MHA OF NYC

The Center for Policy, Advocacy, and Education
Of The Mental Health Association of New York City

A MENTAL HEALTH AGENDA
FOR THE 2ND DECADE OF THE 21st CENTURY

In the first decade of the 20th century, Clifford Beers, the founder of the Mental Health Association movement, articulated the vision which nearly 50 years later became the core mental health policy of the United States. From his own dreadful experiences as a patient in several psychiatric hospitals came a commitment to devote his life to humanizing the conditions in mental hospitals, to preventing the need for hospitalization, and to preventing mental illness and its disabling consequences. He believed that many people with mental illnesses were treated badly because of stigma and ignorance and sought to build national and international organizations through which myths could be dispelled and progressive public policies championed. With the shift from institution-based to community-based mental health policy in the mid-1950s, Beers' vision became the driving force of public mental health policy in the United States.

While deinstitutionalization, the first wave of community mental health, was of great benefit to people who were able to have better lives outside the hospital, it was a disaster for a great many people who were essentially abandoned in the community without the services and supports that they needed. As a result, they lived in terrible conditions and without adequate treatment or became the responsibility of their families, who simply refused to let family members live in danger and squalor.

In the late 1970's, about 10 years after the most aggressive period of deinstitutionalization began, a community support policy was instituted in The United States. This policy shift resulted in a significant expansion of services in the community for adults with serious and persistent mental illnesses including housing, outpatient services, acute inpatient services in general hospitals, crisis services, rehabilitation, case management, and peer support. Many people who would have been living either in State hospitals or in terrible conditions 30 years ago are now leading lives in the community which are far more satisfying than the lives they would have had without the Community Support Program.

At the same time that a community-based system of care was being created for adults with serious psychiatric disabilities, a system of care was also emerging for people with less severe mental disorders such as mild to moderate anxiety and mood disorders. Funded initially primarily from private sources—self-pay, insurance, and philanthropy, over time more and more public funding became available for services to this population, most of it from Medicaid and Medicare. As a result, many people with distressing but not extremely disabling mental disorders have been able to get treatment through a publicly supported mental health system. Recently, new federal and state "parity" laws have mandated that private health plans and Medicare provide equal coverage of health and mental health conditions. This, hopefully, will result in increased access to mental health services in the coming years.

INADEQUACIES OF THE CURRENT MENTAL HEALTH SYSTEM

Despite the improvements which have emerged because of the Community Support Program, Medicaid, Medicare, and parity, there are a number of notable inadequacies with the current mental health system.

1. There are still unmet needs for a broad range of community supports for adults with long-term psychiatric disabilities—particularly for decent housing.

2. About 60% of people who have diagnosable mental disorders do not get mental health services.

3. The quality of services is extremely uneven. The most recent major epidemiological study estimates that 15-20% of people with mental disorders get treatment only from primary care health providers, who provide "minimally adequate" treatment less than 15% of the time. Most others who get treatment get it from mental health professionals, who provide minimally adequate treatment less than 50% of the time.

4. Despite the clarity that has developed about the importance of integrating the delivery of mental health, substance abuse, and physical health services, integrated treatment is still by far the exception rather than the rule.

5. There are still populations that are markedly underserved—including

    a. children and adolescents
    b. older adults
    c. minorities
    d. people with serious mental illnesses who reject or cannot use traditional services
    e. people with co-occurring severe mental, substance use, and physical health conditions
    f. military personnel, veterans, and their families,
    g. and more.

6. Bio-medical research has not yet produced breakthroughs of the kind that have been expected for the past 25 years.

7. The mental health system has not yet begun to prepare for dramatic changes in demography that are now underway in America, especially the rapid growth of minorities and the elderly.

8. Fundamental changes in the "structure" of the mental health system that have taken place due to the reduced role of state psychiatric hospitals, the growth of reliance on Medicaid, and major shifts in employer-based mental health coverage have resulted in a need to rethink and re-organize service delivery, management, finance, and regulation.

To respond to these inadequacies our society will need to provide substantial additional funding for mental health services and supports through both the public and the private sectors. It will also need to engage in substantial restructuring activities including service integration, removal of legal and regulatory barriers to providing state-of-the-art care, the development of revised payment methodologies, and more.

It is possible that some of these issues will be addressed as part of the process of health policy reform now taking place in the United States, but so far it appears that there will be very limited attention paid to mental health needs if health policy reform moves ahead.

Below are specific changes that are needed to improve mental health policy and practice in both the public and the private sectors.

<u>**Adults**</u>

- A substantial number of **people with recurrent, serious mental illnesses reject, or cannot use, traditional mental health services**. Some people who avoid treatment manage quite well without it, but many end up in crisis and then experience long hospitalizations. An increasing number of them are now in jails and prisons, generally for minor offenses. A very few commit acts of violence which make the headlines that dominate public debate about mental health policy. Many of these episodes of inappropriate treatment and human tragedy could be averted if **relevant and responsive community services** were available.

- A substantial number of people with serious mental illnesses have been **"transinstitutionalized" to jails and prisons, nursing homes, and large congregate care facilities** for poor people who are believed to be unable to live independently in the community. (In New York State they are called "Adult Homes.") Care in these institutions is often poor, sometimes scandalously poor. Solitary confinement and other punishments in forensic facilities are irresponsibly cruel for people with mental illnesses. In addition, adult and nursing homes become dead-ends for people who may be able to live more independently in the community if appropriate housing, services, and supports were available.

- There is **not enough appropriate housing** for people with serious mental illnesses, who often need help finding and paying for decent places to live and who often also need a variety of supports to be able to live in the community. Lack of housing results in homelessness, in living in squalor and danger, in excessive reliance on inappropriate institutions of various kinds, and in family burden.

- Despite decades of talk about providing **integrated treatment services for people who are mentally ill and abuse substances**, such services are still not widely available.

- People with serious mental illness die 10-30 years sooner than the general population in large part because of poor health. In addition, people with chronic physical conditions and mental illness are at high risk for disability, institutionalization, and premature death. They also have far higher medical costs than people without mental disorders. There is a clear need to **integrate physical and mental health care** in primary, specialty, and long-term care.

- Mental health services for adults with serious mental illnesses and their families are often **not based on practice models for which there is research support** because **many mental health professionals are inadequately trained in state-of-the-art models and because regulatory and financing structures are frequently based on outmoded treatment models**.

- Even when they get decent care and treatment, **most people with serious psychiatric disabilities are not employed** despite their desire to work and despite the existence of a

rehabilitative technology which might help them to get and keep jobs. Unfortunately rehabilitative opportunities are not widely enough available.

- **Services provided by people with mental illnesses for their peers**, while growing, remain limited and tenuous despite successful experiences throughout the country.

- There has never been adequate **support for families** of adults with serious mental illnesses even though they provide a large amount of care for their family members. As the current generation of parents providing care for their family members with psychiatric disabilities becomes too old to provide care and eventually dies, a resource on which our society depends informally will be lost.

- **Military personnel, veterans, and their families** have high rates of depression, post traumatic stress disorder, substance abuse, family dysfunction, and suicide. Many of those who would like help from the military or from the Veteran's Administration are not able to get it due to limited capacity, bureaucratic barriers, and stigma. Many, however, will not turn to these channels for help. Unfortunately, the generic health and mental health systems have generally not proved to be good at identifying mental and/or substance use problems or at engaging these people in treatment that is sensitive to their special problems and needs.

- Many adults with mental illnesses, whether mild, moderate, or severe, **cannot get access to mental health services in the private sector.** Parity laws may improve access for those who have not been able to afford treatment.

- But **mental health professionals**, in both the public and the private sector, are in short supply and are simply **not available** in some parts of the country.

Children and Adolescents

- **Children and adolescents with serious emotional disturbances frequently do not get mental health services or do not get the mental health services that would best meet their needs**.

- The average age of onset of a protracted mental illness is 14, but most people do not get treatment until about 10 years after the illness first appears. This **failure of early intervention** probably results in more personal problems and increased risk of disability in adult life.

- There are **not enough mental health services for children and adolescents in the public mental health system or in the private sector.**

- This reflects

  - **Insufficient public funding**
  - **Inadequate insurance coverage**
  - **A shortage of mental health professionals for children and adolescents**.

- Mental health services for children and adolescents are often **not based on practice models for which there is research support** because **many mental health professionals are**

inadequately trained in state-of-the-art models and because regulatory and financing structures are frequently based on outmoded treatment models.

- Outpatient services generally are **not flexible enough** with regard to time, place, and nature of services provided. In addition they generally are **not responsive enough to crises** in the lives of emotionally disturbed children and their families.

- **Inpatient services and residential treatment**, which are critical elements of a comprehensive mental health system for children and adolescents, are **over-utilized because of the absence of a comprehensive system of community-based services which provides a full continuum of services**.

- **Involvement of families in the treatment of their children and support for these families** or caretakers is not nearly as widespread as it should be.

- Children with serious emotional disturbances often are served in several child-serving systems. Little progress has been made in the effort to **integrate child-serving systems.**

Readiness for Demographic Shifts

- The mental health system generally has **not** been **preparing for dramatic demographic shifts** which will take place within the next two decades—especially the growth of older adults (the "baby boom generation") and the growth of cultural minorities.

- As the number of **older adults** grows, so will the number of older adults with significant mental health problems. And they will be more likely to seek out and use mental health services than the current generation of older adults. Nevertheless, meeting the need for more mental health services for this population is not generally included in plans for new mental health services.

- **Minority and immigrant populations** are also growing rapidly. Lack of widespread **cultural competence** will become an ever-greater problem as minority populations grow.

Quality of Care and Treatment

- Despite remarkable improvements in the effectiveness of treatment over the past 25 years and a dramatic shift in attitude among the best practitioners towards recipients of services and their families, **serious problems with the quality of care** remain**.**

- A **human resources crisis** has emerged. Recruitment and retention of well-qualified staff has become exceedingly difficult resulting in serious problems maintaining minimally adequate staffing levels and in providing continuity of care.

- **Many providers are not adequately trained in new treatment methods** and/or in the **need for respect and humanity regarding people with serious mental illnesses and their families**.

- **Research has not yet provided the dramatic breakthroughs in treatment** which have been the central hope for mental health, even though there have been important strides made.

MHA's 12-POINT MENTAL HEALTH POLICY AGENDA

In order to promote a meaningful response to the inadequacies noted above, MHA has formulated the following 12-point advocacy agenda.

1. **Mental health policy reform should be a major component of national and state health policy reform.** This should include: preservation of parity commitments, enhanced integration of mental and physical health care, provisions for workforce development, and revisions of Medicare to cover long-term care and to reflect the special mental health needs of older adults.

2. **Mental health policy should be built on an understanding of the populations** for whom mental health services would be beneficial. There should be a public commitment to meet the mental health needs of these populations by **progressively developing a comprehensive and integrated array of community-based mental health services** including crisis intervention, outpatient services, housing, rehabilitation, case management, peer support services, and inpatient services.

   Progressive expansion of the mental health system should focus particularly on **underserved populations** including (a) children and adolescents, (b) older adults, (c) minorities, (d) people with serious mental illnesses who do not use traditional services, (e) homeless people, (f) people with co-occurring severe mental, substance use, and physical health conditions, and (g) military personnel, veterans, and their families.

   An **empirically based needs assessment and multi-year planning** process should guide this process of development.

3. There should be a multi-year commitment to expand **housing, treatment, support, and rehabilitation and healthcare services for adults with serious mental illnesses** who are not adequately served by the current mental health system, especially those who are:

   - Homeless
   - Living in "adult homes" or nursing homes
   - Involved with the criminal justice system
   - Unwilling or unable to use mental health services
   - Unemployed
   - Substance abusers
   - Veterans.

   This effort should include expanding initiatives which **stress recovery, enhance access to mainstream society, and improve quality of life**.

   It is particularly important to work for better health of people with serious mental illness through improved access to high quality health care and through health promotion activities.

4. There should be a multi-year commitment to **build a comprehensive, community-based system of care for children and adolescents** including:

   - **Development of a full range of services**—crisis, outpatient, community support, case management, family support, residential, and inpatient.

- **Expansion and reshaping outpatient and community services** with emphasis on services that are flexible, mobile, and responsive to crisis
- **Increased use of state-of-the-art treatment models**
- Increased attention to children and adolescents who are **victims of abuse or neglect, caught up in the juvenile justice system, or are failing in school.**
- An emphasis on **early intervention** and the provision of services **to build emotional resilience**
- **Improved integration with other child-serving systems.**

5. There should be a multi-year commitment to **prepare for predictable demographic shifts**, especially for:

- **Older adults** with mental health problems including:

  - The development of long-term, inter-agency plans for geriatric mental health and addiction services at federal, state, and local levels
  - Expansion of geriatric mental health and addictions services especially in home and community settings
  - Improvement of geriatric mental health and addictions services in institutional and community service settings
  - Integration of physical and behavioral health services in primary, specialty, mental health, and long-term care and of behavioral health and aging services
  - Improved funding through optimized use of existing funding streams (especially Medicare), through modification of funding structures to support home and community-based services and service integration, and through increased funding
  - Development of a workforce with clinical, cultural, and generational competence and which is large enough to match the growth of the aging population
  - A research agenda for geriatric mental health that will contribute to improved services in all systems serving older adults with mental and/or addiction problems.

- **Cultural minorities and immigrants** with mental health problems including:

  - Increased availability of bi-lingual mental health professionals and of good translators
  - Improved access of cultural minorities to high quality service providers in the private as well as the public sector
  - Improved engagement of cultural minorities in mental health programs
  - Improved clinical services to culturally diverse people
  - Workforce development to build cultural competence
  - Fair promotional opportunities
  - Dealing with race relations issues in mental health programs and facilities.

6. **Access to mental health services in the private and public sectors should be improved** by:

- Making mental health services more available in primary health care, social services, and other community settings.
- Increasing the availability of mental health professionals especially in underserved geographic areas.

- Implementing **parity** between health and mental health insurance coverage as required by new federal and state laws.
- **Assuring that care is available to people without insurance coverage or with inadequate insurance coverage**, including immigrants and undocumented aliens

7. There should be a commitment to enhance quality of care by:

- Addressing the need for **enhanced clinical and cultural competence** of health and social services providers as well as mental health professionals and paraprofessionals
- Providing **integrated treatment and collaborative service programs** for people with co-occurring mental, physical, and/or substance use disorders
- Supporting mental health biomedical, clinical, services, and policy **research** which is **responsive to contemporary mental health policy goals** and which seeks breakthroughs in knowledge and treatment.
- Assuring **widespread knowledge of state-of-the-art treatment and rehabilitation**
- **Eliminating abuse** of people with mental illnesses wherever it occurs.

8. **Major workforce development initiatives** should be launched at both the federal and state levels

- **Addressing the shortage** of mental health professionals, especially for children, older adults, and minorities via
    - Expanded education and training programs
    - Removing barriers such as the high cost of education
    - Creating incentives to become a mental health professional
    - **Developing useful roles for peers, family members, and retired people** as respected providers of services that support and complement professional mental health services.

9. There should be a commitment to a widespread **family support initiative** to assist families who are providing housing and other forms of care for their mentally ill family members including parents of children with serious emotional disturbance, parents of adult children with serious and persistent mental illness, adult children caring for parents with mental disabilities, and grandparents raising their grandchildren.

10. There should be a commitment to **overcome stigma and discrimination** and to educate the public about the realities of mental illness.

11. Federal, state, and local governments should make a **financial commitment** commensurate with progressive mental health policy including:

- **Maintenance of adequate financial support for core** community mental health services with **routine adjustments for inflation** and **assurance of living wages**.
- **Progressively increasing funding** for:

- **Services for populations who are not adequately served by the current system**
- **Improved education and training** of mental health providers
- **Research**.

12. Federal, state, and local governments should work together to rethink and re-organize service **structural, regulatory, and financial models so as to support the progressive development of a comprehensive community-based mental health system.**