Policy Debate

BROKEN PROMISES - DISASTROUS CONSEQUENCES FOR PEOPLE WITH MENTAL ILLNESSES

by
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I am convinced that, if we apply our medical knowledge and social insights fully, all but a small portion of the mentally ill can eventually achieve a wholesome and constructive social adjustment. It has been demonstrated that two out of three schizophrenics – our largest category of mentally ill – can be treated and released within 6 months. … If we launch a broad new mental health program now, it will be possible within a decade or two to reduce the number of patients now under custodial care by 50 percent or more. … Reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern and capability.

"Message of John F. Kennedy, the President of the United States", February 5, 1963, reprinted in Henry A. Foley and Steven S. Sharfstein, *Madness and Government* (Washington, D.C.: American Psychiatric Press, 1983), p. 47.

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The comments of President Kennedy printed above serve as a poignant reminder of the optimism that prevailed in 1963 when the U.S. Congress enacted the Community Mental Health Centers Act of 1963. In that Act, Congress authorized $150 million of federal money for construction grants to build Community Mental Health Centers (CMHCs) and (two years later) another $735 million in grants to staff these centers.

The idea was that CMHCs could effectively serve formerly institutionalized individuals with mental illnesses in the community – thereby permitting these individuals to live safely outside the confines of institutional settings.

The idea seemed a good one. Books such as Alfred Deutsch's *Shame of the States* had revealed in shocking detail the dehumanizing conditions inside many state hospitals ("insane asylums"). But, the idealism and optimism driving passage of the Community Mental Health Centers Act never translated into reality.

True, President Kennedy's dream of reducing the census of large public psychiatric hospitals has largely come true. In 1955, there were approximately 565,000 individuals with mental illnesses in public psychiatric hospitals across the country. Today, there are barely 40,000 individuals with mental illnesses in these hospitals.

In one sense, this is truly good news. Advances in science have led to the discovery of new treatments for brain disorders such as schizophrenia, bipolar disorder (manic-depressive illness), major depression and other mental illnesses. Today, a psychiatric diagnosis doesn't have to mean a life sentence to a psychiatric hospital. With appropriate treatment and services, most people with mental illnesses can recover – and live productive and dignified lives in the community.

But, President Kennedy's vision of large numbers of individuals with mental illnesses living safely and independently in the community never truly materialized. The reasons are complex and multi-faceted.

Certainly, inadequate funding is one culprit. In 1980, the Community Mental Health Centers categorical grant program was repealed and replaced by the Community Mental Health Services Block Grant. Since then, according to the National Council on Disability, federal funding of community mental health services through this block grant program has decreased in real dollar value (factoring in inflation). (National Council on Disability, "The Well Being of Our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports", (September 16, 2002), p. 7, available at www.ncd.gov/newsroom/publications/mentalhealth.html.

And, funding of vital services for people with mental illnesses is today at even greater risk, as states respond to budget deficits by considering cuts in mental health services and Medicaid.

But, inadequate funding is only part of the problem. Perhaps an even a greater factor has been lack of coordination and fragmentation at all levels of the mental health services system. The stage for this fragmentation was set early on – in the regulations enacted to implement the Community Mental Health Centers Act of 1963 – which neglected to require coordination between the institutions discharging individuals and the CMHCs expected to serve them following discharge. (See e.g. R.J. Isaac and V.C. Armat, *Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally Ill,* pp. 82-83 (1990).

In hindsight, it was naïve to expect that CMHCs could effectively address the needs of formerly institutionalized individuals through simply providing medications and psychotherapy. The law and regulations implementing the Community Mental Health Centers Act of 1963 barely mentioned housing, despite the fact that many individuals discharged after long periods of institutionalization had no place to go. (Isaac and Armat, Id., pp. 80-81).

Today, we know that people with serious mental illnesses require multiple services and supports to live in the community. Responsibility for these services is today vested with multiple agencies – all of which may be funded differently, and adhere to different rules. These agencies frequently don't communicate with one-another – or work together to find ways to blend their services and resources. In view of this, is it any wonder why America's mental health service delivery system is, as stated by Michael Hogan, Chair of the President's New Freedom Commission on Mental Health in a letter to President Bush, "in shambles"?

The Consequences of Lack of Treatment and Services.

A recent study revealed that less than 40% of Americans with mental illnesses today receive stable treatment. (D.A. Kessler, et al, "The prevalence and correlates of untreated serious mental illness", *Health Services Research* 36(6), 9870-1007 (2001). When people with people with serious mental illnesses don't receive the services they need, the results are often catastrophic. "The evidence of our failure to help (people with mental illnesses) is most apparent and most glaring on our Nation's streets, under our bridges, and in institutions like nursing homes and jails." (President's New Freedom Commission on Mental Health, *Interim Report to the President,* (October 29, 2002), p. 8.

The costs and consequences of untreated or inadequately treated mental illnesses for persons with mental illnesses themselves as well as for American society are evident in a many ways. These costs and consequences include:

Economic Consequences: As a nation, we have paid a tremendous price for our failure to develop and implement effective mental health service systems. This price is reflected both in the direct costs of providing crisis-oriented mental health care and in indirect costs such as productivity losses due to disability, productivity losses for individuals providing care, and the costs of public benefits such as Supplemental Security Income (SSI) and Medicaid.

An important report recently issued by the World Health Organization (WHO) revealed that serious mental illnesses (including depression, bipolar disorder and schizophrenia) ranks **first** in terms of causing disability in the U.S., Canada and Western Europe. (World Health Organization, *The World Health Report 2001 – Mental Health: New Understanding, New Hope, (*2001), **www.who.int/whr/**. And, the Surgeon General's 1999 report revealed that the cost to the U.S. economy due to lost productivity caused by mental illnesses was **$63 billion**.[1] (*Mental Health: A Report of the Surgeon General*, (1999), p. 411.

Supplemental Security Income (SSI) is a federal program that provides income supports for individuals with disabilities who are indigent and whose disabilities prevent them from working. In 2001, 36% of SSI recipients nationally were diagnosed with mental illness. By comparison, 25% of SSI recipients had mental retardation, 9% suffered from disabilities of the nervous system (strokes, traumatic head injuries, etc.), and 8% from disabilities of the Musculoskeletal system. (Social Security Administration, SSI statistics for 2002, www.ssa.gov/statistics/ssi_annual.stat/2001/.

The costs of failing to provide adequate care for persons with mental illnesses are staggering! And, these costs are frequently unnecessary. With appropriate services and supports, many people with these illnesses can recover and become productive. We have truly paid a tremendous price for our short-sighted and ineffective mental health policies.

Homelessness: There are currently approximately 600,000 individuals who are homeless in the U.S. on any given day. According to the U.S. Conference of Mayors, approximately 40% of these, or 240,000 persons, suffer from chronic mental illnesses. Many of these individuals also have co-occurring substance abuse disorders.

Poverty is frequently cited as the leading cause of homelessness in the U.S. While individuals with severe mental illnesses are often very poor, the causes of homelessness among people with mental illnesses are more frequently attributable to the symptoms of these illnesses themselves. For example, individuals experiencing terrifying paranoid delusions caused by their untreated schizophrenia may become suspicious of family members or friends trying to help them and end up living in the streets.

The solution to ending this tragedy is treatment – treatment and services that can control these horrific symptoms and help the person recover. However, these services are frequently unavailable, particularly for individuals who are homeless or have otherwise "fallen through the cracks."

Criminalization: One of the most disturbing trends is the emergence of U.S. jails and prisons as "psychiatric treatment facilities." A report issued by the U.S. Department of Justice in 1999 revealed that 16% of all inmates in these facilities**, 283,000 persons**, suffered from serious mental illnesses. (U.S. Department of Justice, *Mental Health and Treatment of Inmates and Probationers,* (1999), www.ojp.usdoj.gov/bjs/pubalp2.htm. **Today, the Los Angeles County jail, the Cook County (Chicago) jail, and Rikers Island (New York City) are the largest de-facto psychiatric hospitals in the U.S.**

Individuals with mental illnesses in jails have usually not committed serious crimes. Most have been arrested for non-vio-

lent misdemeanors or felonies that can be directly attributed to the untreated symptoms of their illnesses.

Some individuals with mental illnesses are held in jails on no charges at all. They are brought to jail because there are no beds available in local hospitals, or because the police deem jails to be a safer place for these individuals than the streets. (National Alliance for the Mentally Ill and Public Citizen's Health Research Group, *Criminalizing the Seriously Mentally Ill: The Abuse of Jails as Mental Hospitals,* (1992); revealing that 29% of U.S. jails acknowledged that they sometimes hold people with mental illnesses without charges).

African-Americans and Latinos are disproportionately represented among the population of persons with mental illnesses incarcerated in jails and prisons. This, of course, is a microcosm of the general inmate population in the U.S. It is not hard to speculate that an African American individual with mental illness who acts in a psychotic or bizarre way in the streets will more likely be arrested and brought to jail than a Caucasian individual with mental illness.

Suicides: According to the National Institute of Mental Health, scientific evidence has shown that almost all people who take their own lives have a diagnosable mental or substance abuse disorder, and the majority have more than one disorder.

The prevalence of suicide is particularly high among teenagers and young adults. In 1966, more teenagers and young adults died of suicide than from cancer, heart disease, AIDS, birth defects, stroke, pneumonia, influenza, and chronic lung disease **combined.**

Treatment is the best way to reduce the risk of suicides. But, due to stigma and continuing taboos surrounding mental illnesses, many people may tragically avoid treatment until it is too late. (Visit the NAMI website, www.nami.org/illness/info.html#19, for more information about suicide).

Violence: Age-old myths linking mental illness with violence are just that – myths. Research has firmly established that there is no general correlation between mental illnesses and violence.

However, there are certain factors that may increase potential risks for violence in certain cases. By far the greatest risk factor is the presence of a mental illness and co-occurring substance abuse. Lack of treatment can also be a risk factor in certain cases. But, with treatment, the risks of violence are minimal, no greater than with anyone else. In fact, as the next section describes, people with mental illnesses are more likely to be victims of violence than perpetrators of violence.

For more information about the relationship between mental illness and violence, see H. Steadman, et al, "Violence by People Discharged From Acute Psychiatric Inpatient Facilities and by Others in the Same Neighborhoods", *Archives of General Psychiatry,* (May 1988). See also the website of the Treatment Advocacy Center, www.pscyhlaws.org.

Victimization: Studies have shown that people with mental illnesses are at high risk of victimization by others. This is particularly true for individuals who are homeless or living in substandard housing. Studies have also shown that individuals with mental illnesses who are receiving treatment and services are less likely to be the victims of crimes by others. (See e.g. V.A. Hiday, et al, "Criminal Victimization of Persons with Severe Mental Illnesses" *Psychiatric Services* 50: 62-68 (1999).

Potential Solutions:

In 2003, NAMI's advocacy priorities at Federal and State levels focus on finding solutions to the problems described above. A comprehensive discussion of these potential solutions is beyond the purview of this article. However, a few of these priorities will be described in this final section.

1. Protect state funding and Medicaid benefits for vital services and supports for people with mental illnesses. In 2003, already inadequate state funding for mental health services is at grave risk, as states respond to budget deficits by cutting discretionary mental health budgets. States are also considering damaging cuts to Medicaid benefits, including limits on access to newer psychiatric medications, as cost-cutting options. State governors and legislators must understand that the consequences of cutting state mental health services for children and adults with mental illnesses will be more misery, more suffering and ultimately more state and local resources depleted through responses to people experiencing psychiatric crises or emergencies due to lack of treatment.

2. Achieve parity in private and public systems that finance care for individuals with mental illnesses. Disparities exist in virtually every private insurance policy and public program that pays for treatment and services for individuals with mental illnesses and other medical disorders. NAMI's advocacy in 2003 will include:

- Advocating for enactment of a federal law requiring treatment of mental illnesses in the same way as other medical conditions in private health insurance policies.
- Advocating for a Medicare prescription drug benefit for persons with disabilities and mental health benefits in Medicare equal to benefits for all other medical disorders. (Currently, Medicare requires a 50% co-pay for outpatient mental health treatment, whereas it requires only a 20% co-pay for outpatient treatment for other medical conditions).
- Advocating for elimination or a narrowing of the "Institutes for Mental Diseases" exclusion in federal Medicaid law, a federal policy that currently prevents federal Medicaid funds from being used to pay for inpatient treatment in psychiatric hospitals.

3. Promote Mental Health Courts, Crisis Intervention Teams and other strategies to divert non-violent offenders with mental illnesses from incarceration into treatment.

Advocate for humane treatment, including access to the most effective medications, for individuals with mental illnesses who are incarcerated.

Promote linkages with services, benefits and housing for individuals with mental illnesses upon discharge from jails and prisons.

The U.S. Congress has exerted leadership in recent years by authorizing federal funding for a variety of jail diversion initiatives. In 2003, Congress will be presented with an opportunity to take the next step by passing a bill to authorize resources to fund services linking individuals diverted from incarceration with needed services and supports to achieve recovery and prevent recidivism. This bill, called the "Mentally Ill Offender and Crime Reduction Act of 2002", is supported by a bipartisan coalition of Senators and Representatives, led by Senator Mike DeWine (R. Ohio) and Congressman Ted Strickland (D. Ohio).

4. Promote meaningful work incentives in the Federal Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs.

In 1999, Congress enacted the "Ticket to Work and Work Incentives Improvement Act of 1999", a milestone law designed to provide incentives for SSI and SSDI recipients to enter or re-enter the workforce without fear of immediate loss of benefits. Unfortunately, the law has been implemented in a way that does not effectively help individuals whose severe disabilities may require a more gradual reentry into the workplace, such as people with serious mental illness.

In 2003 and beyond, NAMI will promote changes that enable individuals with schizophrenia and other serious mental illnesses to benefit from this important new law. We will also undertake efforts to ensure that this law is effectively implemented at state and local levels.

5. Advocate for funding of programs that provide integrated and coordinated mental health and substance abuse treatment through the federal mental health and substance abuse block grants and other funding streams.

Seven to ten million Americans suffer from at least one mental disorder plus a co-occurring substance abuse or addictive disorder. Scientific evidence demonstrates that the most effective way to treat people with "co-occurring disorders is through treatment that combines mental health and substance abuse treatment simultaneously, under one administrative roof.

Unfortunately, very few programs providing integrated mental health and substance abuse treatment exist across the country. The reason for this is that mental health and substance abuse services are financed through separate funding streams, with different rules and requirements. This is an example of what the New Freedom Commission means by "fragmentation of services".

In 2003 and beyond, NAMI will advocate strenuously at federal and state levels to promote policies that increase the availability of integrated treatment for individuals with co-occurring mental illnesses and substance abuse.

(For more information about best practices in responding to people with co-occurring disorders, see "Report to Congress on the Prevention and Treatment of Co-Occurring Substance Abuse Disorders and Mental Disorders", available at www.samhsa.gov.

- For information about NAMI's advocacy agenda for children and adolescents with mental illnesses, see D. Gruttadaro, "Child and Teen Mental Illnesses and the National Healthcare Crisis", *Rostrum,* 77:4 (December, 2002), pp 4-9.

- Finally, for more information about NAMI's advocacy and policy priorities, see NAMI's Testimony Presented to the New Freedom Commission on Mental Health, July 18, 2002, available on the NAMI website at www.nami.org/pressroom/testimony/mcnultyjuly2002.html.

Conclusion:

To paraphrase Charles Dickens, 2003 is both the best of worlds and the worst of worlds for people with mental illnesses. It is the best of worlds because scientific progress has made recovery, productivity and dignity real possibilities for many people with these illnesses. But, it is the worst of worlds because the promises of discovery have not been adopted into actual practice. The consequences for people with mental illnesses have been disastrous. As a nation, we cannot afford to continue the shameful legacy of neglect that has so often characterized our mental health systems. We know how to do better – and we must do better

[1] The $63 billion figure was derived from 1990 data, the most recent year that such data was available. The costs to American society in terms of lost productivity due to mental illness are undoubtedly far greater today.

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