The State of Mental Health Care in the United States



BACKGROUND PAPER COMMISSIONED FOR:

THE MEASURE OF AMERICA

American Human Development Report 2008-2009

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May 2007

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The Problem and How We Got There

According to President Bush's 2003 New Freedom Commission, the mental health system is in a state of "shambles" (New Freedom Commission on Mental Health, 2003). In his call for the report, he pointed to stigma, unfair treatment and financial limitations in mental health care coverage, and a fragmented system as barriers preventing Americans from getting adequate mental health treatment. The Commission states that the "mental health delivery system is...in disarray...[leading] to unnecessary and costly disability, homelessness, school failure and incarceration" (New Freedom Commission on Mental Health, 2003).

The United States mental health care system is currently made up of a fragmented decentralized system—or virtually non-system—of services and financing, resulting from inconsistent legislation over several decades. The result is that coordinating services and care for people with mental illness has become complicated, and at times impossible, leading to disparities in access to care, quality of care, and quality of life among certain populations. Moreover, the U.S. has the largest rate of uninsured individuals compared to other developed countries, and even those who do have coverage are not guaranteed mental health benefits. The high cost and prevalence of mental illness is a larger burden on society than many other medical conditions for social and economic reasons, including increased risk of HIV infection, diabetes, and cardiovascular disease among the mentally ill and high prevalence of mentally ill among the homeless and incarcerated. Furthermore, mental illness is often accompanied by stigma that can make seeking treatment for a mental health disorder taboo or render policymakers hesitant in formulating legislation. Making these realities all the more startling are studies indicating that the numbers of people with mental illness are on the rise. Since the 1960s, mental health legislative power, formerly belonging to states, has been transferred more and more to administrative bodies within the federal government, resulting in decisions made by policymakers who may not fully understand mental health needs. While today's mentally ill individuals overall receive better medical care, are more independent, and face less stigma than ever before in United States' history, they still do not receive the same standard of care as is expected for other conditions and face inequalities in care depending upon demographics and mental disorder diagnosis.

Mental illness in the United States is more common than many Americans may realize, with most estimates for the American adult population falling between 20 to 30 percent (Frank and Glied, 2006). In 1999, the Surgeon General's report on mental health estimated 21 percent of the adult population had a mental illness based on criteria for a 12-month mental disorder according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Surgeon General, 1999). A more recent estimate by Kessler et al. places this figure even higher at approximately 30 percent and found the rate has remained relatively unchanged over the past 15 years (Kessler, 2005). Unfortunately, many who have a mental illness do not receive any treatment for it. The Surgeon General's estimated one-third of those who had a diagnosable mental illness did not

receive treatment, whereas Kessler et al., estimated fewer than 50 percent of those with a diagnosable mental illness receive treatment (Kessler, 2005).

The severity levels of the estimated one-fifth of adult Americans believed to have a mental illness during a one year time frame varies greatly (Frank and Glied, 2006), and it is important to distinguish severe and persistent mental illness (SPMI) from serious. moderate, and mild mental illness classifications. Moderate and mild mental disorders represent the majority of diagnoses (Kessler, 2005). According to Kessler et al.'s recent study, individuals with mild disorders comprised about 11 percent of the total mentally ill population, while those with a moderate disorder comprised 13.5 percent. Approximately 6 percent of individuals with a diagnosable mental illness were considered to have a serious disorder (Kessler, 2005). Of those, 2 to 3 percent had a SPMI (Grob, 2006). While about half of total mental illness cases met criteria for having only one diagnosable disorder, the remaining half were evenly split between meeting criteria for having two diagnosable mental disorders or three or more, an important finding given that severity of mental illness is highly correlated with co-morbidity. Half of individuals classified as having a serious mental illness, had three or more diagnosable disorders. Within the serious mental illness group, mood disorders were the most prevalent, with bipolar disorder being the most common. While Kessler chose not to analyze schizophrenia due to problems in properly diagnosing the disorder, it falls under the SPMI group and is typically estimated to comprise about 1 percent of the population (Mechanic, 1999). The Surgeon General's 1999 report on mental illness estimated the prevalence for 18 to 54 year old adults at 1.3 percent (Surgeon General).

Children also suffer from mental illness. The Surgeon General estimated the prevalence of mental illness in children as equal to that in adults at 21 percent. Of these, according the New Freedom Commission, approximately 5 to 9 percent of children have a serious emotional disturbance (New Freedom Commission). The most commonly diagnosed mental illness class in children and adolescents is anxiety disorders. These disorders, such as separation anxiety, generalized anxiety, social phobia, and obsessive compulsive represent 13 percent of the mental illness prevalence rate in children aged 9 to 17 years. According the Surgeon General's report, half of adults with reported generalized anxiety disorder claim it began during childhood. Mood disorders are the second most frequently diagnosed mental illness in children and adolescents (Surgeon General, 1999). Mood disorders carry a great risk of suicidal tendencies, a very serious concern among clinicians. In fact, suicide is the third leading cause of death among children and adolescents (Healthy People 2010, 2000), with the highest suicide rate occurring in 15 to 19 year olds (9.5 per 100,000). Approximately 10 to 15 percent of children and adolescents exhibit some symptoms of depression at any given time, and the rate of major depression in children is estimated at roughly 5 percent. Major depressive disorder in children is highly correlated with having another mental health disorder, and age of onset of depression is predictive of recurrences and developing a mental disorder later in life. Finally, disruptive disorders, such as conduct disorder, occur between 1 to 6 percent of the population.

Unfortunately, the majority of children and adolescents with mental health disorders do not receive any mental health services. The report indicated that approximately only 21 percent of children and adolescents with mental health disorders used mental health services annually (Surgeon General, 1999). Postulated reasons for

these low utilization rates include stigma, cost, and dissatisfaction with services. Use of services is considerably higher for those individuals who have both a mental diagnosis and impaired functioning. Between 40 to 60 percent of children that begin some form of treatment do not complete the full treatment regimen, possibly because treatment was not directly initiated by the child or family but rather referred by the school, court, or agency.

It is only within the past several decades that legislators have begun paying much attention to mental health needs. Historically, mentally ill individuals were cared for by their families, in almshouses or psychiatric institutions with few regulations for how to care for individuals within the institutions. The quality of care individuals received varied from one institution to the next, and the increasing numbers of patients made proper care and treatment nearly impossible. Furthermore, not all facilities were particularly interested in treating patients but rather in keeping them confined. This was frequently because etiologies of mental illnesses were poorly understood and not necessarily viewed as treatable. To compound matters, demented elderly individuals were routinely institutionalized alongside those with psychiatric illnesses (Rochefort, 1997). Hospital personnel were lacking in manpower and ill equipped to successfully care for the diverse needs the patient population required in psychiatric institutions (Mechanic, 1999).

From a culmination of events in the 1940s and 1950s, the 1960s saw a shift in the way mentally ill individuals were treated and cared for. First, screening of potential servicemen in World War II revealed that psychiatric disorders were not uncommon and needed to be addressed. Of those screened, 12 percent were deemed unfit for service based on neurological or psychiatric evaluations, and an additional 37 percent were later discharged from service for the same reasons. During this period, employer-sponsored health insurance was popularized. Shifting a portion of health care payment to insurance companies, made health care more accessible to many who previously may not have been able to afford it.

After the war, a cascade of events led to new legislation for the mentally ill. Increased interest in treating and curing psychiatric disorders spurred the creation of the National Institute of Mental Health in 1946, which had enormous political clout and funded many endeavors for new scientific discoveries about the brain and treatments for mental illness. Among these, discoveries of drugs—such as chlorpromazine for schizophrenia in the 1950s and tricyclic antidepressants in the early1960s for depression—were heralded as the beginning of a new era in treating mental illness. These breakthroughs not only improved the quality of life for those with mental illness and their caretakers by significantly reducing symptoms (Rochefort, 1997), their efficacy helped in reducing stigma by demonstrating a powerful link between psychiatry and biology (Mechanic, 1999). Finally, several studies revealed the abuses within institutions during a time when civil rights were politically hot, and there was an outcry for social change for those with severe mental illness (Mechanic, 1999).

Advocates for change embraced the idea that Community Mental Health Centers (CMHCs), an outpatient based system, would allow mentally ill individuals to participate in society and lead relatively normal lives while also alleviating overcrowding and unsafe conditions in psychiatric institutions. President Kennedy was receptive to the idea and established the Community Mental Health Centers program in 1963 (Mechanic, 1999; Frank and Glied, 2006). Despite the fact that implementation of the centers was

incomplete (650 were created and publicly funded, but more than double that amount had been planned for), psychiatric institutions began discharging patients based on the continuum of care module developed for CMHCs depending on patients' psychoses' levels. Since CMHCs were federally subsidized, discharging state financed psychiatric patients to CMHCs was an appealing option to states since it effectively reduced their financial burden (Mechanic, 1999). In fact, eleven years after CHMC implementation began, nearly 25 percent of treatment episodes occurred in CMHCs (Frank and Glied, 2006). The effect deinstitutionalization had in terms of reducing the number of inpatients in clear when comparing numbers of inpatient and outpatient treatment episodes before and after deinstitutionalization (Frank and Glied, 2006). In 1955, 77 percent of treatment episodes took place in inpatient settings, a number reduced to 28 percent by 1977. Moreover, the number of outpatient episodes in 1955 was very small at 379,000, but by 1977 the total number of outpatient treatment episodes was close to two million.

In addition to deinstitutionalization and CMHCs, the passage of Medicare and Medicaid in 1965 brought about significant changes in mental health care financing that significantly impacted the ways for which mentally ill individuals were cared. States were financially motivated by the advent of Medicaid to deinstitutionalize their patients, in part due to the Institution of Mental Disease (IMD) exclusion. Under the IMD exclusion, mental hospitals were not eligible for Medicaid payment, meaning that states choosing to keep patients in mental hospitals stood to lose much financing. From an economic perspective, it was better to transinstitutionalize them—moving patients from one institution to another—to settings in which the states would receive federal funding. Thus, it became common practice to shift patients from psychiatric institutions to nursing homes or general hospitals, whereby states did not have to pay the full cost of patient care. The annual rate of patient decline in state and county mental hospitals after 1965 was approximately 8 percent, compared to a modest 1.5 percent decline in the ten years prior. Between 1955 and 1973, the number of people aged sixty-five and older in state and county mental hospitals dropped by 70.6 percent. Conversely, there was a 74 percent increase in nursing homes in elderly adults between 1960 and 1970 (Frank and Glied, 2006). Another way to look at the phenomenon is by comparing the numbers of mentally ill elderly adults in nursing homes pre- and post-Medicaid's enactment. In 1963, approximately half of the total nursing home population had a mentally illness; however, only six years later, three-fourths of the total nursing home population had a mental illness (Frank and Glied, 2006).

Over the next three decades, several policies were enacted that further impacted mentally ill individuals. In 1956 and 1972, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) were respectively implemented to financially aid disabled, low-income individuals. Today, approximately 27 percent of SSDI and 35 percent of SSI recipients have a disabling mental illness (Frank and Glied, 2006). In addition to these instrumental programs, the federal government revised Welfare requirements in 1962 to include nonelderly mentally ill individuals as potential recipients, began offering food subsidies in the form of food stamps in the 1960s, and created community support programs for shelter and offered subsidizing housing in the 1970s (Grob, 1994; Frank and Glied, 2006). Currently, 13 percent of those entitled to subsidized housing are disabled (Frank and Glied, 2006). These programs largely

allowed mentally ill individuals to live outside of psychiatric institutions and to participate in the community health center model.

The community health movement ended in 1980 with the President Reagan's Omnibus Budget Reconciliation Act (OBRA). Prior to his departure from office, President Carter was responsible for passing the Mental Health Systems Act (1980), which would have given more funding to CMHCs. However, OBRA repealed the Act, replacing funding to CMHCs with block grants to states for no specified designation other than use for mental health and substance abuse (Grob, 1994). By this time, many mentally ill individuals were successfully residing within communities funded though social welfare policies passed in the two previous decades (Grob, 1994), and the ways in which people thought of mental illness had changed. In fact, several court decisions in the 1980s gave more autonomy to mentally ill individuals (Frank and Glied, 2006), and the Americans with Disabilities Act (ADA) was passed in 1990. The ADA specified that impaired function due to a mental illness was a disability, legitimizing for many people mental ill individuals their impairments.

Finally, the introduction of managed care behavioral health (MCBH) "carve-outs" in the 1990s successfully reduced costs (first in the private insurance sector and later in Medicaid) by strategies such as reducing the allowable number of inpatient days and outpatient visits and decreasing provider payment. The net result was a 15 to 45 percent savings. Though many critics of MCBH were concerned that quality of care would decrease, there has been no indication this has occurred, with the exception of individuals who have schizophrenia (Frank and Glied, 2006). In fact, in most cases, increased access to care has been reported. An indirect result of MCBH was a decrease in states' control over their mental health systems as they began to rely more heavily on MCBH to manage their Medicaid programs.

There is no doubt that mentally ill individuals living in the United States today fare better overall than those who lived with mental illness only sixty years ago. Only the most severely and persistently mentally ill spend time in psychiatric hospitals, and most lead fairly normal lives. In part, this is due to advances in innovation and diffusion of medical technology that allows doctors to treat these illnesses in more humane and efficacious manners, which may have contributed to better adherence to treatment regimens (Frank and Glied, 2006). Moreover, some disorders, such as panic disorder and obsessive-compulsive disorder, were not formally recognized as diagnoses and were not effectively treated until the early 1980s (Frank and Glied, 2006). Additionally, gross health financing changes as well as mental health and social welfare legislation have allowed more mentally ill individuals access to care and the possibility to lead independent lives. Finally, court decisions recognizing autonomy of mentally ill individuals and legislation acknowledging mental illness as a disability for many increased mentally ill individuals' power. Given all these improvements, how is it possible that mental health care falls short in comparison to the standard that is given for general health care?

Manifestations of the Problem

Unintended outcomes of social policies and health care financing surrounding mental illness include an uneven distribution of mental illness among members of society and uneven access to mental health care services among the mentally ill. These outcomes are visible when comparing mentally ill individuals by race, gender, education, insurance status, mental disorder diagnosis, geographic location, and socioeconomic status. These disparities likely exist due not only to inequalities in inputs to the mental health system, but also to other policies that may inadequately address generalized social disparities.

A superficial view into these inequalities is apparent by looking at the correlation of psychiatric disorders with various demographic characteristics in the United States. For instance, Frank and Glied found that peak prevalence age of mental illness is in the twenties and that mental impairment prevalence increases with age (Frank and Glied, 2006). Among men and women, mental illness rates are similar but only when accounting for substance abuse. When substance abuse is removed as a diagnosable mental illness, women have much higher prevalence rates, with depression and other affective disorders being most common. In terms of race, they found no overall prevalence difference when controlling for socioeconomic status, as also reported the Surgeon General (Surgeon General, 1999). Kessler, Chui, Demler, and Walters found several disparities in mental health prevalence among groups. The population least likely to experience mental illness was the married, non-Hispanic black or Hispanic, college educated male with a high income living in rural areas. Married women with a high school education residing in metropolitan area suburbs were most likely to experience affective disorders, such as depression and anxiety, whereas young Hispanic men residing in rural areas were more prone to behavioral disorders. Correlates for having comorbid major depressive disorder were non-Hispanic white unmarried low-educated women with less than low income who reside in non-rural areas. Bipolar disorder was most strongly associated with having only completed high school and living in cities or suburbs. The socio-demographic variation for predicting disorders was strongest in predicting either being unaffected or having co-morbid major depressive disorder and weakest for predicting affective disorders and highly co-morbid disorder. These correlations, however, do not paint a complete picture (Kessler, Chui, Demler, and Walters, 2006).

Socioeconomic Status (SES) is by far the largest predictor of mental illness. The association between psychiatric disorders and low SES (Frank and Glied, 2006) has been documented for decades (Surgeon General, 1999). One estimate indicates that those in the lowest SES categories are more than two and half times more likely to experience a mental disorder compared to those in the highest SES category (Surgeon General, 1999). While this relationship does not imply causality, most studies indicate that the relationship has not been due entirely to mental illness causing or precipitating low SES (Frank and Glied, 2006). The main hypothesis for this observed correlation between mental illness and low SES is stress from being in a disadvantaged situation, including quality of housing, living arrangements, higher frequency of uncontrollable life events, and education (Alegría, 2003; Surgeon General, 1999). There is an indirect relationship between education and mental illness, whereby it is possible that the more education one has, the more likely she will have access to or knowledge about resources to help cope with adversity, leading to a better sense of control (Alegría, 2003).

Given the association between SES and prevalence of psychiatric disorders and the well-documented association between SES and ethnic minorities, it is not surprising that racial and ethnic characteristics are confounders for predicting mental illness. As Frank and Glied demonstrated by controlling for SES, distribution of mental illness among race groups is relatively equal. However, since financial resources are more limited among the four minority groups formally recognized by the U.S. government (Surgeon General, 1999), the prevalence of mental disorders is higher among some minorities (Surgeon General, 1999). Due to disparities in income among minorities and the negative impact this has on access to care, it follows that minorities are generally underserved in the mental health system (Surgeon General, 1999). For instance, Alegría reported that fewer than one in eleven Latinos with a diagnosable disorder contacts a health professional for treatment compared to one in every three non-Hispanic whites, and 50 percent fewer African Americans receive mental health treatment compared to whites. These figures contrast sharply with statistics on indicators of mental illness. Latino youth have nearly twice the suicide attempt rate as do whites, and African American youth are almost twice as likely to have behavioral problems as whites (Alegría, 2003). Additionally, the Surgeon General reported that African Americans compared to whites were most underrepresented in privately financed outpatient care (which tends to be the most expensive type of care), while utilization was equal in community-based programs and other publicly financed outpatient treatment (Surgeon General, 1999). Shockingly, African Americans have double the utilization rate for public psychiatric inpatient facilities.

Geographic location also plays a role in the disparities in access to receipt of care. Some research indicates that individuals living in rural communities have a lower prevalence of mental illness than those in urban areas, but rural inhabitants with a mental illness may face more disease burden (Lix, 2006). Possible explanations for the greater disease burden among rural residents are greater barriers to treatment, possibly due to fewer provider choices and a heavier reliance on primary care, differences in needs, and greater stigma (Surgeon General, 1999).

Perhaps these inconsistencies are partially explained by the existing inequalities in public and private health insurance coverage. An individual with a diagnosed mental disorder must be both sufficiently impaired and financially destitute to qualify for public assistance programs that allow him access to affordable mental health services. Mentally ill individuals who do not meet minimum qualification requirements, may be unable to work full-time, have difficulty finding or retaining employment, or otherwise have insufficient income to pay out of pocket for mental health services. Due to U.S. demographics and income distribution, minorities are more likely to be members of the low-income group, making them most at risk for being uninsured. Distribution of private insurance is also skewed. Those eligible for employer-based insurance are, must also be able to afford the option, while those who purchase private insurance must have sufficient income to do so. Overall, African Americans are almost twice as likely and Latinos more than three times as likely to be uninsured compared to whites. This is of great significance when considering who seeks treatment, keeping in mind that policies at the state and federal levels tend only to impact individuals with mental health care coverage (Alegría, 2003).

Other possible explanatory factors for inconsistencies in treatment among racial and ethnic minorities include lack of adequate language skills and lack of respect for different cultures, traditions, beliefs, and value systems—or cultural competence. Reports indicate that some minority group members do not trust the mental health

system, believing the system to be a dominated by white European culture. Also, there is a lack of ethnically and socioeconomically diverse providers with which potential mental health consumers from different economic and cultural backgrounds may not feel comfortable. Moreover, there may be cultural differences in reporting mental illness based on the severity of the illness (Alegría, 2003), differing coping styles for mental illness or life events, ties to family and community, or differences in ways mental illness are experienced (for instance, somatization) (Surgeon General, 1999).

Those who are most severely and persistently mentally ill face the greatest risks for inequitable access to care and poor outcomes. Individuals in this population need continuous care; yet, if obtaining health care is difficult for them, they may often neglect to do so without careful monitoring. A disproportionate number of SPMI individuals receive care from the public sector (Grob, 2004), a product of their low-income status (Mechanic, 1999) that often results from being unable to find or keep employment. Moreover, many do not have the secondary education (Mechanic, 1999) necessary for higher paying incomes. This population is also especially at-risk for comorbidities such as diabetes and cardiovascular disease (Bermudes, Keck, Weldge, 2006), partially due to an inability to self-monitor, low-income status, or housing status. Because this group tends to be a highly mobile population (Bachrach, 1992), moving frequently from places of residence or psychiatric institutions, they are at great risk of homelessness (Mechanic, 1999). In fact, an estimated 30 percent of homeless individuals are mentally ill (Frank and Glied, 2006), increasing their chances of substance abuse and HIV infection from intravenous drug use (Levounis, 2002). Additionally, they are at increased risk of being arrested (Junginger, 2006). A 1998 estimate indicated 16 percent of incarcerated individuals were mentally ill (US Department of Justice, 1999). Once a mentally ill person enters the correctional system, getting proper treatment for her mental illness is unlikely because the system is not equipped to handle the large numbers of mentally ill inmates (Manderscheid, Gravesande, and Goldstrom, 2004).

Causes of the Problem

There is not any one cause directly leading to the problems encountered by people with mental illness in the mental health system but rather the combination of legislation made by a variety of policymakers with different interests and the naturally arising disparities from different income levels among society members. Of these, fragmentation of the mental health care system, managed care, lack of mental health parity, under- and over-utilization of services, the extreme cost of treating mental illness, a lack services or providers, and increased homelessness and incarceration at a societal level have created barriers to care.

The fragmentation of the U.S. mental health care system poses major challenges for diagnosing, treating, and following up with mentally ill individuals and is one reason why many with a diagnosable mental illness do not receive the care they need. The fragmented system arose as a result of decentralization—or the move from a state-centralized mental health system to uncentralized market forces system (Frank and Glied, 2006). In 1959, the states were responsible for 59 percent of mental health care financing, the federal government financed 25 percent, and the remaining 16 percent came mainly from private insurance and out of pocket payments. Today, the states are

responsible for about 23 percent of direct mental health care spending, a rate that has remained constant since 1971. State mental hospital spending decreased by two-thirds from 1971 to 2001, and use of general hospital psychiatric units grew from 9.7 percent in 1971 to 16 percent in 2001 (Frank and Glied, 2006). While the increase in federal spending has protected people from the burden of severe and persistent mental illness it has led to an inability for mental health care authorities to directly shape the mental health system, making public policy making is difficult (Frank and Glied, 2006). Split among federal, state, local, and private service and financing systems, institutions at different levels do not always agree on best policies, argue over whose duty it is to care for someone, and lack efficient interagency communication leading to an uncoordinated system of services that are difficult to navigate—or worse inaccessible to—mentally ill individuals.

One consequence of decentralization was deinstitutionalization, which had many positive outcomes for mentally ill individuals. Grob states "[mentally ill individuals'] visibility on the streets often overshadows some of the inadvertent success of deinstitutionalization" (Grob, 1994). For many who were discharged to life in the community, CMHCs and social welfare programs enabled them to lead more fulfilling lives. Additionally, due to the large number of individuals discharged, the remaining mental hospital population drastically decreased, making the patient-staff ratio much more acceptable. In fact, studies show that patient care and treatment improved dramatically in institutions after deinstitutionalization (Frank and Glied, 2006). There were, however, downsides to deinstitutionalization for some. Patient discharge from psychiatric institutions was often poorly planned, leaving Single Room Occupancies (SROs) or the streets as their only options (Mechanic, 1999). Furthermore, to the extent that SSI and SSDI was beneficial to those entitled, the amount of income provided was (and still is) only sufficient for keeping an individual at the federal poverty line. Finally, those ineligible for public assistance or unable to access private insurance were left without many treatment options (Wang et al. 2005; Pogorzelski et al. 2005).

Despite legislation that has allowed many to access the insurance system, there are still many individuals who do not qualify for public coverage and cannot afford private insurance. Just over half of all individuals who have a mental illness are covered by private insurance (Frank and Glied, 2006), and the percentage of uninsured individuals with mental health conditions (20%) (Frank and Glied, 2006) is greater than that for the general American population (roughly 16%) (Kaiser Family Foundation, 2007). For those who are insured, lack of mental health parity compared to all other medical conditions is a reason why some individuals do not get the care they need. For decades, access to mental health providers, services, and treatments has been more expensive than for any other medical condition. For instance, until 1990, Medicare beneficiaries had to pay 50 percent of outpatient mental health costs, rather than the 20 percent required for all other services. Additionally, there was a \$500 limit in annual charges that could be made that did not apply to other health services (Frank and Glied, 2006). While the rationale was in keeping costs down by minimizing moral hazard, the effect was inadequate mental health care for many individuals who reached the annual maximums or simply could not afford the additional co-payments.

Treating mental illness is expensive, but there is no clear answer for why. Is it due to the moral hazard incurred by those having insurance plans with low co-payments

and deductibles, increased parity for mental health care, more mental illness due to more stressful lifestyles, better awareness (and thus decreased stigma) and diagnosis of mental illness, or more effective treatments? On the one hand, U.S. spending on mental health is a favorable sign that more people are getting the help they need for their condition. On the other hand, however, policymakers feel that escalating mental health care costs are out of control, despite the fact that those who most need care are unable to easily obtain it. While the lowest-income groups receive less than adequate mental health care, individuals with generous health insurance policies may feel freer to overutilize services, placing undue burden on the entire mental health care system. Overutilization at low individual costs raises the overall cost of care, which in turn raises managed care insurance premiums and increases employee contributions for purchasing employer-based insurance. The result is a widening disparity between the insured and uninsured and access and affordability of care.

Consequences

In economic terms, the U.S. spent \$104 billion directly on mental health and substance abuse treatment in 2001, with a 5.6 percent annual spending growth rate from 1991 to 2001 (Mark, 2005). Mental health spending alone tallied at \$85.4 billion, representing 6 percent of total national health care spending and roughly 0.85 percent of GDP (Frank and Glied, 2006). The President's 2003 New Freedom Commission reported the annual indirect cost of mental illness was \$79 billion, of which \$63 billion was due to loss of productivity resulting from mental illness. The rest was due to mortality costs, loss of productivity for incarcerated individuals, and the time family members spent as a caregiver (New Freedom Commission, 2003). During this period, Medicaid became the largest payer of mental health care (Mark, 2005), making for the first time, the U.S. government the largest spender on mental health. Despite the increase in spending over the ten-year span, the percentage of national income devoted to mental health care has remained relatively constant over the past thirty years, growing more slowly than did general health care spending in the same time frame (Frank and Glied, 2006). Additionally, prescription drugs for mental health disorders were the fastest growing component as can be seen in annual spending for them which ranged from 9 percent to 22 percent in 1987 to 2001 when (Frank and Glied, 2006). The group that accounts for the majority of healthcare costs is the severely and persistently mentally ill (Frank and Glied, 2006). In spite of the rapid increase in mental health costs, the combined mental health and substance abuse spending during this period ranked nearly one percent below the total health care spending rate (Mark, 2005).

Despite the slower rate of federal spending on mental health care compared to general health care, non-institutional mental health spending has increased, and utilization of non-institutional mental health services have nearly doubled since 1977 (Frank and Glied, 2006). As previously mentioned, there are several factors that have played a role in this phenomenon, such as the shift to employer-based insurance, the introduction of Medicare, Medicaid, SSI, SSDI, and housing programs in the 1960s and 1970s. Additionally, changes in technology, an increase in the supply side of care, and evolving perceptions of mental illness were partially responsible.

While states' portion of mental health care financing has decreased, Medicaid, Medicare, and private insurance have all increased their contributions since 1971. The addition of social welfare programs indirectly contributed to reducing states' share of mental health financing by providing financial viability for people with mental disabilities outside of psychiatric institution settings. Frank and Glied estimated that states' share of mental health expenditures through various mechanisms in 1971 was 30 percent, a figure that dropped to 23 percent by 2001. While the increase in public spending has been incredibly beneficial to individuals SPMI, it has also had at least one negative consequence: reduced input from mental health care providers on key policy issues. Current administrators responsible for driving policy are removed from firsthand exposure to the needs of the mentally ill population, and may not always understand what reforms are most needed, including gaps and limitations of the system (Frank and Glied, 2006).

The mentally ill population relies heavily on social welfare programs (Frank and Glied, 2006). A recent estimate shows about 27 percent of SSDI recipients, a comparable 28 percent on welfare assistance, and 35 percent of adults on SSI have a disabling mental illness. Of Medicare recipients, 10 percent of noninstitutionalized individuals used mental health services in 2002, and a quarter of this population was under age 65. Medicare mental health spending in 1971 was 2.6 percent, and by 2001 it was up to 7.3 percent. For Medicaid, 1971 spending on mental services was 16.2 percent, and by 2001 it increased to 27.4 percent, equating to \$23.4 billion.

Beyond purely economic costs, there are many other consequences of mental health prevalence, policy, and financing. On a global burden scale measured in Disability Adjusted Life Years (DALYs), mental disorders rank almost as high as do cardiovascular disease and respiratory disease, surpassing cancer and HIV (Ünstun, 1999).

The estimated 30 percent of homeless single adults with a mental illness is a reflection of fragmented U.S. social policy, poor access to, and poor quality of care (Frank and Glied, 2006). Homelessness is highly stigmatized, and is a high risk factor for substance abuse, HIV infection, incarceration, and mortality (Takahashi et al, 2002; Riley et al, Dec 2007; Wolitski et al, 2007; Riley et al, May 2007). The percentage of mental illness in prisons and jails is also high at 16 percent (Ditton, 1999), again, a reflection of fragmented social policy. White incarcerated females have the highest mental illness prevalence at 29 percent (US Department of Justice, 1999). Unfortunately, incarcerated mentally ill individuals often do not receive treatment, receive inadequate treatment, tend to be repeat offenders, and disproportionately represent violent crime offenses (Ditton, 1999).

Furthermore, mental illness is often a barrier to securing and retaining employment, and individuals with mental illness represent a low work-force presence (Frank and Glied, 2006). Individuals with mental illness report a willingness to hold a job (Mechanic, Blider, and McAlpine, 2004; Cook, 2006), allowing them an income and participation in society (Frank and Glied, 2006). Unfortunately, many face discrimination in the workplace or lack the skills/education to perform a job (Cook, 2006). The burden to society of the high unemployment rate among the mentally ill population is lost tax revenue and increased SSI and SSDI payments (Cook, 2002).

Beyond general societal costs, the cost of having a mentally ill family member is significant. There are financial costs that accompany treatment and services for the

individual, such as cost of insurance, out of pocket expenses, and general living costs. Studies indicate that parent caregivers are more financially responsible for their mentally ill children than are those whose children do not have a mental illness, particularly when the child has a SPMI (Perlick, 2007). Adult children with schizophrenia, for instance, rely on lifelong parental support (Jungbauer, 2006). An additional financial cost often overlooked is the amount of time a caregiver must be absent from work to care for the individual. Moreover, caregivers report more depressive symptoms, physical health problems (Perlick, 2007), and stigma (Gonzalez, 2007). Having a child with a SPMI is especially worrisome to parent caregivers who want to make sure their child is well-cared for when they can no longer assume the responsibility. Often, this entails securing supportive housing, but the supply of this type of housing is low in supple and high in demand.

Mental illness also takes its toll on employers. Employees with mental illness miss more days of work than non-mentally ill individuals, a phenomenon called absenteeism. Regarding mentally ill employees in the work place, previous studies focused on the economic cost to employers of providing mental health benefits. However, recent studies have focused more on the costs to the employer of absenteeism in efforts to demonstrate to employers that providing mental health coverage is more effective in the long run than not offering it. When an employee is absent, others must cover for this person or the employer must pay someone to temporarily replace the individual. Neither solution is cost-effective because it requires someone who is not familiar with the exact tasks for which the absent employee is responsible. Furthermore, mentally ill employees who do not or cannot seek help for their mental illness, often experience other somatic symptoms requiring more frequent visits to their primary care provider (Langlieb, 2005). Research has shown that mental health coverage improves work productivity by reducing absenteeism and presenteeism (being at work but not being productive) as well as reducing utilization costs of general medical services (Langlieb, 2005).

Current Solutions and Costs

The President's New Freedom Commission on Mental Health called for the need to "identify policies that could be implemented by Federal, State, and local governments to maximize the utility of existing resources, improve coordination of treatments and services, and promote successful community integration" for adults and children with mental illness (Alegría, 2003). There are a plethora of recommendations and possible solutions to improving the state of mental health care in the U.S. Some will argue that national insurance would solve the fragmentation problem, while others are opposed to the idea because they believe too much government intervention will limit choices. More feasible proposed solutions to lessen disparities in mental health include expanding Section 8 housing benefits, work and school place mental health screenings and interventions, primary care depression screening, and more thorough follow-up and medication monitoring for severely and persistently ill individuals, increasing numbers of caseworkers, and training psychiatric nurses to address disease management for comorbidities such as diabetes. The following are a few other proposed solutions in more detail.

Mental health parity has recently been a hot topic. In the 1990s, several unsuccessful attempts were made in the House and Senate to enact some from of mental health parity to employees (Grob, 2004). Before leaving office, President Clinton enacted the Federal Employees Health Benefits Act in 1999 which made mental health and substance abuse treatment parity available to all federal employees through approximately two hundred managed care plans (Grob, 2004). Additionally, states such as New York, are taking action in this arena by implementing legislation requiring employers to provide mental health parity. In December 2006, New York Congress passed Timothy's Law (S.8482), requiring that employers provide health benefits to extend mental health coverage and/or parity to employees (Timothy's Law, 2006). Congressmen in both the House and Senate are still fighting to make mental health parity mandatory for all employers with two legislative proposals, the Paul Wellstone Mental Health and Addiction Equity Act (HR 1424) and the Mental Health Parity Act 2007 (S558).

Full mental health parity is certainly a step in the right direction; however, parity only addresses the mental health needs of those who have insurance. As discussed, 20 percent of mentally ill individuals are uninsured (Frank and Glied, 2006), and the populations most desperately in need of mental health services are low-income minorities and homeless and incarcerated individuals. Furthermore, parity does not address social issues, such as employee discrimination, vocational training, lack of supportive housing, large numbers of homeless and incarcerated individual, or stigma.

Low underrepresentation of mentally ill individuals in the workplace is a major problem, with approximately 61 percent of those not in the labor force. This becomes especially pertinent when considering that approximately half of mentally ill adults consider themselves able to work and want to work (Cook, 2002). Some studies have shown greater outcomes for mentally ill individuals in the workplace when they receive coordinated vocational and clinical services (Cook, 2002). However, most receive little to no training, service coordination is often poor when training is received, and experience discrimination in the labor force (Cook, 2002). Moreover, many lack the education or skills needed for beginning a career (Cook, 2002). According to employer surveys over the past five decades, mentally ill individuals face more employer discrimination than other disability groups (Cook, 2002). A challenge often faced by the mentally ill consumer is the financial disincentive to work. Unemployed and earning no income from employment, entitles many to SSI or SSDI. These individuals face a dilemma when grappling with remaining unemployed and knowing they will have a steady income, or becoming employed, whereby they will lose their benefits and face an uncertain financial outcomes (Cook, 2002). Furthermore, by becoming employed, they stand to lose Medicaid benefits and yet are unlikely to find employment somewhere that offers benefits, offers them at an affordable price, or equal in quality (Cook, 2002).

There are a couple of proposed solutions regarding low participation in the workforce by mentally ill individuals. Studies have shown mixed results that vocational training has better rates for employment retention and satisfaction among mentally ill consumers (Cook, 2002). Those that report positive outcomes indicate that training is helpful for the employee and for employers, who report higher satisfaction with employees who underwent the training (McGrew, 2007; Hutchinson, 2007). In addition, mental health SSI and SSDI recipients should not have to face benefits termination

immediately upon receiving income. There is often a waiting period before benefits are reinstated upon losing employment, placing individuals at great risk of having no medical care and becoming homeless (Cook, 2002). The benefits of these solutions outweigh the costs in several ways. Two important reciprocal needs met by successfully training and placing individuals in jobs are the mentally ill individual's desire to work and the employer's need for an employee. If the mentally ill employee retains employment, he becomes a free member of society, able to participate in the community. Society benefits also. Besides having a healthier happier member, society gains because the individual becomes a contributor to the economy through increased tax revenues and decreased social welfare payouts (Cook, 2002).

A lack of supportive housing remains a source of constraint in terms of placing people in health environments in a timely and effective manner. Studies show that the best outcomes for placement are when neighborhoods and residences are clean, have no signs of deterioration, and have fewer numbers of units and residents (Harkness, 2004). While creating more supportive housing with these features is costly, studies indicate that mental health patient adjustment is improved and mental health costs decrease when the built environment is favorable (Evans, 2003; Harkness, 2004). Perhaps the front-end costs of providing healthy environments for mentally ill individuals would lower some of the financial burden to the government of mental health care. Furthermore, other possible benefits are improved esteem and satisfaction among mentally ill individuals and improved neighborhoods.

Studies evaluating the effects of supportive housing have found that participants' earned income increased by 50 percent and the rate of participant employment increased by 40 percent when employment services were provided as part of supportive housing (Corporation for Supportive Housing). This is corroborated by the near \$1,450 decrease in dependence on entitlements per tenant each year. For the mentally ill population, supportive housing provides the independence most adults strive for with the element of support as needed. In one study of approximately 900 homeless mentally ill individuals given supportive housing, participants who were still in housing one year later experienced decreased symptoms of schizophrenia and depression. Another study with nearly 5,000 homeless individuals in New York placed in supportive housing revealed that almost 80 percent remained in housing one year later, and about 10 percent had moved to independent housing.

One possible solution to reducing the quantity of mentally ill individuals is preventing mental illness. Given the high number of children with mental illness, the increasing percentage of the population with mental illness, and the extreme cost of mental health, it is a solution worth exploring. Because children with a diagnosable mental illness are highly susceptible for retaining the disorder or acquiring other mental disorders in adulthood, it is extremely important that children be treated for mental illness early in the course of the disease (Surgeon General, 1999). In fact, most mental illness in adults develops before they reach adulthood (Surgeon General, 1999). The human brain does not finish developing until an individual is in her late teens to early twenties (Giedd et al, 1999;NIMH), and neuroscience has shown the plasticity of the brain (Surgeon General, 1999). Therefore it is possible that mental health interventions at the earliest signs of mental illness in children could be effective in preventing a more serious disorder or preventing one from developing (Surgeon General, 1999). Further, since

there is a high correlation between mental illness and low SES, interventions should especially target low SES populations.

David Olds began a program that has shown long-term positive outcomes in lowincome single pregnant women and their children. In the Preventive Intervention Nurse Home Visitation Model, nurses provided pre-natal and child-rearing education during inhome visits to low-income unmarried mothers and followed up with the new mothers after the children were born. Through providing parenting education, child development information, and social support for the mothers, Olds' goals were reducing children's neurodevelopmental impairment by improving pre-natal health behaviors, reducing dysfunctional care of the child, and increasing economic self-sufficiency among mothers. Tested in three sites with differening ethnic and racial populations nationwide, long-term results reveal positive outcomes. Child abuse and neglect were lower compared to the control group, and mothers reported less substance abuse impairment. Furthermore, the fifteen year-old children had 50% fewer arrests, 69 percent fewer convictions, 28 percent less use of cigarettes, and 56 percent less use of alcohol. The program benefited the neediest families the most. Results have been corroborated in other sites, and programs have begun in many states. The RAND corporation did an economic analysis showing that there was an estimated four dollars saved to every dollar invested by the fourth year of life. So successful, the program, now called Nurse-Family Partnership, is funded in part by the NIH, the Robert Wood Foundation, and others, is now serving 20,000 mothers nationwide (RWJF).

What the Numbers Cannot Say

While the data from the Elmira study confirm the positive impact the nurses had on the lives of the women and children they visited, it may inadvertently paint a picture that is as clean and neat as a computer printout. Rarely was this the case, and there is no more dramatic example of how raw the picture could be than the story of Bonnie, an Elmira mother, and Stacy, the nurse who visited her. (While names have been changed to protect the privacy of the individuals in this story, the details are based on an actual case.)

Bonnie was 17, and her "home" was a dirt-floor basement apartment that was infested with roaches. She drank, smoked, was frequently in trouble with the law, but most important of all, she was pregnant. Stacy, a registered nurse who began visiting regularly with Bonnie, asked her if she would consider stopping smoking. "This baby's taken everything else away from me," Bonnie spat back referring to her swollen belly. "It's not going to take my cigarettes." She threatened to slap the nurse across the face, and given that she had already broken her mother's ribs in a fight, it was not a threat to be taken lightly.

Bonnie had been tortured as a child and had cruelly mistreated babies entrusted to her for baby-sitting jobs, and while this might have appeared as one more indication that she would be a disaster as a mother, it actually turned out to be her saving grace. During one visit, she broke down and confessed, "I'm afraid I'm going to do that to my own baby—especially if it's a crier," and

for the first time Stacy felt that she could help—because when Bonnie revealed her fear, it was a cry for help.

During pregnancy, before the baby was even on the scene, Stacy asked Bonnie whom she would call for help if, when she returned home with her baby after delivery, the baby was crying inconsolably at night. Bonnie had no idea. After some probing by Stacy, Bonnie said a neighborhood "grandma" (not really related) would help. Stacy asked Bonnie to write down this woman's phone number and tape it up on the wall so she would be prepared when she needed help, and she suggested some other strategies to help Bonnie cope with situations that she was worried about.

Bonnie's baby was born prematurely, but she dutifully visited her child in intensive care every day. When the baby was discharged from the hospital, Bonnie moved in with the neighborhood "grandma" rather than return to her basement apartment so the baby could be raised in a safer environment. Even the baby's father, who had been absent until this time, started participating in the home visits, and became deeply invested in his child. Bonnie and her boyfriend managed the care of their child remarkably well in spite of overwhelming odds against them. Today, her child has graduated from high school and avoided many of the difficulties experienced by her mother. Had Stacy not become a part of Bonnie's life, such a happy ending is difficult, if not impossible to picture. It is also an outcome that numbers alone cannot describe.

—excerpt from RWJF's The Story of David Olds and the Nurse Home Visiting Program

In July 2003, the President's New Freedom Commission on Mental Health issued a report entitled, *Achieving the Promise: Transforming Mental Health Care in America*. The report identified the Nurse-Family Partnership as a "model program" for "intervening early to prevent mental health problems."

—excerpt from RWJF's The Story of David Olds and the Nurse Home Visiting Program

A RAND Corp. study, *Early Childhood Interventions: Proven Results, Future Promise*, released in January 2006, identified Nurse-Family Partnership as an early childhood program that "can return more to society in benefits than [it] costs." (Another RAND study conducted in 1998 estimated that, over time, the Elmira program would save as much as \$4 in government spending for every \$1 in program costs.)

—excerpt from RWJF's The Story of David Olds and the Nurse Home Visiting Program

Finally, a wave of mental health courts have been implemented since 1990 to route arrested mentally ill individuals away from the criminal justice system. The goal is rehabilitative, by reducing recidivism rates and keeping individuals out of prisons and jails where adequate treatment is unlikely. While the results have been mixed, often showing that mental health courts are not any more effective at reducing rearrest rate than the criminal justice system, a few studies have shown that with the proper strategy, the rehabilitative goals can be somewhat achieved (Moore, 2006). Still relatively new in conception, mental health courts warrant further attention and revisions in attempt to reduce the number of mentally ill individuals in prisons and jails. In a similar vein, SAMHSA awarded a 7.2 million dollar grant to jail diversion programs across the country (SAMHSA, 2005). In these programs, individuals will be provided treatment and other services based on evidence-based practices that include case-management. Additionally, grantees will coordinate with social services, such as vocational training and job placement, to enhance an individual's chances of leading normal lives and staying away from the justice system. A 2004 SAMHSA study found jail diversion programs do not increase public safety risk while reducing the time mentally ill individuals spend incarcerated, linking them to community-based services (Daly, 2005).

Unfortunately, there is no magic bullet to solving the mental health care crisis. The best recommendations are those evidenced-based practices that have shown positive outcomes for improving people's lives. Critics will usually point to the high cost of implementing such programs and claim they are ineffective. The reality is that with mental illness, no program is going to have 100 percent positive outcomes; therefore, one must not have such high expectations when evaluating outcomes. Furthermore, while there is a cost return on many solutions, the more important goal is improving quality of life for mentally ill individuals.

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