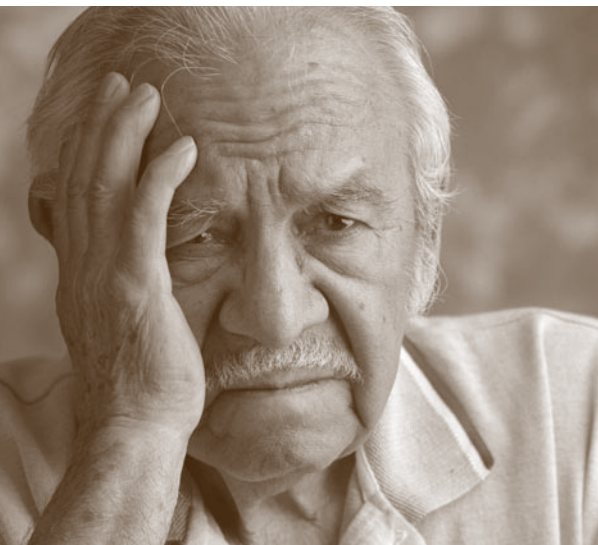




EMERGENCY RESPONSE

A Roadmap for Federal Action on America's Mental Health Crisis

The Campaign for Mental Health Reform July 2005



American Academy of Child and Adolescent Psychiatry
American Psychiatric Association
American Psychological Association
Bazelon Center for Mental Health Law
CHADD - Children and Adults with Attention-Deficit/Hyperactivity Disorder
Depression and Bipolar Support Alliance
Federation of Families for Children's Mental Health
NAMI - National Alliance for the Mentally Ill
National Association of County Behavioral Health Directors
National Association of State Mental Health Program Directors
National Council for Community Behavioral Healthcare
National Empowerment Center
National Mental Health Association
National Mental Health Consumers' Self-Help Clearinghouse
Suicide Prevention Action Network USA
USPRA - United States Psychiatric Rehabilitation Association

Acknowledgements

The Campaign for Mental Health Reform is a national partnership of organizations representing millions of people with mental disorders, their families, service providers, administrators, and other advocates. Its goal is to make access, recovery and quality in mental health services the hallmarks of our nation's mental health system.

From concept to individual policy recommendations, *Emergency Response* represents the collective effort of dozens of staff members who work with the organizations that make up the Campaign for Mental Health Reform. This report would not have been possible, however, without the abundant research and initial drafting provided by Jennifer Urff, J.D. The Campaign thanks her for her invaluable contributions.

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Campaign Steering Committee:

Robert Bernstein, Ph.D., Bazelon Center for Mental Health Law

Robert W. Glover, Ph.D., National Association of State Mental Health
Program Directors

Michael Faenza, M.S.S.W., National Mental Health Association

Michael Fitzpatrick, M.S.W., National Alliance for the Mentally Ill

Emergency Response is also available online at www.mhreform.org. For questions about this report or the Campaign, contact the Campaign at info@mhreform.org.

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Executive Summary

Three years ago, President Bush established the New Freedom Initiative, dedicated to ensuring that people with disabilities, including those with mental disorders, have “the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life.”

A key component of the New Freedom initiative was the appointment of an independent, nonpartisan commission charged with assessing America’s mental health system and making recommendations for improvements.

The final report of the President’s New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America*, released in July 2003, offered hope for millions of Americans and their families who are affected by mental disorders. The Commission found that recovery from mental illness is possible and that promoting recovery — not merely managing symptoms — should be the driving goal of America’s public mental health system.

The report made clear that effective and cost-effective treatments exist, and that early identification and intervention can prevent the negative consequences associated with unmet mental health needs.

Unfortunately, the Commission also found that the system designed to provide services to people who need mental health care is “fragmented and in disarray, lead[ing] to unnecessary and costly disability, homelessness, school failure and incarceration.”¹ As a result, only a fraction of the people who need services gets them, and most individuals cannot access the services that would best increase their independence.

The Commission’s final report called for “fundamental transformation” of the mental health system as the only option for meaningful reform. Outlining goals and recommendations to provide a framework for such transformation, the report raised hopes that people who have mental disorders could and would realize the promise of leading more productive and independent lives in their communities.

To date, however, few concrete steps have been taken to realize the Commission’s goals or implement its recommendations. For millions of Americans with mental disorders and their families, the consequences of this inaction have been tragic and sometimes fatal. Since the release of the Commission’s final report:

- More than 63,000 Americans have been victims of suicide.²
- An estimated 206,000 people with mental illnesses were admitted to state and federal prisons³ — many of them

incarcerated due to the consequences of homelessness and neglect.

- More than 25,000 families relinquished custody of their children to child welfare or juvenile justice systems because it appeared to be the only way to secure the mental health services their children needed.⁴
- Juvenile detention centers spent \$200 million warehousing children — some as young as 7 years old — because needed mental health services were unavailable in the community.⁵
- As many as 13 percent of the thousands of veterans who have returned from military operations in Iraq and Afghanistan are estimated to show signs of post-traumatic stress disorder (PTSD). Left untreated, PTSD can lead to suicide, unemployment, divorce and misery for veterans and their families.⁶
- The American economy lost an estimated \$158 billion in productivity due to unaddressed mental health needs.⁷

Continued inaction is unacceptable. The tremendous human and financial costs of unmet mental health needs must be addressed.

Immediate federal action is needed if access, recovery and quality services are to become the hallmarks of America’s now-dysfunctional public mental health system.

The Campaign for Mental Health Reform is a national partnership of organizations representing millions of people with mental or emotional disorders, their families, service providers, administrators and other concerned Americans. *Emergency Response* is the Campaign’s call to action and roadmap for reform.

Seven Steps to Successful Mental Health Reform

“The promise of the New Freedom Commission — a life in the community for everyone — can be realized.

— *Michael F. Hogan*
Chair, President’s New Freedom Commission on Mental Health

Rooted in the promise of the President’s New Freedom Commission on Mental Health, the *Roadmap for Federal Action on America’s Mental Health Crisis* reflects the widely accepted view that mental health reform is essential: The federal government must act now to reduce preventable suicides, lost productivity, high rates of homelessness, unnecessary involvement with the criminal justice system and other consequences of America’s failed mental health policies.

The Campaign for Mental Health Reform presents the *Roadmap* as a constructive set of steps to implement the vision of the President’s New Freedom Commission. Effective transformation — and fulfillment of the promise of the New Freedom initiative — is possible only with improved federal leadership in each of the following areas:

- Step 1:** Maximize the effectiveness of scarce resources by coordinating programs and making systems “seamless” to consumers.
- Step 2:** Stop making criminals of those whose mental illness results in inappropriate behavior.
- Step 3:** Make Medicaid accountable for the effectiveness of the mental health services it pays for.
- Step 4:** Prevent the negative consequences of mental disorders by getting the right services to the right people at the right time.
- Step 5:** Invest in children and support and value their families’ role in making treatment decisions.
- Step 6:** Promote independence by increasing employment, eliminating disincentives for economic self-sufficiency and ending homelessness.
- Step 7:** Address the mental health needs of returning veterans and their families.

In developing the *Roadmap* and the action items set forth below, the Campaign for Mental Health Reform and its members consulted with hundreds of state, county and local government officials, mental health consumers and their families, and state and local mental health advocates about how they viewed federal leadership and what the federal government must do to support mental health systems transformation. We conducted site visits to key states and to effective community mental health programs to learn from their transformation efforts and identify recommendations for change at the federal level.

We hope that this roadmap will inspire federal leadership to keep the New Freedom Commission’s promise that people with mental disorders be afforded “the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life.”

“People with disabilities want to be employed, educated, and participating citizens living in the community. In today’s global new economy, America must be able to draw on the talents and creativity of all its citizens.”

— *George W. Bush*
President of the United States

Background: Why Reform is Essential and Why the Federal Government Must Lead It

Mental illness was once considered shameful. People with mental illnesses, especially those who had the most serious mental illnesses such as schizophrenia, bipolar disorder and major depression, were shut away in institutions — first jails and poorhouses and then state mental hospitals. In their heyday 50 years ago, state hospitals held almost 560,000 people, many of whom had lost any hope for an independent life.⁸

Today, fewer than 65,000 people are in state hospitals⁹ and most of them stay for only a few weeks.¹⁰ Many individuals with mild or moderate mental disorders are successfully treated at home. Many Americans have friends, neighbors and loved ones living with a serious mental health disorder who prove every day that, with treatment and support, people with mental illnesses can and do lead successful, productive lives in the community.

Unfortunately, too little of the money saved from downsizing psychiatric hospitals has been reinvested in building and maintaining an effective system of community-based treatment, housing, job training or other supports. Adjusted for inflation and population growth, states spent 30 percent less on mental health in 1997 than they did in 1955.¹¹ Medicaid spending on psychiatric medications has increased,¹² but too little else has been done to help people with mental illnesses live successfully in the community. Lingering stigma surrounding mental illness remains pervasive, perpetuating inaction and discrimination that, according to the U.S. Surgeon General, is “inexcusably outmoded.”¹³

The nation’s inadequate, fragmented mental health system leaves many without the care they need:

- Mental illness is the leading cause of disability in the United States,¹⁴ accounting for more than 15 percent of the overall burden of disease from all causes — slightly more than the burden associated with all forms of cancer.¹⁵ Despite this, only 6 percent of all health care expenditures are targeted for mental disorders.¹⁶
- Many of the 5.6 million adults and 1.2 million children in America who have the most serious mental illnesses and emotional disorders receive inadequate treatment.¹⁷
- About 200,000 people with mental illnesses are homeless — approximately one third of the nation’s total homeless population.¹⁸
- The Surgeon General found that a majority of youth (ages 9 to 17) with a specific mental, emotional or behavioral disorder do not receive any treatment.¹⁹



- On any given night, nearly 2,000 children and youth languish in juvenile detention facilities across the country solely because they cannot access mental health services in the community.²⁰
- Lack of access to appropriate and timely services contributes to the over-crowding of jails and prisons. An estimated 16 percent of jail and state prison inmates and 7 percent of federal prison inmates have a diagnosable mental disorder.²¹ Nearly 60 percent of males and more than two-thirds of females in juvenile detention have at least one mental disorder.²² Much of the burden of this “criminalization” of mental illness will fall on already-strapped local and county governments, but the impact on the federal government and states is also significant.

Although policymakers acknowledge that people with mental disorders have the potential for self-sufficiency, our systems perpetuate dependence. Consider the following:

- People with mental illnesses make up more than one quarter of Americans who receive Social Security Disability Insurance (SSDI) and more than one third of those who receive Supplemental Security Income (SSI).²³ Perhaps most important, people with mental illnesses are younger and stay on disability rolls longer than people with other kinds of disabilities.²⁴
- Surveys show that the majority of people with serious mental illnesses want to work and, with services and supports, would be able to do so.²⁵ Yet 60 percent of people with serious mental illnesses are unemployed, and many who have jobs are “underemployed.”²⁶

The enormous financial costs of our inadequate mental health system are surpassed only by the human costs. Research has shown that more than 90 percent of people who die by suicide have a diagnosable mental or substance abuse disorder, or both.²⁷ Every 17 minutes, suicide claims another

American life.²⁸ More Americans are victims of suicide than of homicide.²⁹ Among 10- to 24-year-olds, suicide is the third leading cause of death.³⁰

Effective Treatment Exists, But Too Few Have Access to It

These tragic outcomes and wasted resources are directly attributable to the nation's policy choices on mental health. Less than one third of people with a diagnosable mental disorder — and an even smaller proportion of children and minorities — receive help.³¹ Individuals with the most serious forms of mental illness have slightly higher rates of treatment at about 50 percent.³²

A 2001 report by the U.S. Surgeon General found that the prevalence of major mental disorders between races is similar, but significant disparities exist in the provision of mental health services to racial and ethnic minorities. The report found that:

- Minorities have less access to mental health services and are less likely to receive needed mental health services.
- Minorities often receive poorer quality mental health care compared to the general population.
- Minorities are underrepresented in mental health research.
- Minorities are overrepresented in the homeless population and in institutions.³³

For all Americans, treatment rates are appallingly low, given the impact of disorders such as schizophrenia and manic depression on people's lives. Americans would not tolerate such an abysmal rate of treatment for people with cancer, diabetes or other life-threatening illnesses.

Such a lack of access to mental health services is all the more appalling given how effectively mental health disorders can be treated. Scientific research over the last few decades has given us a range of effective treatments for most mental illnesses.³⁴ Treatment outcomes for people with even the most serious mental illnesses are comparable to outcomes for well-established general medical or surgical treatments for other chronic diseases.³⁵

Specifically, success rates for most mental illnesses do not reflect a narrow approach to treatment. Sometimes a particular treatment is effective by itself. Often, the most effective treatment combines two or more approaches to address the person's individualized needs. Diagnosis, level of functioning, treatment history and personal preferences should guide decisions on how best to meet a person's mental health needs.

Medication and psychotherapy are just two in an array of proven approaches. In fact, common-sense approaches, such as teaching people how to cope with their illness and improve everyday life skills, can be a critical part of a cost-effective treatment plan that promotes recovery from mental illness.

Tools to Succeed Are Often Unavailable

As noted above, many people with mental illnesses are unable to access the supports, such as housing, skills training and employment, which are essential to leading successful, independent lives in the community. As a result, homelessness, suicide, incarceration and the enormous human and financial costs of needless dependence continue to burden Americans who have mental illnesses, their families and their communities.

People should have choices between effective treatments, as they do with physical health disorders. Public policy increasingly recognizes that treatment is most effective when the person with a mental illness (or the family of a child who has a mental disorder) has a meaningful say in choices between effective interventions, and is directly involved in developing and implementing the treatment plan. This greatly improves service outcomes and system efficiency. Yet historically, people with the most serious mental disorders have been most often barred from choosing the treatment approach that is most acceptable to them (and therefore the most likely to be effective).

Veterans and the Need for Mental Health Reform

The large numbers of veterans returning from Iraq, Afghanistan and other dangerous military assignments give new weight to the importance of making mental health a national priority. Suicide rates³⁶ and symptoms of psychological trauma³⁷ have increased both overseas and among veterans returning from Iraq and Afghanistan. Without immediate and adequate resources, the high incidence of mental health disorders among returning veterans could be disastrous for veterans and their families across the country. The Department of Veterans Affairs' health care system and the community mental health system³⁸ face formidable challenges in providing ongoing and effective support to the one in six veterans returning from Iraq and the one in 10 veterans returning from Afghanistan who are estimated to suffer from mental health problems.³⁹

The nation has a moral obligation to its veterans to ensure that their mental health needs are fully and immediately addressed — a task that is further compromised by the inadequacy of the nation's overall mental health system.

The Federal Government Must Lead

The federal government has repeatedly affirmed the importance of its role in ensuring access to opportunity and

freedom from discrimination for people with mental illnesses and other disabilities.

The landmark Americans with Disabilities Act, reinforced by the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C.*, bars discrimination on the basis of disability and requires states to provide services to people with disabilities in the most integrated settings appropriate for their needs. More recently, President Bush's New Freedom Commission affirmed the federal government's responsibility to support people with disabilities in leading "full and independent lives."

Yet poorly funded and fragmented public mental health systems are often unable to provide access to needed services for millions of Americans with mental illnesses and afford them the opportunity to live more independent and successful lives in the community. Numerous federal programs across many departments and agencies affect the lives of people with mental illnesses. The federal government needs to lead an effective partnership with state and local mental health systems in order to achieve a well-aligned and coherent mental health system.

The federal government also has a major fiscal stake in improving public mental health systems. In 2001 alone, the federal government spent \$85 billion on the treatment of mental illnesses.⁴⁰ But indirect costs of the nation's failed mental health policy may equal or exceed that amount — in 1990 (the most recent year for which data are available), these costs totaled \$79 billion, mainly from lost productivity.⁴¹



Medicaid alone accounts for about 63 percent of all public mental health spending, with the federal government responsible for around half of those expenditures and states providing the rest.⁴² State mental health authorities, which traditionally are financed through state and local general revenue funds, have tripled their reliance on Medicaid

Federal Leadership Works

There is no question that when the federal government chooses to exercise its leadership on behalf of people with mental illnesses, its actions can improve and even save lives.

For example, recent legislation and regulations prompted a sharp reduction in the use of seclusion and restraint in mental health treatment facilities. These interventions had been linked to an estimated 50 to 150 deaths and hundreds of serious injuries each year.

Licensing mental health and mental retardation facilities has long been the purview of state governments, as has the development of policies about the quality of care in those facilities. In 1998, however, the *Hartford Courant* (Conn.) published a groundbreaking series of investigative articles identifying 142 deaths — one fourth of them children — resulting from the improper use of physical restraints and seclusion in facilities for people with mental disorders. Recognizing its responsibility to prevent the unnecessary deaths and possible abuse of hundreds of our most vulnerable citizens, the Centers for Medicare and Medicaid Services (CMS) developed regulations governing the use of seclusion and restraint and requiring deaths and serious injuries to be reported to CMS. Similarly, Congress developed guidelines and restrictions on the use of restraints and seclusion, which were included in the Children's Health Act of 2000. The Substance Abuse and Mental Health Services Administration then sponsored summit meetings with consumers and advocates and produced training materials to foster meaningful change in this area.

The results of federal leadership were dramatic. In a two-year period beginning October 2000, the number of hours that mental health patients in state psychiatric hospitals spent in restraints **decreased by one third** and the percentage of patients restrained **decreased by about 20 percent**. Similarly, the number of hours that mental health patients spent in seclusion and the percentage of clients secluded **decreased by about 25 percent**.⁴⁴

funding, from 13 percent of their budgets in 1987 to more than 33 percent in 2001.⁴³ Other federal programs also provide significant resources to meet the needs of people with mental illnesses, including Social Security disability programs, housing, education and child welfare. Several federal grant programs — such as the Community Mental Health Services Block Grant — add to the federal contribution toward mental health services funding.

The increasing reliance on Medicaid to fund mental health services has made the Centers for Medicare and Medicaid Services the *de facto* federal mental health authority. Other federal agencies, such as the Social Security Administration and the Departments of Labor, Housing and Urban Development, Justice, Veterans Affairs, Education, and Health and Human Services — particularly the Substance Abuse and Mental Health Services Administration — are also essential partners with state and local mental health systems.

Given its central role in financing and providing direction for public mental health systems, the federal government must exercise leadership to implement needed reforms.

Too many lives have been lost and too many taxpayer dollars squandered on ineffective public mental health systems that are teetering on the brink of collapse. The federal government has a responsibility to invest in services and supports that promote better outcomes and recovery for people with mental illnesses.



“Government likes to begin things — to declare grand new programs and causes. But good beginnings are not the measure of success. What matters in the end is completion. Performance. Results. Not just making promises, but making good on promises.”

— *George W. Bush*
President of the United States

A Roadmap to Transform Mental Health Care

Recognizing the critical need for reform, the President's New Freedom Commission on Mental Health called for a fundamental transformation in the nation's mental health policy. Its final report calls for a fundamental shift in the way mental health services and supports are delivered. In particular, three goals articulated by the Commission would, if achieved, dramatically improve the public mental health system:

- (1) Inefficient, ineffective services that are now delivered without any coordination among different programs should be streamlined. Mental health should be integrated into other human services systems that address the needs of people with mental illnesses (such as education, vocational rehabilitation, housing, etc.).
- (2) Early identification and early provision of services should replace a crisis-oriented approach that denies care until individuals are in extreme need before services beyond a bare minimum are delivered.
- (3) Services should be consumer-directed, allowing individuals themselves (and families of children) to have a meaningful say in how their mental health needs are addressed. Consumer-directed services would allow people who have mental illnesses to choose from an array of effective options, set goals, and make decisions about services that promote their independence and enhance their ability to meet personal objectives.

The release of the New Freedom Commission's final report creates an historic opportunity — and responsibility — for the federal government to lead meaningful reform of the nation's public mental health system. *Emergency Response: A Roadmap for Federal Action on America's Mental Health Crisis* provides a seven-part plan and concrete policy proposals to achieve that goal.

“Untreated mental illness and addictive disorders exact a cost on our society; our choice is how we invest our resources to pay the bill.”

— Charles G. Curie
Administrator, Substance Abuse and Mental
Health Services Administration

Step 1: Maximize the effectiveness of scarce resources by coordinating programs and making systems “seamless” to consumers.

Adults and children who require mental health services usually have many other needs. Safe and decent housing, a job, primary health care, education and income support are essential components of a plan to achieve self-sufficiency. Unfortunately, the myriad federal agencies that can foster recovery and support people in achieving these goals are driven by different missions and inconsistent laws and regulations. As a result, people with mental disorders often find themselves trapped between bureaucracies, unable to get all the services they need for independent living. The President's New Freedom Commission identified fragmentation in mental health services and supports as one of the most significant barriers to effective treatment and recovery.

For example, the Department of Education and the Substance Abuse and Mental Health Services Administration (SAMHSA) have very different definitions of emotional disorders in children. Families who need services from programs funded through different federal programs must often submit their children to repeated mental health assessments to diagnose their disorders because one agency cannot accept a diagnosis paid for by another.

Adults who wish to return to work from the federal disability rolls face economic hardship because the resulting loss of federal benefits means that working is too great a risk. Rules in Social Security take account of this; rules in the Food Stamp program and public housing do not.

As the single largest payer of mental health services in the country, the federal government has a vested interest in ensuring that scarce federal resources are used effectively and efficiently. No single action can eliminate fragmentation, and not all fragmentation can be removed if programs are to retain their basic missions, but some action is essential so that all necessary services are provided as seamlessly as possible.

Action Item: Create a federal interagency task force to review and align federal programs affecting people with mental disorders.

Following the release of the New Freedom Commission's final report, SAMHSA convened a multi-agency working group to address the Commission's findings. This interagency work can be further enhanced through a congressional mandate that defines objectives, sets timetables and requires appropriate reporting.

Recommendation:

- Congress should create a new Federal Interagency Task Force on Mental Health, chaired by the Executive Office of the President, with senior-level agency representation, to establish a framework and process to improve federal collaboration and coordination on mental health policy, financing and management. The task force should:
 - (1) Address the need for alignment of federal policy and rules across agencies;
 - (2) Identify policies and practices (including inconsistent eligibility, service definitions and reporting requirements) that contribute to fragmentation in care-delivery;
 - (3) Develop regulatory changes and propose legislation to foster coordination of services and eliminate barriers in financing, eligibility and other requirements so as to support integrated systems of care; and
 - (4) Transmit to Congress within one year of its creation a report on its initial recommendations and a timetable for future action.

Recognizing how difficult it is for states and communities to weave disparate funding streams together, the task force's enabling legislation should authorize federal agencies to pool limited funds to support demonstration projects of integrated service delivery.

Key agencies represented on the task force should include the Departments of Health and Human Services (especially the Centers for Medicare and Medicaid Services, the Substance Abuse and Mental Health Services Administration and the Administration on Children and Families), Labor, Housing and Urban Development, Justice, Veterans Affairs, Education, and the Social Security Administration.

The task force should be encouraged to make recommendations that overlap individual departments and agencies. For example, it could propose policies that provide greater flexibility to localities for use of Medicaid waivers. Under current law, a state is required to demonstrate that its Medicaid waiver does not increase federal Medicaid costs. Because of the silos in federal programs, savings to other programs — such as Social Security disability payments, federal corrections programs or child welfare programs — are not considered. Allowing consideration of these additional costs would enable states and localities to provide services that are cost-effective on an overall basis.



Action Item: Reauthorize the Substance Abuse and Mental Health Services Administration (SAMHSA) and provide real incentives to develop and implement individualized, comprehensive plans of care and state and local interagency planning regarding mental health service delivery and financing.

SAMHSA is the only federal agency specifically devoted to the needs of people with mental disorders and substance abuse. It identifies and disseminates evidence-based practices and leads federal policy development regarding mental health.

It is critical that this agency continue to play its key leadership role. The Commission report underscores the importance of redefining SAMHSA's mission to ensure that the agency and its programs are best situated to support the Commission's goals and recommendations. To that end, the Campaign for Mental Health Reform urges significant changes in SAMHSA programs.

One of the Commission's most significant recommendations is that each person receiving services have an appropriate, individualized plan of care and access to the services and supports needed to implement that plan. This would avoid piecemeal responses to comprehensive needs, which waste resources and fail to help people with mental illnesses move toward recovery. The Commission noted that individualized plans of care would improve service coordination, permit consumers to make informed choices and make treatment more effective.

Recommendation:

- Congress should establish a robust competitive grant program for states and localities to encourage the shift in service delivery and make the necessary funds available to

support state efforts. Multi-year grants should enable states to establish local systems of care that can provide the range of comprehensive services detailed in individual consumer plans. Such plans should be consumer-driven and address all service needs to promote independent living and recovery.

Resources should be provided to enable states and localities to engage in interagency planning for statewide systems of care. Funding should be contingent on whether states and localities:

- ✓ provide meaningful consumer and family participation in the development, implementation and evaluation of state and local plans for systems of care;
 - ✓ establish Consumer and Family Satisfaction Teams to provide continuous feedback regarding the responsiveness, appropriateness and quality of services received by consumers and families; and
 - ✓ address the unique needs of children, adolescents and those making the transition from adolescence to adulthood, as well as adults and elderly adults.
- Other changes should be made to SAMHSA projects of national significance, the child mental health services program and other existing agency programs to align these initiatives with the Commission's vision of a recovery-oriented system. Specific recommendations are outlined in other briefing materials available by request from the Campaign for Mental Health Reform (see the inside cover of this document for contact information).

Action Item: To the greatest extent possible, assess the impact of proposed laws and regulations on people with disabilities and publish a Disability Impact Statement.

Major federal efforts such as the New Freedom initiative reaffirm the federal government's commitment to supporting independent living for people with physical and mental disabilities. However, many federal laws and regulations — including those not directly connected to programs explicitly targeted to people with disabilities — have significant consequences for people with mental disabilities. These consequences are often not considered and may not even be known by policymakers when they adopt new laws and regulations.

For example, policies in the Section 8 housing program, which provides housing subsidies to people with very low incomes, almost always have a significant impact on people with mental disabilities because, as a group, they are disproportionately poor and face significant barriers in finding adequate housing. However, because the program is not targeted specifically to people with disabilities, no assessment is made of the impact of various rules on this population.

Recommendation:

- Congress should hold itself and federal agencies accountable for how federal policies affect one of American's most vulnerable populations by requiring all new laws and proposed regulations to be accompanied by a Disability Impact Statement. This would ensure that Congress and federal agencies carefully consider the impact of their actions on people with mental and physical disabilities as well as the costs and benefits of new policies. It would also establish a procedure that affords members of the public meaningful participation in decision-making.

“There is a better, a more humane way to work with these individuals [with mental illnesses] who come through the doors of the justice system simply because there is nowhere else for them to go. Our challenge is to create a path that is fair to everyone, treats people with dignity and balances public safety concerns with individual needs.”

— *Michael D. Scbrunk*
District Attorney for Multnomah County,
Oregon in testimony before House Judiciary
Subcommittee on Crime, Sept. 21, 2000.

Step 2: Stop making criminals of those whose mental illness results in inappropriate behavior.

Crisis Intervention Teams

Crisis Intervention Teams (CIT) are police-based, pre-arresting jail diversion programs, formed through partnerships among law enforcement and mental health and substance abuse agencies. The CIT concept was initiated by the Memphis Police Department in 1988 in response to an increase in contacts between police officers and individuals with serious mental illnesses. Patrol officers, normally volunteers, receive intensive training in psychiatric disorders, substance abuse issues and de-escalation techniques, and in the legal issues related to mental health and substance abuse. They also receive information on community resources for people experiencing a mental health crisis.

CIT officers respond immediately, usually within five minutes of a call. Ideally, teams are available 24 hours a day, seven days a week. In Memphis, about half of all calls are resolved at the scene, with the individual in question being referred directly to community-based services. The program has created a seamless link between law enforcement and emergency mental health services, providing an efficient single point of entry into the mental health system. Officers can make referrals or transport the individual to an emergency service that accepts all police referrals with no refusals. Officers are then able to return to duty, usually within 15 minutes.

CIT has been replicated in more than 20 communities across the nation.

In the United States today, 700,000 people with mental illnesses are incarcerated in jails and prisons every year.⁴⁵ Most have committed minor, non-violent offenses, often directly related to their mental illness or a related substance abuse disorder. Nearly all of them will be released to their communities, generally without having received treatment. For most, this trend of neglect continues after their release; a survey of parole administrators found that less than one fourth say they provide special programs for people with mental disorders.⁴⁶ The result, too often, is a revolving door of recidivism and despair.

The “criminalization” of mental illness represents a potential disruption to the structure and routine of criminal justice settings and an inappropriate, inefficient diversion of resources. Police officers, judges, corrections officials and probation officers feel ill-equipped to meet the special needs of this population. For people with mental illnesses and their families, this practice is a human tragedy.

Action Item: Fund programs to divert people with mental illnesses who have committed nonviolent crimes into treatment instead of jail or prison.

Recommendation:

- Congress should fully fund the Mentally Ill Offender Treatment and Crime Reduction Act. In 2004, Congress passed this bill and the President signed it into law. The law authorizes funds for programs to facilitate collaboration among the criminal justice, juvenile justice, mental health and substance abuse systems. These collaborations would divert people with mental illness from incarceration, provide treatment for mental illnesses within criminal justice or juvenile justice settings, and establish re-entry programs that provide essential services. This is a good framework; Congress should now fund the program.

Action Item: Eliminate ineffective “warehousing” of youth with mental disorders in juvenile justice facilities.

People with mental disorders are often criminalized from an early age. The President’s New Freedom Commission on Mental Health found that “an astounding 80 percent of children entering the juvenile justice system have mental disorders.”⁴⁷ A bipartisan Congressional survey released last year found that, in at least 33 states, children and adolescents are held in juvenile justice facilities awaiting mental health treatment even though they have no current charges against them.⁴⁸ Many facilities reported holding children 12 years old and younger, and at least one was holding an eight-year-old. Overall, these youth are held twice as long as youth without mental or emotional disorders in detention. Significantly,

85 percent of facilities reported that these children and adolescents either attempted suicide or used aggressive behavior against others while in juvenile detention facilities. This practice is also costly; in California, for example, it costs \$116 a day to incarcerate a child with a mental disorder.⁴⁹

Recommendation:

- Congress should provide resources for activities that will divert youth who need treatment for mental, emotional or behavioral disorders to systems that offer appropriate mental health and social services. Training for juvenile court judges and linkages between these courts and local systems of care for children and youth are also needed. Juvenile justice facilities should meet national standards for evaluating youth at intake for evidence of mental disorders, provide further assessment and treatment as needed, and develop (at admission) individualized discharge or transition plans.
- Congress should also pass legislation that provides incentives for juvenile justice facilities to become accredited by appropriate professional organizations, establishes a system for monitoring these facilities, and requires states to report to Congress on their compliance with national standards.

Action Item: Promote successful community re-entry through prompt reinstatement of Social Security disability benefits, Medicaid, and other federal benefits when individuals with mental illnesses are released from jail or prison. Individuals who have not previously received these federal benefits, but who may be eligible, should be provided assistance in making appropriate applications while incarcerated.

A landmark 2002 report by the Council on State Governments, developed in consultation with panels of criminal justice and mental health experts, concluded that “individuals with mental illnesses leaving prison without sufficient supplies of medication, connections to mental health and other support services, and housing are almost certain to decompensate, which in turn will likely result in behavior that constitutes a technical violation of release conditions or a new crime.”⁵⁰ This conclusion is consistent with research findings that show high rates of recidivism for people with mental illnesses.

When incarcerated in jail or prison, people with disabilities, including those with mental illnesses, generally lose their eligibility for critical federal programs that can provide the support for them to live in the community. Supplemental Security Income (SSI), Medicaid, Food Stamps and other federal benefits are discontinued and individuals must re-

apply and wait to be approved again upon release. As a result, many find themselves homeless, without medications or other treatment, and without any source of cash income.

This problem can be eased with simple changes to the SSI program, along with some changes to the Social Security Disability Income program (SSDI). Post-release waiting times could be eliminated for those who previously received these benefits, and pre-release actions could enable others to make new applications.

Recommendation:

- The Centers for Medicare and Medicaid Services should clarify how states can more quickly reinstate Medicaid benefits for incarcerated people under current federal law.



“Too often, today’s system simply manages symptoms and accepts long-term disability.”

— *Michael F. Hogan*
Chair, President’s New Freedom Commission on Mental Health

Step 3: Make Medicaid accountable for the effectiveness of the mental health services it pays for.

Many individuals with mental illnesses, especially those with serious disorders, are poor and lack private health insurance. As a result, significant numbers rely on Medicaid — 16 percent of adult Medicaid enrollees and 8 percent of children.⁵¹ Access to Medicaid mental health services is essential to self-sufficiency for adults and often enables children to stay in school, continue to learn, and avoid juvenile arrest.

Congress and the Administration are now considering several proposals to reduce Medicaid costs. Many of the ideas on the table are short-sighted and fail to consider the real and long-term costs of changes that are designed only to restrict eligibility or choice of services. Instead, reform should begin with an assessment of how Medicaid can be more effective in helping people toward recovery, reducing the negative consequences of disability, and expanding opportunities for independence and personal choice.

Medicaid spends 9 to 13 percent of its overall expenditures on mental health services.⁵² But much of that is spent on an old model of care — one that emphasizes costly medical services and residential care, rather than on the community-based services that consumers want and need.

Congress should hold Medicaid more accountable for the money it spends on mental health services by focusing on outcomes and by making it easier for states to fund the integrated, comprehensive, cost-effective services that individuals with mental disorders often require.

Action Item: Provide cost-effective home- and community-based care in lieu of institutional care, whenever possible.

Medicaid covers psychiatric inpatient services for children, general-hospital psychiatric care for adults 22 to 64 years old, psychiatric-hospital care for adults age 65 and over (at state option), and nursing-home care for individuals with mental illnesses who also have other disorders. Medicaid does not cover psychiatric-hospital care for adults ages 22-64 or residential alternatives (such as crisis residential programs or group homes) for adults. While a range of community services

can also be covered, some services can only be covered through a waiver of federal rules.

Existing Medicaid law permits a state to provide a specialized array of home- and community-based services to a targeted group of people if the state can demonstrate that its proposal will not result in additional costs to the Medicaid program. However, because Medicaid generally does not pay for services provided to adults ages 22-64 in psychiatric hospitals, states are not able to take account of those costs in demonstrating the savings that result when adults are served in home- and community-based settings. As a result, Medicaid waiver services — a critical source of services to promote independence among most disability groups — are virtually unavailable to adults ages 22-64 who have mental illnesses.

Some adults with mental disorders may still be eligible for a home- and community-based services waiver, but states are uncertain how to account for budget neutrality for these populations. For example, adults over age 64 in psychiatric hospitals, nursing homes or general hospitals might be eligible under a home- and community-based services waiver if cost-neutrality can be demonstrated.

An additional problem arises for home- and community-based services waivers for children with mental disorders. For purposes of the waiver, the cost of care for children in a residential treatment center (RTC) cannot be considered in the cost-neutrality calculation, even though Medicaid pays the costs of care in these facilities. Waivers can be obtained for children who otherwise would be hospitalized, but in many states children with serious mental or emotional disorders are institutionalized in RTCs, not in hospitals. However, the cost-effectiveness of home- and community-based services is evident in the three states that now have waivers for children in psychiatric hospitals.⁵³

Kansas: Average annual per-child costs were \$12,900, compared with institutional costs of \$25,600

Vermont: Average annual per-child costs were \$23,344, compared with inpatient costs of \$52,988

New York: Approximate annual per-child costs were \$40,000, compared with institutional costs of \$77,429.

Recommendation:

- Congress should amend federal law to allow funding of home- and community-based services for children and youth in lieu of placements in a residential treatment center funded through Medicaid. This can be accomplished by including RTCs in the section of the law that now allows home- and community-based services

waivers for children at risk of placement in an Institution for Mental Retardation or a hospital. The Centers for Medicare and Medicaid Services (CMS) should develop a series of templates for waiver applications for states seeking a waiver under current law to provide home- and community-based services to people with mental disorders. This would enable states to more readily understand the budget-neutrality calculations CMS desires, thereby enabling them to apply for waivers to provide home- and community-based services to people with mental illnesses who are now served in a nursing home, general hospital, or psychiatric hospital (for those 65 and over in states with this option).

Action Item: Amend federal Medicaid law to cover room and board costs for therapeutic foster care placements under Medicaid.

Medicaid reimburses the full cost of hospital and RTC placements for children and youth with mental disorders, including room and board. However, for the more cost-effective alternative of therapeutic foster care, Medicaid pays only for services. This creates an incentive to place children and youth in a higher level of care than necessary.

Recommendation:

- Medicaid should cover the full cost of therapeutic foster care, an evidence-based practice for children with serious mental disorders, including the cost of room and board.

Action Item: Increase opportunities for personal choice.

Many federal programs, including Medicaid, have recognized the wisdom and importance of giving people a real say in deciding what kinds of treatment and services they need. CMS' *Independence Plus* demonstration project is specifically designed to "increase personal autonomy while promoting rational, cost-effective decision-making about supports and services, rather than encouraging dependence and over-reliance on institutional care."⁵⁴

The principles driving self-direction in Medicaid are particularly important in mental health, where research demonstrates that treatment is more likely to be effective when people have meaningful choices in their treatment and are directly involved in treatment planning. Unfortunately, CMS initiatives encouraging self-direction are relatively narrow. They are used by states principally in the context of waivers that do not generally serve people with mental disorders. Congress and CMS should take action to increase opportunities for personal choice in two ways.



Recommendation:

- CMS should require State Medicaid Plan amendments and waiver requests regarding mental health services to demonstrate how the state intends to incorporate increased opportunities for personal choice.
- Congress should direct CMS to identify barriers to the application of consumer self-direction initiatives to people with mental illnesses and make recommendations for eliminating them. This should include an assessment of ways in which states might operate self-direction initiatives for adults and families of children with mental disorders. CMS should then issue guidance and technical assistance to states on how to run such initiatives.

Action Item: Permit states to provide a comprehensive array of critical mental health services that combine rehabilitation, clinic services, and targeted case management under a single Medicaid option.

Medicaid already finances many of the mental health services needed to promote independence for people with mental disorders living in the community. However, state and local providers must piece together multiple Medicaid options and bill separately for each service. This results in administrative burdens that significantly discourage states from planning comprehensively for services to people with mental disorders.

Recommendation:

- Congress should provide a single Medicaid service option for Intensive Community Mental Health Treatment, which would include targeted case management, psychiatric rehabilitation and clinic services.

Action Item: Require states to coordinate Medicaid policy changes that affect people with mental disorders with State Mental Health Plans.

Recommendation:

- CMS should require that all State Plan amendments and waiver requests be incorporated in and consistent with the respective state's comprehensive plan for mental health services. This will ensure that state mental health agencies and Medicaid agencies are working together to maximize the effectiveness of federal resources.

Action Item: Establish a system to offer technical assistance on mental health to states and providers.

Medicaid policy is extremely complex and the rules regarding the array of services required by people with mental health care needs are particularly confusing. Medicaid agencies are generally unable to develop the level of expertise required for efficient delivery of Medicaid mental health services. State mental health authorities, while they have the expertise on mental health service delivery, do not always understand the full complexities of Medicaid. As a result, providers are often confused and individuals do not always receive the most appropriate and effective services.

Federal support and guidance to state Medicaid directors and mental health providers regarding the needs of people with mental disorders would be invaluable.

Recommendation:

- A federal Technical Assistance Center on Mental Health should be established, jointly funded by CMS and SAMHSA. This Center should reflect the needs and perspectives of consumers and families in its governance and in its work.
- The Centers for Medicare and Medicaid Services should establish and provide to states information on minimum standards for early identification of mental, emotional or behavioral disorders in children who receive EPSDT screens in primary care settings.

“Remarkable treatments exist, and that’s good. Yet many people — too many people — remain untreated. Some end up addicted to drugs or alcohol. Some end up on the streets, homeless. Others end up in our jails, our prisons, our juvenile detention facilities.”

— *George W. Bush*
President of the United States

Step 4: Prevent the negative consequences of mental disorders by getting the right services to the right people at the right time.

Mental health treatment works, but only if people get the services they need when they need them. Unfortunately, timely provision of appropriate services is the exception, not the rule, in today’s mental health care system.

First, stigma or lack of awareness prevents many people from asking for help from mental health professionals. This problem is especially significant in rural areas, where there may be limited access to mental health professionals, and among older people, who often are reluctant to seek help.

Second, even people who actively seek mental health services are likely to face great difficulty paying for them. Although 94 percent of Americans say that their mental health is at least as important as their physical health, most have health insurance that fails to provide coverage for mental health services that is adequate or equal to the benefits provided for their physical health problems. People with the most serious mental illnesses often have no health insurance at all and only receive uncompensated care in emergencies. Others are eligible for Medicaid, but may wait weeks for their eligibility to be confirmed, only to find that the lack of services in their community prevents them from getting the help they want and need.

Ensuring that people can access timely and appropriate services should be a principal goal of transforming mental health care.

Action Item: Promote early detection of mental disorders and, when appropriate, early intervention services for at-risk mothers and children who receive health care at federally funded maternal and child health clinics.

Early detection and treatment of mental disorders can result in a substantially shorter and less disabling course of illness.⁵⁶ Successfully treating parents’ mental disorders also benefits their children.⁵⁷

Public Opinion Supports Mental Health Care Coverage⁵⁵

- 94 percent of Americans say that their mental health is as important as or more important than physical health.
- 64 percent of Americans believe that physical health is treated with more importance than mental health in our health care system.
- 91 percent of Americans somewhat agree or strongly agree that health services that address mental health, such as suicide prevention and treatment for depression, are fundamental to overall health and should be part of any basic health plan.

Recommendation:

- Congress should require the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Health Resources and Services Administration (HRSA) to collaborate in an initiative to ensure that community health centers and maternal and child health programs provide early detection of mental disorders and appropriate follow-up services to people who are most at risk.

Action Item: End discrimination against mental health treatment in Medicare and cover essential services.

Medicare provides health care coverage to nearly 40 million Americans, many of whom require mental health services. Nearly one in five Americans over 55 years old experiences a specific mental disorder that is not part of the “normal” aging process.⁵⁸ The rate of suicide is highest among older adults relative to all other age groups.⁵⁹ In addition, more than 2 million individuals with mental illnesses are covered by Medicare by virtue of their eligibility for Social Security Disability Insurance (SSDI).⁶⁰

Medicare currently discriminates against people with mental illnesses by requiring a higher co-payment for outpatient care and limiting hospital coverage. It also fails to reimburse many of the critical rehabilitative services needed by people with mental disabilities. These limits are applied without regard to evidence-based best practices and they restrict the ability to choose treatment approaches that are most effective.

Largely as a result of this discriminatory approach to covering treatment for mental illnesses, only about 5 percent of total Medicare expenditures are used for mental health services, and only a fraction of that amount is used for services in non-institutional settings.⁶¹ The historical reason for these limits is likely rooted in the now-discredited belief that mental health

treatment is ineffective and recovery is not possible. In fact, treatments for mental illnesses are now so effective that they can reduce psychiatric-hospital stays and utilization of other, non-psychiatric health care services, and result in overall cost savings.

Recommendation:

- Congress should amend Medicare law to equalize the co-payments for mental and physical outpatient health care, eliminate the 190-day lifetime limit on psychiatric-hospital care, and add a Part B benefit of psychiatric rehabilitation for individuals with serious mental illnesses.

Action Item: Ensure that the primary health care needs of adults and children who receive services through the public mental health system are met.

Research demonstrates that individuals with mental illnesses are at risk for higher rates of physical health problems than the general population. As many as one third of people with serious mental illnesses have at least one undiagnosed medical problem,⁶² and as a group, people with mental illnesses have age-related mortality rates 2.4 times higher than the general population.⁶³

Despite the frequent co-occurrence of mental and physical disorders, most public clinics — Community Health Centers (CHCs) and Community Mental Health Centers (CMHCs) — continue to treat only one disorder at a time. A few community providers have begun to explore solutions, such as staffing CMHCs with primary care providers or combining agencies in order to administer a CHC and CMHC through a single entity. So far, this has been a “bottom-up” transformation of the system, but some federal rules act as barriers.

The federal government should lead and support the adoption of effective strategies to integrate primary care and behavioral

health care. Barriers in federal policy should be removed. For instance, the Centers for Medicare and Medicaid Services (CMS) does not currently permit a provider agency to bill for more than one service to the same individual on the same day, defeating the purpose of co-locating providers to improve access to both mental and physical health services.

Recommendation:

- A joint HRSA/SAMHSA initiative should be established to provide incentives for integrating primary care services within behavioral health care programs for individuals with serious mental illnesses. HRSA and SAMHSA should also study and evaluate the effectiveness of different approaches, disseminate best practices and provide technical assistance to states, localities, CHCs and CMHCs.
- Medicaid policy should be changed to permit payment for more than one office visit on the same day so that co-located providers of mental health and other health care may treat the same individual during the same office visit.

Action Item: Require parity in private health insurance plans.

Since 1996, federal law has prohibited private insurance companies from imposing discriminatory annual or lifetime limits on mental health services. Initial claims by opponents of the law that it would drive up insurance premiums or force companies to abandon mental health coverage altogether have proven unfounded.⁶⁴

The mental health parity law established an important principle, but its application is limited. The General Accounting Office (GAO) — now the Government Accountability Office — reported in 2000, after assessing the law’s impact, that most employers complied with the law, but 87 percent of those who complied placed limits on the number of covered hospital days or outpatient office visits or required higher cost-sharing, such as co-payments and co-insurance.⁶⁵

Providing full mental health parity not only greatly benefits those who need services, it’s cost-effective. The full-parity laws passed in Vermont (1998) provided parity at a cost ranging from zero to 2 percent; Maryland (1995) from 0.2 percent to 1 percent; and Minnesota (1995) at 1 percent.⁶⁶ In Texas and North Carolina, where parity insurance coverage for state employees was introduced in 1992 with managed care, the costs dropped 30-50 percent, while the percent of the population accessing some care increased 1 to 2 percent.⁶⁷ These findings mirror those of employers that have committed to providing parity mental health insurance benefits, including McDonnell Douglas, Delta and the Kennecott Copper Corporation.⁶⁸



Recommendation:

- Congress should close the loopholes in the 1996 law requiring parity in private insurance coverage of mental health and medical services.

Action Item: Permit presumptive eligibility for SSI and Medicaid for people who are homeless and have a serious mental illness.

The vast majority of people who are homeless and have a serious mental illness meet eligibility requirements for SSI and Medicaid. However, bureaucratic processes require each person to obtain and complete application materials and wait — often for weeks, months or sometimes years — for approval. During that time, many have no access to medications or other health care, resulting in unnecessary emergency care and inpatient admissions, further deterioration and death.

Recommendation:

- Congress should provide immediate, short-term access to covered benefits for homeless individuals who have a mental illness and who are considered highly likely to qualify for SSI or Medicaid. Enactment of this proposal would help people live successfully in the community and avoid the increasingly common reliance on emergency rooms and costly crisis care.

Action Item: Develop a strategic plan to address all mental health workforce issues and pass legislation to redefine and expand the Mental Health Professional Shortage Area Designation program.

The President's New Freedom Commission on Mental Health found a "workforce crisis" in mental health care. There is a shortage of mental health professionals, especially in rural areas, and not enough practitioners serve individuals in the public system. There is also a training gap in evidence-based and emerging best practices and in cultural competency, which hinders conversion of the latest science into innovative service.

Particularly severe is the shortage of professionals trained to diagnose and treat older Americans, children, and adolescents. The scarcity of community-based children's mental health professionals is one of the key reasons why some families are forced to relinquish custody of their children to state child welfare or juvenile justice agencies.

Recommendation:

- Congress should redefine and expand the Mental Health Professional Shortage Area Designation program to include service within any public sector agency providing services to Medicaid beneficiaries. In this and other workforce development efforts, special attention must be given to the challenges faced in inner-city, rural and frontier areas.
- Congress should pass the Child Health Care Crisis Relief Act, which would increase the number of children's mental health professionals through the creation of education incentives.
- Congress should pass legislation that re-institutes historic federally funded scholarship programs to increase the number of individuals, particularly ethnic minorities, who attend professional schools in medicine, social work, psychology, nursing, and marriage and family therapy.
- Congress should expand the J-1 Visa Waiver program to expand the number of mental health professionals in underserved areas.
- SAMHSA should partner with local and state public authorities and private-sector entities to create a leadership development program that provides opportunities and incentives for mental health professionals to enhance their skills and play a role in creating and mapping the future of public mental health services in this country.
- SAMHSA, in collaboration with HRSA and in consultation with appropriate accrediting bodies, should assess and update the quality of mental health professionals' practice and education to ensure that evidence-based practices are being taught and incorporated into practice in the field in terms of philosophy, practice and standards.

“We know about risk factors, we know about existing interventions and treatments that work and we know about the consequences when there is no intervention. True, unlike other childhood diseases, we do not have a vaccination that can immunize someone from a mental disorder. But by intervening early, we can prevent the disorders and symptoms from worsening and improve outcomes significantly.”

— *Larke Nabme Huang, Ph.D.*
Commissioner, President’s New Freedom Commission on Mental Health, in speech at Capitol Hill briefing of the Campaign for Mental Health Reform, May 11, 2005.

Step 5: Invest in children and support and value their families’ role in making treatment decisions.

Children are more likely to succeed when they have the support of loving, involved parents. For children with serious emotional disorders, having their parents make treatment decisions is especially important because no one understands the consequences of their illness as well as their parents, and no one is as personally invested in their successful recovery.

The costs of mental health treatment can strain the budgets of even moderate-income families. Families who lack access to mental health care often turn to the public system. However, since many of them do not meet the eligibility criteria on income and resources, their children cannot qualify for Medicaid or public mental health services. As a result, parents are forced to choose between giving up custody of a child to state child welfare or juvenile justice agencies and having them go without care. These families have no history of abuse, neglect or violation of the law — they simply need mental health services for their children.

In 2003, the Government Accountability Office (GAO) released a study on custody relinquishment. According to that report, child welfare directors in 19 states and juvenile justice officials in 30 counties estimated that parents placed more than 12,700 children into their systems to access mental health services in 2001 alone.⁶⁹ Significantly, the GAO concluded that the federal government could take action to end this appalling and counterproductive practice.

Action Item: Pass legislation to allow families the opportunity to buy into Medicaid to access services for a child with a disability.



Families with children who have disabilities and whose family income is up to 250 percent of the federal poverty level should have the opportunity to access the range of comprehensive rehabilitative and treatment services covered by Medicaid. Children with disabilities, including emotional and behavioral disorders, require a range of services that are expensive and often unavailable through private insurance plans. Bipartisan proposals introduced in Congress include this provision (the Family Opportunity Act).

Recommendation:

- Congress should enact the Family Opportunity Act (S. 183 introduced by Senators Grassley and Kennedy, and H.R. 1443 introduced by Representative Sessions). The Senate passed this legislation in the last session of Congress and a majority of House members co-sponsored the House bill.

Action Item: Track the incidence of children being placed in child welfare and juvenile justice systems solely to obtain mental health services.

Among the most disturbing findings of the 2003 GAO report was the observation that no agency tracks these children or maintains data on their characteristics. In fact, only 19 of 51 state child welfare directors (including the District of Columbia’s) responded to the GAO’s survey, and several states acknowledged that they were unable to provide an estimate even though they believed that such placements occurred.

Recommendation:

- The federal government should explore the feasibility of tracking children placed in child welfare or juvenile justice settings, as recommended by both the GAO and the President’s New Freedom Commission on Mental Health.⁷⁰

Action Item: Support state efforts to establish interagency systems of care for children.

Many communities have, with the support of Substance Abuse and Mental Health Service Administration (SAMHSA) grants, developed comprehensive systems of care for children with mental health needs. These grants have proven cost-effective in preventing the negative consequences of mental disorders. Few states, however, have developed such systems on a statewide basis. It is noteworthy that the New Freedom Commission recommended that such comprehensive state plans be developed as an essential component of mental health systems.

Recommendation:

- Congress and the Administration should encourage states to develop comprehensive plans for systems of care for children by providing one-year, non-renewable grants through SAMHSA to support this effort. States should be required to demonstrate the participation of a broad range of state agencies with responsibility for meeting children's health and social needs. These may include mental health, substance abuse, Medicaid, public health, developmental disabilities, social services, criminal and juvenile justice, housing employment/vocational rehabilitation, and education agencies and departments.

“[T]oo many Americans with disabilities remain trapped in bureaucracies of dependence, denied the tools they need to fully access their communities.”

— *George W. Bush*
President of the United States

Step 6: Promote independence by increasing employment, eliminating disincentives for economic self-sufficiency and ending homelessness.

Increasing Work Opportunities for People With Mental Disorders

People with mental illnesses are best served by a range of supports to enable them to escape poverty, function successfully in the community, and be the productive, contributing members of society they are capable of being. Unfortunately, assistance in finding and keeping a job is too often lacking, and living on the streets makes the road to recovery extremely difficult.

A Tough But Rewarding Job

Tresa Lucas, a 38-year-old employment specialist, job coach and mother from Ohio, learned a maxim of mental health treatment first-hand: “When you go back to work, you get better faster.” Tresa has bipolar disorder, and she knows that getting back to work when you have a chronic illness is not easy — but it is rewarding.

Fewer than one in five people with serious mental disorders is employed.⁷¹ For these individuals, access to appropriate and timely vocational services is the key to employment. However, federal training programs designed to teach people with disabilities new skills and help them find jobs don’t use the employment models that have been found effective for people with mental illnesses. And successful job-hunting too often means losing one’s income safety net and, most important, access to health care services.

Action Item: Eliminate disincentives to work and self-sufficiency that are inherent in the Social Security Disability Insurance (SSDI) program.

Even when appropriate rehabilitation services are available to them, the sad reality for many people with mental illnesses is that they can’t afford to work. Under current law, people who receive SSDI lose their entire benefit if they earn a single dollar over the allowable limit of \$740 per month. Along with

their SSDI benefit, they also lose Medicare coverage. If they are unable to sustain employment at a living wage, they must begin the lengthy process of applying for SSDI eligibility all over again. There is a need for a more rational public policy that values work and independence.

Recommendation:

- SSDI program rules should be amended to more closely track Supplemental Security Income (SSI) rules. SSI has a graduated approach to independence: A person loses one dollar in benefits for every two dollars earned. Using the SSI program as a model, Congress should reform the SSDI “earnings cliff” to remove disincentives to work.
- Congress and the Administration should devise changes to policies in the Food Stamp program, public housing, SSI and SSDI to support incentives to work and ensure that people with disabilities will not face new financial hardships when they return to work.

Action Item: Help people with mental illnesses join the workforce by reforming the payment system used under the Ticket to Work and Work Incentive Act of 1999 (TWWIA).

Under the Ticket-to-Work program, rehabilitation providers are paid by the federal government for vocational rehabilitation services furnished to individuals who receive SSI disability benefits. However, payment is made only after the person with disabilities has returned to work and federal disability payments have stopped. This payment system has created incentives for rehabilitation providers to serve only people who are considered mostly likely to be immediately employable on a full-time basis. This defeats the purpose of the law, which is to expand opportunities and work incentives for people with severe disabilities.

Recommendation:

- Congress should change federal law to allow payment to providers when they successfully place someone in a job with earnings sufficient to reduce (even when not eliminating) his or her monthly SSI payments.

Action Item: Promote integration of federal and state vocational rehabilitation funding into state and local (including county) mental health budgets.

State vocational rehabilitation (VR) agencies serve all people with disabilities, including those with mental disorders. However, most of these agencies rely on a service model that was designed for people with physical disabilities and that does not take into account the episodic and, at times, recurring,

nature of mental illnesses. Supported employment and transitional employment programs have a clear track record of effectiveness. Adopting these approaches would save money and improve outcomes. State vocational rehabilitation agencies receive limited federal funding for supported employment, but they receive significantly more resources through a block grant that funds an array of more traditional vocational services that are not effective for people with mental illnesses.



Second, state VR counselors' performance is evaluated on the basis of how many people they place and keep in jobs for a 90-day period. This means they have little incentive to serve people with long-term and cyclical illnesses, as mental disorders often are. Most states also still do not have specialized vocational rehabilitation counselors with expertise in mental illness, despite evidence that work outcomes improve when vocational counselors are specialized.

Assisting people with mental illnesses in their efforts to get back to work and on the road to self-sufficiency requires a fundamentally new approach to providing and paying for vocational rehabilitation services.

Recommendation:

- Congress should redirect a portion of all state vocational rehabilitation grants to state mental health agencies, based on the proportion of people with disabilities in that state whose principal disability is mental illness, for use in supporting employment approaches that are effective with this population and that are delivered by individuals with specialized training in helping people with mental illnesses. State mental health agencies should be responsible for integrating federal and state vocational funding for distribution among local providers of employment services for people with mental illnesses.

Increasing Access to Stable, Affordable Housing for People with Mental Disorders

For about 200,000 Americans who have a mental illness and are homeless, the first step to self-sufficiency is finding decent, stable housing. The lack of a permanent address and telephone number to give prospective employers, the lack of access to laundry and bathing facilities, and poor self-esteem all stand in the way of their getting a job. Even with effective mental health treatment, finding and keeping a job is an uphill battle for anyone who is homeless.

In a 2002 report, a bipartisan panel of experts (the Millennial Housing Commission) warned of “the most serious housing problem in America” — the mismatch between the number of people with extremely low incomes and the number of safe, decent housing units available to them.⁷² For people with mental disorders, this caution is not academic; because people with disabilities are among the poorest in our country, they live every day with the threat of homelessness.

Action Item: Maintain HUD's Section 8 housing programs as a viable safety net for people with mental disabilities who are at risk of homelessness.

For 1.4 million people with mental illnesses who rely on SSI, finding safe, decent housing is an uphill battle. The average monthly SSI payment (about \$455⁷³) constitutes only 13 percent of average median income,⁷⁴ meaning that a person whose sole source of income is SSI cannot afford to rent a modest efficiency or one-bedroom apartment in any of the 2,702 housing market areas identified by the U.S. Department of Housing and Urban Development (HUD).⁷⁵

Many of these individuals are spared homelessness through Section 8, HUD's program of rental subsidies and other housing assistance to support people most in need. Section 8 has long been considered extremely effective as a flexible, market-based approach to support people with very low incomes — including at least 1 million with disabilities such as mental disorders⁷⁶ — in finding and keeping stable housing. Section 8's capacity to provide decent, stable housing for people with mental disorders should be protected.

Recommendation:

- Congress should provide full funding for the 2 million housing vouchers that are authorized under Section 8. This funding should be accompanied by requirements that local Public Housing Authorities (PHAs) distribute all the vouchers available to them.
- Congress should also guarantee that scarce Section 8 resources are targeted for those most in need. Current

rules require PHAs to distribute at least 75 percent of their housing vouchers to people with incomes below 30 percent of the average median wage in that area. This requirement should be retained because removing it could have disastrous consequences for thousands of SSI recipients who rely on Section 8 to supplement their income and who could not afford safe, modest housing without this support.

Action Item: Create a National Affordable Housing Trust Fund to build, rehabilitate and preserve 1.5 million units of rental housing by the end of the decade.

Legislation to create a National Affordable Housing Trust Fund to significantly increase low-income housing was introduced in the 108th Congress. This proposal is backed by thousands of organizations, elected officials and religious leaders. The Trust Fund would fund construction, rehabilitation and preservation of 1.5 million units of housing, targeted principally for families and individuals with extremely low incomes, such as people with disabilities living on SSI benefits.

Penny-Wise and Pound-Foolish

Despite clear evidence that providing appropriate mental health intervention, treatment and services *when they are needed* saves money over the long term, policymakers at all levels of government who are struggling with budget constraints often fail to consider long-term savings — especially savings that occur across service systems.

Supportive housing is a case in point. Research has demonstrated that when people who are homeless receive supportive housing, they experience the following benefits:

- 58 percent reduction in emergency room visits;
- 85 percent reduction in emergency detoxification;
- 50 percent decrease in jail time; and
- 50 percent increase in earned income.

Significantly, 80 percent of people in supportive housing are still housed one year later. When compared to the costs of a stay in a hospital, jail or homeless shelter, the cost-effectiveness of a day in a supportive housing program is obvious. As an example, the following chart describes the relative costs of supportive housing versus the consequences of homelessness in Phoenix, Arizona:⁷⁷



“A veteran returning today from Operations Iraqi Freedom or Enduring Freedom, who suffers from depression and suicidal ideation related to deployment, will find the availability of appropriate evidence-based care is haphazard and spotty.”

— *Secretary of Veterans Affairs Task Force on Mental Health, March 11, 2004*

Step 7: Address the mental health needs of returning veterans and their families.

Veterans of combat in Iraq and Afghanistan are at significant risk of mental health problems. An early study shows high rates of traumatic stress among soldiers serving in Iraq, and evidence of major depression, anxiety or post-traumatic stress disorder (PTSD) in up to one in six of these veterans.⁷⁸ The suicide rate for soldiers deployed to Iraq is higher than the rate over the previous eight years and higher than rates reported during the Gulf or Vietnam Wars;⁷⁹ suicides among returning combat veterans have also been reported.⁸⁰

Complications of traumatic stress are often severe and can include major depression, substance abuse, job loss, family dissolution, homelessness, violence to self and others, and incarceration, according to the most recent report to Congress from the Department of Veterans Affairs’ (VA’s) Special Committee on Post-Traumatic Stress Disorder (hereafter referred to as “the Special Committee”).

The VA has long had a special obligation to veterans with mental illnesses, given both the prevalence of mental health and substance use problems among veterans and the high numbers of those whose illnesses resulted from their time in the service. Recent VA data show that more than 480,000 veterans have a service-connected mental disorder. Of that number, more than 215,000 are service-connected for PTSD. Some 17 percent — nearly 800,000 — of the 4.7 million who received VA care in fiscal year 2003 received some type of mental health service.⁸¹

Years of oversight have underscored the VA health care system’s uneven record of service to veterans with mental health needs. The VA’s own statutorily created Committee on the Care of Veterans with Serious Mental Disorders has emphasized in annual reporting to the Department and the Congress the enormous variability across the country of the availability of VA mental health treatment services and the relatively limited capacity devoted to rehabilitative help in areas where services are available.

Action Item: Provide early identification and effective treatment for returning veterans at risk of post-traumatic stress disorder and their families.

Decisive action to promote early intervention should be taken to avert the risk of suicide and PTSD among veterans. As the Special Committee has emphasized, the recovery model, which is central to the recommendations of the President’s New Freedom Commission on Mental Health, provides a paradigm that would involve veterans’ and their families’ active participation and focus on solving problems rather than being ill. The most formidable challenge is reaching out to veterans whose needs are often not recognized during demobilization.

Recommendation:

- Congress should pass legislation directing the VA, in consultation with the Special Committee, to develop mechanisms that are appropriate to meeting the health risks associated with PTSD and other deployment-related health problems. Congress should also require an annual report from the VA to ensure that any such mechanisms are effective in realizing this objective.
- Congress should also pass legislation to address the needs of the immediate family members of returning veterans, whose eligibility for any VA mental health services is very limited. As the VA’s National Center for PTSD has reported, because the symptoms of PTSD change the way veterans feel and act, severe untreated trauma reactions can cause major problems for other family members. These include depression, anxiety, substance abuse and stress-related medical problems. Psychological stress itself can take a toll on family members, who are living with fear for their loved ones’ safety, the hardship of separation, and uncertainty associated with extended tours of duty and other signs of an overstretched military.



Action Item: Provide effective mental health and substance abuse treatment and services to veterans.

Following the release of the New Freedom Commission's final report, the VA undertook an unprecedented and critical examination of its mental health services. Like other institutions providing mental health care, the VA has tended to focus on managing the symptoms of mental health problems. VA leaders, to their credit, understood the importance of achieving the mental health system change the Commission envisioned, and developed an agenda for realizing that goal.

An important milestone was achieved with the establishment of a task force in December 2003, which was designed to review the VA's ability to provide mental health and substance abuse treatment, and with the adoption of the task force's recommendations. Those recommendations called for eliminating the variability and gaps in VA care for veterans with mental illnesses; restoring the VA's ability to deliver state-of-the-art care to veterans with substance abuse disorders; establishing case-management programs for homeless veterans with mental health problems; and providing supportive, rehabilitative services to veterans with mental illnesses.

Implementing these steps will require sustained leadership and support on the part of both the VA and the Congress. The VA does not, for example, have in place the needed arsenal of rehabilitative services — from supported employment to housing assistance to peer supports — that veterans need to achieve the fullest possible recovery from chronic mental illness.

Recommendation:

- Given the wide gap between VA's mental health service capacity and the needs veterans have for treatment and support services, Congress must provide new funding to close these gaps.

Conclusion

It is time for Congress and the Administration to reject the soft bigotry of low expectations that has for too long defined America's national policy on mental health. The ongoing crisis in public mental health systems is both tragic and needless.

Families need not be torn apart when they attempt to secure help for their children. Older Americans need not spend their golden years struggling with depression and other mental illnesses. Police officers, court officials and corrections administrators need not be forced by failing public mental health systems to deal with a population they are ill-equipped to serve. And mental trauma suffered in service to America need not derail the lives of our nation's veterans and threaten the stability of their families.

Improved identification, early intervention and effective long-term treatment could greatly improve the lives of millions of Americans with unmet mental health needs and their families. Improved access to housing and employment opportunities could reduce dependence and promote independence. Billions of dollars could be saved that are now squandered on warehousing adults and children with mental disorders in criminal and juvenile justice settings. Each of these goals can be accomplished, but federal leadership is desperately needed.

The time has come to move beyond rhetoric and take concrete steps to address the unmet mental health needs of millions of Americans.

More than two years ago, the President's New Freedom Commission on Mental Health articulated a vision in which Americans with mental disorders have the opportunity to lead more productive, independent and successful lives. It is time that Americans with mental disorders finally be afforded the opportunity to live, work, learn and participate fully in their communities.⁸² The Campaign for Mental Health Reform and the millions of people with mental or emotional disorders, family members, service providers, administrators and other concerned Americans whom the Campaign represents, call on Congress and the Administration to demonstrate the leadership needed to make the Commission's vision a reality.

Notes

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Emergency Response is also available online at www.mhreform.org. For questions about this report or the Campaign for Mental Health Reform, contact the Campaign at info@mhreform.org.

Partner Organizations:

American Academy of Child and Adolescent Psychiatry, www.aacap.org
American Psychiatric Association, www.psych.org
American Psychological Association, www.apa.org
Bazelon Center for Mental Health Law, www.bazelon.org
CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder),
www.chadd.org
Depression and Bipolar Support Alliance, www.dbsalliance.org
Federation of Families for Children's Mental Health, www.ffcmh.org
NAMI (National Alliance for the Mentally Ill), www.nami.org
National Association of County Behavioral Health and Developmental Disability
Directors, www.nacbhd.org
National Association of State Mental Health Program Directors, www.nasmhpd.org
National Council for Community Behavioral Healthcare, www.nccbh.org
National Empowerment Center, www.power2u.org
National Mental Health Association, www.nmha.org
National Mental Health Consumers' Self-Help Clearinghouse, www.nmhselfhelp.org
Suicide Prevention Action Network USA, www.spanusa.org
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The Campaign for Mental Health Reform