheimer's disease (HHS 1999). After Alzheimer's disease, the most common mental disorders affecting older adults are anxiety disorders and mood disorders (HHS 1999).

The severe impact of depression on the elderly has gained increased attention in recent years. It is estimated that from 8 percent to 20 percent of all older adults exhibit some symptoms of depression (HHS 1999). The rate is even higher for those seeking primary care: 17 percent to 35 percent of older primary care patients show symptoms of depression, although the symptoms sometimes do not meet the criteria for a formal diagnosis. Stressful life events, such as declining health and the loss of loved ones, may contribute to late-onset depression among seniors. Of the 800,000 older Americans widowed each year, an estimated 10 percent to 20 percent will develop clinically-significant depression (HHS 1999). The relatively high rate of depression among the elderly is a leading contributor to suicide among older adults. The rate of suicide among adults over age 85 is the highest of all age groups at 21 suicides per 100,000, almost twice the overall national rate of 10.6 suicides per 100,000 (HHS 1999).

The co-occurrence of mental and physical disorders is relatively common in older adults (HHS 1999). Some physical disorders can cause cognitive, emotional, and behavioral symptoms, either because of direct effects of the physical disorder on the central nervous system or because of side effects of medication. Some of the resulting mental conditions may be severe enough to qualify as mental disorders (HHS 1999). Similarly, in some cases, mental disorders can decrease the ability of older adults to care for themselves or to seek care, while in other cases, the presence of a mental problem or disorder can directly contribute to the development of physical illness. For example, increased levels of stress can suppress immunity and increase the risk of coronary heart disease (HHS 1999).

Diagnosis of mental disorders in the elderly can be challenging. Elderly individuals with mental disorders frequently present first in primary care with physical complaints. As a result, their primary care physicians may treat the physical symptoms and miss the presence of the mental disorder. In addition, older adults may experience symptoms that do not meet the full diagnostic criteria for depression or anxiety disorders, making identification and diagnosis difficult.

Lack of Treatment for Mental Disorders

Although effective treatments are available for most illnesses, only one in three of those with mental disorders receives any treatment (Manderscheid and Henderson 2001; HHS 1999). Despite evidence showing that appropriate treatment can lessen the severity of mental disorders, studies indicate that only a minority of patients receives therapies that even minimally satisfy current treatment guidelines (Manderscheid and Henderson 2001). One study of individuals with schizophrenia found that only 29 percent

received appropriate dosages of medication, only 46 percent of those who also had depression received any antidepressant medication, and only 54 percent received treatment to counteract side effects of their antipsychotic medications (Lehman 1999).

Racial and ethnic minorities are even less likely to receive treatment, despite having similar rates of mental disorders as the general population (HHS 2001). Studies also suggest that members of most minority groups typically receive poorer quality of care. For example, African Americans with schizophrenia are less likely to receive appropriate care and medications than their white counterparts (Lehman 1999).

In addition to causing unnecessary suffering for individuals and families, untreated mental illness can have a negative impact on the treatment and management of physical disorders (Manderscheid and Henderson 2001). The presence of co-occurring disorders can complicate or delay the treatment of both the mental disorder and any medical or substance abuse problem, resulting in higher morbidity and mortality rates (Bianco et al. 2001). In one example, researchers found that untreated depression is a powerful predictor of early mortality among survivors of first heart attacks.

As many as half of all people with serious mental illnesses develop alcohol or other drug abuse problems during the course of their lives (HHS 1999). Some will find treatment for their mental illness in the mental health service system and treatment for their drug or alcohol problem in the substance abuse service system. Many more, however, will encounter formidable barriers to treatment for either their mental

disorder or their substance abuse problem because many providers in these systems are ill-equipped or unwilling to treat individuals with co-occurring disorders.

Barriers to Mental Health Treatment

Various barriers serve as obstacles to treatment. A recent study by the U.S. Department of Health and Human Services identified several obstacles, including financial barriers, a lack of awareness about available treatments, perceptions that treatment is not effective, beliefs that the problem will go away by itself, and a desire to handle problems without outside help (Manderscheid and Henderson 2001). Other related obstacles include the following:

Social stigma – Stigmatization of those with mental disorders persists despite efforts to educate the public about mental health and mental illness. For example, many Americans believe that people with mental disorders are more likely to commit acts of violence than other people (American Psychiatric Association 2002). Stigma affects individuals' willingness to seek treatment and the public's willingness to pay for treatment (Bianco et al. 2001).

Shortages of mental health providers in many areas – Provider shortages in many areas prevent people from receiving appropriate treatment. Access issues are particularly acute for those who are uninsured and those who live in rural areas.

Fragmented, confusing, or inaccessible service systems – In many communities, the use of the word system to describe mental health services is a misnomer. Mental health

services typically are not well-coordinated, even for those with serious mental illness who may lack the capacity to navigate complex service structures on their own. In addition, information and assistance in obtaining necessary documentation and completing paperwork is usually lacking. The move to managed behavioral health care by both public and private payers has not always improved coordination of services and, in cases where individuals with mental disorders also need care for a physical disorder, may have made the situation worse (Bianco et al. 2001).

Lack of insurance coverage or ability to pay for care – People with serious mental illness are disproportionately uninsured, and those with health insurance often have only limited coverage for mental health services (Manderscheid and Henderson 2001).

Lack of identification and targeted early interventions – As previously noted, the symptoms of many mental disorders begin to emerge early in life. Schools and primary health care are good settings for identifying children with mental, emotional, or behavioral disorders, but staff are often not trained to identify these children or refer them to appropriate services. Targeted interventions to prevent progression of these conditions to diagnosable mental disorders could help reduce the prevalence of mental disorders among both children and adults.

Lack of trust in the mental health service system – Some individuals with mental disorders have had negative experiences with mental health treatment or mental health providers. As a result, they do not trust the mental health service system to meet their needs and do not seek or comply with treatment.

Human and Financial Costs of Untreated Mental Disorders

The economic costs of untreated mental disorders are high: their direct and indirect costs exceed $300 billion annually, due to health care expenditures, productivity losses, and other societal costs. Of this amount, approximately $73 billion is direct costs of treating mental disorders, which represent around 7 percent of all spending for health care (Mark et al. 2000; HHS 1999). Because mental disorders have relatively low mortality and a younger age of onset than many physical disorders, a large portion of the indirect costs, estimated at $78.6 billion in 1990, is due to productivity losses among those currently ill (HHS 1999). Roughly $12 billion of the economic costs represents mortality costs, that is, lost productivity due to premature death. Another $4 billion is due to productivity losses for incarcerated individuals and the time family members spend providing care to mentally-ill family members (HHS 1999).

The economic and societal costs to communities can also be high. Lack of treatment for mental disorders can result in homelessness, victimization, and incarceration (GAO 2000b). Approximately 1 in 20 adults with serious mental illness is homeless, and people with mental illness account for an estimated one-third of the approximately 600,000 homeless adults in the United States. At least half of homeless people with serious mental illness also have substance abuse disorders. Accessing the treatment they need to get off the streets or

"Compared to other major categories of illness, mental illness is the only one where a greater portion of the cost to society is due not to the cost of care, but to the cost of not providing care or the cost of bad care."

MICHAEL HOGAN,
OHIO DEPARTMENT
OF MENTAL HEALTH

out of shelters is particularly problematic for individuals with mental disorders, who are frequently unable to navigate the complexities of most mental health service systems on their own.

People with serious mental illness are also overrepresented in the criminal justice system. An estimated 16 percent of those in state prisons or local jails have a serious mental illness, while 7.4 percent of those in federal prisons have mental illness (Council of State Governments 2002; Ditton 1999). This compares to 5 percent with serious mental illness in the general population. In 1998, there were more than 280,000 people with mental illness in jails and prisons and more than half a million more on probation (Ditton 1999; Manderscheid and Henderson 2001). The co-occurrence of substance abuse disorders and mental disorders contributes to this problem, as many of those with mental disorders were incarcerated for offenses that occurred while under the influence of alcohol and drugs (Manderscheid and Henderson 2001). While some people with mental illness are involved in the criminal justice system because they have committed serious and violent crimes, many others commit so-called nuisance offenses and are jailed for only short periods of time.

The Demand for Community Mental Health Services

In the past four decades, there has been a dramatic shift in the way society views mental disorders and the care and treatment of those with serious mental illness. In 1955, 75 percent of all mental health care was provided in state psychiatric hospitals or other institutions, with the remaining 25 percent provided in community settings. Twenty years later, the deinstitutionalization movement had reversed those statistics: by 1975, almost three-quarters of the care was provided in community-based settings (National Council for Community Behavioral Health 2002).

The demand for community mental health services has four components. First, there is a need for ongoing services for individuals receiving appropriate mental health treatment. Many conditions require such ongoing treatment and monitoring to achieve and sustain recovery. Second, there is a need for more appropriate treatment for the many individuals receiving suboptimal care. Third, there is a need for services for individuals with diagnosed mental conditions who, for a variety of reasons, have stopped receiving needed services. Finally, there is a need for services for individuals with mental disorders who have not yet received a diagnosis or treatment, but could if readily accessible screening, assessment, diagnostic, and treatment services were available.

There is some documentation of the growth in demand for community-based mental health services. The rate of outpatient treatment for depression, for example, has increased from 0.73 per 100 people in the general population in 1987 to 2.33 in 1997 (Olfson et al. 2002). A picture of the increasing demand for children's mental health services is emerging, with one study showing that the number of children receiving mental health services in 1997 (1.3 million) was almost double the estimated number who received services in 1986 (Pottick et al. 2002). Less is known about the level of need among individuals with mental disorders who are not receiving appropriate treatment or who are not currently receiving any treatment for their conditions.

Many factors are influencing demand for services delivered in community settings. Some, like deinstitutionalization and the changes in laws and policies that triggered it, began affecting the demand for community-based services decades ago and continue to do so today. Others factors, such as increasing awareness of mental disorders among children and adults, the development of more effective treatment models, and direct-to-consumer advertising of psychotropic medications, are of more recent origin. This section of the Issue Brief discusses several of the most important factors influencing the demand for community mental health services.

Impact of Deinstitutionalization on the Demand for Community Mental Health Services

The transition of large numbers of people with serious mental illness from state psychiatric hospitals to community settings has been a major factor driving the increase in demand for community-based services over the past 40 years. Between 1955 and 1996, the number of residents in state psychiatric hospitals dropped by 86 percent, from 560,000 to 77,000.

In the 1950s and 1960s, a wave of change in the treatments and services available to those with mental illness paved the way for deinstitutionalization. There was also a profound transformation in the legal and political environment that hastened the movement of people out of institutional settings and into communities.

Development of New Treatments for Mental Disorders

The development of medications in the 1950s to treat serious mental disorders has been characterized as a revolution that forever changed the outlook and prospects for people with serious mental illness (WHO 2001). In the 1950s, researchers discovered entire new classes of drugs, such as antipsychotics and antidepressants that, for the first time, allowed doctors to target specific symptoms of mental disorders. While these new drugs did not cure the underlying mental disorder, they did reduce or control symptoms, allowing people with serious mental illness to live successfully in community settings.

The 1950s and 1960s also saw the development of new models for mental health treatment that made integration of people with serious mental illness into community settings possible. For example, developments in psychotherapy added to the repertoire of approaches available to mental health providers. Derived from different theoretical frameworks than psychodynamic or Freudian therapy, new approaches

such as behavioral therapy and cognitive therapy focused on changing thought patterns and behavior. In contrast to psychodynamic therapies, which typically involve long courses of treatment, the new approaches offered the option of shorter courses, making them more attractive for those with relatively mild disorders. The 1960s also saw the development of new service delivery models, such as psychosocial rehabilitation, that provided critical supports to enable people with serious mental illness to be successful in community settings.

Development of New Federal Programs
In the early 1960s, as the first wave of deinstitutionalized people began to return to their homes and communities, many localities found themselves unprepared for the influx of people needing mental health and other services. The federal government responded by developing new programs to provide mental health services, medical assistance, income support, housing, and other services to individuals with disabilities living in the community.

In 1963, the federal Mental Retardation Facilities and Community Mental Health Centers Act was enacted, authorizing the development of a network of community mental health centers (CMHCs). These new community-based providers were intended to replace state institutions as the main source of treatment for people with serious mental illness (GAO 2000b).

Other federal programs were also enacted in the 1960s, in part to provide access to the supports and services needed by people with disabilities. These programs included Medicaid and Medicare, Social Security Disability Insurance and Supplemental

Security Income, federal housing programs, and federal employment and training programs.

Changes in the Legal Environment
Starting in the 1960s, consumers, families, and advocates for people with mental disorders were successful in winning and safeguarding important rights for those with mental disorders. These included the right to treatment, the right to refuse treatment, restrictions on involuntary commitments, and the delivery of services in the least restrictive setting (Bianco et al. 2001; Manderscheid and Henderson 2001).

During the 1960s and 1970s, court decisions and new laws forced government agencies to restructure their service systems away from a reliance on institutional care for those with mental illness and toward treatment in community settings. Many of these legal changes began at the state level. For example, in the 1960s, states began amending their involuntary commitment laws to restrict them only to people who were a danger to themselves and others. Similarly, court cases challenging the treatment of institutionalized people with mental disabilities resulted in consent decrees that required states to move people out of institutions and into community settings.

Starting in the mid-1970s, the United States Supreme Court issued a number of decisions that influenced the rights and treatment of people with mental disorders nationwide. Two Supreme Court decisions in 1972, *Pennsylvania Association for Retarded Citizens* [PARC] v *Pennsylvania* and *Mills* v *Washington, DC Board of Education* addressed the education of children with disabilities and laid the

groundwork for future federal legislation on this issue. The 1975 Supreme Court decision in the case of *O'Conner* v *Donaldson* established the right of people with mental illness to refuse treatment, if the person is competent to make that decision and is not a danger to himself or herself or to other people.

New federal laws enacted in the 1970s also established important rights for people with disabilities, including those with mental disorders. Among these were:

- Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination on the basis of disability in any program or activity that receives federal funds; and
- The Education for All Handicapped Children Act of 1975 (later renamed the Individuals with Disabilities Education Act or IDEA), which requires states to provide a free, appropriate education to children with disabilities in the least restrictive setting possible.

Changes in the Political Environment
As deinstitutionalization progressed, consumers of mental health services and their families became an increasingly strong force in policy development and service delivery. National organizations, as well as state and local nonprofit advocacy groups, have been successful in convincing public officials of the need to expand access to community-based mental health treatment and other services.

Recent Factors Influencing the Demand for Community Mental Health Services

In recent years, new factors have emerged that have increased the demand for community mental health services. In some cases, they have accelerated the movement of individuals with mental illness from institutional settings to community settings. In other cases, new demand has been created among individuals who previously might not have sought treatment for their mental disorder.

New Medications for Mental Disorders
In the 1990s, after a 40-year gap, pharmaceutical companies once again turned their attention to the development of medications to treat mental disorders. The result is a second wave of new antidepressants and antipsychotic medications that are as effective as the older medications, but with significantly fewer and less severe side effects. As a result, some of these drugs are attractive for treating those with relatively mild conditions, as well as those with serious mental illness.

Some of these new drugs are now being marketed directly to consumers through television and radio advertisements, a method that was infrequently used before 1997 when the federal Food and Drug Administration relaxed its requirements for broadcast advertisements. Prior to this change, ads for prescription drugs were required to include comprehensive information about possible side effects and contraindications. While this was possible for print ads, the requirements made radio and television ads impractical. The rules change now allows pharmaceutical

companies to include only information about major side effects if the ad also includes guidance about how to obtain more complete information.

Several drugs for mental disorders are among those being marketed directly to consumers. Prozac®, Paxil®, and BuSpar® have all been marketed directly to consumers and were among the top 20 drugs for direct-to-consumer advertising for at least one year between 1997 and 2000 (Frank et al. 2002).

Direct-to-consumer advertising of prescription drugs is controversial. Proponents point to the educational value of the ads and claim that direct-to-consumer advertising helps consumers play an active role in their health care. Detractors point to advertising's primary purpose — selling — in warning about the potential of ads to mislead and create unwarranted demand for expensive name-brand drugs that may be unneeded or no more effective than less expensive drugs.

Although the value to consumers of direct-to-consumer advertising is unclear, the impact is not. Recent surveys have found that approximately one-quarter of those surveyed reported speaking to their doctors about a drug or condition in response to advertising (Mintzes et al. 2002). Six percent to nine percent reported that they directly requested an advertised drug, and, of these, 80 percent to 84 percent reported receiving a prescription. A recent survey also found that 28 percent of those responding said they would switch doctors to get a desired drug. On the provider side, about 70 percent of physicians surveyed

reported writing brand-name prescriptions for at least half of their patients who request them.

New Laws and Legal Decisions
New laws and legal decisions continue to shape the delivery of community-based services to people with mental disorders. The most important new law affecting people with mental disorders is the Americans with Disabilities Act of 1990 (ADA), which prohibits discrimination in public programs, services, and activities on the basis of disability. It also requires employers to provide reasonable accommodations to protect the rights of individuals with disabilities in the workplace and requires public accommodations (if newly constructed or modified) to be accessible to individuals with disabilities or to remove barriers if readily achievable.

The ADA is being used to challenge arrangements and programs that impede full community participation by individuals with mental illness. In *Olmstead* v *L.C. ex. rel Zimring,* the 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. This decision is requiring states to reexamine their policies and programs regarding institutional versus community-based care for individuals with mental illness and other disabilities.

Public Awareness Efforts
Increasing public awareness and eliminating stigma associated with mental disorders are among the top goals of many of the national organizations that deal with mental health and the mental health

professions. The process of public education has also been greatly aided by high-profile spokespersons, including former First Lady Rosalyn Carter, Tipper Gore, and celebrities such as Rosie O'Donnell and Mike Wallace, who have publicly shared their personal experiences with mental illness.

Although public education has not completely eliminated the stigma associated with all mental disorders, it has been relatively successful with some conditions. For example, awareness and understanding about depression, anxiety disorders, and attention-deficit/hyperactivity disorder has increased, leading more people to seek treatment for these conditions (Olfson et al. 2002; HHS 1999).

Other Reasons for Increased Demand
Other factors are also influencing the demand for community mental health services. These include the following.

New research – Research on the impact and treatment of mental disorders influences demand for community mental health services. For example, research showing that treatment can reverse or prevent physical changes in the brains of those experiencing recurrent episodes of depression is leading some experts to call for expanded efforts to identify and treat at-risk children and adolescents.

September 11, 2001 terrorist attacks – The terrorist attacks of September 11, 2001 resulted in an increase in the number of people experiencing mental health problems. Although studies of reactions to other crises have shown that stress reactions in most people with indirect exposure wane over time, some experts speculate that because of continued media attention and the threat of future attacks, the impact of the September 11th attacks may not diminish as quickly (Lankarge 2001).

Faltering national economy – A weakening national economy and the resulting job losses and job insecurity may be causing an increase in mental health problems. Studies of the effects of layoffs during previous economic downturns indicate that increases in unemployment result in increases in mental health problems (Hamilton et al. 1990).

OLMSTEAD V L.C. EX. REL ZIMRING

The *Olmstead* case was brought by two women in Georgia. Both had mental retardation and mental illness and were being treated in institutions, even though their conditions had stabilized and their treatment providers had concluded that their needs could be met in community-based programs supported by the state. The women could not obtain community-based care because the state had limited the number of placements available in the appropriate program (Kaiser Commission on Medicaid and the Uninsured 2000).

Although the case was brought against only one state, the Supreme Court decision is affecting disability policy and planning in all states.

The Supply of Community Mental Health Services

The current mental health system is a mix of public and private services provided or administered by government, nonprofit, and private organizations and individuals. This section of the Issue Brief provides an overview of community mental health services. It starts with an explanation of how the public and private components of the community mental health system are administered. It then describes the various types of community mental health services. It concludes with a review of the different types of providers and provider organizations that deliver mental health services in community settings.

Administration of Community Mental Health Services

The public mental health system is designed to serve primarily as a safety net for those who are uninsured or unable to pay for services. As a safety net system, it is administered by government agencies. States have primary responsibility for administration of the public system, although the federal government also funds a variety of activities.

Each state has a designated mental health authority, and, in most states, the mental health authority is responsible for administering state psychiatric hospitals, as well as community-based mental health services.

In some states, the mental health authority is an independent state agency, while in others, the mental health authority is part of a state agency that also addresses substance abuse or developmental disabilities (National Association of State Mental Health Program Directors 2002).

State mental health authorities play many roles. They provide services directly through state-owned or operated psychiatric hospitals and other facilities. They purchase services through contracts with nonprofit or private providers. And they regulate providers, enforce quality standards, and coordinate support services for those with mental illness (GAO 2000b).

Other state and local public agencies also play a role in administering mental health services. These include: state Medicaid agencies, which set policies for reimbursing providers for mental health services and authorizing providers to serve Medicaid beneficiaries; state education agencies, which may set licensing and certification standards for mental health providers in both the public and private systems; protection and advocacy councils, which monitor treatment of individuals with mental disorders; and substance abuse and criminal justice agencies, which may administer, provide, or reimburse for mental health services provided to their clients. In most states, local governments play a significant role in administering mental health services, through county behavioral health authorities, community planning boards, and other entities.

CONTINUUM OF COMMUNITY MENTAL HEALTH SERVICES

The following describes the types of mental health services often needed by those with mental disorders. The specific combination of services needed by a particular individual will vary across diagnoses, across time, and along the spectrum of severity from mild to serious. As a result, most people will use only some of the services described. It should also be noted that not all of the services described here are readily available in all communities. In fact, the absence of a full continuum of services in many communities is one facet of the crisis facing mental health systems nationwide.

Early intervention – Early intervention programs are generally targeted toward children and adolescents and aim to detect and address mental, emotional, behavioral, or learning problems before they become established and more difficult to treat or reverse. Early intervention programs: use screening tools to identify children with or at risk for mental health problems; make trained professionals available to consult with parents, teachers, and other caregivers; and work with children in their natural environments to provide needed supports and guidance.

Screening and evaluation services – Screenings are designed to identify those who have or are at risk for mental health problems, determine if services are needed, and connect individuals with appropriate services. Evaluations are performed by mental health professionals to determine a diagnosis and provide the information needed to develop a service plan. Screenings may be formal or informal and may be conducted by health professionals in their offices or by other types of workers in schools, at health fairs, and in other community settings.

Outpatient treatment – Outpatient treatment is the term used to refer to psycho-therapy and counseling provided by licensed mental health professionals in an outpatient clinic, private office, school- or home-based setting, or other community locations. Psychotherapy or counseling can occur with individuals, groups, couples, or families.

Medication and medication monitoring – Many children and adults with mental disorders need access to medications prescribed by a physician. In some cases, individuals with serious mental illnesses may also need medication dispensing and monitoring services in which medications are directly administered by a health professional and the individual is closely monitored to identify both beneficial and undesirable effects (GAO 2000b).

Crisis intervention services – Crisis intervention services are used in emergency situations to provide immediate care when individuals are or are at high risk of becoming a danger to themselves or others. Such services are available 24 hours a day and provide screening, psychiatric evaluation, emergency intervention and treatment, stabilization services, and referral to community services and resources. Crisis intervention services take many forms, including telephone hotlines, crisis group homes, walk-in crisis inter-vention services, runaway shelters, mobile crisis teams, and therapeutic foster homes for children who need short-term crisis placements (HHS 1999).

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Intensive community treatment – Intensive community treatment programs provide a range of services to help those with serious mental disorders live successfully in community settings. One commonly-used model, Assertive Community Treatment (ACT), uses multidisciplinary teams to provide intensive services in the community or at home, with services available 24 hours a day for as long as the client needs them. Teams typically include case managers, a psychiatrist, nurses, social workers, vocational specialists, substance abuse specialists, and peer specialists (HHS 1999). For children with serious emotional disturbances, similar services are available through programs that may be called family- or home-based services, family preservation services, intensive family services, or family-centered services. The term wraparound services is used to refer to a package of flexible services that are tailored to meet the unique needs of children and their families (Katz-Leavy and Tesauro 1998).

Psychosocial rehabilitation – Psychosocial rehabilitation refers to programs that offer a combination of services to individuals with serious and persistent mental illness to help them live successfully in the community. Services typically include independent living and social skills training, psychological support to clients and their families, housing assistance, vocational training, social support and network enhancement, and access to leisure activities (HHS 1999).

Consumer and family self-help – Self-help groups and other consumer- or family-run self-help services are based on the premise that people who share a condition also share common experiences and, therefore, can help each other by providing information, as well as practical and emotional support. Self-help groups are peer-led and range from small informal groups to well-organized national networks. Consumer- and family-run organizations may include drop-in centers; businesses; and case management, outreach, employment, housing, crisis, and family support programs.

Partial hospitalization – Partial hospitalization, also called day treatment or partial care, is a specialized form of treatment that is less restrictive than inpatient care, but more intensive than other forms of outpatient care. It typically combines education, counseling, and family interventions and may be provided in a variety of settings, including hospitals, schools, or clinics. Partial hospitalization is sometimes used as a transitional service for those leaving inpatient or residential care; in other cases, it is used to prevent institutional placement.

Residential services – Residential services for people with mental disorders are provided in group homes, independent or shared apartments, and single-room occupancies. Services in residential programs may include training, support, medications, and supervision of routine activities, including community orientation, meal preparation, financial management, and transportation (GAO 2000b). Children who require residential services may be placed in specialized, licensed facilities called residential treatment centers for emotionally disturbed children (RTCs). RTCs may have a formal structure that resembles a psychiatric hospital or may be structured more like a group home or halfway house. Children who do not require the level of services offered by RTCs may be placed in therapeutic foster care or therapeutic group homes.

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Inpatient mental health services – Inpatient services are the most restrictive of the set of community mental health services. This term refers to short-term, intensive mental health services provided on an inpatient basis. Community inpatient services may be provided by a general hospital or by an inpatient unit of a community mental health clinic.

Case management – Case managers help coordinate the various services needed by people with mental disorders. Usually available only to those with severe conditions, case management services are particularly important for individuals who need services from more than one provider or system. There are many different models of case management, but case managers are often involved in assessing needs, developing service plans, contacting service providers on a client's behalf, and working with the client and his or her family to facilitate access to needed services.

Rights protection and advocacy – Rights protection and advocacy systems were established in 1975 in response to public outrage over incidents of abuse and neglect of individuals with disabilities who resided in institutions. Although initially focused on individuals with mental retardation and other developmental disabilities, these systems have since been expanded to include services to individuals with mental illness in institutional or community settings.

Services for co-occurring substance abuse and mental disorders – These specialized programs for individuals with co-occurring disorders combine interventions directed at treating both disorders simultaneously.

Providers of Community Mental Health Services

Many different types of public and private organizations provide community-based mental health services.

Primary Care Providers

Many people with mental disorders first seek care for co-occurring physical symptoms from their primary care doctors. As the first point of contact for most patients, primary care settings can play a critical role in removing obstacles to treatment for the estimated 25 percent of primary care patients who have diagnosable mental disorders. Primary care is often easier to access than specialty mental health services and may offer the possibility of more cost-effective care (HHS 1999). In addition, many consumers view mental health treatment in primary care settings as less stigmatizing than treatment received in specialty mental health settings and are therefore more likely to seek diagnosis and treatment for mental disorders from their primary care provider. Despite these advantages, most primary settings are ill-equipped to identify, diagnose, and treat mental disorders. There is heightening awareness of the need to educate primary care physicians about mental disorders, especially depression.

Licensed Mental Health Service Providers in Private Practice

Many individuals with mental disorders receive care and treatment from licensed mental health providers in private practice. These include psychiatrists, psychologists, social workers, professional counselors, marriage and family therapists, and nurses.

Outpatient Mental Health Clinics

Outpatient mental health clinics may be freestanding or part of another organization such as a hospital or a nonprofit organization. Clinics typically provide a range of services, which may include outpatient counseling, day treatment, emergency services, partial hospitalization services, inpatient services (often under arrangement with community hospitals), psychosocial rehabilitation, vocational rehabilitation, residential services, consultation and education services, and services for special populations. Some also provide services for co-occurring addiction disorders (National Council for Community Behavioral Health 2002). Outpatient mental health clinics often serve individuals regardless of their ability to pay and thus act as a safety net provider for uninsured individuals who cannot pay for mental health treatment.

Many outpatient mental health clinics began as federally-qualified community mental health centers established under the federal Mental Retardation Facilities and Community Mental Health Centers Act of 1963. Currently, 750 community mental health centers provide services to about 6.1 million people who would otherwise lack access to behavioral health services (National Council for Community Behavioral Health 2002).

Other Providers of Community Mental Health Services

Other public and private entities provide mental health services to the populations they serve. For example, schools are the largest provider of mental health services to children and adolescents (HHS 1999). School psychologists provide assessment, planning, and treatment services to children with learning problems. There were approximately 31,000 practicing school psychologists serving children in 85,000 schools in 2000 (Manderscheid and Henderson 2001).

In many communities, general hospitals provide mental health services. In 1998, 1,707 general hospitals had separate psychiatric services, which may include inpatient and outpatient services (Manderscheid and Henderson 2001). In addition, roughly 350 private psychiatric hospitals nationwide provide mental health treatment. In 1998, these institutions represented nearly 13 percent of the country's inpatient treatment capacity (33,635 beds).

Other public and private providers of inpatient or outpatient mental health services include the following.

• Jails, prisons, and juvenile justice facilities – Many youth and adults who become involved with the juvenile or adult justice systems have mental disorders, many of them untreated. As a result, state correctional and juvenile justice agencies provide mental health services to incarcerated adults and adjudicated youth.
• VA hospitals.
• State and county mental hospitals.

• Nursing homes – The U.S. Congress in 1987 required nursing homes to have the capacity to provide care and treatment to the two-thirds of residents who have mental disorders (HHS 1999).

• Other private and nonprofit organizations, including family counseling services, self-help groups, senior centers, employee assistance programs, local mental health associations, and youth centers.
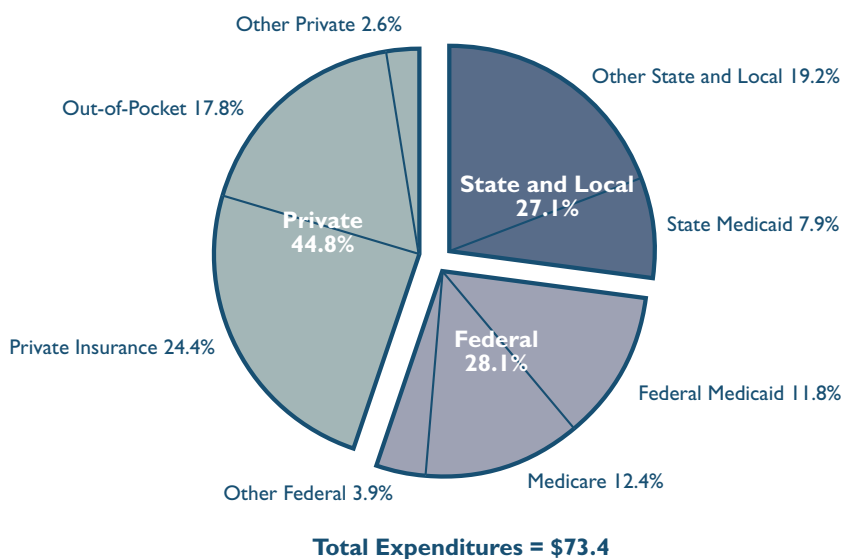
Financing of Mental Health Services

Between 1987 and 1997, spending on mental health services provided by both public and private providers grew dramatically, from $37 billion in 1987 to approximately $73 billion in 1997 (Mark et al. 2000). The rate of growth in mental health spending, however, was slightly lower than the increase in overall health spending over the same time period. As a result, spending for mental health care has declined as a percentage of overall health spending (GAO 2000b; HHS 1999). In 1997, mental health spending represented just under 7 percent of all health care spending.

Various payers contribute to mental health spending (Figure 1). Of the amount spent in 1997, approximately 55 percent ($40.5 billion) came from federal, state, or local governments. The share of mental health spending coming from all public sources has increased in recent years, rising from 49 percent in 1986 to 55.2 percent in 1997 (HHS 1999; Mark et al. 2000). Between 1987 and 1997, the federal government's share of costs grew from 22 percent to 28 percent, while the state and local share dropped from 31 percent to 27 percent (GAO 2000b).

The remainder of mental health spending in 1997 ($32.9 billion) was supplied by private sector sources. Private insurance accounted for 55 percent ($17.9 billion) of private sector payments, while 45

Figure 1. *Percentage of Total Mental Health Expenditures by Funding Source, 1997*

Other Private 2.6%
Out-of-Pocket 17.8%
Other State and Local 19.2%
State and Local 27.1%
State Medicaid 7.9%
Private 44.8%
Private Insurance 24.4%
Federal 28.1%
Federal Medicaid 11.8%
Other Federal 3.9%
Medicare 12.4%

Total Expenditures = $73.4

Source: GAO 2000b.

> *"By 1997, Medicaid mental*
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> *health expenditures,*
>
> *including the state's share,*
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> *represented the biggest single*
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> *treatment expenditure for*
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> *mental health care in the*
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> *country . . . in a lot of states*
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> *now, for all practical*
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> *Except that the Medicaid*
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> *director may not know that*
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> *because they have got*
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> *nursing homes and drug*
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> *costs and all these other*
>
> *things to worry about."*
>
> MICHAEL HOGAN,
> OHIO DEPARTMENT OF
> MENTAL HEALTH

IF IT MOVES, "MEDICAID IT"

Although the original legislation creating the Medicaid program in 1965 did not contain an explicit mental health benefit, since the late 1970s, states have been given a number of options to expand Medicaid coverage for services important to individuals with mental disorders. Many states have used these options to maximize federal Medicaid payments for community mental health services. By 1997, in fact, total mental health expenditures in the Medicaid program (excluding medications) exceeded those of state mental health agencies, making Medicaid the second biggest mental health program in the country (after Social Security Administration payments to individuals with serious mental illness).

Growing reliance on the Medicaid program to fund community mental health services has its problems, including shifting general fund dollars from more flexible state and local programs to Medicaid to meet federal matching requirements. This is particularly worrisome for low-income and uninsured individuals who are not disabled enough to qualify for Medicaid. The shift of state funds into Medicaid has also led to greater fragmentation of services, planning, and accountability.

percent ($15 billion) came from clients' out-of-pocket payments and other private sources. Out-of-pocket payments by clients include copayments under private insurance plans and Medicare, copayments and prescription drug costs under Medicare supplemental insurance policies, and other direct payments (HHS 1999).

Medicaid

Medicaid is a federal-state partnership that provides medical assistance to qualified children and adults. Approximately 12 percent of adults and 20 percent of children are covered by Medicaid nationwide (HHS 1999; Kaiser Commission on Medicaid and the Uninsured 2002).

States operate their own Medicaid programs within broad federal requirements. States are required by federal law to cover some populations, such as low-income children and families, low-income preg-

nant women, and low-income elderly. States may also elect to provide Medicaid coverage to other populations and develop their own eligibility policies for these optional populations. Some people with mental illness gain access to Medicaid through their participation in the Supplemental Security Income (SSI) program. SSI provides benefits to elderly individuals and disabled adults and children who meet certain disability, income, and other eligibility requirements. Individuals who qualify for SSI are generally eligible for Medicaid coverage.

Medicaid pays for mandatory services, such as physicians' services and hospital care, and will also pay for optional benefits that states may choose to provide. States establish the payment rates for services; decide which optional services to cover; and set their own limits on the type, amount, duration, and scope of covered

services. The federal government pays part of the cost of Medicaid, with states and localities paying the rest.

From 1987 to 1997, the proportion of Medicaid spending that went to mental health increased from 15 percent to about 20 percent, or $14.4 billion (GAO 2000b). The increase has been attributed to a trend toward using psychiatric units of general hospitals, rather than state or county psychiatric hospitals, to provide inpatient care to Medicaid beneficiaries. Medicaid will cover inpatient psychiatric services provided in general hospitals, but does not cover these services in state or county psychiatric hospitals.[2] Other factors include increased costs for psychiatric medications and states' increased use of Medicaid to pay for a broader range of community-based mental health services.

State Children's Health Insurance Program

The State Children's Health Insurance Program (SCHIP) is a federal program enacted in 1997 that provides funding to states for health coverage of low- and moderate-income children. In federal fiscal year 2001, 4.6 million children were enrolled in SCHIP (Centers for Medicare and Medicaid Services 2002). In addition, over 230,000 adults were enrolled in SCHIP under approved federal waiver projects. It is estimated that around 15 percent of SCHIP-eligible children need mental health or substance abuse services (Howell, Roschwalb, and Satake 2000).

Because the SCHIP program is relatively new, national data on SCHIP expenditures for mental health are not yet readily available. A simulation of mental health and substance abuse spending in the benchmark plans for SCHIP programs in six states suggests that expenditures for mental health and substance abuse ranged from 3.4 percent to 6.3 percent of all expenditures (Howell, Roschwalb, and Satake 2000). Another model estimated total mental health expenditures for children enrolled in SCHIP in a hypothetical state that covered inpatient and outpatient care, as well as mental health case management, school health, and pharmacy services. The model yielded an estimate of $638,100 in mental health expenditures for every 3,000 children enrolled (Howell, Roschwalb, and Satake 2000).

Medicare

Medicare is a federal program that provides health coverage to the elderly and disabled. Some individuals gain access to Medicare through their participation in the Social Security Disability Income program (SSDI). SSDI benefits are available to qualified disabled individuals who have been employed and have paid Social Security taxes. SSDI recipients are eligible for Medicare if they have received SSDI benefits for 24 months or longer. From 1987 to 1997, Medicare spending on mental health services increased from $3 billion to $9 billion, representing an increase from 8 percent of total spending on mental health from all sources to just over 12 percent.

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[2] The federal legislation establishing the Medicaid program prohibits states from using Medicaid funds to pay for care provided in institutions for mental disease, which are defined as institutions with more than 16 beds where more than half of the residents have a psychiatric diagnosis. Often referred to as the "IMD exclusion," this provision of Medicaid law prevents states from supplanting state funds historically provided to state and local psychiatric facilities with federal funds.

SAMHSA and Other Sources of Federal Funding

In addition to funding for Medicare and Medicaid, the federal government also provides categorical funding to states and localities for mental health services. The most important funding source is the Community Mental Health Services Block Grant, administered by the Substance Abuse and Mental Health Services Administration (SAMHSA). The block grant provides formula grants to states for community-based mental health services to adults with serious mental illness and children with serious emotional disturbance. In federal fiscal year 2002, the block grant provided $399 million to states, the same as the amount provided in federal fiscal year 2001. States are not required to providing matching funds, but must comply with maintenance-of-effort requirements. While states must target block grant funds toward services for adults with serious mental illness and children with serious emotional disturbance, they use the block grant to support a wide range of community mental health services.

The federal government also supports the provision of mental health services through its funding for federally-qualified health centers (FQHCs) that provide health care to uninsured and underserved populations. Some, but not all, FQHCs provide mental health services. Federal funding to FQHCs is increasing. In fiscal year 2002, funding for FQHCs rose to $1.3 billion, up from $802 million in 1997 (Landa 2002). Under an agreement between the Congress and the George W. Bush Administration, the funding for FQHCs will rise to $2.2 billion by 2006. A small amount of the new funding, $14.6 million, is aimed at helping FQHCs bolster their ability to provide an expanded range of services to their clients, including mental health, substance abuse, and oral health services.

SAMHSA PRIORITIES

At the Issue Dialogue, SAMHSA Administrator Charles Curie outlined the agency's plans to create a mental health system that builds resilience and promotes recovery by helping those with mental illness manage their illness, function in a competitive job, live in a home, and forge meaningful emotional relationships with friends and family members. SAMHSA's Center for Mental Health Services has an overall budget of just over $800 million to implement this vision. Priority programs and issues for this funding include: co-occurring disorders, substance abuse treatment capacity, eliminating use of seclusion and restraints, prevention and early intervention, children and families, terrorism and bioterrorism, homelessness, aging, HIV/AIDS, criminal justice, and implementing the New Freedom Initiative (a federal government-wide action plan for reform that aims to remove barriers for people with disabilities). SAMHSA bases its funding decisions on a set of principles, including supporting evidence-based practices, promoting workforce development, encouraging cultural competency and eliminating disparities, reducing stigma, and identifying innovative financing strategies.

THE NEW FREEDOM COMMISSION ON MENTAL HEALTH

On April 29, 2002, President Bush announced the formation of the New Freedom Commission on Mental Health and charged it with conducting a comprehensive study of the United States' mental health service delivery system and making recommendations for improvement. The commission is relying on a variety of mechanisms for collecting information, including holding public hearings, reviewing reports and documents, inviting public comment at all meetings, conducting outreach through both members and staff, and searching the Internet. The commission issued an interim report in October 2002 that outlined the issues the commission is examining and highlighted several exemplary community-based programs. The commission's final recommendations are due to the President by April 29, 2003. More information on the commission is available at www.MentalHealthCommission.gov.

In addition to the Community Mental Health Services Block Grant, SAMHSA administers a range of funding programs that address the mental health needs of various populations. More information on SAMHSA's programs can be found in Appendix I.

Programs administered by federal agencies other than SAMHSA can also support the provision of mental health services if states choose to use their federal funding for this purpose. These include: the Social Security Block Grant and Temporary Assistance to Needy Families (TANF), both administered by the U.S. Department of Health and Human Services; Welfare to Work Block Grants administered by the U.S. Department of Labor; and the Byrne Discretionary Grants Program, Community Prevention Grants Program (Title V), Juvenile Accountability Incentive Block Grant, and Reentry Initiative Grant Program, all administered by the U.S. Department of Justice (National Governors' Association 2001).

Other State and Local Funding for Mental Health Services

Although the federal government and states contribute almost equally to the financing of mental health services overall, states bear a greater share of costs for the public mental health system, covering two-thirds of the funding (National Council for Community Behavioral Health 2002). In 1997, state mental health agencies provided $9.1 billion to support community mental health services and $6.6 billion for state psychiatric hospital inpatient care (National Association of State Mental Health Program Directors Research Institute 1999).

The amount and share of state funds for community-based services increased steadily from 1981 to 1997 (Figure 2). In the mid-1990s, funding for community-based

services surpassed funding for state psychiatric hospitals for the first time. Most state funding for community-based services is directed toward those with serious and persistent mental illness, often leaving little for services to those with less severe conditions (HHS 1999).

In many states, the system for delivering public mental health services is county based. While counties receive state funds to support the delivery of mental health services to county residents, most localities also provide their own funding. For example, localities may fund the delivery of services to indigent clients who are not eligible for Medicaid or may provide funding to supplement low state Medicaid provider payment rates. In some states, localities are required to pay a share of the state Medicaid match for services provided to county residents enrolled in Medicaid. Local funds may also support prevention and early intervention programs, as well

as county clinics, general hospitals, psychiatric hospitals, and services provided in county jails.

Coverage for Mental Health Services

Most private insurance plans and all public health coverage programs provide coverage for some mental health services. The details of coverage, however, can vary greatly. Public health coverage programs such as Medicaid, SCHIP, and Medicare usually cover a limited set of services or impose significant limitations on coverage. Coverage for mental health services in private insurance plans varies substantially across plans. It should be noted that even if individuals have public or private coverage for mental health services, they may encounter difficulties accessing care for a range of reasons, including lack of appropriate providers,

Figure 2. *State Mental Health Agency Controlled Expenditures for State Psychiatric Hospital Inpatient and Community-Based Services as a Percent of Total Expenditures: FY 1981 to FY 1997*
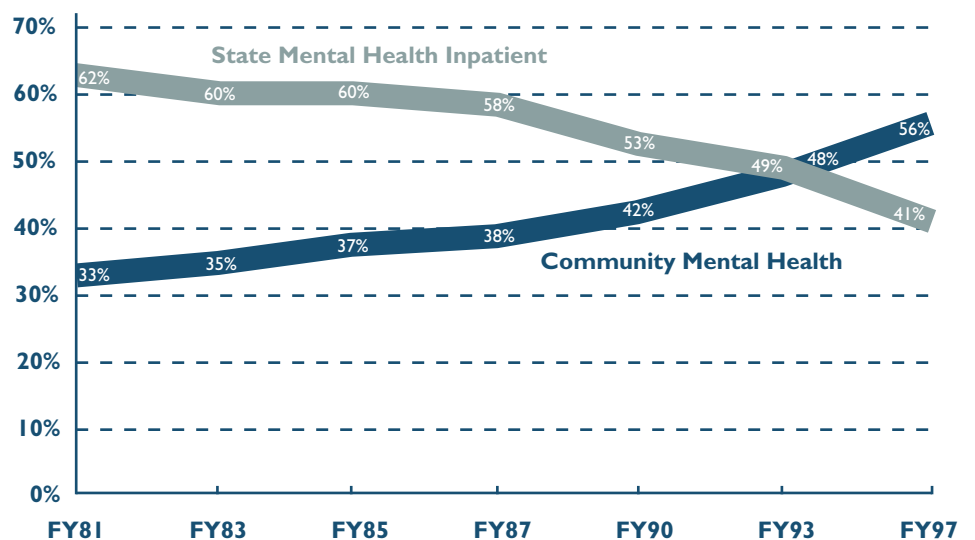
Source: Manderscheid and Henderson 2001.

insufficient numbers of slots in community-based programs, or difficulties navigating a complex service system.

Coverage Under Private Insurance

Employer-sponsored group plans typically cover some mental health services within limits. One study of employer-sponsored plans found that 99 percent of plans covered inpatient psychiatric care, and 97 percent covered outpatient services. But only 66 percent covered intensive nonresidential care, 43 percent covered crisis services, and 36 percent covered residential care not provided by a hospital. In addition, most group health plans impose limitations on covered services. The same study found that 58 percent of employer-sponsored group plans limited the annual number of covered inpatient days, and 33 percent limited the annual number of outpatient visits. Over half also imposed lifetime dollar limits on both inpatient and outpatient care psychotherapy (Buck and Umland 1997).

Individual health insurance plans typically cover some types of mental health services, but place greater restrictions on those services than group plans. For instance, most individual insurance policies impose greater limits on covered inpatient days, covered outpatient visits, and lifetime coverage than are typically imposed in group plans (GAO 2002). Some individual market health insurance plans do not cover mental health services at all or cover them under a separate policy with its own premium.

Coverage Under Medicaid

The specific services covered by Medicaid vary from state to state and between adults and children. For adults, states are not required to cover many services that are important to people with mental disorders, such as prescription drugs and case management. In addition, for adults age 22 to 64, Medicaid does not cover most services provided in institutions for mental disease (IMD), defined as hospitals, nursing facilities, or other institutions of more than 16 beds where more than half of the residents have a psychiatric diagnosis. The IMD exclusion does not apply to Medicaid-eligible children 21 or younger or to adults 65 or older. States may opt to provide Medicaid coverage for institutional care for these populations.

There are many options and demonstration programs available to states that permit them to cover services needed by individuals with mental disorders. Most states exercise one or more of these options (Bianco et al. 2001). Among the options are:

Medicaid rehabilitation option – Under this option, states can offer coverage for services recommended by a licensed provider aimed at reducing physical or mental disability and restoring individuals to the best possible functional level. Mental health services such as psychotherapy and psychosocial services, as well as addiction treatment, occupational therapy, and physical therapy, can be covered under this option. States offering Medicaid rehabilitation services can include some of these services and exclude others.

Case management options – States can opt to cover various types of case management services. One option, targeted case management, is defined as services that assist an individual in gaining access to needed medical, social, educational, and other services. Another option available to states is to extend Medicaid coverage for intensive case management programs such as Assertive Community Treatment.

Personal care option – States can opt to cover personal care services to help Medicaid beneficiaries accomplish tasks of daily living. Personal care must be authorized by a physician or other approved provider.

Work incentives programs – The Balanced Budget Act of 1997 created a new optional Medicaid eligibility group, allowing states to provide Medicaid coverage to working individuals with disabilities who, because of their earnings, cannot otherwise qualify for Medicaid. The Ticket to Work and Work Incentives Improvement Act of 1999 further expanded eligibility for Medicaid by removing income limits for working individuals with disabilities and continuing coverage for individuals with disabilities whose conditions improve with treatment.

Independence Plus – Independence Plus is a demonstration program that permits states to create and fund programs to delay out-of-home placements for individuals with disabilities requiring long-term support and services. Independence Plus is intended to help states meet their legal obligations under the ADA and the Supreme Court's *Olmstead* decision.

Demonstration to maintain independence and employment – This demonstration program provides funds to states that expand Medicaid coverage to workers who are not yet disabled, but whose potentially severe physical or mental impairments are likely to lead to disability. The goal of the demonstration is to determine whether providing Medicaid coverage to these individuals earlier improves their health status and increases their ability to stay employed and self-sufficient.

Home and community-based waivers – These waivers have been available to states since 1981 and allow states to provide home- and community-based services to individuals with disabilities who would otherwise qualify for institutional placement. Services include case management, homemaker/home health aide services, personal care services, adult day health, rehabilitation, respite care, and other services requested by states and approved by the federal government. All states operate at least one home and community-based waiver program.

Coverage for adults residing in group homes – Although the IMD exclusion prohibits Medicaid coverage for adults residing in psychiatric institutions, facilities with 16 or fewer beds are not considered IMDs. As a result, states can choose to provide Medicaid coverage for staffing and other costs associated with providing mental health services to group home residents.

Coverage for medically-needy populations – States may opt to extend Medicaid coverage to individuals who would qualify for Medicaid except for their income and resources. Medicaid will cover services to medically-needy individuals once they have incurred a certain level of medical expenses (often referred to as the spend down).

Children who are covered by Medicaid are entitled to a comprehensive range of health and mental health services through Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). EPSDT rules require states to cover regular health and development screenings for children and to cover diagnostic services and medically-necessary treatment for conditions discovered during a screening, including mental health conditions. As a result, children who are enrolled in Medicaid are entitled to a broader range of mental health services than may be available to Medicaid-eligible adults in the same state.

Coverage Under SCHIP

All state SCHIP programs provide some coverage for mental health services, typically inpatient and outpatient mental health services, but not residential care or school-based health services. This pattern of coverage is similar to that found in private insurance and is more restrictive than coverage available to children enrolled in Medicaid. There is wide variation in the amount of mental health benefits covered by state SCHIP programs (Howell, Roschwalb, and Satake 2000). Coverage for outpatient visits, for example, varies from a limit of 20 visits per year to an unlimited number of visits. Similarly, coverage for hospital stays ranges from a maximum of 15 days per year to unlimited coverage.

Coverage Under Medicare

Like Medicaid, Medicare pays for certain mental health services for eligible beneficiaries, but does not cover some services critical to those with serious mental illness, such as case management, psychiatric rehabilitation, and outpatient medications.

In addition, Medicare's coverage for mental health services is different from its coverage of physical disorders. Beneficiaries must pay a 50 percent copayment for outpatient care of mental disorders, compared with 20 percent for other medical outpatient treatment (GAO 2000b). Furthermore, treatment in a freestanding psychiatric hospital is limited to a total of 190 days in a patient's lifetime.

Another limitation is the requirement that physicians be involved in the delivery of Medicare-reimbursable services. For example, Medicare does not cover services provided by state-licensed counselors or marriage and family therapists (American Counseling Association 2002). This requirement creates barriers to services, particularly in rural areas.

Reasons for the Current Crisis in Community Mental Health Services

There are many reasons why community mental health systems are in trouble. This section discusses two major sets of issues: those related to the financing of community mental health services and those related to the mental health workforce.

Financing Issues

In real dollars, funding for community mental health services has declined over the past two decades (Judge David L. Bazelon Center for Mental Health Law 2001). As the crisis in financing has deepened, public mental health providers have been especially hard hit. Many have increasingly focused

on those with the most severe mental illness, 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 services such as assertive community treatment, psychiatric rehabilitation, and intensive case management. The state of the public system for children and adolescents is even worse than it is for adults. Children experiencing mental health emergencies 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.

Although state budget shortfalls exacerbated the financing problem in 2002, other factors have influenced mental health funding over the years, including changes in mental health economics, the trend toward managed care, rising pharmaceutical costs, deficiencies in private insurance, and issues related to federal and state funding decisions. Funding for mental health services is also being influenced by state responses to the Supreme Court's *Olmstead* decision and by requirements of the Health Insurance Portability and Accountability Act (HIPAA). Each of these issues is discussed in more detail. While the contribution of any one factor to the current crisis varies across states, provider types, and locations, the aggregate impact of these factors has created a nationwide crisis in financing.

Changes in Mental Health Economics
Although deinstitutionalization has largely improved the quality of life for individuals

with serious mental illness, it also changed the economics of mental health service delivery from a planned economy to a decentralized market economy. In the planned economy that existed prior to the 1960s, state mental health facilities provided the vast majority of the services, and state mental health authorities controlled both planning and financing. In the new decentralized economy, services are delivered in a wide range of settings by a host of different providers, responsibility for planning rests in many hands, and services are financed by a mix of public and private sources (Manderscheid and Henderson 2001).

While a decentralized market economy can provide more choices for some consumers, it does have several downsides. One consequence has been an increase in the number of mental health organizations, with a growth from 3,005 organizations in 1970 to 5,722 in 1998 (Manderscheid and Henderson 2001). Most of the increase can be attributed to increases in the number of private psychiatric hospitals, separate psychiatric services of general hospitals, freestanding psychiatric outpatient clinics, partial care organizations, and multiservice mental health organizations (Manderscheid and Henderson 2001). Because of the increase in the number of providers, there is increased competition for clients, funding, and staff. This competition consumes resources that could otherwise be directed toward treatment and other services and also results in imbalances in the distribution of providers.

Another downside of the competition is that it does not guarantee equal access to services for all consumers (Manderscheid and Henderson 2001). Public providers

often cannot compete with private providers for clients who are insured or capable of paying for services out of pocket. Because public funds are insufficient and do not cover all needed services, public systems frequently concentrate on serving those with serious and persistent mental illness. Individuals with milder conditions who must rely on the public system (because they are uninsured and unable to pay out of pocket) may find that some services are not available to them or that their choices are extremely limited.

Move Toward Managed Care

The move toward managed mental health care and behavioral health carveouts has substantially reduced funding for some mental health service providers (Manderscheid and Henderson 2001). Approximately 35 percent of large employers and 3 percent of small employers contract separately for managed behavioral health services for their employees (Manderscheid and Henderson 2001). In addition, recent estimates suggest that more than half of all health plans effectively create their own carveouts by using subcontracts with behavioral health management companies to provide behavioral health services to enrollees. Among state Medicaid programs, 42 use managed care approaches to provide mental health services to at least some Medicaid beneficiaries (SAMHSA 2000). Of these, 29 use behavioral health carveouts.

Managed mental health care has resulted in lower payments for services provided by both individual mental health providers and institutions (HHS 1999). In the private insurance market, studies show that the move to managed mental health care reduced spending on specialty mental health services, with 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, while another study found that Medicaid managed mental health programs reduced overall costs for mental health services in four of seven states (GAO 1999; Manderscheid and Henderson 2001).

In states that use realistic 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, with disastrous results for mental health service providers. For example, separate case studies of the managed mental health systems in Montana and Los Angeles, California found that both programs set initial capitation rates at levels significantly less than the previous year's fee-for-service spending for mental health services (Manderscheid and Henderson 2001). The managed care organizations had difficulty meeting the mental health service needs of enrollees and paying for the services that were provided. In the Montana case, the program was terminated by the state legislature after 23 months, but not before a well-respected community mental health center went bankrupt. In Los Angeles, when providers were offered an opportunity to disenroll clients and return them to the fee-for-service system, they exercised this option for over three-quarters of their clients.

Rising Pharmaceutical Costs

Community mental health service providers are also being negatively affected by rising pharmaceutical costs. The impact is particularly severe for public providers, which often supply medications for their poor and uninsured clients.

The rate of growth in spending for prescription drugs for mental disorders has averaged 10 percent per year since the mid-1980s (HHS 1999). The growth is due in part to an increase in the number of visits during which medication for mental disorders was prescribed, which rose from 33 million in 1985 to almost 46 million in 1994 (HHS 1999). The new medications now available to treat mental illness also cost much more than older medications. For example, the annual cost of Clozapine®, a newer antipsychotic used to treat schizophrenia (among other conditions), is $6,200 per patient, compared to a cost of $1,300 for the older drug Haldol® (Boulard 2000). Similarly, the cost of treating depression with Prozac® is about $800 per year, much more than the $200 cost for Tofranil®, an older drug for depression. Costs for new medications are likely to continue growing, as there are over 80 new drugs for mental disorders currently under development.

Deficiencies in Private Insurance

Many private insurance packages are deficient when it comes to mental health coverage. Individuals who need mental health services often cannot obtain private insurance coverage or find that their coverage for mental health services is limited. In addition, there remains a lack of parity between coverage for mental disorders and physical disorders.

In 34 states, private insurance carriers are permitted to deny coverage to applicants with mental disorders or other health conditions (GAO 2002). A study conducted by the General Accounting Office found that carriers in these states would decline to provide coverage to applicants with mental disorders over 50 percent of the time (GAO 2002). This was significantly higher than the 30 percent denial rate for applicants with chronic physical conditions. Carriers were most likely to deny coverage for applicants with post-traumatic stress disorder, schizophrenia, manic depressive and bipolar disorder, and obsessive compulsive disorder. When coverage is not denied, premiums and other costs are often higher, which may make the policies unaffordable.

State-sponsored high-risk pools offer coverage to individuals denied coverage in the private market, but this option has limits. Some states have waiting lists for their high-risk pools. In addition, the premiums in high-risk pools may be as high as 200 percent of standard rates for healthy people (GAO 2002).

For those who have private insurance, coverage for mental health services is typically more limited than for physical health services, and cost sharing is generally higher. Insurers limit coverage and impose higher cost sharing because of concerns about costs and competition.

The federal Mental Health Parity Act was passed in 1996 to address concerns about access to care and fairness. The act prohibits group health plans that offer mental health benefits from imposing more restrictive annual or lifetime limits on spending for mental illness than for physical illness.

While this was considered by many to be a valuable first step, it did not result in full parity. The law did not require group health plans to provide mental health coverage and did not address deductibles, coinsurance, copayments, and other forms of cost sharing. It also left health insurers free to impose prior authorization requirements and service limits and did not address the mental health service needs of those insured by small group plans or individual policies, which are not covered by the federal legislation.

A General Accounting Office study found that although most employers are complying with the federal mental health parity law, 87 percent of those in compliance report that their insurance coverage contains at least one other feature that is more restrictive for mental health benefits than for medical and surgical benefits (GAO 2000a). For example, 65 percent of employer plans place more stringent restrictions on the number of outpatient office visits or days of covered inpatient mental health care. The study also showed that many of these restrictions were added to plans after the passage of the federal mental health parity law.

Reduced Federal Funding
Insufficient federal funding for community mental health centers is a longstanding problem, stemming in part from provisions of the law that originally created them. At the height of deinstitutionalization, many communities found themselves ill-prepared to provide services to those leaving state psychiatric hospitals. Although the Mental Retardation Facilities and Community Mental Health Centers Act of 1963 helped fill the gap, fewer community health centers than anticipated were funded after

the passage of the act. Of those that were funded, most offered primarily clinic-based services that were inaccessible or inappropriate for individuals with the most serious disorders (Bianco et al. 2001).

In addition, the 1963 law assumed that the community mental health centers created with federal funds would eventually transition to self-sufficiency by providing services to individuals who could pay for their care, either directly or through public or private insurance coverage. Once this transition to self-sufficiency was accomplished, so the thinking went, designated federal funds would no longer be needed. In reality, this self-sufficiency requirement proved difficult to meet: by 1978, only 60 of the 675 community mental health centers then in existence no longer received federal funds (Ray and Finley 1994).

The Community Mental Health Services Block Grant, the federal government's primary funding stream for community mental health services, has historically suffered in the federal appropriations process. The value of the block grant (when adjusted for inflation in medical costs) has actually declined since 1981 (Figure 3) (Judge David L. Bazelon Center for Mental Health Law 1999).

Community mental health centers have keenly felt the effects of the declining value of the mental health block grant (Simmons 2002). In 1981, the creation of the block grant took away community mental health centers' designated funding and required them to compete with other providers for a fixed allocation of funds. Since the funding for the new block grant was reduced by 14 percent from the

"Federal funding for community mental health centers was limited to seven years, which meant that in seven years, the mental health organization had to go out and find paying customers or go out of business. So there was a big disconnect between the theory on the one hand and the operational requirements on the other."

MICHAEL HOGAN,
OHIO DEPARTMENT OF
MENTAL HEALTH

funding levels of the programs that were folded into it, fewer dollars were available overall to support community mental health services. As a result of this double blow, community mental health centers lost 30 percent of their funding at that time (Simmons 2002).

Reduced State Funding

State spending is also declining when measured in constant dollars, shrinking by 7 percent between 1990 and 1997 (Judge David L. Bazelon Center for Mental Health Law 1999). State mental health funding declined as a proportion of state spending as well, falling from 2.12 percent of state spending in 1990 to 1.81 percent in 1997.

This downward trend in state mental health funding will likely continue given state budget shortfalls in 2002 and projected shortfalls in 2003. Although states have used funds from tobacco settlements and so-called rainy day funds to cover a portion of the shortfalls in tax revenues, budget gaps and balanced budget requirements are forcing states to cut agency and program budgets. Because of political pressures to preserve funding for education and public safety programs, many states have cut the budgets for other discretionary health and human service programs, including programs providing mental health and related services (Carey and Lav 2002).

In many states, budget cuts have included measures intended to reduce the cost of Medicaid and SCHIP programs. Medicaid expenditures comprise the second largest share of state budgets, after education (Ku, Ross, and Nathanson 2002). Medicaid costs are escalating relentlessly in most states, with overall state Medicaid expenditures expected to grow by an additional 6.4 percent in 2003 (National Association of State Budget Officers 2002a). Of particular concern to state officials is the dramatic increase in expenditures for drugs for Medicaid beneficiaries. Since the 1990 implementation of a federal law requiring state Medicaid programs to cover all drugs manufactured by companies willing to provide rebates, drug costs have soared from $4.4 billion in 1990 to almost $12 billion in 1997 (Boulard 2000). In 2000,

LOSING THE AUTOMATIC BUDGET INCREASE

An unintended side effect of the transition from institutional care to community services has been a loss in budget clout for mental health services. When most mental health care was provided in institutional settings, state and local psychiatric hospitals were typically financed by secure government funding streams that were automatically indexed for inflation and wage increases. Often, these were approved without debate. In contrast, funding for community-based programs is now debated in governors' offices and state appropriations committees each year as part of state budget processes, thus subjecting these programs to the political and economic realities of the moment.

pharmacy costs for nearly every state skyrocketed, with the increases ranging from 17 percent to 21 percent (National Governors' Association 2000).

In 2002, 47 states either took steps or proposed steps to reduce future Medicaid expenditures (Ku, Ross, and Nathanson 2002). Most states avoided the most damaging type of cuts, reductions in income eligibility levels. With the outlook for state budgets remaining bleak, however, actions to balance state budgets in 2003 may need to rely on more damaging options, such as scaling back eligibility.

States are also requesting federal Medicaid waivers, in some cases to gain better control over Medicaid expenditures. In one example, a recent waiver granted to Utah permits the state to offer a limited package of preventive and primary care services to some new enrollees and reduce benefits for other beneficiaries. Reductions include, among other things, a cap on the number of visits to psychiatrists.

State fiscal worries are also affecting state decisionmaking about SCHIP. Before the current downturn, efforts to expand coverage for mental health services in states with restrictive coverage policies were often successful. Now, such efforts are encountering roadblocks as states attempt to deal with substantial budget shortfalls. In addition, some states are reluctant to expand SCHIP coverage when they may soon be facing shortfalls in federal SCHIP funds due to structural problems in the 1997 SCHIP legislation.[3]

Figure 3. *Decline in the Community Mental Health Block Grant 1981-1998 (in medical inflation adjusted dollars)*
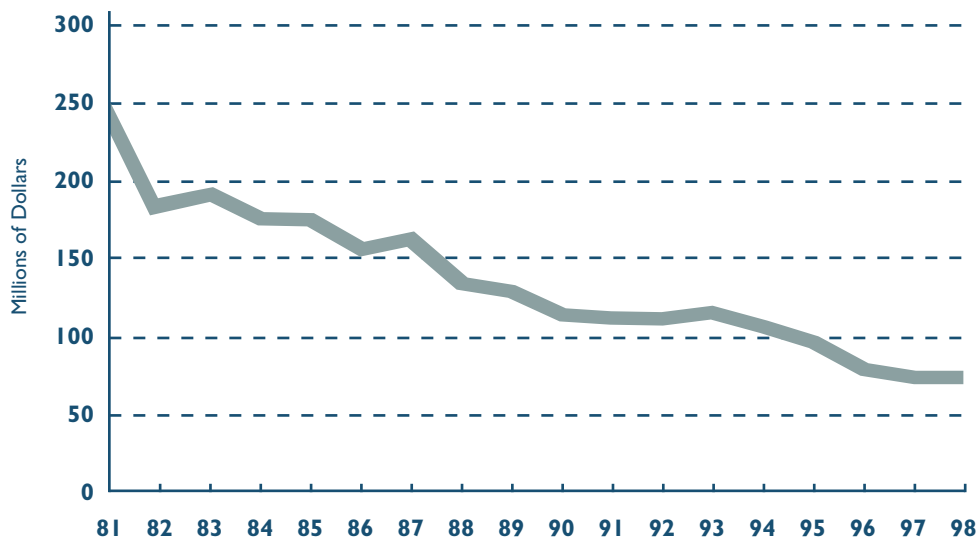
Source: Judge David L. Bazelon Center for Mental Health Law 1999.

[3] The SCHIP financing provisions of the Balanced Budget Act of 1997, the federal legislation that created SCHIP, reduce federal funding for SCHIP for federal fiscal years 2002, 2003, and 2004. This funding reduction was included in the legislation as a means of achieving a balanced federal budget in fiscal year 2002; similar funding reductions were applied to other programs authorized by the Balanced Budget Act of 1997. As a result, states with high SCHIP enrollment rates are likely to experience shortfalls in funding as their state allotments and the total amount of federal SCHIP funds available nationally decrease. Experts expect the shortfalls to have an impact on states starting in 2003 as states exhaust their supplies of unspent SCHIP funds from previous years.

"Institutional care for mental illness probably ought to be thought of in the same way as inpatient care for other health conditions. There are probably times when you want to be in a hospital for acute treatment, but nobody wants to live there."

MICHAEL HOGAN,
OHIO DEPARTMENT OF
MENTAL HEALTH

**Implementation of the
Olmstead Decision**

State budgets and administrative capacity are also being strained by the need to meet the conditions of the Supreme Court's 1999 *Olmstead* decision, which held that unjustified isolation of persons with disabilities in institutions is a form of discrimination prohibited by the ADA. The decision requires states to ensure that community-based treatment options are available if three conditions are met: (1) the treatment is determined to be medically appropriate; (2) community-based treatment is not opposed by the patient; and (3) the treatment can be "reasonably accommodated" based on available resources (National Governors' Association 2001). The decision has been characterized as a *Brown* v *Board of Education* for individuals with disabilities, placing legal mandates on states to meet the need for community-based treatments for people with disabilities, including those with mental disorders.

It is unclear exactly which populations the findings may apply to or how states, the federal government, and the courts will interpret the reasonable accommodation requirement. Although the specifics of the case concerned patients receiving services in a state psychiatric hospital, some legal advocates believe that the findings may apply to other populations such as nursing home residents, individuals who cycle in and out of psychiatric hospitals, individuals at risk of psychiatric hospitalization, and individuals who are inappropriately incarcerated, as well as other individuals receiving services in unnecessarily segregated settings (Bianco et al. 2001).

Although the outcome of state *Olmstead* planning processes will expand access to community treatment for those with mental disorders, the planning process and subsequent alterations to existing infrastructure are placing strains on the system. Since the decision, states have devoted significant staff time and funding resources to developing *Olmstead* plans and implementing new assessment procedures to identify institutionalized individuals that could be served in community settings. State budget shortfalls may limit the ability of states to allocate new state funds for implementation of *Olmstead* plans and increase competition for funding among various types of mental health community providers (Fox-Grage et al. 2002).

There are also concerns that state efforts to meet *Olmstead* obligations may result in new inequities. States may place a higher priority on funding services for individuals transitioning from institutional placements than on funding services for individuals already residing in communities (National Alliance for the Mentally Ill 2001). In addition, some populations may be overlooked in state budgeting and planning processes, such as children and adolescents.

**Implementation of New Federal
Requirements Governing Treatment
and Use of Health Information**

The implementation of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) is also straining the mental health system. HIPAA requires all public and private health care providers, payers, and other holders of health information to use standard codes for electronic data transactions and also requires them to establish policies and procedures to guarantee the privacy and

security of individually-identifiable medical information.[4] In many cases, the transition to standard codes is requiring states, service providers, and health plans to upgrade or replace their current information systems or to contract with a health information clearinghouse to translate information so that it complies with HIPAA requirements.

The burden of HIPAA compliance on states is particularly high. Many agencies and programs within state government are affected by HIPAA, including state Medicaid programs, employee health plans, public health programs, and health services operated by state departments of corrections. Because HIPAA requirements are so far-reaching, the National Governors' Association has warned states that the cost of compliance with HIPAA may exceed costs incurred in Y2K preparations (National Governors' Association 2002). California estimates that costs to its state Medicaid program will exceed $100 million, while Indiana estimates that costs outside of its Medicaid program could reach $160 million. Estimates of Medicaid and non-Medicaid costs in Pennsylvania place the total between $50 million and $200 million (National Governors' Association 2002).

Workforce Issues

Community mental health systems nationwide are facing a workforce crisis that is impeding access to mental health services. The crisis manifests differently for different providers and across the various populations in need of mental health services.

Although staffing issues are affecting both public and private mental health providers, the crisis is most acute for public providers.

Tracking the supply and distribution of mental health professionals and documenting workforce shortages is difficult. 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, shortages 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). But there are limits to substitution. For example, a lack of psychiatrists, common in rural areas, may prevent individuals with mental disorders from receiving prescription medications to treat their conditions.

Another factor that makes tracking the mental health workforce difficult is the variation in licensing and certification requirements across states. Because each state makes its own decisions about which types of providers need to be licensed or certified, the universe of licensed mental health professionals varies considerably. For example, not all states license professional counselors. Only four states (Arkansas, California, Colorado, and Kansas) license psychiatric technicians. Due to the lack of consistency in licensure, some national workforce studies rely on data from higher education programs (which may overstate

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[4] The deadline for compliance with HIPAA's data standardization rules was October 16, 2002 (covered entities could apply for a one-year extension). The deadline for compliance with HIPAA's privacy rules is April 14, 2003.

supply since not all graduates are employed in the field) or membership statistics from professional associations (which may understate supply since not all professionals join associations).

Despite the lack of consistent national data on the mental health workforce, there is general consensus among experts that workforce shortages are reaching crisis proportions in many states and localities. Some aspects of the staffing problem could be solved if the financing issues laid out in the previous section were addressed. For others, however, additional funding alone will not be sufficient. This section of the Issue Brief discusses two of the major workforce problems facing community mental health providers: an inadequate supply of mental health professionals and uneven geographical distribution of providers.

Inadequate Supply of Mental Health Professionals

Over 3,500 urban, suburban, and rural areas nationwide have been designated as mental health professional shortage areas by the U.S. Department of Health and Human Services, meaning that they have shortages of core mental health professionals, including psychiatrists, clinical psychologists, clinical social workers, psychiatric nurse specialists, and marriage and family therapists (American Academy of Child & Adolescent Psychiatry 2002). There are many reasons for the shortages of mental health workers, many of them the same as for the health field generally. In some professions and specialties, there are fewer workers entering the field. In addition, low pay and lack of training opportunities lead some mental health workers in the public mental health system

to seek higher paying jobs in the private sector (Bianco et al. 2001). An additional factor contributing to shortages of mental health workers is the lack of state reciprocity for nonphysician mental health providers; not all states recognize the licenses or certifications issued by others (Mertz 2001). Supply problems are exacerbated by an uneven distribution of mental health workers across urban, suburban, and rural areas and across regions of the country; these issues are discussed further in the next section.

The supply of psychiatrists and nurses is particularly problematic. Fewer medical school graduates are entering the field of psychiatry (Ivey, Scheffler, and Zazzali 1998). Only 3 percent to 4 percent of medical school graduates are choosing psychiatry as their specialty, leading to concerns about the availability of psychiatrists to serve individuals with serious mental illness (Ro and Shum 2001). The war on terrorism is also affecting the supply of psychiatrists. After the September 11, 2001 terror attacks, the U.S. Department of Agriculture (USDA) abruptly stopped issuing waivers for a federal program (commonly known as the J-1 program) that allowed foreign medical residents to remain in the United States if they committed to working in underserved areas. This action by the USDA interrupted the longstanding practice of recruiting foreign-born psychiatrists to staff community mental health centers in underserved areas. In December 2002, the U.S. Department of Health and Human Services announced that it would begin sponsoring waivers for the J-1 program.

The mental health field is also experiencing shortages of nurses, as is the health care field generally. As with other nursing specialties, the supply of psychiatric nurses is dwindling as older nurses retire and fewer young people enter the profession. In 1998, the number of nurses completing graduate programs in psychiatric nursing was only 55 percent of the number completing such training in 1980 (Manderscheid and Henderson 2001).

Mental health professionals specially trained to work with children are in particularly short supply. The federal Bureau of Health Professions estimates that the demand for child and adolescent psychiatrists will increase by 100 percent by 2020. The number of these professionals, however, is expected to increase by only 30 percent, resulting in a shortage of over 4,000 child and adolescent psychiatrists nationwide by 2020. In addition, the National Center for Educational Statistics reports that the national student-to-school-counselor ratio in U.S. schools is 513:1, more than double the recommended ratio of 250:1 (American Academy of Child & Adolescent Psychiatry 2002).

Also of concern is the relative dearth of providers from ethnic and racial minority groups. Racial and ethnic minorities constitute approximately 25 percent of the population, but less than 10 percent of mental health providers (American Psychological Association 2002). A diverse pool of providers is critical for addressing the linguistic, cultural, and other special access barriers experienced by individuals who are members of racial and ethnic minority groups.

Uneven Geographical Distribution of Providers

An uneven distribution of mental health professionals is exacerbating the workforce problem in some areas. For example, workforce shortages are particularly acute in rural communities. Nearly three-quarters of the mental health professional shortage areas are in rural communities, with 1,682 rural counties (55 percent of all counties nationwide) having no core mental health professionals (Wayman 2000; Ro and Shum 2001). The average number of specialty mental health organizations in nonmetropolitan areas is substantially lower than in metropolitan areas, as is the percentage of hospitals offering inpatient and outpatient psychiatric services (National Rural Health Association 1999). Similarly, only 18.6 percent of non-metropolitan hospitals offer emergency psychiatric services, compared to 37.4 percent of hospitals in metropolitan areas (National Rural Health Association 1999).

There is also considerable variation in the distribution of psychiatrists and other mental health professionals across regions of the country. For example, the ratio of psychiatrists in the New England states was 21.3 per 100,000 in 1996, while the ratio in the region comprising Alabama, Kentucky, Mississippi, and Tennessee was 6.8 per 100,000 (Ro and Shum 2001). Similarly, the ratio of clinically-trained social workers in New England was 76.4 per 100,000, compared to 17.6 per 100,000 in the group of southeastern states. Generally, states with high population ratios of psychiatrists tend to have high levels of other mental health professionals as well (Ivey et al. 1998).

"What if you have a wonderful benefit that you can't access? Parity legislation will produce the first. Whether or not it deals with the second is another question."

MICHAEL HOGAN, OHIO DEPARTMENT OF MENTAL HEALTH

Opportunities for Grantmakers

Foundations of all types and sizes are making a difference in the lives of individuals with mental disorders, their families, and their communities by working to strengthen national, state, and local service systems and increase access to care for individuals who need mental health services. Despite their efforts, mental health grantmaking represented only 7 percent of all health grantmaking in 2000 (Foundation Center 2001). With mental disorders affecting approximately one in five Americans, it is clear that mental health grantmaking is not commensurate with the needs of individuals with mental disorders and their families and communities. This section describes some of the strategies that health grantmakers can use to meet those needs and preserve access to community mental health services.

Grantmakers Are Helping States and Localities Understand and Strengthen Their Mental Health Systems

When funding is tight, planning and needs assessments are among the activities that are often put on a back burner. Over time, however, ignoring these activities can result in mental health service systems that are out of step with current needs and changes in clinical practices.

Some foundations have found that even relatively modest grants that help states and communities plan for the future can result in dramatic improvements in services and outcomes for clients. This type of grant-making has an ancillary benefit as well: it can help grantmakers gain a better understanding of the mental health service systems in their geographic service areas and help them identify effective ways to target future grantmaking to address identified problems.

A good example of this approach comes from The Health Foundation of Greater Cincinnati. In 1999 and 2000, the foundation released a Request for Proposals to the 12 local boards in its geographic service area that make decisions about the allocation of mental health funding. These 12 boards were offered the opportunity to request support for planning and needs assessments, things that few of them had the resources to do on their own. Nine of the 12 funding boards applied for and received one-year grants ranging from $80,000 for a single county to $194,000 for an eight-county region.

The funding boards were given significant latitude in how to use the grant money. For instance, they could hire project staff or use consultants, and they could use the grant funds to conduct a wide range of activities related to planning and needs assessment. The only requirement from the foundation was that the boards develop strategic plans for redesigning their mental health systems or reallocating resources to better meet the needs of the local population, as well as implementation plans that assigned timelines and responsibility for implementing components of the strategic plans. The boards were also expected to report back to the foundation on the impact of the grants after the grant funds ended.

As of September 2002, all but one of the nine strategic plans had been completed and implementation had begun, with dramatic changes and positive outcomes in many localities. For example, one local funding board redesigned its system of care for adolescents by bringing together all child-serving agencies to focus on pooled funding, sharing of client information, and cross-system training. Early results show a decrease in out-of-home placements for youth and an increase in family involvement. Another used input from consumers and families to become more consumer-friendly in its operations by expanding intake capacity and enhancing e-mail and Web site capabilities. Still another board that served a five-county region used the results of a needs assessment to spur development of a partnership among schools, the juvenile justice system, treatment providers, and parents that is leading to more collaboration among systems and coordinated care for children with behavioral health problems. As a result of the planning grants, other local boards improved data collection systems, implemented evidence-based practices, and secured additional funding for mental health services.

Another example of support for planning and needs assessment comes from Colorado, where a group of grantmakers interested in mental health is conducting a study to evaluate the status of mental health in the state, with an explicit aim of identifying how grantmakers can help address problem areas. The Colorado Mental Health Funders Group was formed in September 2001 in response to a wave of activity on mental health by grantmakers and others in Colorado. It consists of eight

foundations, including three foundations formed from hospital and health plan conversions, two community foundations, a corporate foundation, a donor-advised fund, and a hospital foundation. The participating members have signed a formal memorandum of understanding that includes requirements for participation, as well as rules for decisionmaking and voting. Each grantmaker gets one vote, regardless of its original contribution to the study (which ranged from $1,500 to $30,000 per organization).

The Mental Health Funders Group issued a Request for Qualifications in July 2002 that asked potential applicants to provide their views on what the sponsoring foundations needed to learn and how the members of the funders group could participate in the study process. A Colorado firm was selected to conduct the study, with completion expected by July 2003. The sponsoring foundations each believe that the study will lead to action — collectively or individually — to improve the mental health system in the state.

The California Endowment started examining mental health issues several years ago when it began receiving large numbers of funding requests from California mental health providers and other nonprofit organizations concerned about the mental health of Californians. In September 2000, the foundation leadership committed to funding a $10 million program, known as the *Special Opportunity in Mental Health Funding.* When it was originally conceptualized, the primary purpose of the initiative was to learn about mental health at the community level as a first step toward a larger, long-term statewide initiative. But after

"Strategic planning with the funding authorities has had a big impact on organizations and their systems of care, and it is an impact that has endured."

JANICE BOGNER,
HEALTH FOUNDATION OF
GREATER CINCINNATI

"This is the best money we have ever received. It's made all the difference for our system of care."

RECIPIENT OF A
PLANNING GRANT FROM
THE HEALTH
FOUNDATION OF
GREATER CINCINNATI

receiving an overwhelming response to an initial Request for Proposals, the foundation decided to raise its commitment to an initial level of funding of $24 million and to continue multicultural mental health grantmaking as an area of strategic focus and funding within the foundation for an additional five-year period.

In setting up this initial program, The California Endowment sought to create a learning community among its 46 grantees. To that end, the foundation hired The Lewin Group to conduct an ongoing evaluation of the program that focused on four critical issues: whether grantees reach underserved populations, the role of community-based models in improving mental health services, the impact of cultural competence (or the lack thereof) and stigma on mental health services, and the types of improvements and problems that come out of the initiative. The early results from the program are positive. Through partnerships, community involvement (for example, in program design and implementation), and a variety of programs oriented at improving cultural competence, grantees have used initiative funds to provide services to 19,000 Californians (many of whom previously lacked access to services) over a 15-month period since implementation began. Grantees have identified strategies to destigmatize mental health and the reluctance to access services among traditionally hard-to-reach populations and have implemented treatment intervention and outreach and training models that promise to yield evidence-based effective practices in the area of mental health for multicultural populations.

Grantmakers Are Improving Services for Special Populations

Many grantmakers are supporting mental health programs and services that fill gaps and provide critical services to those in need. Often, this type of support is targeted toward a special population at high risk of remaining unserved or underserved. This section highlights mental health grantmaking that targets the elderly; children and adolescents; racial, ethnic, and sexual minority groups; and people who are homeless or incarcerated.

Elderly

Until recently, mental health problems in older adults went largely unrecognized and, therefore, untreated. Fortunately, this is changing, due in part to the efforts of health grantmakers that have worked to increase awareness of mental disorders among seniors and improve the diagnosis and treatment of mental disorders in this population.

Some grantmakers have used funds to develop and test new models for diagnosing and serving elders with mental health problems. For example, The John A. Hartford Foundation in New York launched an $8 million initiative in 1998 to support the development, implementation, and evaluation of a model that can be used by primary care physicians to identify and care for depressed elders. Seven university-based health care systems received funding from The John A. Hartford Foundation, and two received funding from the California HealthCare Foundation to implement the disease management model, which adds a specialist nurse or other health professional to the

primary care team to educate patients and families about depression and its treatment, monitor patients and assist with treatment sessions, and conduct individual and small group therapy sessions. The initiative included funding for centralized data analysis and dissemination activities and to educate providers about the potential benefits of the enhanced model. In 2000, The John A. Hartford Foundation provided supplemental support to extend the period of patient follow-up from one to two years in order to better document the effectiveness of this model.

Another example of this approach comes from The Fan Fox and Leslie R. Samuels Foundation of New York. Its project, *Identifying Mental Health Disorders Among Elderly Primary Care Patients,* has supported an examination of variations in screening and assessment of mental health disorders in two health plans, each with different delivery systems. The project assessed the strengths and limitations of using a patient health questionnaire in general practice to screen for emotional disorders among older patients.

Other foundations are expanding access to mental health services for seniors by funding direct services. For example, the *Project HEARTH Program,* funded by the HCR Manor Care Foundation, Inc., in Toledo, Ohio helps maintain the emotional well-being, autonomy, independence, and safety of area elderly clients by providing needed in-home mental health counseling by a geriatric social worker and peer counselor volunteers. In other examples, the Rose Community Foundation in Denver, Colorado helped a community center provide independent living skills training to older adults with chronic mental

disorders, and the Altman Foundation supported mental health outreach to elders participating in senior organizations and the provision of mental health services to seniors living in a naturally occurring retirement community in New York City.

Children and Adolescents
When children and adolescents with mental health problems do not receive the treatment and services they need, there are ramifications for the rest of their lives. Grantmaker projects targeting children and youth range from ambitious, long-term efforts aimed at redesigning state and local service systems to more focused projects designed to improve access to services or the quality of services.

One example of a long-term investment in local system improvement comes from the Quantum Foundation, Inc. The foundation's *Children's Behavioral Health Initiative* is aimed at reforming the present system of fragmented, isolated, and under-funded programs in Palm Beach County, Florida for children who need behavioral health services. A cornerstone of the initiative is an assessment and prevention strategy that focuses on resiliency and building behaviorally-related assets in children to promote positive behavioral health. Components of the initiative include: placement of behavioral health professionals in schools; involvement of teachers in the identification and assessment of children with potential behavior problems; better intervention and treatment, including school-based services and referrals to community providers; creation of a healthier environment in schools and in the community; and improved parent and community involvement in the lives of children.

Other examples of investments in community system redesign include the Connecticut Health Foundation's *Mental Health Initiative* and the Blue Cross Blue Shield of Massachusetts Foundation *Building Bridges in Children's Mental Health* initiative. The Connecticut Health Foundation initiative is speeding the development of family-centered local systems of care and addressing current problems such as an insufficient supply of in-state residential placements for children with mental health needs and a lack of access to community-based services and evidence-based treatments for children who need mental health services. Grants have supported advocacy and policy development; training of primary care physicians, pediatricians, and other providers who work with children to help them identify children at risk and refer them to appropriate services; and early assessment and intervention services for young children.

Similarly, the Blue Cross Blue Shield of Massachusetts Foundation initiative is supporting 15 community-based collaborations to improve access to mental health services for low-income and uninsured children and their families. These three-year *Building Bridges in Children's Mental Health* grants will provide $25,000 to support planning during the first year and $50,000 each year for program implementation in the second and third years. The grants will help reduce fragmentation of services for children; improve support for their families; and train nontraditional mental health providers (for example, pediatricians, teachers, and nurses) in early identification, assessment, and referral of children with emotional problems.

Some grantmakers work with state policymakers to help improve policies, programs, and systems of care for children and adolescents who need mental health services. For example, The Annie E. Casey Foundation's *Mental Health Initiative for Urban Children* helped states, localities, and neighborhoods work in partnership to rethink the design of mental health services and to create a blueprint for a neighborhood-based system of service delivery. This work included developing a more effective array of services and supports for children and families living in disadvantaged neighborhoods; reconfiguring the systems (including finances, information management, personnel, policymaking, and case management) that support these services; engaging neighborhood residents, service providers, government officials, and other relevant stakeholders in new partnerships; and creating opportunities for families with children who have special needs to play a significant role in shaping the services provided to their children.

The Robert Wood Johnson Foundation also worked with policymakers through its *Mental Health Services Program for Youth Replication* (MHSPY). MHSPY provided states with relatively small grants to help them improve services for children and youth by applying an array of tools and techniques that had been developed in eight original MHSPY sites. The tools and techniques included use of managed care capitation rates tailored to the needs of the children and their families and blended funding streams that combined funds from the different child-serving agencies responsible for children with mental health problems (child welfare, mental health, education, health, juvenile justice, and

substance abuse). The results of the replication program were less fragmentation of services, greater efficiency of service delivery, positive treatment outcomes, and greater client and family satisfaction with overall services.

Some foundations are focusing on improving specific services for children and youth, such as school-based services. For example, the Health Foundation of Greater Cincinnati is providing grants aimed at expanding existing school-based mental health services into a coordinated system of care to reach all students in one Ohio county, regardless of age or level of need. The program works with a formal collaborative body that coordinates services, provides training for teachers on behavioral health issues, and collaborates with schools to improve parental involvement and education. The Alliance Healthcare Foundation provided a grant to support coordinated, intensive school- and home-based mental health counseling services for students and families in the San Diego area. The range of services included triage, referrals, case management, individual and group counseling, and parent and school staff training. Services were provided on-site at schools, as well as in students' homes. The program addressed cultural needs of students and families by providing services in the languages and cultural contexts of the highly diverse student body (Vietnamese, Cambodian, Lao, Spanish, and Somali).

Racial, Ethnic, and Sexual Minority Groups

Some grantmakers are working to reduce disparities in health outcomes among minority groups, including disparities related to mental health. As noted earlier,

members of minority groups who have mental health service needs are at higher risk of remaining unserved and of receiving lower quality care.

The Colorado Trust is funding a $7 million, five-year initiative aimed at enhancing the mental health and social adjustment of immigrants and refugees across the state of Colorado. The trust will support up to 20 organizations that provide services that affect mental health in various ways. Direct mental health services will include psychotherapy, counseling, or support groups, while indirect services might include parenting classes, English as a Second Language, or social events. The goals of the initiative are to: encourage the coordination of services through enhanced collaboration between agencies and enhanced referral capabilities; build capacity for organizations that serve the mental health needs of immigrants and refugees; enhance organizations' ability to respond to the needs of new and emerging immigrant/refugee populations; and create strategies for sustaining programs.

In another example of a grantmaker addressing mental health service needs of underserved populations, the Klingenstein Third Generation Foundation, through its *Center for American Indian and Alaskan Native Health,* has provided funding to address depression prevention and treatment intervention among American Indian adolescent parents and their offspring. A pilot project will identify, treat, and prevent depression and depressive symptoms in a cohort of high-risk adolescent American Indian mothers and promote optimal bonding and attachment between these mothers and infants. The intervention and related data collection will be carried out

"On the children's side, it's real critical to see what the relationships are like between the mental health system and the school systems, as well as the juvenile justice system."

CHARLES CURIE, SAMHSA

by American Indian paraprofessionals from the Navajo and White Mountain Apache nations. Data will be gathered through this pilot demonstration to inform future efforts.

The New York Community Trust provided support for a program aimed at improving access to primary care and mental health care for Asian-American girls and young women in New York City. The program had several components: training for health professionals to help them diagnose the early stages of psychological distress and coordinate treatment and follow-up care, focus groups with Asian-American girls to identify barriers to care and issues leading to psychological distress, direct care for at least 75 girls and young women, and outreach and education in four public schools regarding recognition of mental health problems and ways to support students who need confidential health care and support services.

The New York Community Trust has also made several grants that are directed toward meeting the mental health needs of individuals who are gay, lesbian, bisexual, or transgendered. One grant supported expansion of a program for gay, lesbian, and bisexual youth that included evaluation by a psychiatrist and development of a treatment plan, as well as training for youth agency staff to help them recognize early signs of mental illness and make referrals. Another grant helped increase referrals for mental health care and expand low-cost treatment for gay and lesbian adults. Priority for low-cost treatment was given to poor people no longer eligible for Medicaid as a result of changes in welfare. The grant also supported training for therapists so they could better help gay men and lesbians deal with psychological problems caused by life experiences and issues not related to sexual orientation.

Homeless or Incarcerated People

Untreated mental illness is a primary cause of homelessness and a risk factor for involvement in the juvenile and adult justice systems. Some health grantmakers provide critical support for projects that address the mental health needs of homeless and incarcerated people.

For example, The van Ameringen Foundation has made funding of mental health services in prisons and jails a priority. Projects funded by the foundation include the following: support for a consulting psychiatrist to serve young people who are currently incarcerated or being released from prison; individual and group counseling for incarcerated and formerly-incarcerated women and their children in a family reunification program; screening of juveniles in probation for emotional disturbance, training for probation officers, and development of an advocacy campaign; and support for an alternative sentencing program for felons with mental disorders.

Other examples come from Hogg Foundation for Mental Health and The Dorothy Rider Pool Health Care Trust. The Hogg Foundation for Mental Health has supported improvements in the services provided to the state's mentally-ill, homeless population. The program provides professional training for staff at emergency shelters, transitional housing centers, and other agencies serving the homeless. The Dorothy Rider Pool Health Care Trust supported a pilot project designed to provide integrated care to homeless individuals who

have been diagnosed with both mental illness and substance abuse problems. The project used an intensive case management model to serve these dual-diagnosed individuals. The pilot project results demonstrated improvements in clinical outcomes and quality of life, along with reductions in overall costs.

Grantmakers Are Supporting Workforce Development Efforts

Some grantmakers are working to address shortages of mental health workers, diversify the provider community, and ensure that providers are able to appropriately recognize and serve patients with mental health care needs.

One workforce strategy is to support programs designed to increase the number of qualified workers who are members of racial and ethnic minority groups. For example, the Hogg Foundation for Mental Health sponsored a program that seeks to meet the growing demand for well-trained minority professionals in the fields of mental health services and mental health research. The grant supported the development of an enhanced mental health academic program within a university school of social work, as well as graduate school preparation programs and career placement resources. The grantee also developed a new mental health course curriculum exploring the latest research, literature, and treatment modalities, as well as concerns for providing culturally-relevant services to diverse populations. Another example of this approach comes from the Healthcare Foundation of

New Jersey, which supported internships for minority graduate students at a local mental health clinic.

Other foundations are addressing the workforce issue by focusing on supporting family members, who often serve as the primary caretakers for many individuals with mental illness. For example, the Sisters of Mercy of North Carolina Foundation, Inc. provided support to the North Carolina state chapter of the National Alliance for the Mentally Ill (NAMI) for the operation of the organization's *Family-to-Family Education Program.* This program provides education and training for family caregivers of people with serious mental illness. The course is taught by specially-trained family members and teaches the knowledge and skills that caregivers need to provide care to their loved ones, including teaching them how to help ensure that a family member with a serious mental illness accesses appropriate treatment when needed.

Issue Dialogue participants highlighted an untapped opportunity in the area of workforce development—supporting policy changes to make it easier for immigrants with backgrounds in mental health services to become licensed or certified in their current state of residence. Many mental health professionals who were born and received their training in other countries do not work in the mental health field because they cannot obtain required state licenses or certifications. If they do work in the mental health field, they are often employed in lower-level positions that do not take full advantage of their abilities and skill levels.

"Eighty-three percent of our grantees had staffing difficulties in trying to get their grants up and running. Most of that was because they were trying to hire culturally-appropriate staff that do not exist."

MARY RAINWATER,
THE CALIFORNIA
ENDOWMENT

Grantmakers Are Developing and Testing New Models of Service Delivery

Some health grantmakers provide support for projects to develop new models of service delivery and help mental health providers adapt to changes in the field. Examples of this work include support for models that integrate mental health and primary care, ensure that managed care arrangements work well for individuals with mental health needs, and test new approaches for dealing with individuals with untreated mental illness who are in the criminal justice system.

Integration of Mental Health and Primary Care

Several health grantmakers are working with researchers, primary care providers, mental health professionals, policymakers, and others to promote the integration of mental health services and primary care. For example, The Robert Wood Johnson Foundation has launched a new, five-year, $12 million national initiative that aims to increase the use of effective models for treating depression in primary care. Three facts about mental health and primary care serve as the framework for this program: depression is a serious and prevalent chronic disease that should be conceptualized in a manner parallel to other chronic conditions; longitudinal chronic illness care approaches to depression treatment are effective, but are not currently implemented; and effectively putting these approaches into place requires a combination of clinical and economic systems strategies at multiple levels. The program will fund three different areas: demonstration project grants in the area of incentives, value research grants, and leadership grants.

Another example comes from The John D. and Catherine T. MacArthur Foundation. The foundation's *Initiative on Depression and Primary Care* is designed to increase the quality of care received by patients with depression who are seen in primary care settings. To that end, it is funding research to examine how—and how well—primary care physicians diagnose and treat depression in their patients and how they can improve their effectiveness in both areas. The research projects fall under four major headings (1) improving the understanding of current practices in primary care; (2) evaluating the effectiveness of treatment for depression in primary care; (3) developing, evaluating, and disseminating educational interventions to help primary care physicians better recognize and manage patients with depression; and (4) developing, evaluating, and disseminating methods to enhance office routines and practice patterns that promote high-quality care of depression.

Other funders are funding more modest integration projects. The Health Foundation of Greater Cincinnati provided a grant to support the expansion of a four-year project to integrate mental health care into primary care at community health centers in four medically-underserved communities in Cincinnati. The expansion will serve 600 children, adolescents, and their families annually. A previous grant helped the project receive a matching grant of $460,000 from The Robert Wood Johnson Foundation. The Washington Square Health Foundation, Inc., in Chicago, Illinois, sponsored a project to develop health services that integrate primary and mental health care

for people with severe and persistent mental illness, targeting an underserved minority population in Chicago.

Adapting to Managed Mental Health Care

Grantmakers have responded to the move to managed mental health care by providing support for projects to assess the impact of managed care on mental health consumers and ensure that managed care systems respond to the needs of those with mental disorders. For example, the Hogg Foundation for Mental Health awarded funds to a county mental health and mental retardation authority to study the impact of Medicaid managed care on children and adolescents with severe mental illness or emotional disturbance in the Greater Houston area. The New York Community Trust funded the development of a community-based managed care plan for children and adolescents with serious mental illness, including completion of operational and business plans, development of clinical protocols to integrate medical and social service needs of children with mental and emotional disorders, and completion of legal requirements for applying for state approval.

Other grantmakers have responded by supporting projects to help providers adjust to the new environment and help mental health consumers navigate complex managed care systems. The Pew Charitable Trusts funded the delivery of training and technical assistance in behavioral managed health care to county administrators and providers in various parts of Pennsylvania, including Bucks, Chester, Delaware, and Montgomery Counties. The Consumer Health Foundation in Washington, DC provided a grant to a national mental

health organization to educate mental health consumers about the District of Columbia's plan to shift the delivery of mental health services to a managed care system, empower them to participate in the policy planning process for the new system, and provide them with the information to effectively access and navigate the new system once implemented.

Community Treatment for Those in the Criminal Justice System

Some grantmakers are supporting state and local programs that seek to demonstrate the effectiveness of alternatives to incarceration for individuals with mental illness, including the use of mental health courts and mandated community treatment to divert individuals with untreated mental illness from the criminal justice system. For example, the Jewish Healthcare Foundation supported the establishment of Pennsylvania's first mental health court. The court will include a dedicated judge, assistant district attorney, forensic case manager, mental health court monitor, and dedicated probation officers. This team will ensure that people with mental disorders who are involved in nonviolent and misdemeanor cases in Allegheny County will receive alternative adjudication and specialized community mental health services that will support their health and stability in the ommunity.

Similarly, The Health Foundation of Greater Cincinnati funded two planning grants and subsequent start-ups of mental health courts in two Ohio counties. These courts are pre-trial programs designed to divert people with severe mental illnesses from jail and into community-based treatment. Program participants are individuals who are

charged with misdemeanors and who also have serious mental illnesses that are factors in their criminal justice involvement. The court-ordered treatment will help improve mental functioning of participants and enhance their ability to lead law-abiding lives.

Another example comes from The John D. and Catherine T. MacArthur Foundation, which is supporting the *Initiative on Mandated Community Treatment,* a $1.2 million program that is housed at the University of Virginia School of Law. Launched in 2000, this initiative seeks to establish a basis for an informal debate on the efficacy of mandated community treatment and its impact on mental health law and policy.

Grantmakers Are Supporting Research and Advocacy to Improve Mental Health Services and Systems

Some grantmakers provide support to national, state, and local organizations to help them collect and analyze data on the status of individuals with mental disorders, educate the public and policymakers about issues affecting children and adults with mental disorders, and advocate for improvements to the community mental health services system.

Several foundations have supported research designed to collect and analyze data that can be used to improve services and systems. For example, The Boston Foundation funded a study to track the expenditure of public allocations and private insurance premiums for mental health services in Massachusetts, while St. Luke's Health Initiatives in Phoenix,

Arizona, supported an investigation of service use and costs for mid- and high-level users in a public behavioral health system. The John D. and Catherine T. MacArthur Foundation supported the development of a set of performance indicators for behavioral health to help consumers, purchasers, and health plans assess the quality of mental health care services.

Grantmakers have also supported policy analysis aimed at identifying gaps and deficiencies in mental health services or systems and recommending solutions. For example, the William T. Grant Foundation provided support to a national mental health organization to assess the availability of home- and community-based mental health services for children and youth with serious emotional disturbances and identify ways to expand such services using funding from Medicaid and the Individuals with Disabilities Education Act. Similarly, the Connecticut Health Foundation funded a project to assess publicly-funded mental health services for children in Connecticut and develop a financing and implementation plan for an integrated community-based service delivery system.

Some foundations are active in promoting advocacy efforts. For example, St. Luke's Health Initiatives has invested more than $1 million over a three-year period to build a virtual network of direct advocacy and communications activities in Arizona. The aim of the network is to enhance community services for people with serious mental illnesses and children with mental disorders. Working with consumers, advocacy groups, providers, public officials, and the legal community, the network has been

instrumental in increasing public funding levels for mental health in Arizona. In other examples, the Jewish Healthcare Foundation funded the formation and operation of an action group to advocate for insurance parity for mental health in Pennsylvania, while the Public Welfare Foundation supported the *Idaho Leadership Academy*, which organizes and supports mental health consumers and their families throughout Idaho to decrease the stigma associated with mental illness and to promote the integration of individuals with mental health illness into the community.

Grantmakers Are Building the Capacity of Community Mental Health Providers

Some grantmakers are helping to build the capacity of mental health service providers and advocacy organizations. Such assistance can help organizations improve the management and administration of programs and the delivery of services to clients.

The New York Community Trust, for example, supported the work of a consortium of four nonprofit agencies that is developing simple low-cost software products that help small mental health agencies to coordinate and track their services and expenses. This support will help the consortium learn to store client information that can be easily accessed during repeated admissions and discharges, instead of reentering the information each time. It will also create a system to improve billing and the tracking of services provided by others (which helps to ensure better coordination of care). Similarly, St. Luke's Episcopal Health Charities of Houston, Texas supported a technical assistance

project to help behavioral health providers develop a shared management information system.

Another type of management support was provided by Pfizer, Inc when it awarded a grant to an interfaith health center in the state of Washington to develop a referral network of local mental health professionals who were willing to accept patient referrals and provide mental health treatment services at a significantly reduced rate. Both the Alliance Healthcare Foundation and The Boston Foundation provided support for the development of business plans for mental health organizations. In the case of the Alliance Healthcare Foundation, the support went to a new nonprofit entity for work with a local integrated system of care to develop a business plan for comprehensive mental health services for children and adolescents in San Diego County. In the case of The Boston Foundation, funds were provided to support the preparation of a marketing and business plan to guide the development of geriatric mental health services for the Boston area's only independent nonprofit nursing home serving an inner-city, multiracial population.

A different approach to capacity building comes from the Hogg Foundation for Mental Health, which provided a three-year grant to a local United Way for a program that will help recruit and train minority volunteers to serve on the boards of community-based organizations — especially those serving people with mental illness. The foundation believes that having greater minority representation on these boards will enhance the capacity of these organizations to effectively serve minorities with mental illness.

Lessons Learned

Health grantmakers face great challenges in trying to ensure that the limited funds available in the area of mental health have a significant and lasting impact. Grantmakers must help grantees to overcome the many barriers resulting from an environment dominated by limited service delivery capacity, deficiencies in financing, problems with the supply and distribution of mental health professionals, and a continued stigmatization of mental illness. The discussions and presentations during the Issue Dialogue highlighted a number of lessons learned by mental health grantmakers that have successfully improved the mental health systems in their states and communities.

Lesson 1: Seek Partnerships with Other Funders

Linkages among grantmakers and with state and local officials can help increase the impact of mental health grants. As a first step, grantmakers should identify other initiatives affecting the mental health system in their state or community, including those funded by federal, state, or local governments and other grantmaking or community organizations. For example, grantmakers may have opportunities to partner with local or state government funders to promote best practices in areas such as workforce development and cultural competence. Grantmakers can also seek linkages with community and government agencies that provide vital services to individuals with mental illness, including housing agencies, community development agencies, employment and training programs, and local and state departments of mental health. Grantmakers may also consider seeking greater

linkages between the corrections department/juvenile justice system and mental health. While mental health funding in many states is flat, funding of prisons and the criminal justice system is skyrocketing. There may be an opportunity to make the case for greater investment in mental health as a means of curbing these costs.

Collaboration offers the opportunity to have a bigger impact through pooled resources and enhanced credibility and influence with other stakeholders. While collaboration creates some potential problems (for example, delays, difficulties in managing communications across collaborators), the benefits of a well-run collaboration usually outweigh any drawbacks.

Lesson 2: Promote Linkages Among Grantees

Grantmakers should work to promote partnerships and linkages among their grantees so they can work together to educate the public about mental health, heighten awareness of community needs, share resources, and set up referral systems, among other things. Grantmakers can encourage the involvement of community leaders and consumers in program design and implementation. When done consistently, community involvement can help to increase public awareness and knowledge of mental health issues, increase consumer empowerment, build community leadership, and improve outcomes.

Lesson 3: Support Grantees and Be Flexible

Because the environment for mental health services varies dramatically from area to area and can also change significantly over time, grantmakers should not be too

prescriptive in their demands on grantees. For example, recognizing wide variations across its geographic service area, the Health Foundation of Greater Cincinnati was purposely not prescriptive in asking local funding boards to submit requests for support for needs assessments and planning. Even after grants are funded, moreover, changes may still need to occur. The California Endowment found that 93 percent of its grantees needed to make at least one modification to their interventions and/or techniques after submitting the initial funding request.

Grantmakers should also create mechanisms for identifying and sharing best practices among grantees, from periodic informal meetings where grantees come together to formal evaluations.

Lesson 4: Advocate for Better Public Policy
Grantmakers can help remedy deficiencies in public policies and programs by supporting advocacy.

For example, grantmakers can support efforts to change policies that discourage individuals with mental illness from seeking employment for fear of losing disability and Medicaid benefits. Grantmakers can also support efforts to document linkages between the provision of nonhealth supportive services and mental health outcomes. Government agencies and health grantmakers alike may be better able to fund nontraditional areas if they see evidence of a health benefit.

Lesson 5: Promote Education
Grantmakers need to promote public education about mental health and mental illness to overcome stereotypes and encour-

age individuals to recognize the true nature of mental disorders. Grantmakers should also consider bringing in mental health experts to improve the understanding of staff and board members about mental health issues, particularly if mental health grantmaking represents a move beyond the organization's traditional areas of funding.

Conclusion

Mental health issues are increasingly coming to the fore in states and communities across the country. The increased attention is a result of many factors, including the publication of the Surgeon General's report on mental health in 1999, the impact of the Supreme Court's decision in the *Olmstead* case, the mental health effects of the terror attacks on September 11, 2001 and the threats of future attacks, and the impact of state budget shortfalls on community mental health service systems.

Despite the needs, mental health issues are often overlooked or given short shrift by health grantmakers. The work of health grantmakers currently funding in mental health is proving crucial as communities struggle to preserve their mental health systems. Given the urgency of the crisis facing many localities, however, there is an urgent need to expand the base of funding for efforts to preserve community mental health services. Information sharing about effective mental health grantmaking can help stimulate interest among health grantmakers in working to preserve essential community mental health services and reduce the unnecessary costs and suffering associated with untreated mental disorders.

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Appendix I

Selected SAMHSA Programs Supporting Community-Based Mental Health Services

Program Name	Description	Funding Level (Fiscal Year 2002)
Community Mental Health Services Block Grant	Formula grants to states provide financial assistance to help them provide comprehensive community mental health services to adults with serious mental illness and children with serious emotional disturbance.	$399 million
Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbance	Project grants are helping states, localities, and tribes provide coordinated community-based systems of care for children and adolescents with serious emotional disturbance (and their families). Programs ensure that children receive an individualized, coordinated set of services developed with the participation of the family and a case manager.	$88 million
Protection and Advocacy for Individuals with Mental Illness	Formula grants to states enable them to expand their systems to protect and advocate for the rights of individuals with mental illness and investigate incidents of abuse, neglect, serious injury, or death.	$29.4 million
Projects for Assistance in Transition from Homelessness	This annual formula grant provides states and territories with a flexible funding source specifically to serve homeless individuals with serious mental illness, including those with substance abuse problems. The program is designed to provide services that will enable homeless people with a mental disorder to find appropriate housing and mental health treatment.	$35.8 million
Projects of Regional and National Significance	Grants support projects that address priority substance abuse and mental health issues and provide immediately useful and practical knowledge that can be disseminated to service providers.	$650 million (estimated)
Mental Health Disaster Assistance and Emergency Mental Health	Project grants provide supplemental emergency mental health counseling to individuals affected by major disasters, including training of workers to provide such counseling.	$10 million

Source: Catalog of Federal Domestic Assistance <http://www.cfda.gov>