The State of Mental Health Services in Massachusetts

The Impact of Inadequate Funding

NAMI's Campaign for the Mind of America

April 28, 2004

NAMI National and NAMI Massachusetts * www.nami.org

The State of Mental Health Services in Massachusetts: The Impact of Inadequate Funding

April 28, 2004

After several years of cutbacks and service reductions, the Commonwealth of Massachusetts is proposing to cut even more from its mental health system.

- The recently released House budget restores vital research funding and provides crucial funding for under-paid mental health workers, yet there is still a dire shortage of mental health services.

- Earlier this year there was a proposal to cut more than $5 million in 2005, cutting adult in-patient care and emergency services. This came on the heels of years of budget cuts, including $7.8 million in fiscal year 2002, more than $13.8 million in 2003, and another $12.7 million last year.

- In 2003, services provided by the Department of Mental Health (DMH) in county jails were eliminated.

- The recently released House budget funds the DMH at $586,123,295. This is almost $8.5 million below their reported maintenance need of $594,612,932, and is $6.6 million below their FY04 funding level (after the $1.5 million supplemental budget is considered).

- Although language is currently being debated as a budget amendment, there is currently no legislative language on the disposition of the Medfield Hospital property that would insure any support for the mentally ill who once relied on that facility. NAMI has been advocating for the development of the site to include housing for the mentally ill, either on-site or through a trust fund. This is an ongoing issue as more hospitals are eyed for closing by the state in the future. State hospitals were originally intended to serve the mentally ill. When they are disposed of the assets should serve people with mental illness. Not only is this good economic and public policy, but it is prudent and just.

- The recently released House budget takes a huge, insupportable 10% cut out of DMH's administration (which would cut another 67 staff positions from an agency that has lost 243 since FY01!).

- DMH reports that the recently released House budget will support the plan to create 268 community beds by the end of FY06 while concurrently terminating a total of 160 adult continuing care inpatient beds. DMH reports that the $1.49 million in the Emergency Programs account would serve as bridge funding to create some of these community placements (approximately 22). However, there remain concerns that adequate community development funding may not be available to see this Olmstead initiative through.

Citizens of the Commonwealth with chronic mental illnesses still languish waiting for community based services, wander our streets homeless, fill up emergency rooms when preventive treatment should have been provided, and needlessly end up in the criminal just system. This is a human travesty that is avoidable with adequate funding and services. Treatment means the difference between hope and despair, struggle and recovery, and even life and death. Limiting mental health treatment does not save tax-payers dollars. Instead limiting mental health treatment results in tragic unintended consequences and cost-shifting.

Let's take a look at the impact of Massachusetts' underinvestment in mental health services.

- The Governor of Massachusetts own Executive Commission for Homeless Services Coordination concluded that the number of homeless individuals has reached alarming levels, with the state having the least affordable rental properties in the United States. According to a study by the Technical Assistance Collaborative, Inc., and the Consortium for Citizens with Disabilities Housing Task Force, disabled individuals receiving SSI must spend 134.7 percent of their income to rent a one bedroom apartment in the state, and the problem is growing, with SSI benefits increasing only 5 percent between 2000 and 2002, compared to a 33 percent increase in one-bedroom apartment rents in that same time period.

The Department of Mental Health's Fiscal Years 2002-2004 State Mental Health Plan estimates that there are 2,000 adults in the Commonwealth with a severe and persistent mental illness who are homeless at any one point in time, and it acknowledges that the problem is growing. According to a 2002 survey, Boston had 6,000 homeless individuals in 2001 and this was a growing problem, with a primary reason for the problem being attributed to the lack of services for people with severe mental illnesses. According to a Department of Mental Health Budget analysis in November of 2002, 3,540 individuals are awaiting housing. In fact, 3,163 adults were estimated by the Department's most recent and comprehensive report to be awaiting residential services in the third quarter of 2000, 526 of whom were eligible homeless individuals. According to the Department of Mental Health's extraction of data from "The State Continuum of Care: Gaps Analysis" of June 1999, there are 3,777 people with severe mental illnesses who are homeless and that given the inventory of placements at the time, there were no placements available for 1,193, giving it a priority rating of high in that report. The recent outcry over possible reduction in housing vouchers and the Governor's own homeless report show that housing is a critical need in the state that the budget crisis continues to threaten.

- According to the Massachusetts Department of Corrections, in March 2003, 20.85 percent of the prison population—1,999 people—have a serious mental disorder, with 1,391 individuals receiving psychotropic medication. According to national statistics from the National GAINS Center and the Bureau of Justice Statistics, 1,016 individuals in Massachusetts' prisons have a severe mental disorder—schizophrenia or other psychotic illness, bipolar disorder, or severe depression. Another 718 individuals in Massachusetts' jails were estimated to have a psychotic or severe mood disorder.

- Of the 46,683 adults with severe mental illnesses in Massachusetts, less than half will receive *any* type of community-based treatment through the public mental health system. Hospital stays have also declined, reflecting budget cuts and managed care. Hospitals in Massachusetts are discharging patients earlier and earlier, at the demand of managed care corporations such as Magellan Health Services. State reviews of discharge appeals found the managed care entity in the wrong as much as 75 percent of the time.

- The lack of services translates into emergency room overload in Massachusetts. According to a *Boston Globe* article, Massachusetts General Hospital's emergency room had a near 50 percent increase in the number of individuals with serious mental illnesses in the last year; the ER at Boston Medical Center had a 20 percent increase. The ER health care professionals know why this is happening, as a survey of emergency room physicians published this month shows: increasing state health care budget cuts and decreased hospital care for people with serious mental illness. In fact, this survey shows that ER physicians are not only treating more people with serious mental illness in the ER but they are boarding them as well, until a hospital bed can be found.

- Children with serious mental disorders also face historic lack of services in Massachusetts. The problem is dramatically revealed in the juvenile justice system, which shuddered from the suicide of two young people who were in the correctional system instead of receiving appropriate treatment this last year. The state's Department of Youth Services expects to find in their current assessment that at least half of the girls and boys entering juvenile justice have a serious mental disorder. The young people are warehoused in facilities that are often decrepit. In the Dorchester facility, for example, the girls' wing has erratically working heating and air conditioning, as girls are lodged two by two in small cells that the corrections officers cannot get in, according to a Boston Globe article. Massachusetts estimates that there are 59,338 young people between the ages of 9 and 18 with extreme dysfunction due to a serious emotional disturbance; 93,246 children and adolescents in that age group are estimated to have substantial functional impairment due to a serious emotional disturbance. Another 18,446 children below the age of 9 are estimated to need mental health services. Of this more than 100,000 children and adolescents with serious emotional disturbance, less than 5 percent, by the state's own assessment, receive case management services, residential services, or any other community based care. The Department of Mental Health acknowledges as well, in its 2003 Block Grant application that there are long waiting lists for case management and residential services.

It is a cruel irony that 163 years ago, Dorothea Dix began her crusade to improve care for people with severe mental illnesses in Massachusetts. For two years, she visited jails and almshouses throughout the state, providing witness to the shackling and torture endured by individuals with mental illness. This witness was the impetus for the state's expansion of psychiatric asylums. Today, there are fewer than 900 state hospital beds, 300 of which are for forensic patients. With today's modern medications and community based treatment the majority of people living with chronic mentally illness can successfully live in the community. Yet given the crushing blows to mental health's budget and the lack of community placements, investigations of Massachusetts jails and streets would reveal horrors similar to those found by Dix in 1841.

But today, Dorothea Dix would not be promoting asylums as the solution, which she believed would lead to recovery for many people with these brain disorders. She would, instead, be promoting the supports and services needed for community living, including the implementation of evidence-based practices (EBPs)--interventions that are shown by research to work and promote recovery. These, together with stable housing, really work at helping people with severe mental illnesses live in the community—and are required by the law of the land, the Americans with Disabilities Act. Unfortunately, Massachusetts' level funding of its mental health service system in the 1990s and dramatic cuts over the past three years translates into an estimated 20,000 individuals with severe mental illnesses desperately waiting for Department of Mental Health services, of which over 3,381 are waiting for residential placement. These more than 3,000 individuals include homeless persons and individuals who are ready to be discharged from inpatient settings. The fact that Massachusetts is committed to a trajectory of closing state long-term care facilities for individuals with severe mental illnesses, without committing the necessary resources to housing and community-based care to address the already swelling waiting lists means the situation will undoubtedly get much worse. Furthermore, Massachusetts must go farther in implementing EBPs, with the vast majority of individuals who need these services and can benefit from them not receiving them, an overview of which is provided below, following a description of EBPs.

Evidence-based Practices for Severe Mental Disorders in Adults	
Evidence-based Practice	**Description**
Assertive Community Treatment	ACT is one of the most well-documented services that help individuals with severe and persistent mental illnesses live in the community and avoid hospitalization. It consists of a diverse team of mental health care providers who together care for consumers, reaching out to them in their own communities and providing the full-range of services needed.
Evidence-based Medication Decision Making	Various mechanisms can help translate the latest available knowledge about medications into practice by helping physicians and patients choose the appropriate medication. Decisions about medication must be made at the individual level, with the full-support of scientific evidence.
Supported Employment	This employment service is the most effective in gaining individuals with severe mental illnesses competitive jobs. Working with consumers to identify their interests, supported employment finds a job for the individual and provides ongoing support as needed on the job.
Integrated Dual Diagnosis Treatment	Because individuals with serious mental disorders often have a co-occurring substance abuse problem, the optimal form of treatment addresses both issues, rather than leaving patients to be ping-ponged between mental health care and substance abuse service providers, as is typically the case.
Family Psycho-education	Since family members of individuals with severe mental illnesses often provide support and care for their loved one, services that help them understand mental illness and how best to cope with it have been shown to help family members cope better and helps consumers avoid psychiatric crises. An estimated 50 percent of family members provide intensive care for individuals with severe and persistent mental illness—and thus should be receiving psychoeducation services.
Illness Self-Management	Interventions that help consumers better understand their illness and take charge of their treatment decrease symptoms and improve outcomes. All consumers with a severe and persistent mental illness should receive this intervention.
Jail Diversion Services	A variety of programs, including mental health courts, police training, and special police/treatment professional outreach teams can reduce inappropriate criminalization of people with mental illnesses.

Assertive Community Treatment (ACT) Massachusetts has 14 ACT teams operational statewide, spending $7,777,581in fiscal year 2004 on the program and serving 727 people. The most conservative estimate of how many adults in Massachusetts who need ACT services is 20 percent of those with a severe and persistent mental illness—9,337 individuals. Some experts believe as many as half of adults with severe and persistent mental illness require ACT services—23,342 Massachusetts adults. Thus, even though Massachusetts has made a real effort to expand ACT services, at best only 7.8 percent of those requiring this intervention receive it, This is especially of concern, given the many long-term and acute hospital beds lost and on the cutting block in Massachusetts, as ACT

is the one service that helps those with intense service needs to reside in the community successfully.

Supported Employment: Massachusetts boasts 25 supported employment programs, serving 1,700 people in 2004 and costing the commonwealth $6,279,264. Research has led to the conclusion that one-half of all individuals with severe and persistent mental illness should receive supported employment services—which are the one intervention proven to lead to competitive employment outcomes. Thus, Massachusetts is providing this essential service to less than 5 percent of the population who should receive this service. Another sign of inadequate supported employment services is the fact that more than 200 clients quarterly are on waiting lists for the services that exist, according to the most comprehensive assessment of the situation by the Department of Mental Health (2000).

Appropriate Use of Medication: For the vast majority of individuals with severe mental disorders, medication is the cornerstone of treatment. Massachusetts has enacted a number of initiatives to improve provider prescribing behavior, including residency training contracts with state professional schools and a system to ensure that the use of multiple medications is safely accomplished. Clinical guidelines based on the schizophrenia PORT treatment recommendations, a nationally renowned guide to evidence-based treatment of schizophrenia, were also developed in 1999. The bigger issue at the present time for the state is the perpetual threat to access to necessary medications. While there are multiple medications for the treatment of schizophrenia, all research-based guidance shows that decisions about which medication to use with a particular individual must be individually determined—the way each patient reacts to a medication and the side-effects they experience are not predictable and vary greatly between patients. Thus, the commonwealth's continued threat to appropriate and effective access provides a real threat to public health and, ultimately, costs. It is absolutely necessary that decisions about medication access in Massachusetts be made individually and under the guidance of optimal clinical knowledge, including the Department of Mental Health, and that cost offsets of limitations on medication access be provided to the tax-paying public of Massachusetts.

Integrated Mental Health and Substance Abuse Services: Massachusetts' Department of Mental Health reports that it is implementing this service statewide, but did not provide any data on costs or clients served, raising the question about how widespread this service is. Since half or more of adults with severe mental illness have a co-morbid substance abuse problem, and account for the most disabled portion of this population, assuring and documenting integrated treatment is the only sensible thing to do. Caution is also necessary given significant funding cuts in substance abuse services over the last few years--$11 million cut since 2001--suggesting that the state thinks it is doing more with much, much less.

Jail Diversion: Massachusetts does not have a statewide jail diversion program. There is one prebooking jail diversion program in Framingham through the initiative of Advocates, Inc., who got a grant to work with and train the Framingham police. There is one post-arraignment jail diversion program that is phasing out at the West Roxbury District Court due to lack of funding and there is one pre-booking jail diversion program being planned by the Massachusetts Jail Diversion Program under the auspices of UMASS Medical School. Only four police forces have had training on how to deal with people with mental illness in crisis resulting in as many as eight mentally ill persons killed by police during the last two years. Massachusetts does not have any mental health courts.

SOURCES:

American College of Emergency Physicians, April, 2004.

The Boston Globe, "Poorly Served Youths," February 23, 2004.

Governor's Executive Commission for Homeless Services Coordination, *Housing the Homeless: A More Effective Approach: Final Report*, November, 2003.

Kowalczyk, L., "Insurer Pressure Cited as Psychiatric Stays Shortened," *The Boston Globe*, December 13, 2003.

Lutz, K., "Mental Patients Turning to Ers: Cuts Force Many to Try Hospitals," *The Boston Globe*, August 20, 2003.

Massachusetts Budget and Policy Center, "Cuts That Hurt: An Examination of Some of the Painful Cuts in the FY2004 State Budget," January 2004.

Massachusetts Department of Corrections, 2004.

Massachusetts Department of Mental Health, "2003 Community Mental Health Services Block Grant Application (P.L. 102-321)," September 2002.

Massachusetts Department of Mental Health, "Clinical Practice Guidelines for the Treatment of Schizophrenia," 1999.

Massachusetts Department of Mental Health, "Fiscal Years 2002-2004 State Mental Health Plan and Fiscal Year 2001 Adult and Child/Adolescent Implementation Report," December, 2001

Massachusetts Department of Mental Health, Inpatient Study Report for the General Court, March 2004.

Massachusetts Department of Mental Health, Service Needs Assessment, 2000.

Massachusetts Human Service Agency Overview of Family Support, Draft.

Massey, J., "Housing Plan Stirs Concerns on Vouchers; US Cuts Could End Aid for Many Families," *The Boston Globe*, April 18, 2004.

NAMI-Massachusetts, personal communications.

National GAINS Center, personal communication, 2003.

National GAINS Center, *Survey of Mental Health Courts*, 2003.

Technical Assistance Collaborative, Inc. and Consortium for Citizens with Disabilities Housing Task Force, *Priced Out in 2002*, May 2003, Boston, MA.

United States Conference of Mayors, *A Status Report on Hunger and Homelessness in America's Cities*, 2002.

TRIAD

Treatment/Recovery Information and Advocacy Database

Shattered Lives: Results of a Survey of NAMI Members Living with Mental Illnesses and Their Families in Massachusetts

Results from NAMI's nationwide survey show that the failing mental health system in Massachusetts translates into lives shattered by disabling illness and inadequate services in this state.[i]

Massachusetts residents with severe mental illnesses represented in the NAMI survey, most having a diagnosis of bipolar disorder or schizophrenia, were largely working-age adults with considerable education (figure 1, table 1). Ninety-one percent were between the ages of 18 and 54 and 72 percent had graduated from high school, received some college education, or actually had received an undergraduate degree.

Figure 1: Age of Individuals with Serious Mental Illnesses

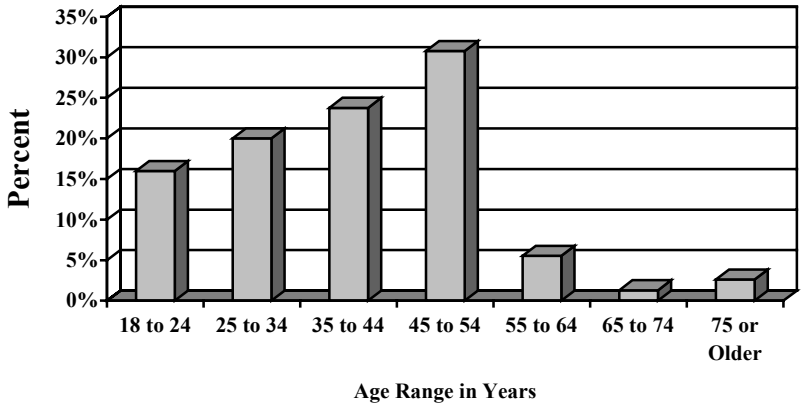


Table 1: Educational Achievement of Individuals with Severe Mental Illnesses

Highest Level of Education	Percent
Less than high school	8.79
Some high school	4.30
High school graduate/G.E.D. recipient	22.73
Some college	31.37
Undergraduate degree	17.78
Some graduate school	2.51
Graduate degree	10.01
Vocational training	2.51

But that's where the similarities with other working age adults ends. Most of the individuals with a serious mental illness had never married—70 percent; just over half lived alone (27 percent) or with their aging parents (25 percent); 69 percent were unemployed. The result: extreme poverty. Twenty-two percent had an annual income of $5,000 or less (table 2). Nearly three-quarters lived on $20,000 or less each year.

Table 2: The Annual Income of Individuals with Severe Mental Illnesses

Annual Income	Percent	Cumulative Percent
Less than $5,000	21.68	21.68
Between $5,000 to $10,000	28.28	49.96
Between $10,000 to $20,000	22.75	72.71
Between $20,000 to $35,000	2.62	75.33
Between $35,000 to $50,000	3.18	78.50
More than $50,000	8.35	86.85
Not sure	13.15	100.00

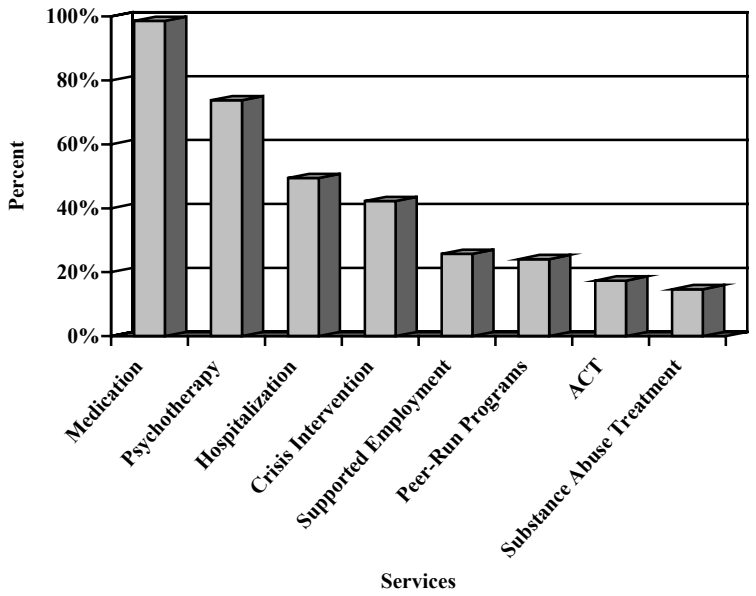
Residents of Massachusetts with severe mental illnesses represented in the survey get the little money that they have through public income replacement programs, including Supplemental Security Income (SSI)—45 percent—and Social Security Disability Income (SSDI)—33 percent. Family members are also a significant source of financial support, with 20 percent of the individuals represented in the survey reporting the receipt of money on a regular basis from family.

Individuals in Massachusetts with serious mental illnesses also rely on public programs, oftentimes, for their health insurance. Thirty-three percent and 41 percent, respectively, rely on Medicare and Medicaid. Still, one-third have private health insurance and another 7 percent have no health insurance at all.

All of the individuals with severe mental illnesses represented in the Massachusetts NAMI survey have received medication for their psychiatric condition (100 percent) and the vast majority have been hospitalized (89 percent). Evidence-based, recovery-oriented services, however, were far less frequently accessed. Only 19 percent of the individuals with severe mental illnesses ever received Assertive Community Treatment services (or ACT); 30 percent ever received supported employment services; 16 percent integrated treatment of substance abuse problems and their mental illness. Less than one-third of the consumers ever received peer-provided services.

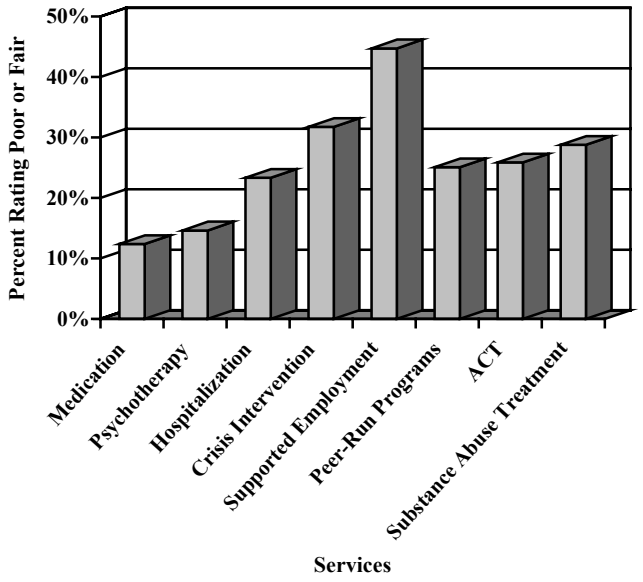
A similar pattern held true in the last year (figure 2). Virtually all of the individuals with severe mental illnesses received medication. **Half—50 percent—were hospitalized in the last year.** Far fewer than half of these individuals received ACT services, supported employment, peer-provided services, or substance abuse treatment.

Figure 2: Mental Health Services Received by Massachusetts Residents with Mental Disorders in the Last Year



The quality of the services received in the last year often was found lacking by the NAMI respondents. Supported employment services, crisis intervention services, and substance abuse treatment were rated especially poorly by respondents to the survey (figure 3).

Figure 3: Quality of Mental Health Care Received in the Last Year



The individuals in Massachusetts who responded to the NAMI survey identified several barriers to housing and employment. Cost, far and away, was the leading barrier to appropriate housing (table 3), with the lack of housing supports and stigma/discrimination also cited as barriers. Stigma and discrimination was the leading barrier to employment cited, by 44 percent of the respondents (table 4). Fear of losing health or disability benefits and a lack of jobs in the community were the other two leading barriers to employment.

Table 3: Barriers to Housing

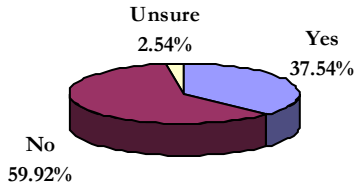
Barriers to Housing	Percent
Housing costs are too expensive	50.42
Appropriate housing is limited due to stigma against people with mental illness	28.93
Lack of community supports for independent living	31.28
More structured care not available	26.73
No financial assistance from government to pay for housing and support	18.11
Family does not support living independently	14.00
Other	18.12
Unsure	4.66

Table 4: Barriers to Employment

Barriers to Employment	Percent
Lack of jobs in the community	34.59
Stigma and discrimination against people with mental disorders	43.83
Lack of vocational services	18.70
Fear of losing health or disability income benefits	43.10
Inadequate treatment of mental health condition	22.83
Lack of transportation to job/employment services	19.80
Other	35.75
Unsure	9.83

The results of these barriers and lack of recovery-oriented care? More than one-third of the respondents indicated that the individuals in Massachusetts with severe mental illnesses represented in the NAMI survey have been arrested or detained by police (figure 5).

Figure 5: Criminalization of Mental Illness in Massachusetts



Individuals with mental illness living in Massachusetts who were ever arrested or detained by police, from the national survey.

[i] Nationwide, 3,400 individuals with serious mental illnesses and their families were represented in the survey, with 90 individuals living in the state of Massachusetts. The survey was conducted in the spring of 2003. Full details and results of the survey can be found at www.nami.org/triad.