State of Delaware Delaware Health Care Commission COMMITTEE ON MENTAL HEALTH ISSUES

FINAL REPORT TO THE DELAWARE HEALTH CARE COMMISSION



March, 2004

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*Mental Health – the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity; from early childhood until late life, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and selfesteem.

*Mental Illness – the term that refers collectively to all mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behaviors (or some combination thereof) associated with distress and/or impaired functioning.

^{*}Surgeon General's report on Mental Health

Roster of Committee Members

Mental Health Issues Committee

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Delaware Health Care Commission

Committee Members

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National Alliance for the Mentally Ill - DE

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UAW/Daimler Chrysler

Janis G. Chester, MD

Medical Society of Delaware Psychiatric Society of Delaware

Susan Cycyk

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Quality Insights of Delaware

Jacquelyne W. Gorum, DSW

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Delaware State Chamber of Commerce

Renata J. Henry

Division of Substance Abuse and Mental Health

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Mujib Obeidy, MD

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Delaware Department of Insurance

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Delaware Health Care Commission

Timothy Toole, LCSW

Blue Cross Blue Shield of Delaware

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Donna Lee Williams

Delaware Department of Insurance

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St. Jones Center for Behavioral Health

EXECUTIVE SUMMARY

Access to mental health services is an integral component of any comprehensive health care system. Recent increased focus on mental health issues and a growing sense of awareness that maintaining optimal mental health is essential for maintaining optimal overall health led the Delaware Health Care Commission to form a Mental Health Issues Committee to identify barriers to care in Delaware and recommend strategies to overcome those barriers.

Increased research and medical breakthroughs shed new light on mental health and mental disorders and allow discussion to occur in a new spirit of optimism.

This point was underscored in 1999 when the United States Surgeon General David Satcher issued the first ever surgeon general's report on mental health. *Mental Health: A Report of the Surgeon General* emphasized the importance of good mental health in the context of its inseparability from physical health. In July 2003, the importance of seeking mental health services was again underscored with the issuance of the President's New Freedom Commission on Mental Health. The report called for a transformation of mental health care in America.

ABOUT THE PROCESS

The Delaware Health Care Commission empanelled a committee of diverse professionals to explore the issues of access to mental health services in the state. The Committee's task was to *identify* key issues surrounding access to mental health services in Delaware, but not necessarily find the answers. The Committee preferred to articulate the key issues and offer them to the Commission and the citizens of Delaware. Solutions are complex and long-term in nature. Some of the issues are not limited to mental health conditions, but pervade the state and national health care system. Therefore the Committee opted to clearly and succinctly paint a picture of mental health services in Delaware.

The Committee formed four sub-committees to explore key themes in more detail:

- Treatment Protocols
- Data Gathering
- Employer Education
- Education and Training

KEY FINDINGS

General Findings

There are multiple and complex dimensions of mental health service delivery in Delaware and the nation.

The public continues to attach stigma to accessing mental health services.

As a result of stigma, many seek care from other primary care health practitioners.

Children and Mental Health Services

Children are particularly vulnerable when it comes to mental health services. Survey analyses from the American Journal of Psychiatry reveal that 79 percent of 6 - 17 years olds with a need for mental health services did not receive them in the past 12 months.

In Delaware, Medicaid eligible children and children without private insurance coverage receive mental health and substance abuse treatment services through the Department of Services for Children, Youth and Their Families, Division of Child Mental Health. The Division also operates the Terry Children's Psychiatric Center in Wilmington and Silver Lake Residential Treatment Center in Middletown. Currently, the Department contracts with eight providers who offer outpatient services in fourteen sites across the state. In 2003, the Division of Child Mental Health treated 2,183 children ages 3 to 17.

Schools also play a vital role in promoting good mental health. At present, school wellness centers are located in all but two high schools in Delaware. Thirty percent of the total 50,774 visits to wellness centers in 2002 were for mental health reasons.

The Division of Child Mental Health is currently working with the Department of Education on an innovative model, known as the Positive Behavior Support. The model promotes consistent school conduct schoolwide. Expected behavior is articulated and enforced consistently throughout the school. Delaware data indicate a reduction in behavior problems, referrals for time-out from the classroom, and out of school suspensions.

Adult Mental Health Services

The Division of Substance Abuse and Mental Health in the Department of Health & Social Services provides services for adults with mental health needs. The Division served 13,000 people in state fiscal year 2003.

The Division offers a range of outpatient services through clinics, substance abuse clinics, day treatments, counseling for gambling problems, crisis intervention. The Division is working on methods to reduce hospitalizations for mental health and substance abuse conditions.

The Division reports that maintaining an adequate health professional workforce supply is a challenge. Work is underway to explore having Delaware designated as a mental Health Professional Shortage Area (HPSA) by the federal Health Resources and Services Administration (HRSA).

Elderly and Mental Health

The elderly are besieged with mental health problems as well as children and adults. The problems are unique for this group because the elderly are less able to adapt to change as they age. Older adults with mental illness will increase from 4 million in 1970 to 15 million in 2030. Depression and dementia are common mental health disorders among the elderly population. The over 65 population has the highest rate of suicide of any age group.

Role of Primary Care Health Practitioners

Primary care health practitioners are usually the "front line" of mental health service providers. Approximately 70 percent of mental health services in the country are provided by primary care practitioners. Often, however, they do not receive sufficient training to identify when a physical symptom actually has an underlying emotional or mental cause.

RECOMMENDATIONS

The Mental Health Issues Committee identified key issues across all age groups arising from personal professional experience and presentations offered throughout the process, grouped the issues into key themes and identified four priority items. The four priority items were:

- 1. Data Gathering
- 2. Treatment Protocols
- 3. Training
- 4. Employer Education and Public Awareness

Data Gathering

The subcommittee identified a need for better data about mental health professionals in Delaware. Data can aid in better understanding the number, distribution and characteristics of mental health professionals in the state. Data gathering activities should address both the demand and the supply side of the scope of mental illness.

Recommendation – Data Gathering

Data gathering and analysis should be addressed with long-term and short-term strategies.

Short Term: The Delaware Health Care Commission coordinate a short term data collection activity, working in collaboration with the Department of Health & Social Services, the Department of Services for Children, Youth and Their Families and pertinent private organizations, such as the Medical Society of Delaware, Mental Health Association and the Delaware Chapter of the National Alliance for the Mentally Ill. Sources of funding for such a study must be identified first.

Action Step: Forward a copy of this report to the Delaware Health Care Commission with a request that it consider undertaking this recommendation.

Long Term: Include data collection and analysis of mental health professionals in discussions about possible roles and functions of an Area Health Education Center or a Health Professions Center. Discussions are currently underway within the Delaware Health Care Commission, the Delaware Institute of Medical Education and Research (DIMER) and the Academy of Medicine.

Action Step: Forward a copy of this report to the Delaware Health Care Commission and the Delaware Academy of Medicine and request that its contents be considered in the discussions about AHECS or a Health Professions Center.

Treatment Protocols

There is a wide disparity of how mental health conditions are treated. Collaboration among professionals often does not occur, and the public and private systems of care are fragmented.

Two key issues regarding treatment protocols are criteria for patients to access services and collaboration of care among specialists.

Criteria for patients to access services

There is no uniform definition of medical necessity, leading to a wide disparity over how mental conditions are treated from provider to provider and covered from insurance plan to insurance plan.

Recommendation: Criteria to access services

Develop standardized definition of "medical necessity," using a model developed by the American Medical Association.

Action Step: Forward a copy of this report to the Medical Society of Delaware for consideration of incorporating this into its Uniform Treatment Guidelines project.

Collaboration of care among specialists

Professionals often do not have complete information about their patients. Better information allows more comprehensive and collaborative clinical decision-making and reduces the potential for medical errors.

Recommendation: Collaboration of care among specialists

Support the work of the Delaware Health Care Commission's Delaware Health Information Network's clinical information sharing utility as a way to foster better clinical decision-making by providing physicians with real time information about a patient's medical history through the use of information technology.

Action Step: A copy of this report, once adopted, should be forwarded to the Board of Directors of the Delaware Health Information Network with a request that this be considered during the development of the clinical community information sharing utility.

Training

In some cases there is inadequate professional training or a shortage of professionals adequately trained to deal with people with complex conditions or severe mental disorders.

Recommendation: Training

Priority should be given to training front line health professionals to identify conditions that have an underlying mental health cause. Training about the special needs of some target populations could be included as part of continuing education.

Action Step: An ad hoc committee should be appointed to develop a plan and funding sources to implement training recommendations.

Employer Education and Public Awareness

It is necessary for employers to be aware of the financial and human toll of mental illness on the workplace. Disparities continue to exist among private health insurance plans over the extent to which mental health treatments are covered. Employers, as purchasers of health insurance, largely determine the extent to which any condition is covered. Currently both large and small employers are facing the largest increases in health insurance premiums in over a decade.

Nonetheless it is important to communicate the need for access to mental health services to employers. The National Comorbidity Study sponsored by the National Institutes of Health and published in June 2003 in the Journal of the American Medical Association estimates that more than 16 percent – as many as 35 million people suffer from depression severe enough to warrant treatment at some time in their lives. A second survey published in the same issue estimated that depression costs employers \$44 billion a year in lost productive time, eclipsing the \$31 billion lost because of illnesses in people who do not have depression.

Recommendation: Employer Education and Public Awareness

The Health Care Commission could promote and organize community forums with employers to focus on the importance of addressing mental health issues for employees.

Action Step: Form an ad hoc committee to develop a plan for a media campaign, including potential funding sources, and present the plan to the Commission. The campaign should include anti-stigma messages.

Implementation Activities

The members of the Mental Health Issues Committee strongly believe that this document should be a living document that outlines the key issues surrounding mental health services in Delaware. Periodic monitoring of activities undertaken as a result of this report should occur.

Recommendation: Implementation Activities

The Mental Health Issues Committee should meet within one year to report on progress in implementing the recommendations.

WHY MENTAL HEALTH?

Access to mental health services is an integral component of any comprehensive health care system. In recent years the Delaware Health Care Commission had addressed mental health issues in two contexts: (1) analyzing Delaware's mental health parity law enacted in 1998, and (2) analyzing the state's health professional workforce needs. Recent increased focus on mental health issues, and a growing sense of awareness that maintaining optimal mental health is essential for maintaining optimal overall health led the Commission to form a Mental Health Issues Committee to identify barriers to care in Delaware and recommend strategies to overcome those barriers.

This report is intentionally brief and designed to be in an easy to read format. Additional information abounds for the reader interested in learning more about mental health issues. A reference list at the end of this report lists some key sources of information, including sub-committee reports.

Increased research and medical breakthroughs shed new light on mental health and mental disorders and allow discussion to occur in a new spirit of optimism. Mental health professionals generally agree that failure to access appropriate, evidence-based mental health services and a fragmented delivery system lead to unnecessary and costly disability, homelessness, school failure, and incarceration.

This point was underscored in 1999 when the United States Surgeon General David Satcher issued the first ever surgeon general's report on mental health. *Mental Health: A Report of the Surgeon General* emphasized the importance of good mental health in the context of its inseparability from physical health. It focused on mental disorders as real health conditions, and emphasized that the efficacy of treatments is well documented. A range of treatments exists for most mental disorders. The report sought to confront a profound obstacle to public understanding – a centuries old artificial separation of mind and body.

In July 2003, the importance of seeking mental health services was again underscored with the issuance of the President's New Freedom Commission on Mental Health. The report called for a transformation of mental health care in America. In creating the commission, President Bush cited three obstacles preventing Americans with mental illness from getting the care they deserve:

- Stigma that surrounds mental illnesses
- Unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance
- The fragmented mental health service delivery system.

Citing the complexity and fragmentation of the existing mental health delivery system, the report called for the elimination of disparities in the delivery of services, early screening and assessment, greater use of information and technology, and accelerated research. Over-arching themes, however, were that services should be consumer and family driven, and that Americans must understand that mental health is essential to overall health.

These same themes were echoed throughout the deliberations of the Mental Health Issues Committee.

Mental Health Fast Facts

According to the President's New Freedom Commission on Mental Health:

In any given year, about 5-7 percent of adults have a serious mental illness.

About 5 - 9 percent of children have a serious emotional disturbance.

In 1997 the US spent more than \$1 trillion on health care; almost \$71 billion was on treating mental illness.

The annual economic indirect cost of mental illness is estimated to be \$79 billion. Of that approximately \$63 billion reflects loss of productivity as a result of the illness.

Mental Health expenditures are predominately publicly funded at 57%, while overall 46% of health care expenditures are publicly funded.

Between 1987 and 1997 mental health spending did not keep up with general health care because of declines in private spending under managed care and cutbacks in hospital expenditures.

According to the World Health Organization (WHO) suicide worldwide causes more deaths every year than homicide or war.

The WHO reports that mental illness ranks first in causing disability in the United States, Canada and Western Europe, above cancer and heart disease. Twenty-five percent of all disabilities are cause by mental illness.

In Delaware, according to the Mental Health Association in Delaware:

- Over 50,000 Delawareans suffer from depression and bipolar disorder each year
- Over 65,000 Delawareans have anxiety disorders each year
- Over 7000 Delawareans suffer from schizophrenia each year
- Only \(\frac{1}{4} \) to \(\frac{1}{3} \) seek treatment

A University of Delaware Community Needs Assessment Survey revealed:

- Health access and mental health treatment cited as the #1 community issue for Kent County
- Medical care and mental health care cited as the #1 community issue for Sussex County

The state Behavioral Risk Factor Surveillance Survey reported that 9.2% of respondents said they had emotional problems significant enough to disrupt daily lives.

The National Vital Statistics Report for 2000 and the Delaware Health Statistics Center - 1994-1998 report that:

- Nationally suicide was the 11th leading cause of death in the US and the 3rd leading cause in the 15-24 age group.
- In Delaware, from 1994 to 1998 suicide was the 2nd leading cause of death in the 15-24 age group (49 deaths) and the 5th leading cause of death in the 25-44 age group (179 deaths).

The Delaware Youth Behavioral Risk Factor Surveillance Survey 2001 revealed:

- 27% reported feeling sad or hopeless
- 16.3% contemplated suicide
- 12.1% had a suicide plan
- 7.1% attempted suicide
- 2.4% received medical attention for the attempt

ABOUT THE PROCESS

The Delaware Health Care Commission empanelled a committee of diverse professionals to explore the issues of access to mental health services in the state. The Committee's task was to *identify key issues* surrounding access to mental health services in Delaware and recommend possible strategies to address the issues. The Committee preferred to articulate the key issues and offer them to the Commission and the citizens of Delaware. Solutions are complex and long-term in nature. Some of the issues are not limited to mental health conditions, but pervade the state and national health care system. Therefore the Committee opted to clearly and succinctly paint a picture of mental health services in Delaware.

The Committee began the project with a "discovery phase" to assure that all pertinent issues were identified. Presentations from government, private sector professionals and education served to "round out" all members' general knowledge of the key issues surrounding mental health in Delaware. A list of presenters and topics covered can be found on page 30 of this report.

Based on the information provided, the committee formed four subcommittees to explore key themes in more detail:

- Treatment Protocols
- Data Gathering
- Employer Education
- Education and Training

The sub-committees presented their findings and recommendations, which have been synthesized into this report.

KEY FINDINGS

General Findings

- 1. There are multiple and complex dimensions of mental health service delivery in Delaware and the nation. It is important that services be delivered in a culturally appropriate manner. It is equally important to recognize the variation of the delivery of services along the life span. Services for children will be delivered and accessed differently than those for adolescents, adults and the elderly.
- **2.** The public continues to attach stigma with accessing mental health services. Many people believe that mental disorders are a type of behavior or character flaw, rather than a disease with a biological cause, and, often, a treatment. Research has revealed important new information about the workings of the brain, and the connection between the mind and the body. However, new evidence and facts about mental disorders are generally not publicized. Absent education, old myths and, therefore, stigma persist.

3. As a result of the stigma, many seek care from other primary care health providers.

Health professionals other that those who are specifically trained to deliver mental health care services are often the "front line" of contact for a patient in need of care. Many seek care with a primary care physician, or others. This is discussed in more detail under the heading "Role of primary care practitioners", page 18.

Children and Mental Health Services

Children are particularly vulnerable when it comes to mental health services. Survey analyses (American Journal of Psychiatry, 159:1548-555, 2002 – Variation by Ethnicity and Insurance Status) reveal that 79 percent of 6-17 year olds with a need for mental health services did not receive them in the past 12 months. Hispanic children are at greater risk, at 88 percent not receiving services. Hispanic adolescents have higher rates of suicidal thoughts, depression, anxiety and greater rates of dropping out of high school than non-Hispanics.

In Delaware, Medicaid eligible children and children without private insurance coverage receive mental health and substance abuse treatment services through the Department of Services for Children, Youth and Their

Families, Division of Child Mental Health. In addition the Department's Division of Family Services provides services to children who are abused or neglected, and the Division of Youth Rehabilitation Services provides services for children who have had an encounter with the court system. In all cases the children have experienced a severe emotional event, requiring specialized services.

Currently, the Department contracts with eight providers, who offer outpatient services in fourteen sites across the state. Crisis intervention services are offered as well. In 2003, the Division of Child Mental Health treated 2,183 children ages 3 to 17.

There are six residential treatment centers and one therapeutic home to serve children and adolescents. The Department has as a goal to move as many children as possible into community based treatment settings, per best practice, but there is insufficient capacity to accommodate the need.

Schools also play a vital role in promoting good mental health. At present school wellness centers are located in all but two high schools in Delaware. Five of the centers are mental health models and the center coordinator is a licensed clinical social worker. The remaining twenty-two are medical models, generally staffed by a physician's assistant or nurse practitioner. Thirty percent of the total 50,774 visits to wellness centers in 2002 were for mental health reasons. Eighty percent of the total school population was enrolled in school wellness centers.

In addition schools can help promote positive behavior by creating environments where expected behavior is consistent. The Division of Child Mental Health is currently working with the Department of Education on an innovative model, known as the Positive Behavior Support. The model promotes consistent school conduct school-wide. Expected behavior is articulated and enforced consistently throughout the school. Hence, the consequences of arriving late for class, or uncompleted assignments, as well as understanding of expected behavior when class begins is well known to the student, and consistently enforced, regardless of the teacher or the class. This model is now being used in 39 schools in all three counties; 20 have embraced the concept in 100% of their educational and management programs. National data shows that discipline problems diminish when this model is applied. Delaware data indicate a reduction in behavior problems, referrals for time-out from the classroom, and out of school suspensions. The

Division will encourage more schools to follow this path. The results are positive because they send consistent messages about appropriate behavior to children.

Adult Mental Health Services

The Division of Substance Abuse and Mental Health in the Department of Health & Social Services provides services for adults with mental health needs. Children who attain the age of 17 years and 6 months are transitioned from the Division of Child Mental Health to DSAMH.

The Division served 13,000 people in state fiscal year 2003. It is estimated that approximately 13,685 Delawareans have a Serious Mental Illness and another 15,250 have a serious persistent mental illness.

The Division offers a range of outpatient services through clinics, substance abuse clinics, day treatments, counseling for gambling problems, crisis intervention. Inpatient services are offered through a variety of means ranging from long-term care at the Delaware Psychiatric Center to acute care at Meadowood, Rockford Center and St. Jones Center to community based care in group homes and staffed apartments.

The Division is working on methods to reduce hospitalizations for mental health and substance abuse conditions. In state fiscal year 2003, 1180 indigent people were hospitalized, and another 1600 who had insurance coverage were involuntarily hospitalized. An on-going collaboration with Christiana Care Health System resulted in a crisis triage program to fast track people from the Wilmington Hospital Emergency Department into a special waiting room for triage and care placement. It is hoped that this program will reduce the need for inpatient care.

The Division reports that maintaining an adequate health professional workforce supply is a challenge. Work is underway to explore having Delaware designated as a mental Health Professional Shortage Area (HPSA) by the federal Health Resources and Services Administration (HRSA).

Elderly and Mental Health

The elderly are besieged with mental health problems as well as children. The problems are unique for this group because the elderly are less able to adapt to change as they age. Many of the problems among the elderly are a result of compounding losses – loss of job, of spouse, of independence.

In the US the over-65 population will increase from 20 million in 1970 to 69.4 million in 2030. Older adults with mental illness will increase from 4 million in 1970 to 15 million in 2030. About 16 percent of the over-65 population has a psychiatric disorder, and about 10 percent has dementia.

Depression and dementia are common mental health disorders among the elderly population. Depression often accompanies other diagnoses, such as hip fracture or cancer. The over 65 population has the highest rate of suicide of any age group. The rate for the over 85 population is twice the national average. One third of men saw their primary care physician in the week before completing the suicide.

Many of the elderly suffer from more than one chronic illness and typically have multiple attending physicians, each of whom prescribe medicines without knowing the full range of treatments for the patient. Drug interactions can be a serious problem, which complicates behavioral and physical health. Greater use of medications and health care services can also be associated with depression.

The state Division of Services for Aging and Adults with Physical Disabilities estimates that one-third of older persons who live in the community and need mental health services receive them. The Division has also identified an unmet need for mental health services in nursing homes.

Role of Primary Care Practitioners

Primary care practitioners are usually the "front line" of mental health service providers. Approximately 70 percent of mental health services in the country are provided by primary care practitioners. Often, however, they do not receive sufficient training to identify when a physical symptom actually has an underlying emotional or mental cause. According to work completed by Commission member Joseph A. Lieberman, III, MD, MPH, author of the book *The Fifteen Minute Hour – Practical Therapeutic Interventions in Primary Care*, it is common for primary care physicians to encounter patients who present with ailments for which there is no physical pathology.

In approximately 50 of every 100 visits to a primary care physician, these conditions will be identified as ones with no physical pathology. Of those 50, about 35 will eventually be identified as having a mental disorder as the underlying condition giving rise to the visit. However, primary care physicians are disproportionately trained to cure physical illness, and may not be prepared to address the patient's real underlying problem.

As mentioned above, this similar pattern occurs within the state's school wellness centers, which report that 30% of visits are for a mental health issue.

RECOMMENDATIONS

The Mental Health Issues Committee identified key issues arising from personal professional experience and presentations offered throughout the process, grouped the issues into key themes and identified four priority items. The Committee formed four sub-committees for the purpose of more clearly defining the areas of need and developing recommendations for each. The four priority items were:

- 1. Data Gathering
- 2. Treatment Protocols
- 3. Training
- 4. Employer Education and Public Awareness

Data Gathering

The subcommittee identified a need for better data about mental health professionals in Delaware. Data can aid in better understanding the number, distribution and characteristics of mental health professionals in the state. Data gathering activities should address both the demand and the supply side of the scope of mental illness. Demand data is necessary to determine current and projected need for Delawareans to access mental health services, a critical component to determining provider supply requirements.

Key questions include:

Is there a mental health professional shortage? Some statistics might suggest that there is not, but family practice physicians, and others report a severe need for more mental health services. In some instances it appears as though there may be a mal-distribution of professionals. The extent to which young people are pursuing careers in mental health professions is unclear, and there is only anecdotal information about whether existing professionals are dropping out.

In what settings do professionals practice? How many accept insurance? There is suspicion that, of the professionals who do practice, some limit the types of patients they will accept either by diagnosis or by insurance coverage. Many may not treat people with substance abuse problems, while others may opt to accept only private pay patients.

Is there cultural diversity among mental health professionals? In order to be effective mental health services must be delivered in culturally appropriate ways. In addition, there may be a need for greater diversity among mental health professionals.

Recommendation – Data Gathering

Data gathering and analysis should be addressed with long- term and short-term strategies.

Short Term: The Delaware Health Care Commission could coordinate a short term data collection activity, working in collaboration with the Department of Health & Social Services, the Department of Services for Children, Youth and Their Families and pertinent private organizations, such as the Medical Society of Delaware, Mental Health Association and the Delaware Chapter of the National Alliance for the Mentally Ill, National Association of Social Workers and many other pertinent organizations. Sources of funding for such a study must be identified first. Potential sources include private grants and federal funds.

Action Step: Forward a copy of the report to the Delaware Health Care Commission with a request that it consider undertaking this recommendation.

Long Term: The Delaware Health Care Commission, the Delaware Institute of Medical Education and Research (DIMER) and the Academy of Medicine have begun discussions about comprehensive state-wide data gathering and analysis activities regarding the state health professional supply and needs. Discussions have only begun, but among ideas under exploration are the formation of a Health Professions Center, and the formation of an Area Health Education Center (AHEC). The activities, structure, governance and financing of any future AHEC or a Health Professions Center, have not yet been identified. However, should any comprehensive data collection and analysis on the composition and distribution of the health professions occur, it would be logical to include data collection about the state's mental health professional needs.

Action Step: Forward a copy of this report to the Delaware Health Care Commission and the Delaware Academy of Medicine and request that its contents be considered in the discussions about AHECS or a Health Professions Center.

Treatment Protocols

There is a wide disparity of how mental health conditions are treated. Collaboration among professionals often does not occur, and the public and private systems of care are fragmented.

Key issues surrounding treatment protocols are:

• Criteria for patients to access services

There is no uniform definition of medical necessity, leading to a wide disparity over how mental conditions are treated and covered from insurance plan to insurance plan. The result is confusion among providers faced with a complex set of guidelines over how to treat a patient, and disparity in coverage levels, depending upon the insurance plan. Uniform definitions based upon best medical evidence would reduce wasted time spent on administrative issues and promote better treatment of patients.

Recommendation: Criteria to access services

Develop standardized definition of "medical necessity," using a model developed by the American Medical Association. This should supercede other "risk of harm" definitions commonly used. "Risk of harm" is a commonly used psychiatric term, sometimes adopted by insurance companies as criteria for access to mental health services.

The Medical Society of Delaware has successfully developed uniform treatment guidelines for other diseases, working in collaboration with key insurance companies. The Uniform Treatment Guidelines project is a logical resource, and implementation of this recommendation could be referred to that organization. Any such activity would need to be completed in collaboration with the Psychiatric Society, Department of Health & Social Services and the Department of Services for Children, Youth and Their Families to allow for seamless movement from state funded programs, such as Medicaid, to private payers.

Action Step: Forward a copy of this report to the Medical Society of Delaware for consideration of incorporating this into its Uniform Treatment Guidelines project.

• Collaboration of care among specialists

Professionals often do not have complete information about their patients. This is particularly important for patients with mental disorders, as they are likely to have more than one specialist. Better information allows more comprehensive and collaborative clinical decision-making and reduces the potential for medical errors, duplicate tests or procedures and prescriptions that may counter-act each other.

For maximum effectiveness collaboration should expand beyond care among specialists, however. It should be emphasized and promoted among multiple settings, and include both the public and the private sectors.

Recommendation: Collaboration of care among specialists

The Delaware Health Care Commission, under the Delaware Health Information Network (DHIN), has launched a statewide clinical information-sharing project that will aim to foster better clinical decision-making by providing physicians with real time information about a patient's medical history through the use of information technology. The DHIN project has recently completed a demonstration phase, and is beginning design work and fundraising activities. Implementation of this recommendation could fall under the work currently underway within the DHIN.

Action Step: A copy of this report, once adopted, should be forwarded to the Board of Directors of the Delaware Health Information Network with a request that this be considered during the development of the clinical community information sharing utility.

Training

In some cases there is inadequate professional training or shortage of professionals adequately trained to deal with people with complex conditions or severe mental disorders. For example, people with multiple diagnoses and the developmentally disabled present unique challenges for health professionals, who often lack the comprehensive training necessary to allow optimal treatment protocols.

Some level of training currently takes place within the Department of Health & Social Services and the Department of Services for Children Youth and Their Families. However, with more training, professionals could better serve their clients and patients.

Since many people with mental disorders first seek treatment in a primary care setting, better training of front line workers could aid in spotting an underlying mental health condition and referring patients to appropriate services.

Recommendations: Training

Priority should be given to training front line health professionals to identify conditions that have an underlying mental health cause. These workers are usually the first line of defense, and include a wide variety of professionals, from day care workers, educators, parents, foster families as well as counselors and primary care physicians.

Training about the special needs of some target populations should be included as part of the continuing education. Professional licensure agencies may want to consider this

Action step: An ad hoc committee should be appointed to develop a plan and funding sources to implement training recommendations.

Employer Education and Public Awareness

It is necessary for employers to be aware of the financial and human toll of mental illness on the workplace. Other health conditions, such as diabetes, have received focused attention, but mental health has not. The stigma associated with mental disorders and the shame often associated with seeking treatment continue to prevent employers and the public from embracing mental health services the same way they do physical health services.

Disparities continue to exist among private health insurance plans over the extent to which mental health treatments are covered. Employers, as purchasers of health insurance, largely determine the extent to which any condition is covered. Large employers typically do not purchase commercial insurance, but, rather, pay for services directly, i.e. self-insurance. They contract with an insurance company to administer the plan. Coverage decisions remain with the employer and employees are not covered by true insurance, since there is no pooling of risk. Furthermore, self-insured plans are governed by the federal Employee Retirement Income Security Act (ERISA) and are not regulated by the Delaware Department of Insurance. Small to medium sized businesses typically purchase group health insurance

on the private market. Currently both large and small employers are facing the largest increases in health insurance premiums in over a decade. A Center for Studying Health System Change analysis revealed that from January – June 2003, health spending on all services increased by 8.5 percent, while the Gross Domestic Product increased by 2.9%.

Mental health parity laws offer an appealing solution, but laws regulating insurance have very limited impact in Delaware since the single largest group of residents fall into the ERISA regulated category. (Delaware Health Care Commission report "Delawareans without Health Insurance – 2002", prepared by the University of Delaware's Center for Applied Demography and Survey Research) Delaware enacted a mental health parity law for serious mental illnesses in 1998, which became effective in January 1999. In 2001 the Commission sponsored an analysis of the law. The study, completed by Mercer Consulting revealed that health insurance premiums increased less than 0.3 percent of total medical claims. However, the report cautioned that the analysis was based on only one year of data. In addition the report cited managed care as one of the key factors keeping premiums down and pointed out that the analysis did not address the impact in a managed versus unmanaged environment. A prime contributor to the rise in health insurance premiums is the retreat from tightly managed care, as cited by the Center for Studying Health System Change. These factors suggest that employer education is essential. However it must be recognized that it will be challenging in the current environment. It will be necessary to make the business case for adequate mental health coverage.

Nonetheless it is important to communicate the need for access to mental health services to employers. The National Comorbidity Study sponsored by the National Institutes of Health and published in June 2003 in the Journal of the American Medical Association estimates that more the 16 percent – as many as 35 million people suffer from depression severe enough to warrant treatment at some time in their lives. A second survey published in the same issue estimated that depression costs employers \$44 billion a year in lost productive time, eclipsing the \$31 billion lost because of illnesses in people who do not have depression. Much of the lost time is when workers are actually present on the job, but not functioning at full capacity.

Recommendations: Employer Education and Public Awareness

The Health Care Commission could promote and organize community forums with employers to focus on the importance of addressing mental health issues for employees. Increased awareness could result in better access to services, improved care and a more productive workforce.

A full media campaign should be developed to draw attention to the need to address a variety of mental disorders. Among key messages should be that there is no shame in seeking treatment for oneself or one's family or friends. The President's New Freedom Commission on Mental Health's report set forth a vision of a transformed mental health system that focuses on recovery, and eliminates stigma. The report says:

Because recovery will be the common, recognized outcome of mental health services, the stigma surrounding mental illness will be reduced, reinforcing the hope of recovery for every individual with a mental illness

As more individuals seek help and share their stories with friends and relatives, compassion will be the response, not ridicule.

Action Step: Form an ad hoc committee to develop a plan for a media campaign, including potential funding sources, and present the plan to the Commission. The campaign should include anti-stigma messages.

Implementation Activities

The members of the Mental Health Issues Committee strongly believe that this document should be a living document that outlines the key issues surrounding mental health services in Delaware. It offers a roadmap to finding solutions and offering the hope of treatment for the 100,000+ Delawareans who suffer from a mental disorder. As such, periodic monitoring of activities undertaken as a result of this report should occur. In addition to reporting on progress, periodic monitoring offers the opportunity to share new ideas and updates on mental health issues in the state.

Recommendation: Implementation Activities

The Mental Health Issues Committee should meet within one year to report on progress in implementing the recommendations.

SUMMARY OF KEY RECOMMENDATIONS

DATA GATHERING

Recommendations:

Short Term: The Delaware Health Care Commission coordinate a short term data collection activity, working in collaboration with the Department of Health & Social Services, the Department of Services for Children, Youth and Their Families and pertinent private organizations, such as the Medical Society of Delaware, Mental Health Association and the Delaware Chapter of the National Alliance for the Mentally Ill. Sources of funding for such a study must be identified first.

Long Term: Include data collection and analysis of mental health professionals in discussions about possible roles and functions of an Area Health Education Center or a Health Professions Center. Discussions are currently underway within the Delaware Health Care Commission, the Delaware Institute of Medical Education and Research (DIMER) and the Academy of Medicine.

TREATMENT PROTOCOLS

Recommendation: Develop standardized definition of "medical necessity," using a model developed by the American Medical Association. Refer specific activity to the Medical Society of Delaware's Uniform Treatment Guidelines Project.

Promote collaboration of care among specialists through the Delaware Health Care Commission, Delaware Health Information Network (DHIN), statewide clinical information-sharing project.

TRAINING

Recommendation: Form an ad hoc committee to develop a plan and funding resources to promote training of front line health professionals to identify mental health conditions and cross-training of existing professionals through the professional licensing system.

EMPLOYER EDUCATION AND PUBLIC AWARENESS

Recommendation: Form an ad hoc committee to develop a plan for a media campaign, including potential funding sources, and present the plan to the Commission.

IMPLEMENTATION

Recommendation: The Mental Health Issues Committee should meet within one year to report on progress in implementing the recommendations.

List of Presenters

List of Presenters

Date:	Presentation:	By:
06/23/03	Mental Health in Delaware	James Lafferty Mental Health Association
	The Profession of Licensed Clinical Social Workers	Gail Levinson Clinical Social Work Society of Delaware
07/29/03	The Public Mental Health System: Children and Adolescents	Susan Cycyk Division of Child Mental Health Services
	School Wellness Centers	Gloria James Division of Public Health
	The Public Mental Health System: Adults	Renata Henry Division of Substance Abuse and Mental Health
10/28/03	Geriatric Mental Health	Sandra McNinch Division of Services for Aging and Adults with Physical Disabilities
12/18/03	Psychiatric Physician Supply	Harold Rosen, MD Sr. VP for Medical Affairs Christiana Care Health System & Chair of the Medical Society of Delaware Mental Health and Substance Abuse Committee

Executive Summary –

Presidents New Freedom Commission on Mental Health

President's New Freedom Commission on Mental Health

Achieving the Promise: Transforming Mental Health Care in America

Executive Summary

Vision Statement

We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports - essentials for living, working, learning, and participating fully in the community.

In February 2001, President George W. Bush announced his New Freedom Initiative to promote increased access to educational and employment opportunities for people with disabilities. The Initiative also promotes increased access to assistive and universally designed technologies and full access to community life. Not since the Americans with Disabilities Act (ADA) - the landmark legislation providing protections against discrimination - and the Supreme Court's Olmstead v. L.C. decision, which affirmed the right to live in community settings, has there been cause for such promise and opportunity for full community participation for all people with disabilities, including those with psychiatric disabilities.

On April 29, 2002, the President identified three obstacles preventing Americans with mental illnesses from getting the excellent care they deserve:

- Stigma that surrounds mental illnesses,
- Unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance, and
- The fragmented mental health service delivery system.

The President's New Freedom Commission on Mental Health (called *the Commission* in this report) is a key component of the New Freedom Initiative. The President launched the Commission to address the problems in the current mental health service delivery system that allow Americans to fall through the system's cracks.

In his charge to the Commission, the President directed its members to study the problems and gaps in the mental health system and make concrete recommendations for immediate improvements that the Federal government, State governments, local agencies, as well as public and private health care providers, can implement. Executive Order 13263 detailed the instructions to the Commission. (*See the Appendix*.)

The Commission's findings confirm that there are unmet needs and that many barriers impede care for people with mental illnesses. Mental illnesses are shockingly common; they affect almost every American family. It can happen to a child, a brother, a grandparent, or a co-worker. It can happen to someone from any background - African American, Alaska Native, Asian American, Hispanic American, Native American, Pacific Islander, or White American. It can occur at any stage of life, from childhood to old age. No community is unaffected by mental illnesses; no school or workplace is untouched.

In any given year, about 5% to 7% of adults have a serious mental illness, according to several nationally representative studies. ¹⁻³ A similar percentage of children - about 5% to 9% - have a serious emotional disturbance. These figures mean that millions of adults and children are disabled by mental illnesses every year. ^{1; 4}

President Bush said,

"... Americans must understand and send this message: mental disability is not a scandal - it is an illness. And like physical illness, it is treatable, especially when the treatment comes early."

Over the years, science has broadened our knowledge about mental health and illnesses, showing the potential to improve the way in which mental health care is provided. The U.S. Department of Health and Human Services (HHS) released *Mental Health: A Report of the Surgeon General*, which reviewed scientific advances in our understanding of mental health and mental illnesses. However, despite substantial investments that have enormously increased the scientific knowledge base and have led to developing many effective treatments, many Americans are not benefiting from these investments. 7

Far too often, treatments and services that are based on rigorous clinical research languish for years rather than being used effectively at the earliest opportunity. For instance, according to the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the

lag between discovering effective forms of treatment and incorporating them into routine patient care is unnecessarily long, lasting about 15 to 20 years.8

In its report, the Institute of Medicine (IOM) described a strategy to improve the quality of health care during the coming decade, including priority areas for refinement. These documents, along with other recent publications and research findings, provide insight into the importance of mental heath, particularly as it relates to overall health.

In this Final Report...

Adults with a serious mental illness are persons age 18 and over, who currently or at any time during the past year, have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R (Diagnostic and Statistical Manual for Mental Disorders)¹⁰, that has resulted in functional impairment^b which substantially interferes with or limits one or more major life activities.

A serious emotional disturbance is defined as a mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-III-R that results in functional impairment that substantially interferes with or limits one or more major life activities in an individual up to 18 years of age. Examples of functional impairment that adversely affect educational performance include an inability to learn that cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems.¹¹

Mental Illnesses Presents Serious Health Challenges

Mental illnesses rank first among illnesses that cause disability in the United States, Canada, and Western Europe. 12 This serious public health challenge is under-recognized as a public health burden. In addition, one of the most distressing and preventable consequences of undiagnosed, untreated, or under-treated mental illnesses is suicide. The World Health Organization (WHO) recently reported that suicide worldwide causes more deaths every year than homicide or war . 13

In addition to the tragedy of lost lives, mental illnesses come with a devastatingly high financial cost. In the U.S., the annual economic, indirect cost of mental illnesses is estimated to be \$79 billion. Most of that amount -approximately \$63 billion - reflects the loss of productivity as a result of illnesses. But indirect costs also include almost \$12 billion in mortality costs (lost productivity resulting from premature death) and almost \$4 billion in

productivity losses for incarcerated individuals and for the time of those who provide family care. 14

In 1997, the latest year comparable data are available, the United States spent more than \$1 trillion on health care, including almost \$71 billion on treating mental illnesses. Mental health expenditures are predominantly publicly funded at 57%, compared to 46% of overall health care expenditures. Between 1987 and 1997, mental health spending did not keep pace with general health care because of declines in private health spending under managed care and cutbacks in hospital expenditures. ¹⁵

In 1997, the United States spent more than \$1 trillion on health care, including almost \$71 billion on treating mental illnesses.

The Current Mental Health System Is Complex

In its *Interim Report to the President*, the Commission declared, "... the mental health delivery system is fragmented and in disarray ... lead[ing] to unnecessary and costly disability, homelessness, school failure and incarceration." The report described the extent of unmet needs and barriers to care, including:

- Fragmentation and gaps in care for children,
- Fragmentation and gaps in care for adults with serious mental illnesses,
- High unemployment and disability for people with serious mental illnesses,
- Lack of care for older adults with mental illnesses, and
- Lack of national priority for mental health and suicide prevention.

The *Interim Report* concluded that the system is not oriented to the single most important goal of the people it serves - the hope of recovery. State-of-the-art treatments, based on decades of research, are not being transferred from research to community settings. In many communities, access to quality care is poor, resulting in wasted resources and lost opportunities for recovery. More individuals could recover from even the most serious mental illnesses if they had access in their communities to treatment and supports that are tailored to their needs.

The Commission recognizes that thousands of dedicated, caring, skilled providers staff and manage the service delivery system. The Commission does not attribute the shortcomings and failings of the contemporary system to a lack of professionalism or compassion of

mental health care workers. Rather, problems derive principally from the manner in which the Nation's community-based mental health system has evolved over the past four to five decades. In short, the Nation must replace unnecessary institutional care with efficient, effective community services that people can count on. It needs to integrate programs that are fragmented across levels of government and among many agencies.

Building on the research literature and comments from more than 2,300 consumers, family members, providers, administrators, researchers, government officials, and others who provided valuable insight into the way mental health care is delivered, after its yearlong study, the Commission concludes that traditional reform measures are not enough to meet the expectations of consumers and families.

To improve access to quality care and services, the Commission recommends fundamentally transforming how mental health care is delivered in America. The goals of this fundamental change are clear and align with the direction that the President established.

To improve access to quality care and services, the Commission recommends fundamentally transforming how mental health care is delivered in America. *The Goal of a Transformed System: Recovery*

To achieve the promise of community living for everyone, new service delivery patterns and incentives must ensure that every American has easy and continuous access to the most current treatments and best support services. Advances in research, technology, and our understanding of how to treat mental illnesses provide powerful means to transform the system. In a transformed system, consumers and family members will have access to timely and accurate information that promotes learning, self-monitoring, and accountability. Health care providers will rely on up-to-date knowledge to provide optimum care for the best outcomes.

When a serious mental illness or a serious emotional disturbance is first diagnosed, the health care provider - in full partnership with consumers and families - will develop an individualized plan of care for managing the illness. This partnership of personalized care means basically choosing *who*, *what*, and *how* appropriate health care will be provided:

- Choosing which mental health care professionals are on the team,
- Sharing in decision making, and
- Having the option to agree or disagree with the treatment plan.

The highest quality of care and information will be available to consumers and families, regardless of their race, gender, ethnicity, language, age, or place of residence. Because recovery will be the common, recognized outcome of mental health services, the stigma surrounding mental illnesses will be reduced, reinforcing the hope of recovery for every individual with a mental illness.

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Stigma refers to a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses. Stigma is widespread in the United States and other Western nations. Stigma leads others to avoid living, socializing, or working with, renting to, or employing people with mental disorders - especially severe disorders, such as schizophrenia. It leads to low self-esteem, isolation, and hopelessness. It deters the public from seeking and wanting to pay for care. Responding to stigma, people with mental health problems internalize public attitudes and become so embarrassed or ashamed that they often conceal symptoms and fail to seek treatment.

As more individuals seek help and share their stories with friends and relatives, compassion will be the response, not ridicule.

Successfully transforming the mental health service delivery system rests on two principles:

- First, services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers - not oriented to the requirements of bureaucracies.
- Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience, not just on managing symptoms.

Built around consumers' needs, the system must be seamless and convenient.

In this Final Report...

Recovery refers to the process in which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms. Science has shown that having hope plays an integral role in an individual's recovery.

Resilience means the personal and community qualities that enable us to rebound from adversity, trauma, tragedy, threats, or other stresses - and to go on with life with a sense of mastery, competence, and hope. We now understand from research that resilience is fostered by a positive childhood and includes positive individual traits, such as optimism, good problem-solving skills, and treatments. Closely-knit communities and neighborhoods are also resilient, providing supports for their members.

Transforming the system so that it will be both consumer and family centered and recovery-oriented in its care and services presents invigorating challenges. Incentives must change to encourage continuous improvement in agencies that provide care. New, relevant research findings must be systematically conveyed to front-line providers so that they can be applied to practice quickly. Innovative strategies must inform researchers of the unanswered questions of consumers, families, and providers. Research and treatment must recognize both the commonalities and the differences among Americans and must offer approaches that are sensitive to our diversity. Treatment and services that are based on proven effectiveness and consumer preference - not just on tradition or outmoded regulations - must be the basis for reimbursements.

The Nation must invest in the infrastructure to support emerging technologies and integrate them into the system of care. This new technology will enable consumers to collaborate with service providers, assume an active role in managing their illnesses, and move more quickly toward recovery.

The Commission identified the following six goals as the foundation for transforming mental health care in America. The goals are intertwined. No single step can achieve the fundamental restructuring that is needed to transform the mental health care delivery system.

Goals: In a transformed Mental Health System ...

Goal 1	Americans Understand that Mental Health Is Essential to Overall Health.
Goal 2	Mental Health Care Is Consumer and Family Driven.

Goal 3	Disparities in Mental Health Services Are Eliminated.
Goal 4	Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.
Goal 5	Excellent Mental Health Care Is Delivered and Research Is Accelerated.
Goal 6	Technology Is Used to Access Mental Health Care and Information.

Achieving these goals will transform mental health care in America.

The following section of this report gives an overview of each goal of the transformed system, as well as the Commission's recommendations for moving the Nation toward achieving it. In the remainder of this report, the Commission discusses each goal in depth, showcasing model programs to illustrate the goal in practice and providing specific recommendations needed to transform the mental health system in America.

Goal 1 - Americans Understand that Mental Health Is Essential to Overall Health

In a transformed mental health system, Americans will seek mental health care when they need it - with the same confidence that they seek treatment for other health problems. As a Nation, we will take action to ensure our health and well being through learning, self-monitoring, and accountability. We will continue to learn how to achieve and sustain our mental health.

The stigma that surrounds mental illnesses and seeking care for mental illnesses will be reduced or eliminated as a barrier. National education initiatives will shatter the misconceptions about mental illnesses, thus helping more Americans understand the facts and making them more willing to seek help for mental health problems. Education campaigns will also target specific audiences, including:

- Rural Americans who may have had little exposure to the mental health service system,
- Racial and ethnic minority groups who may hesitate to seek treatment in the current system, and
- People whose primary language is not English.

When people have a personal understanding of the facts, they will be less likely to stigmatize mental illnesses and more likely to seek help for mental health problems. The actions of reducing stigma, increasing awareness, and encouraging treatment will create a positive cycle that leads to a healthier population. As a Nation, we will also understand that good mental health can have a positive impact on the course of other illnesses, such as cancer, heart disease, and diabetes.

Improving services for individuals with mental illnesses will require paying close attention to how mental health care and general medical care systems work together. While mental health and physical health are clearly connected, the transformed system will provide collaborative care to bridge the gap that now exists.

Effective mental health treatments will be more readily available for most common mental disorders and will be better used in primary care settings. Primary care providers will have the necessary time, training, and resources to appropriately treat mental health problems. Informed consumers of mental health service will learn to recognize and identify their symptoms and will seek care without the fear of being disrespected or stigmatized. Older adults, children and adolescents, individuals from ethnic minority groups, and uninsured or low-income patients who are treated in public health care settings will receive care for mental disorders.

Understanding that mental health is essential to overall health is fundamental for establishing a health system that treats mental illnesses with the same urgency as it treats physical illnesses.

The transformed mental health system will rely on multiple sources of financing with the flexibility to pay for effective mental health treatments and services. This is a basic principle for a recovery-oriented system of care.

To aid in transforming the mental health system, the Commission makes two recommendations:

- 1.1 Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.
- 1.2 Address mental health with the same urgency as physical health.

Goal 2 - Mental Health Care Is Consumer and Family Driven

In a transformed mental health system, a diagnosis of a serious mental illness or a serious emotional disturbance will set in motion a well-planned, coordinated array of services and treatments defined in a single plan of care. This detailed roadmap - a personalized, highly individualized health

management program - will help lead the way to appropriate treatment and supports that are oriented toward recovery and resilience. Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved.

An individualized plan of care will give consumers, families of children with serious emotional disturbances, clinicians, and other providers a valid opportunity to construct and maintain meaningful, productive, and healing relationships. Opportunities for updates - based on changing needs across the stages of life and the requirement to review treatment plans regularly - will be an integral part of the approach. The plan of care will be at the core of the consumer-centered, recovery-oriented mental health system. The plan will include treatment, supports, and other assistance to enable consumers to better integrate into their communities; it will allow consumers to realize improved mental health and quality of life.

In partnership with their health care providers, consumers and families will play a larger role in managing the funding for their services, treatments, and supports. Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring, and accountability. This program design will give people a vested economic interest in using resources wisely to obtain and sustain recovery.

The transformed system will ensure that needed resources are available to consumers and families. The burden of coordinating care will rest on the system, not on the families or consumers who are already struggling because of a serious illness. Consumers' needs and preferences will drive the types and mix of services provided, considering the gender, age, language, development, and culture of consumers.

The plan of care will be at the core of the consumer-centered, recoveryoriented mental health system.

To ensure that needed resources are available to consumers and families in the transformed system, States will develop a comprehensive mental health plan to outline responsibility for coordinating and integrating programs. The State plan will include consumers and families and will create a new partnership among the Federal, State, and local governments. The plan will address the full range of treatment and support service programs that mental health consumers and families need.

In exchange for this accountability, States will have the flexibility to combine Federal, State, and local resources in creative, innovative, and more efficient ways, overcoming the bureaucratic boundaries between health care, employment supports, housing, and the criminal justice systems.

Increased flexibility and stronger accountability will expand the choices and the array of services and supports available to attain the desired outcomes.

Creative programs will be developed to respond to the needs and preferences of consumers and families, as reflected in their individualized plans of care.

Giving consumers the ability to participate fully in their communities will require a few essentials:

- Access to health care,
- Gainful employment opportunities,
- Adequate and affordable housing, and
- The assurance of not being unjustly incarcerated.

Strong leadership will need to:

- Align existing programs to deliver services effectively,
- Remove disincentives to employment (such as loss of financial benefits or having to choose between employment and health care), and
- Provide for a safe place to live.

In this transformed system, consumers' rights will be protected and enhanced. Implementing the 1999 *Olmstead v. L.C* decision in all States will allow services to be delivered in the most integrated setting possible - services in communities rather than in institutions. And services will be readily available so that consumers no longer face unemployment, homelessness, or incarceration because of untreated mental illnesses.

No longer will parents forgo the mental health services that their children desperately need. No longer will loving, responsible American parents face the dilemma of trading custody for care. Families will remain intact. Issues of custody will be separated from issues of care.

In this transformed system, stigma and discrimination against people with mental illnesses will not have an impact on securing health care, productive employment, or safe housing. Our society will not tolerate employment discrimination against people with serious mental illnesses - in either the public or private sector.

Consumers' rights will be protected concerning the use of seclusion and restraint. Seclusion and restraint will be used only as safety interventions of last resort, not as treatment interventions. Only licensed practitioners who are specially trained and qualified to assess and monitor consumers' safety and the significant medical and behavioral risks inherent in using seclusion and restraint will be able to order these interventions.

The hope and the opportunity to regain control of their lives -often vital to recovery - will become real for consumers and families. Consumers will play a significant role in shifting the current system to a recovery-oriented one by participating in planning, evaluation, research, training, and service delivery.

To aid in transforming the mental health system, the Commission makes five recommendations:

- 2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.
- 2.2 Involve consumers and families fully in orienting the mental health system toward recovery.
- 2.3 Align relevant Federal programs to improve access and accountability for mental health services.
- 2.4 Create a Comprehensive State Mental Health Plan.
- 2.5 Protect and enhance the rights of people with mental illnesses.

Goal 3 - Disparities in Mental Health Services Are Eliminated

In a transformed mental health system, all Americans will share equally in the best available services and outcomes, regardless of race, gender, ethnicity, or geographic location. Mental health care will be highly personal, respecting and responding to individual differences and backgrounds. The workforce will include members of ethnic, cultural, and linguistic minorities who are trained and employed as mental health service providers. People who live in rural and remote geographic areas will have access to mental health professionals and other needed resources. Advances in treatments will be available in rural and less populated areas. Research and training will continuously aid clinicians in understanding how to appropriately tailor interventions to the needs of consumers, recognizing factors such as age, gender, race, culture, ethnicity, and locale.

Services will be tailored for culturally diverse populations and will provide access, enhanced quality, and positive outcomes of care. American Indians, Alaska Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans will not continue to bear a disproportionately high burden of disability from mental health disorders. These populations will have accessible, available mental health services. They will receive the same high quality of care that all Americans receive. To develop culturally competent treatments, services, care, and support, mental health research will include these underserved populations. In addition, providers will include individuals who share and respect the beliefs, norms, values, and patterns of communication of culturally diverse populations.

In rural and remote geographic areas, service providers will be more readily available to help create a consumer-centered system. Using such tools as videoconferencing and telehealth, advances in treatments will be brought to

rural and less populated areas of the country. These technologies will be used to provide care at the same time they break down the sense of isolation often experienced by consumers.

Mental health education and training will be provided to general health care providers, emergency room staff, and first responders, such as law enforcement personnel and emergency medical technicians, to overcome the uneven geographic distribution of psychiatrists, psychologists, and psychiatric social workers.

In a transformed mental health system, all Americans will share equally in the best available services and outcomes, regardless of race, gender, ethnicity, or geographic location.

To aid in transforming the mental health system, the Commission makes two recommendations:

- 3.1 Improve access to quality care that is culturally competent.
- 3.2 Improve access to quality care in rural and geographically remote areas.

Goal 4 - Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice

In a transformed mental health system, the early detection of mental health problems in children and adults - through routine and comprehensive testing and screening - will be an expected and typical occurrence. At the first sign of difficulties, preventive interventions will be started to keep problems from escalating. For example, a child whose serious emotional disturbance is identified early will receive care, preventing the potential onset of a co-occurring substance use disorder and breaking a cycle that otherwise can lead to school failure and other problems.

Quality screening and early intervention will occur in both readily accessible, low-stigma settings, such as primary health care facilities and schools, and in settings in which a high level of risk exists for mental health problems, such as criminal justice, juvenile justice, and child welfare systems. Both children and adults will be screened for mental illnesses during their routine physical exams.

For consumers of all ages, early detection, assessment, and links with treatment and supports will help prevent mental health problems from worsening. Service providers across settings will also routinely screen for co-occurring mental illnesses and substance use disorders. Early intervention and appropriate treatment will also improve outcomes and reduce pain and suffering for children and adults who have or who are at risk for co-occurring mental and addictive disorders.

Early detection of mental disorders will result in substantially shorter and less disabling courses of impairment.

For consumers of all ages, early detection, assessment, and links with treatment and supports will help prevent mental health problems from worsening.

To aid in transforming the mental health system, the Commission makes four recommendations:

- 4.1 Promote the mental health of young children.
- 4.2 Improve and expand school mental health programs.
- 4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.
- 4.4 Screen for mental disorders in primary health care, across the lifespan, and connect to treatment and supports.

Goal 5 - Excellent Mental Health Care Is Delivered and Research Is Accelerated

In a transformed mental health system, consistent use of evidence-based, state-of-the art medications and psychotherapies will be standard practice throughout the mental health system. Science will inform the provision of services, and the experience of service providers will guide future research. Every time any American - whether a child or an adult, a member of a majority or a minority, from an urban or rural area - comes into contact with the mental health system, he or she will receive excellent care that is consistent with our scientific understanding of what works. That care will be delivered according to the consumer's individualized plan.

Research has yielded important advances in our knowledge of the brain and behavior, and helped develop effective treatments and service delivery strategies for many mental disorders. In a transformed system, research will be used to develop new evidence-based practices to prevent and treat mental illnesses. These discoveries will be immediately put into practice. Americans with mental illnesses will fully benefit from the enormous increases in the scientific knowledge base and the development of many effective treatments.

Also benefiting from these developments, the workforce will be trained to use the most advanced tools for diagnosis and treatments. Translating research into practice will include adequate training for front-line providers and professionals, resulting in a workforce that is equipped to use the latest breakthroughs in modern medicine. Research discoveries will become routinely available at the community level. To realize the possibilities of advances in treatment, and ultimately in prevention or a cure, the Nation will continue to invest in research at all levels.

Knowledge about evidence-based practices (the range of treatments and services of well-documented effectiveness), as well as emerging best practices (treatments and services with a promising but less thoroughly documented evidentiary base), will be widely circulated and used in a variety of mental health specialties and in general health, school-based, and other settings. Countless people with mental illnesses will benefit from improved consumer outcomes including reduced symptoms, fewer and less severe side effects, and improved functioning. The field of mental health will be encouraged to expand its efforts to develop and test new treatments and practices, to promote awareness of and improve training in evidence-based practices, and to better finance those practices.

Research discoveries will become routinely available at the community level.

The Nation will have a more effective system to identify, disseminate, and apply proven treatments to mental health care delivery. Research and education will play critical roles in the transformed mental health system. Advanced treatments will be available and adapted to individual preferences and needs, including language and other ethnic and cultural considerations. Investments in technology will also enable both consumers and providers to find the most up-to-date resources and knowledge to provide optimum care for the best outcomes. Studies will incorporate the unique needs of cultural, ethnic, and linguistic minorities and will help ensure full access to effective treatment for all Americans.

To aid in transforming the mental health system, the Commission makes four recommendations:

- 5.1 Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.
- 5.2 Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.
- 5.3 Improve and expand the workforce providing evidence-based mental health services and supports.
- 5.4 Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.

Goal 6 - Technology Is Used to Access Mental Health Care and Information

In a transformed mental health system, advanced communication and information technology will empower consumers and families and will be a tool for providers to deliver the best care. Consumers and families will be able to regularly communicate with the agencies and personnel that deliver treatment and support services and that are accountable for achieving the

goals outlined in the individual plan of care. Information about illnesses, effective treatments, and the services in their community will be readily available to consumers and families.

Access to information will foster continuous, caring relationships between consumers and providers by providing a medical history, allowing for self-management of care, and electronically linking multiple service systems. Providers will access expert systems that bring to bear the most recent breakthroughs and studies of optimal outcomes to facilitate the best care options. Having agreed to use the same health messaging standards, pharmaceutical codes, imaging standards, and laboratory test names, the Nation's health system will be much closer to speaking a common language and providing superior patient care. Informed consumers and providers will result in better outcomes and will more efficiently use resources.

Electronic health records can improve quality by promoting adoption and adherence to evidence-based practices through inclusion of clinical reminders, clinical practice guidelines, tools for clinical decision support, computer order entry, and patient safety alert systems. For example, prescription medications being taken or specific drug allergies would be known, which could prevent serious injury or death resulting from drug interactions, excessive dosages or allergic reactions.

Access to care will be improved in many underserved rural and urban communities by using health technology, telemedicine care, and consultations. Health technology and telehealth will offer a powerful means to improve access to mental health care in underserved, rural, and remote areas. The privacy of personal health information - especially in the case of mental illnesses - will be strongly protected and controlled by consumers and families. With appropriate privacy protection, electronic records will enable essential medical and mental health information to be shared across the public and private sectors.

Reimbursements will become flexible enough to allow implementing evidence-based practices and coordinating both traditional clinical care and e-health visits. In both the public and private sectors, policies will change to support these innovative approaches.

The privacy of personal health information - especially in the case of mental illnesses - will be strongly protected and controlled by consumers and families.

An integrated information technology and communications infrastructure will be critical to achieving the five preceding goals and transforming mental health care in America. To address this technological need in the mental health care system, this goal envisions two critical technological components:

A robust telehealth system to improve access to care, and

 An integrated health records system and a personal health information system for providers and patients.

To aid in transforming the mental health system, the Commission makes two recommendations:

- 6.1 Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.
- 6.2 Develop and implement integrated electronic health record and personal health information systems.

Preventing mental illnesses remains a promise of the future. Granted, the best option is to avoid or delay the onset of any illness, but the Executive Order directed the Commission to conduct a comprehensive study of the delivery of mental health services. The Commission recognizes that it is better to prevent an illness than to treat it, but unmet needs and barriers to services must first be identified to reach the millions of Americans with existing mental illnesses who are deterred from seeking help. The barriers may exist for a variety of reasons:

- Stigma,
- Fragmented services,
- Cost,
- Workforce shortages,
- Unavailable services, and
- Not knowing where or how to get care.

These barriers are all discussed in this report.

The Commission - aware of all the limitations on resources - examined realigning Federal financing with a keen awareness of the constraints. As such, the policies and improvements recommended in this *Final Report* reflect policy and program changes that make the most of existing resources by increasing cost effectiveness and reducing unnecessary and burdensome regulatory barriers, coupled with a strong measure of accountability. A transformed mental health system will more wisely invest resources to provide optimal care while making the best use of limited resources. The process of transforming mental health care in America drives the system toward a delivery structure that will give consumers broader discretion in how care decisions are made. This shift will give consumers more confidence to require that care be sensitive to their needs, that the best available treatments and supports be available, and that demonstrably effective technologies be widely replicated in different settings. This confidence will

then enhance cooperative relationships with mental health care professionals who share the hope of recovery.

Goals and	Recommendations In a Tra	nsformed Mental Health System	
Goal 1	Americans Understand that Mental Health Is Essentia to Overall Health.		
	Recommendations	1.1 Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.1.2 Address mental health with the same urgency as physical health.	
Goal 2	Mental Health Care Is Consumer and Family Driven.		
	Recommendations	2.1 Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance. 2.2 Involve consumers and families fully in orienting the mental health system toward recovery. 2.3 Align relevant Federal programs to improve access and accountability for mental health services. 2.4 Create a Comprehensive State Mental Health Plan. 2.5 Protect and enhance the rights of people with mental illnesses.	
Goal 3	Disparities in Mental	Health Services Are Eliminated.	
	Recommendations	3.1 Improve access to quality care that is culturally competent. 3.2 Improve access to quality care in rural and geographically remote areas.	

Goal 4	Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.	
	Recommendations	 4.1 Promote the mental health of young children. 4.2 Improve and expand school mental health programs. 4.3 Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies. 4.4 Screen for mental disorders in primary health care, across the life span, and connect to treatment and supports.

Goal 5	Excellent Mental Health Care Is Delivered and Resear Is Accelerated.	
	Recommendations	5.1 Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses. 5.2 Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation. 5.3 Improve and expand the workforce providing evidence-based mental health services and supports. 5.4 Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.
Goal 6	Technology Is Used to Access Mental Health Care and Information.	

Recommendations	6.1 Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations. 6.2 Develop and implement integrated electronic health record and personal health information systems.
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Footnotes:

a. In this Final Report, whenever child or children is used, it is understood that parents or guardians should be included in the process of making choices and decisions for minor children. This allows the family to provide support and guidance when developing relationships with mental health professionals, community resource representatives, teachers, and anyone else the individual or family invites. This same support and guidance can also include family members for individuals older than 18 years of age.

b. Functional impairment is defined as difficulties that substantially interfere with or limit role functioning in one or more major life activities, including basic daily living skills (e.g., eating, bathing, dressing); instrumental living skills (e.g., maintaining a household, managing money, getting around the community, taking prescribed medication); and functioning in social, family, and vocational/educational contexts (Section 1912 (c) of the Public Health Services Act, as amended by Public Law 102?321).

c. In this Final Report, consumer identifies people who use or have used mental health services (also known as mental health consumers, survivors, patients, or clients).