

Responding to the Mental Health Needs of Americans

*A Briefing Document for
Candidates and Policymakers
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Endorsing Organizations

Alliance for Children and Families
American Association of Children's Residential Centers
American Academy of Child and Adolescent Psychiatry
American Association for Geriatric Psychiatry
American Association for Marriage and Family Therapy
American Association of Pastoral Counselors
American Association of Private Practice Psychiatrists
American Counseling Association
American Federation of State, County and Municipal Employees
American Group Psychotherapy Association
American Hospital Association
American Mental Health Counselors Association
American Occupational Therapy Association
American Orthopsychiatric Association
American Psychiatric Association
American Psychoanalytic Association
American Psychological Association
Anxiety Disorders Association of America
Association for the Advancement of Psychology
Association for Ambulatory Behavioral Healthcare
Clinical Social Work Federation
Corporation for the Advancement of Psychiatry
Federation of Behavioral, Psychological and Cognitive Sciences
National Association for Rural Mental Health
National Association of Anorexia Nervosa and Associated Disorders
National Association of Psychiatric Health Systems
National Association of School Psychologists
National Association of Social Workers
Tourette Syndrome Association

The Mental Health Liaison Group (MHLG) is comprised of over 40 Washington, D.C.-based advocacy groups representing mental health consumers, providers, professional associations, families of children and adults with mental disorders, research groups, and advocates. MHLG monitors federal and state policy developments on mental health services, delivery, access and research issues.

Note: Endorsing organizations retain the right to voice views more detailed and at variance with positions in this coalition paper.

Information For Policymakers On The Mental Health System

Who Is Affected By Mental Disorders?

- One in every five adults, or about 40 million Americans, experiences some type of mental disorder every year. Of this number 5 percent of the population have a serious mental illness, such as schizophrenia, major depression or bipolar disorder.¹
- Mental disorders cross all boundaries of race, gender and ethnicity, although the prevalence of some disorders is higher for some population groups. For instance, women and Hispanics are more likely to experience a major depressive episode², and elderly Americans are the demographic group most likely to commit suicide.³
- One in every five children are estimated to have a mental health problem resulting in at least mild functional impairment.⁴ At least one in 20 children -- or as many as three million children -- are estimated to have a serious emotional disturbance. (This term refers to a mental health problem that severely disrupts a person's ability to function socially, academically and emotionally).⁴

How Well Are Needs Met?

- Of individuals with a diagnosable mental disorder, less than half of children and slightly more than one-third of adults receive treatment in any one year.⁵
- The Global Burden of Disease Study, conducted recently by the World Health Organization, indicates that mental illness, including suicide, ranks second in the burden of disease in established market economies.⁶
- Rural and frontier areas have serious problems in the availability and accessibility of specialized mental health services.⁷

What Does the Mental Health System Look Like?

- Caring for people with mental disorders involves a myriad of providers, services and settings. Mental health services are provided by: psychiatrists, clinical psychologists, licensed professional counselors, clinical social workers, marriage and family therapists, psychiatric nurses, physicians in family medicine and other non-psychiatric specialties, and other service providers, such as occupational therapists, school counselors and school psychologists.
- Services range from medical and clinical services, (prescribing of medications, to counseling and psychotherapy), to psychosocial rehabilitation services to help people with severe mental illnesses live successfully in the community, to assisting people with mental illnesses in finding employment or housing.

What Roles Do the Private and Public Sectors Play In Providing Mental Health Services?

- Although mental disorders are typically as treatable as general medical conditions, the historic stigma and misunderstanding surrounding mental health treatment is still reflected in most private health insurance policy benefit packages, which do not provide parity for mental health services.
- Publicly-financed treatment plays a key role in the overall mental health service delivery system. Public sector spending accounts for approximately 53% of all mental health and substance abuse treatment services spending. In comparison, the public sector is the payor for 47% of total personal health care spending.⁸
- Most types of mental health services are available in both the private and public sectors, and individuals often receive services in both sectors.
- Private providers may be non-profit or for-profit, and offer an array of services that include inpatient hospitalization, partial hospitalization, outpatient counseling and psychotherapy.
- The public system is administered by state mental health agencies and financed through state appropriations,

Medicaid and programs of the federal Substance Abuse and Mental Health Services Administration. Many states rely on counties and county-based providers to deliver services. The public mental health system provides a range of inpatient and outpatient mental health treatment, rehabilitation and support services.

- The public system often serves people who lack private health insurance or whose private health insurance has bumped up against inpatient or outpatient visit limitations.
- A growing body of evidence has demonstrated that most people with mental illnesses who need treatment can be treated more effectively and at less cost in community settings than in traditional psychiatric hospitals. In response, the public mental health system has undergone dramatic changes over the last three decades. States have moved rapidly to downsize and close state hospitals and in 1993, for the first time, state spending on community mental health services exceeded spending on state hospital inpatient services.⁹
- Although many people think of the 1970s and 1980s as the decades during which deinstitutionalization gained momentum, more than three times as many hospitals have been closed or downsized during the 1990s than during the two previous decades combined. Today, fewer than 70,000 people receive mental health services as inpatients in state hospitals.¹⁰

How Effective is Mental Health Treatment?

- Diagnoses of mental disorders made using specific criteria are as reliable as those for general medical disorders.¹¹
- According to a 1993 report of the National Advisory Mental Health Council,¹² treatment improves patient outcomes for the majority of Americans, even those with a severe mental illness. The report describes the following treatment success rates for specific severe mental illnesses:

| | <i>Percentage of patients improved (early treatment outcome)</i> | <i>Long-term relapse rate (of those responding to treatment)</i> |
|-------------------------------|--|--|
| Schizophrenia | 60% | 30% |
| Manic-depressive illness | 80% | 30% |
| Major depression | 80% | 15% |
| Panic disorder | 80% | NA |
| Obsessive-compulsive disorder | 60% | NA |

(NA = information not reported)

- These effectiveness rates compare favorably with such well-established general medical or surgical treatments as angioplasty or atherectomy for heart disease, which have success rates at or below 50%.¹³
- Treatment success rates for other mental and emotional disorders are also high. Treatment success rates of 75% for adolescents receiving inpatient care for eating disorders¹³ and 75-90% for children receiving pharmacological treatment for attention-deficit/hyperactivity disorder¹⁴ have been documented.

Treatment for Severe Disorders

- As with certain general medical conditions, such as diabetes, some cases of mental disorders must be categorized as long-term, severe and persistent mental illness. Increasingly, individuals with such disorders can focus on recovery and their well-being and quality of life can be significantly improved with access to services.
- Mental health treatments are provided in a variety of settings including inpatient hospitals, day treatment programs, psychosocial rehabilitation programs, residential treatment centers, outpatient clinics, community mental health centers, community rehabilitation programs and the offices of individual providers.
- The most effective service system is one which combines a full range of treatment options, with assistance in securing housing, income support, job training, social services and social and recreational opportunities.
- For persons with co-occurring mental illness and addictive disorders, integrated treatment interventions delivered simultaneously at the same treatment site, ideally by staff trained in both mental illness and addictive disorders treatment, is more effective than sequential or parallel treatment of each disorder.

Introduction: Closing the Gap

According to a major new report from the U.S. Surgeon General, “a variety of treatments of well-documented efficacy exist for the array of clearly defined mental disorders that occur across the life span.”¹⁵ Dramatic breakthroughs are being made in our understanding of mental illness and in how to treat it, and treatment effectiveness rates for most mental disorders now meet or exceed those for general medical conditions. This is the good news. Although this briefing paper focuses primarily on the improvements that need to be made, the fundamental message for individuals with a mental or emotional disorder and those who care about them is that treatment is effective.

The bad news is that far too few individuals are getting the help they need. Individuals with the most severe mental and emotional disorders are the most seriously injured in this respect. Of the estimated 28 percent of adult Americans with a mental or addictive disorder, only about one in three receives treatment of any kind.¹⁶ This represents a tremendous lost opportunity.

Untreated serious mental and emotional disorders of children and adults constitute one of America’s major public health problems. Our jails and prisons house hundreds of thousands of persons with serious mental illnesses, who would not be there given adequate treatment. Individuals with mental illnesses are also disproportionately represented in our nation’s homeless population. Research cited in the Surgeon General’s Report on Mental Health

shows that in the U.S., mental disorders collectively account for more than 15% of the overall burden of disease from all causes, slightly more than the burden associated with all forms of cancer.¹⁵ In a similar study done by the World Health Organization, unipolar depression ranked second only to ischemic heart disease in an assessment of the leading causes of global disease burden.⁶

People with mental illness face many obstacles to getting treatment. Over 44 million Americans do not have private health insurance, and those who do have private health insurance usually face benefit packages which arbitrarily limit coverage for mental health services. Public mental health systems are chronically under-funded, and often lack accountability for the inadequate resources they have. The persistent stigma associated with mental health care prevents many in need of treatment from seeking it. Without adequate treatment, individuals face loss of work or educational opportunities, homelessness, family breakups, abuse, imprisonment and death.

We need to close this gap between what we know and what we do, and create a coordinated and comprehensive mental health policy for the nation. This briefing paper provides a factual and statistical review of major aspects of mental health policy. Attached to the paper is a questionnaire for candidates for elected public office, which seeks to determine where the candidate stands on these critical mental health public policy issues.

Access To Care

According to the Surgeon General’s report, nearly two-thirds of all people with diagnosable mental disorders do not seek treatment.¹⁷ The minority who do seek help face significant barriers in accessing the most appropriate and effective services, including inadequate insurance coverage, lack of specialized providers or cost. As with other medical conditions, untreated mental disorders can be ruinous or even fatal for individuals and their families.

Inadequate access also carries significant economic costs. It is estimated that the combined indirect and related costs of severe mental illness, including lost productivity, lost earnings due to illness and societal costs such as increased criminal justice and family

caregiving, totaled \$79 billion in 1990.¹⁸ For schizophrenia alone, total indirect costs were almost \$15 billion in 1990.¹⁸ According to the Surgeon General, “these indirect cost estimates are conservative” as they fail to capture “the pain, suffering, disruption and reduced productivity that are not reflected in earnings.”¹⁸ The report goes on to state that “society can no longer afford to view mental health as separate and unequal to general health.”

Even having adequate insurance may not be enough. Only one in seven individuals with a mental or addictive disorder actually receive treatment from a trained mental health professional.⁵ It is estimated

that only one-third of psychotropic medications are now prescribed by psychiatrists, with the remainder prescribed by primary care physicians and other medical specialists.⁸ There are serious shortages of mental health specialists and a lack of necessary support services in rural and frontier areas. There is also a need for specialists trained to work with culturally or linguistically diverse groups. According to the Surgeon General's report, there are particularly keen shortages of mental health professionals to serve children and adolescents with serious mental disorders and older people.¹⁹ Often in employer-sponsored group plans, even when specialists are available, their services may not be covered, due to tightly controlled access to providers or the exclusion of entire classes of providers from panels on the basis of type of licensure.

Alarmingly, we are actually getting *farther away* from establishing a comprehensive and effective mental health treatment "system". As detailed below, over time—and particularly in the last decade—public and private resources for mental health care have been *shrinking* in relation to spending on health care and on other public programs. In 1996, spending in the U.S. on mental health services totaled \$69 billion.²⁰ Private insurance accounted for 27% of this total, out-of-pocket spending for 17%, Medicaid for 19%, state and local governments for 18%, and Medicare for 14%.⁷

Parity In Benefit Design Of Private Insurance

The value of mental health and other behavioral health benefits in private-sector plans has eroded over the last ten years:

- Between 1986 and 1996, spending for mental health treatment grew more slowly than health care spending in general, increasing by more than 7 percent annually compared with health care's overall rate of more than 8 percent.²¹
- When adjusted for inflation, the dollar value of behavioral health benefits declined 54 percent, while the value of general health care benefits declined by 7 percent, between 1988 and 1997.²²
- As a percentage of the total health care benefit, behavioral health spending declined 50 percent over that time period – from 6.2 percent in 1988 to 3.1 percent in 1997.²²

While most insurance policies cover outpatient mental health benefits, few provide coverage equal to coverage for other illnesses. Most policies require higher deductibles and coinsurance payments for mental health services and impose annual visit limits (generally 30 inpatient days and 20 outpatient sessions). Employers often limit mental health benefits out of misplaced fear that the lack of arbitrary limits will cause unacceptable cost increases.

The Surgeon General asserts there is no scientific justification for treating mental and physical health differently; that diagnoses of mental disorders are as reliable as those for general medical disorders and that treatment is of well-documented efficacy.

In 1996, Congress passed the Mental Health Parity Act, barring larger private-sector health plans from imposing lower annual or lifetime *dollar* limits on mental health benefits than on other physical health benefits. However, the Act, which became effective on January 1, 1998, does not affect limits on inpatient days or outpatient visits, or on out-of-pocket expenses, such as deductibles or coinsurance. Health plans may also exempt themselves from compliance if they can prove retrospectively that parity compliance increased their health plan costs by more than 1%. The law "sunset" on September 30, 2001.

Experience under the Mental Health Parity Act is that cost increases due to parity are minimal. Only five health plans applied for the 1% cost exemption. However, the spirit of the law has been evaded through the replacement of dollar limits with limits on inpatient days and outpatient sessions. Legislation has been introduced in Congress to expand the Mental Health Parity Act to cover all aspects of the mental health benefit (H.R. 1515, Roukema; S. 796, Domenici).

Research suggests that the cost of providing parity increases premiums only slightly and saves money over the long term. A report to Congress from the National Institute of Mental Health (NIMH) concluded that treating mental disorders like physical disorders in a managed care plan may increase mental health costs by 1%, but these costs would be more than offset by corresponding decreases in total health costs.²³

Laws in 32 states also require parity for some populations and case studies of five states that had a parity law for at least a year revealed only a small

effect on premiums -- at most a change of a few percent, plus or minus. Further, employers did not attempt to avoid these laws by becoming self-insured or by passing on costs to employees.²³

Some businesses have removed mental health benefit limits and created cost savings by providing access to more appropriate services. However, without federal legislation to create a level playing field, arbitrary limits are unlikely to be removed from all plans.

Access To Services Through Managed Care Plans

Concern over the need for consumer protection in Medicaid and Medicare managed care plans led Congress to enact provisions in the Balanced Budget Act of 1997 which ban gag rules in provider-plan contracts, improve grievance procedures and internal and external appeals rights, and prohibit physician incentives that reduce medically necessary services. A Presidential Advisory Commission in late 1997 developed a Patients' Bill of Rights, which became the starting point for legislation affecting private sector health plans.

Congress is currently considering the extent to which federal legislation should set standards to protect consumers in managed care. The U.S. Senate passed the "Patients Bill of Rights Plus Act" (S. 1344) in July 1999 and the House passed a broader bill, the "Bipartisan Consensus Managed Care Improvement Act" (H.R. 2723, incorporated into H.R. 2990) in October 1999 after rejecting three less comprehensive substitutes. Many mental health advocates are calling for passage of a strong, enforceable federal bill with patient choice of provider, improved internal and external appeals processes, formulary/pharmacy protections and legal accountability of health plans. In particular, legal remedies should not exclude persons with solely a mental injury, as in some possible compromises. At this writing the conference to resolve the differences is underway.

Medicare, Medicaid and other Federal Programs

Combined, Medicare and Medicaid account for roughly one in three dollars spent on mental health services in the U.S.⁸ Unfortunately, spending on mental health services in these programs has decreased in relation to total program spending over the past decade.²¹

Medicare's antiquated benefit package limits the program's effectiveness in meeting the needs of enrollees with mental and emotional disorders. Medicare requires beneficiaries to pay 50 percent of the costs of outpatient mental health treatment, and only 20 percent of other outpatient services. Medicare also provides no coverage for services critical for individuals with serious mental illness, such as case management, psychiatric rehabilitation or medication costs, and imposes a discriminatory lifetime limit of 190 days of care in a psychiatric hospital. In addition, Medicare covers only a limited range of providers.

Federal Medicaid law requires that all covered children have access to all medically necessary services, through the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate. But many states do not adequately implement EPSDT nor do they require their managed care contractors to do so. For adults, Medicaid law permits states to cover a full array of the comprehensive community based services, but many states fail to adopt these options leaving their residents, particularly adults with serious mental illness, without access to evidence-based services such as targeted case management and psychiatric rehabilitation. Medicaid law prohibits reimbursement to psychiatric hospitals for non-elderly adults.

Significant Federal support for the delivery of mental health services is provided through other programs, especially those operated by the Substance Abuse and Mental Health Services Administration (SAMHSA) and its Center for Mental Health Services (CMHS). Key programs include the CMHS Mental Health Performance Partnership (a block grant to states), and the Title XX Social Services Block Grant programs. Other important CMHS programs, including the children's mental health program, the Projects for Assistance in Transition from Homelessness, the Protection and Advocacy for Individuals with Mental Illness program, and the Knowledge Development Application program also provide critical treatment and services for individuals with mental disorders.

SAMHSA, which is the lead federal agency devoted to the research and support of mental health and substance abuse treatment services, has not enjoyed significant funding increases similar to those taking place in other federal health agencies. Appropriate investments in these long neglected programs will not only help many individuals lead healthier and

more productive lives – and avoid many tragic deaths -- but will also help produce safer communities and reduced health and social service costs.

The Health Resources and Services Administration also has programs with important implications for the delivery of mental healthcare services, especially to underserved populations. The National Health Service Corps (NHSC) Loan Repayment Program pays educational loans of mental health professionals (psychologists, psychiatrists, clinical social workers, licensed professional counselors, marriage and family therapists and psychiatric nurses) in exchange for their providing mental healthcare services to the residents of federally-designated Mental Health Professional Shortage Areas. Reauthorizing the NHSC in 2000 and increasing the appropriation for the Loan Repayment Program will ensure an increase in the amount of mental health care available to the underserved.

State Mental Health Systems

State mental health authorities are responsible for caring for those individuals unable to access treatment through other means. State and local governments account for nearly one in five dollars spent on mental health services in the U.S. Here, too, the story is one of shrinking resources.

States have reduced spending (when adjusted for inflation and growth in population) on public mental health systems over the past decade, and continue to do so.²⁴ State mental health appropriations lost ground by 7% between 1990 and 1997 and have fallen significantly in relation to other state spending, including other health and welfare

spending.²⁴ State appropriations are actually less (in real dollars) than in 1955.²⁵ Inadequate funding leaves states unable to include newer, more effective medications in their formularies, and to provide adequate community-based care for those formerly cared for in institutions. Further, states have not effectively addressed the multitude of barriers facing persons with mental disorders living in rural and frontier areas.

In addition, the limited state resources available are not always well utilized. A lack of accountability and inefficiency is found in most public mental health systems. According to the federal Substance Abuse and Mental Health Services Administration, less than half of state systems can offer unduplicated counts of people served, and none can report details on the services provided, their frequency or outcome. Given widespread complaints about lack of services, this paucity of hard data is alarming. Anecdotal evidence in many states suggests systems in crisis. Recent press coverage in newspapers including the *Los Angeles Times*, *Atlanta Constitution*, *Arizona Republic*, *Hartford Courant*, *Tulsa World*, *Tallahassee Democrat*, *Raleigh News & Observer*, *Washington Post*, and *New York Times* has documented the inability of public mental health systems to meet demands.

What is needed is an accountable system of performance-based services, so that consumers and families are able to compare health plans, service systems, and treatment providers using reliable data. States should begin to develop systems to report on the number of persons in treatment, the services such persons receive, delays in access to services, treatment duration and costs of care.

Ensuring Quality of Care

Research

The 1999 U.S. Surgeon General's Report on Mental Health discussed the effectiveness of science-based treatments of mental disorders and concluded that the "nation has realized immense dividends from ...research focused on mental illness." The report underscores that effective treatments for mental disorders will come about only through sustained investment in basic research on the brain and behavior.

Research funded by the National Institutes of Health

(NIH) and particularly the National Institute of Mental Health (NIMH) has been instrumental in the development of treatments for mental illnesses. Many of these treatments are now as effective, if not more so, than treatments for general medical disorders. With accelerated research new, more efficacious (and cost effective) treatments, medications and prevention strategies can help millions more individuals.

In particular, gaps in our knowledge about children's mental health must be addressed, including an

assessment of the long-term effects of medication, behavioral therapies and their combination. Across almost all disorders, there is a great need for studies on the effects of treatments for girls and for children under the age of six. While there is a need for more information about specific interventions, there is also a need to understand more about childhood disorders within the context of family, peers, school, home and community. The development of early preventive interventions for young children at risk of developing later mental and behavioral disorders is another area where more research is greatly needed.

Increased federal support for research programs funded through NIMH is needed to ensure adequate progress in combating mental disorders, and developing effective interventions for use within various health care settings.

Use of Restraint and Seclusion in Psychiatric Settings

Reports of deaths following seclusion or restraint have been the focus of recent national attention. As a result, various governmental and private groups have moved forward to change standards for hospitals and non-hospital facilities with respect to the use of seclusion and restraint. Consensus has arisen that all standards should reflect best practice and emphasize that seclusion and restraint are emergency responses used only to protect the safety of patients and others and should never be used for convenience, discipline or in lieu of adequate staffing. These discussions have focused on common themes, especially the need for appropriate staff training, adequate staffing and accountability, and supervision and oversight by mental health professionals.

Up until now, there has been wide variability in rules and guidelines followed by general hospitals, psychiatric hospitals, nursing facilities, residential programs for children and other settings. In July 1999, the Health Care Financing Administration issued interim final rules governing the use of seclusion and restraint in hospitals participating in Medicare and Medicaid. HCFA is also developing federal standards on the use of seclusion and restraint for residential treatment facilities for children and other non-hospital facilities providing care to Medicaid recipients under age 21. These settings currently have no federal rules governing the use of restraint and seclusion. They must, however, meet national accreditation standards.

Congress has passed legislation setting standards for the use of seclusion and restraint and reporting requirements in medical and non-medical settings. In addition, organizations that accredit health care facilities, such as the Joint Commission on Accreditation of Healthcare Organizations, the Council on Accreditation for Children and Family Services and the Council on Accreditation of Rehabilitation Facilities, have revised their standards for the appropriate use of seclusion and restraint.

Privacy of Medical Records

Privacy of medical records is a foundation of effective mental health treatment. The Supreme Court held in the landmark *Jaffee v. Redmond* case that the mere threat of disclosure of such records undermined effective mental health treatment. Disclosures of patient records can therefore have a devastating effect, particularly for persons seeking and receiving mental health services. The continuing stigma and discrimination associated with mental health means that disclosure can have an affect not only on an individual's professional opportunities and family relationships, but also on the quality of health care. Today we face a privacy crisis regarding health records. For instance, in a recent survey, more than half of those surveyed were very concerned that people with mental illnesses, AIDS or drug and alcohol problems will avoid seeking care for fear of exposure.²⁶

On November 3, 1999 the U.S. Department of Health and Human Services (DHHS) published a proposed rule (expected to be finalized in 2000) to address the privacy of individually identifiable health information. While the proposed rule has some problems, it is considered a good first step by many mental health advocates, most particularly because it preserves from federal preemption stronger state privacy laws. Non-preemption of stronger state laws is considered by many advocates to be especially important with respect to sensitive medical information, such as mental health records.

Before the proposed rule is finalized, additional privacy protections should be added including making patient consent the foundation for any disclosures under the rule and providing stronger protections for other sensitive mental health information, including psychotherapy notes. Congress is considering legislation on the issue, but passage is not likely in 2000. Mental health

advocates continue to monitor federal issues relative to mental health privacy, both in the regulatory and the legislative arenas. Congress could expand upon

the DHHS rules by enacting a more comprehensive medical records privacy law.

Living With Mental and Emotional Disorders

Disability Benefits

Many people with serious mental and emotional disorders rely on federal disability programs for their income support and health insurance: (1) The Supplemental Security Income (SSI) program, which in most states qualifies recipients for Medicaid, and/or (2) Social Security Disability Insurance (SSDI) benefits which, after a 24-month waiting period, entitles recipients to Medicare. Although, SSI and SSDI were created with the assumption that people with disabilities could not work, improved treatment means that employment of people with disabilities is possible, and is often part of the recovery process.

The Ticket to Work and Work Incentives Improvement Act (1999) allows people with disabilities to enter the workforce while maintaining their health benefits. Consumers do not have to choose between health care coverage and a job. The law provides a gradual reduction of benefits as an individual's earnings increase. Such incentives to encourage savings and maintain employment should be encouraged and augmented.

Employment

Access to new and effective treatment and rehabilitation interventions including counseling, psychotherapy, medication therapy, rehabilitation, and better community health services have allowed people with disabilities to function in society, require fewer hospitalizations, and allow many to hold jobs and lead productive lives. However, unemployment among mentally ill people is about 85% – higher than for any other disability group. Much of this is associated with the stigma surrounding mental illness and to the lack of adequate and appropriate services. When treated, most people with mental illnesses are able to work, with the assistance of rehabilitation and job training services.

Federal and state-federal public vocational rehabilitation programs, including those operated under Social Security and the Department of Labor, have helped increase employment among people

with disabilities. Unfortunately, state vocational rehabilitation programs often focus primarily on individuals with less serious disabilities, who require the least resources to place successfully in employment. People with severe mental illnesses, in particular, do not fare well in these systems, because they frequently require intensive services over longer periods of time to obtain and maintain employment.

Vocational rehabilitation programs must be tailored to the special needs of individuals with mental disorders and other disabilities, and need built-in incentives to work for both consumers and employers. It is important that individuals with mental illnesses be allowed to re-enter programs if there is a re-occurrence of symptoms, and that consumers be able to receive assistance through the qualified provider of their choice. Incentives must be maintained and strengthened to encourage private providers to offer ongoing, flexible supports and services designed to keep individuals in jobs, rather than to simply offer pre-employment services. Specialized supportive programs such as transitional employment, "clubhouse" employment, and psychosocial rehabilitation allow those with severe mental illness to work and make successful contributions to society.

Education

The Individuals with Disabilities Act (IDEA) establishes the right of students with disabilities -- including children and youth with a mental disorder or with serious emotional disturbance – to receive a free and appropriate education. IDEA requires that school systems provide assessment, counseling, behavior management and specialized education and related services for students whose disabilities interfere with their education. Schools must develop an Individualized Education Program (IEP) for these students, which sets goals for meeting the child's needs and describes the services to be provided.

Services are to be provided in the least restrictive environment. Schools are the largest provider of mental health services to children.

A requirement that schools continue providing needed services to students who are expelled or suspended must be maintained. Unfortunately, legislation being considered by Congress would allow schools to expel certain students with disabilities without continuing services.

Housing

It is estimated that roughly one in three adult homeless people has a mental illness.²⁷ People with mental illness require access to a wide range of housing options in integrated community settings. These include independent living arrangements, supported living settings (apartments, single room occupancies, condominiums), and supervised living arrangements (group homes, halfway houses). Accessible community support services are needed to facilitate successful integration for these individuals into their communities.

Isolated anecdotes and stigma associated with mental illnesses have undermined the rights of people with disabilities regarding access to housing. The cost of housing is also a major barrier for people with disabilities, even in subsidized housing, which is

becoming limited. Benefits from the SSI program are often not adequate to meet even the reduced costs of supported housing, especially in urban areas; the average rent for a one bedroom apartment consumes 69 percent of the average monthly SSI benefit check, and in many urban markets, exceeds more than 100% of the SSI benefit. Increased funding for permanent housing programs like Section 8 and Shelter Plus Care can help address the issue of access and affordability.

There are other problems, as well. A 1992 law requires HUD to designate units as elderly only, and as a result 200,000 housing units for people with disabilities have been lost. Tenant-based vouchers for non-elderly people with disabilities have been proposed, but not adopted. Disincentives to work that are built in to many of the HUD public housing and Section 8 programs should be corrected to reward work rather than penalize those who do work. Several groups have urged the establishment of an “income disregard” policy, under which working people with disabilities in subsidized housing would be allowed to exclude a limited amount of their earnings from calculation of their monthly housing subsidy.

Adverse Consequences of Inadequate Treatment

Untreated mental and emotional disorders in adults and children leave them vulnerable to a number of adverse consequences stemming from behaviors that are the result of these disorders. In addition, system failures to address the needs of those with the most severe disorders exacerbate this problem considerably. One of the most troubling adverse consequences for individuals with untreated mental disorders is the risk of being the victim of violence. Despite media portrayals to the contrary, the overall likelihood of violence by individuals with mental disorders is low. To quote from the Surgeon General’s report, “The greatest risk of violence is from those who have dual diagnoses, i.e., individuals who have a mental disorder as well as a substance abuse disorder. There is a small elevation in risk of violence from individuals with severe mental disorders (e.g., psychosis), especially if they are noncompliant with their medication.”²⁸

Adults in the Criminal Justice System

One of the most tragic outcomes of the failure to provide adequate mental health services is the high

rate of arrest of individuals with serious mental illness who are frequently arrested for minor offenses, often crimes of survival as they struggle to live on the streets. A significant percentage of police-citizen encounters involve people with mental illness, and a 1991 survey of 1,401 families found that 40% of their family members with serious mental illness had been arrested at some point in their lives.²⁹ An estimated 16% of state and federal prison and local jail inmates have a mental illness.

This situation places a heavy toll on the criminal justice system: police encounters take a considerable amount of time and once in jail, people with serious mental illness have longer stays and can cause significant problems due to their mental illness.

Multiple factors lead to arrest of an adult with serious mental illness, including living in dire poverty and being unable to meet basic needs, lack of access to appropriate mental health treatment or lack of access to substance abuse treatment. According to a report from the Department of Justice, when compared with other inmates, individuals with

mental illness in jail are significantly more likely to be homeless, less likely to have been recently employed, more likely to have a history of alcohol dependence, more likely to have done poorly in school and to have grown up in foster care or with a substance-abusing parent or have been abused.³⁰

A number of communities have programs which divert persons with serious mental illness away from the criminal justice system and into services. These initiatives vary, from teams of police and mental health professionals who respond to emergency calls, to the training of judges (or appointment of special courts) so they can waive or suspend charges pending effective treatment. A federal demonstration of such diversion programs is also showing considerable promise and early success.

Children's Issues

Children and adolescents, like adults, can and do suffer from mental and emotional disorders. In the United States, one in five children and adolescents suffer from a disorder severe enough to cause some level of impairment.⁴ However, less than half of children with a diagnosable mental disorder receive treatment for their problems.⁵ Clearly, many children are not being identified or referred to the services they need.

Unlike adults, children's continuous physical, emotional and intellectual development can make it difficult to identify these disorders, and the multiple systems intended to assist children's successful development too often work at cross purposes in serving identified needs. What is called for is a coordinated system of care to provide necessary services based on individual assessment, regardless of whether the need is identified by a family member, teacher, police officer, child protection worker or health care professional. In the absence of such a system of care, children with mental and emotional disorders suffer the additional threats of suspension or expulsion from school without educational or treatment services, incarceration without assessment or treatment, and even removal from their parents' custody in order to access services.

Multiple issues must be considered to address problems of access. Families need to be able to access an expert in child behavior who can make a thorough assessment and diagnosis. Once a correct

diagnosis is made, families need access to the best treatment for their children.

Several bills are pending in Congress to encourage the development of programs which bring together criminal justice and service system agencies at the local level to identify and divert adults with serious mental illness from jail into appropriate community services. At issue is how much localities will have flexibility to design programs which best meet their needs. The Administration has also requested federal funds for criminal justice diversion programs, which would support a range of interventions and ensure appropriate community services are available to prevent persons with serious mental illness from entering the criminal justice system and to facilitate reintegration into the community of those who are released from jail or prison.

Juvenile Justice

Each year more than one million youth come in contact with the juvenile justice system, and more than 100,000 are placed in some type of correctional facility. Studies have consistently found high rates of mental and emotional disorders among the juvenile justice population: as many as 60-75% of incarcerated youth have a mental disorder, and 50% of youth have substance abuse problems.³¹ Many of these youths have committed minor, non-violent offenses or status offenses. Their incarceration is the result of multiple systemic problems, including inadequate mental health services and the move toward more punitive states laws regarding juvenile offenders.

One opportunity to move towards a coordinated system of care lies in the current conference to reconcile House and Senate versions of a juvenile justice bill. The legislation is a mixed bag. It includes provisions which are harmful to youth with serious emotional disturbances or mental illnesses, among them: amendments to the Individuals with Disabilities Education Act which eliminate the right to a free and appropriate public education for students with disabilities who violate school rules about weapons and permit expulsion without follow-up services; a requirement that judges use federal sentencing guidelines and mandatory minimum

sentences, depriving the courts of flexibility to take into account the child's mental illness or other factors such as home life; and allowing prosecutors to charge children as young as 14 as adults, currently a decision left to a judge's discretion.

On the other hand, the legislation includes provisions to encourage coordinated systems of care, including: cross-training of public mental health and substance abuse workers, law enforcement and court personnel on the appropriate use of community-based alternatives to institutional placements and appropriate linkages between probation programs and community mental health programs; assessments by qualified mental health professionals; individualized treatment plans and discharge plans; and coordination of mental health services among juvenile justice, mental health, substance abuse and other child-serving agencies.

Custody Relinquishment

Another legislative proposal currently before the Senate addresses an alarming incidence of custody relinquishment in order to access necessary services. Pending federal legislation, The Family Opportunity Act of 2000, would give states the option of permitting families with children with severe disabilities (including mental illness) with incomes up to 600% of poverty to buy into the Medicaid program. (S. 2274 Grassley/ H.R. 4825 Sessions). It also includes a provision to allow states to more easily apply for a home- and community-based Medicaid services waiver to provide a broader array of specialized services for children with mental disorders. This legislation addresses the tragic

circumstances which force some families whose children have serious mental illnesses to relinquish custody of their children to the state child welfare agency in order for these children to receive necessary health care services.

School Violence

Unaddressed mental and emotional disorders, emotional distress, and hopelessness can lead children and youth to harm themselves and each other.

Adequately meeting the mental health needs of children and youth can help reduce violence. At any given time, at least one in every five children and adolescents has a behavioral, emotional, or mental health problem, and at least half of the three million young people with a serious emotional disorder are not getting the help they need.

Congress has approved the Safe Schools-Healthy Students Initiative, run jointly by the Departments of Education, Health and Human Services, Justice, and Labor. In fiscal year 2000, more than \$100 million was made available to link services into comprehensive programs providing mental health services in schools and promoting violence prevention. The Center for Mental Health Services, within the Substance Abuse and Mental Health Services Administration, was appropriated \$78 million to implement youth anti-violence initiatives that provide communities with availability of preventive mental health services, which includes mental health professionals.

The Elderly

By the year 2010, there will be nearly 40 million people in the U.S. over the age of 65. Twenty percent of these people will experience mental disorders. Mental disorders are *not* part of the normal aging process. Stereotypes about aging (e.g., that senility, depression, and hopelessness are natural conditions of old age) can interfere with the diagnosis and treatment of mental disorders.

Older persons are often at increased risk of mental disorders due to a higher incidence of general medical conditions and psychosocial stressors such as bereavement and isolation. Substance misuse, especially alcohol, is another complicating factor. A

significant number of older adults with depression are neither identified nor treated in primary care. Depression can occur in up to 20% of older adults, and one of its consequences, suicide, has its highest rate in older adults relative to all other age groups.³²

Prevention of further disability due to a mental disorder is a primary goal of intervention, thus eliminating or postponing the need for costly institutional care. Studies have shown that a disabling mental status is often the seminal cause of physical ailments. Treatment strategies demonstrated to be effective include medication, psychotherapy, ECT (electro-convulsive therapy),

rehabilitation and caregiving training. Cognitive, behavioral and rehabilitative interventions are utilized as therapy as well as training and support of family and caregivers. Treatment must be sensitive

to special needs of older persons with regard to race, ethnicity and gender. As discussed above, mental health treatment of older persons is limited by restrictive payment policies under Medicare.

Co-Occurring Mental and Addictive Disorders

For the 3 percent of Americans (or roughly 8.25 million people) who have co-occurring mental and addictive disorders⁴, prevailing research confirms that integrated treatment for their mental illness and addiction is much more effective than attempting to treat each disorder separately.³³ Yet it is more common that individuals with co-occurring disorders receive sequential treatment (treating one disorder first, then the other) or parallel treatment (in which two different treatment providers at separate locations use separate treatment plans to treat each condition separately but at the same time), both of which are far less effective than integrated treatment.

According to the Surgeon General's report, the research shows that patients with dual disorders can be successfully rehabilitated from substance abuse disorders, and that integrated treatments are superior to nonintegrated treatments. Integrated treatment

means mental illness and addictive disorders services and interventions are delivered simultaneously at the same treatment site, ideally with cross-trained staff. However, according to the National Health Policy Forum, "Most professionals in each field have been trained to work only with individuals having a single disorder."³⁴

Federal agencies funding mental health and addictive disorder treatments are not currently promoting policies to facilitate the development and funding of integrated treatment programs for persons with co-occurring mental and addictive disorders. Specifically, there are administrative barriers that prevent states from blending their funds from the mental health and the substance abuse block grants to achieve this goal.

NOTES

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7. *Mental Health and Rural America: 1980-1993*, U.S. Department of Health and Human Services, National Institutes of Health, Bethesda, MD. 1994.
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14. *Mental Health: A Report of the Surgeon General*, 1999, p.146.
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16. Ibid, p. 75.
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28. Ibid, p. 7.
29. Steinwachs, D.M., et al., *Family Perspectives on Meeting the Needs for Care of Severely Mentally Ill Relatives: A National Survey*. Center on the Organization and Financing of Care for the Severely Mentally Ill, the Johns Hopkins University School of Hygiene and Public Health, Baltimore, MD. August, 1992.
30. *Mental Health and Treatment of Inmates and Probationers*, Bureau of Justice Statistics, U.S. Department of Justice, Washington, D.C. 1999.
31. Cocozza, J.J. (ed.) *Responding to Youth With Mental Disorders in the Juvenile Justice System*. Seattle, WA. The National Coalition for the Mentally Ill in the Criminal Justice System, 1992.
32. *Mental Health: A Report of the Surgeon General*, 1999, p. 342.
33. Ibid, p. 288.
34. Briefing paper, *Dual Diagnoses: the Challenge of Serving People with Concurrent Mental Illness and Substance Abuse Problems*. National Health Policy Forum, George Washington University, Washington, D.C.: April 14, 1998, page 7.

QUESTIONS FOR CANDIDATES

Please check the following initiatives that you support:

- ___ 1. Legislation expanding the number of Americans covered by private health insurance and/or various public programs.
- ___ 2. Expanding the Mental Health Parity Act of 1996 by prohibiting differential day and visit limits and out of pocket expenses while covering more individuals and health plans.
- ___ 3. Managed care reform legislation that improves quality by including a fair internal and external appeals process, appropriate access to specialists, out-of-formulary pharmacy access, and plan legal accountability in the event of physical or mental injury.
- ___ 4. Amending Medicare to cover existing mental health services at parity, include more providers and provide new benefits of prescription drugs, case management and psychiatric rehabilitation.
- ___ 5. Amending Medicaid to encourage states to cover the full array of effective services detailed in the Surgeon General's report, particularly targeted case management and psychiatric rehabilitation.
- ___ 6. Encouraging states to use the public mental health system more efficiently, including an unduplicated count of persons in the system, and the development of systems to report on services such persons receive, delays in access to services, lengths of time services are furnished and costs of care.
- ___ 7. Increasing funds for research to understand, prevent and treat mental disorders and to further our knowledge about the promotion and maintenance of mental health.
- ___ 8. Increasing the protections for mental health records prior to implementation of federal rules on medical records privacy, while permitting states to enact stronger laws.
- ___ 9. Amending SSI and SSDI to encourage more persons with severe mental illness to join the work force and ensure that consumers do not have to choose between health coverage and a job. And, like SSI, gradually reducing SSDI benefits for those entering the workforce.
- ___ 10. Expanding vocational rehabilitation opportunity by broadening the ticket to work program to benefit other individuals with severe mental illness, such as those who can work only part-time or those who are not on disability benefits. And, creation of a new program under the Rehabilitation Act to fund psychiatric rehab, supported employment and other non-time limited VR services to persons with severe mental illness.
- ___ 11. Promotion of independence through expansion of federal support for rental vouchers, group homes and other housing for persons with mental illness and the expansion of various housing options for persons who are homeless and have mental illness.

____ 12. Appropriating federal funds for diversion programs and ensuring availability of community services to prevent persons with serious mental illness from entering the criminal justice system and to facilitate reintegration into the community of those who are released from jail or prison.

____ 13. Opposing legislation which permits schools to expel or suspend a child with a disability for an unlimited period of time should that child carry a firearm to school, and ends the current requirement that schools provide a free and appropriate public education during a period of expulsion.

____ 14. Passage of juvenile justice legislation which includes assessment and treatment provisions, and does not limit the right to a free and appropriate education or limit the flexibility of the courts.

____ 15. Helping prevent family custody relinquishment of children with mental disorders by creating a new option for states to allow families to buy into Medicaid and by providing fiscal incentives so that more states apply for a Home & Community Based Waiver for expanded Medicaid coverage of a broader array of specialized services for children with mental disorders.

____ 16. Removing administrative barriers that prevent states from blending their funds from the mental health and substance abuse block grants, to better integrate treatment programs for persons with co-occurring mental and addictive disorders.

Comments _____

Candidate Name: _____

Signature: _____ *Date:* _____

Office Sought: _____

Please fax this questionnaire back to the MHLG at 202-362-5145 or mail it to: Mental Health Liaison Group, c/o Pat Johnston, NAPTCC, 1025 Connecticut Avenue, Suite 1012, Washington, DC 20036