



NAMI ★ *The Nation's Voice on Mental Illness*
Campaign For The Mind Of America
Partnerships For Recovery

TO LIFT THE BURDEN



Reducing the Costs of Untreated Mental Illness in Ohio While Improving Care

**NAMI OHIO AND PARTNERS OF
THE CAMPAIGN FOR THE MIND OF AMERICA**

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**Presented by NAMI Ohio
A Member of the Coalition of Healthy Communities**

NAMI Ohio Mission

To improve the quality of life,
ensure dignity and respect for
persons with serious mental illness,
and to support their families.

EXECUTIVE SUMMARY

With almost two and a half million Ohioans suffering a mental disorder in any given year, mental illness touches almost every family in the state. The direct and indirect costs to Ohio of mental illness total more than \$6.5 billion a year. State and county governments are forced to pay millions of dollars each year in emergency medical care, education interventions, long-term nursing home care, unemployment, housing, and law enforcement, including juvenile justice, jail and prison costs. Everyone is affected.

And yet, mental illness is a challenge that can be met. The U.S. Department of Health & Human Services (HHS) and experts in the field are promoting proven interventions that promote recovery for people with serious mental illness-- including the implementation of evidence-based practices (EBPs).

Despite advances, nearly 50% of all people with a serious mental illness do not get the treatment they need. In Ohio and other states inadequate health insurance coverage, stigma, financial disincentives to treatment and lack of qualified mental health professionals prevent people from getting the help they need.

To close these gaps and decrease the costs of untreated mental illness, NAMI Ohio and the Campaign for the Mind of America recommend:

- **Mental Health Parity:** *Ohio must join 35 other states and pass a mental health parity law to end the discrimination in insurance coverage for the treatment of mental illnesses.*
- **Access to Medications:** *Doctors must continue to be allowed to utilize the latest breakthroughs in medical science to treat the most severely mentally disabled without bureaucratic restrictions to the access of life-saving medications.*
- **Investment in Core Services:** *Ohio must fulfill its promise to its most vulnerable citizens and fully fund the community mental health care system in this state. The legislature should support the Governor's mental health budget recommendations.*
- **Housing:** *Safe and affordable housing options are essential to ensure that recovery from a serious mental illness is attainable.*
- **Child Custody:** *Parents and caregivers of children living with mental illness must not be forced to relinquish custody of their children to the state of Ohio in order to secure treatment and services.*
- **Employment:** *Every Ohioan must have the opportunity to fully participate in their community and should be supported and encouraged to find and maintain employment.*

In a time of tough choices, this report offers economically sound solutions to protect services for the state's most vulnerable citizens. In particular, Ohio should learn from other states facing

similar budget pressures that have developed innovative programs to care for people with mental illness.

I. INTRODUCTION

Mental illnesses are extremely common; they affect almost every family in Ohio. They affect people from every background and occur at any age. One in five Americans suffer a mental disorder in any given year. This translates into approximately 2.3 million Ohioans.

Without treatment, people living with mental illnesses are rarely able to achieve school success, secure employment, maintain adequate housing, and ultimately live a quality, productive life in the community.

Nationally, between 5 percent and 7 percent of adults in any year have a serious mental illness. The percentage is similar for children: between 5 percent and 9 percent. Proportionately, out of a population of 11.4 million, **more than half a million children, adults and seniors in Ohio are affected by potentially disabling mental illnesses every year.**

II. UNTREATED MENTAL ILLNESS: IMPACT ON OHIO

In the United States, mental illnesses account for more than 15 percent of the overall burden of disease from all causes—slightly more than that of cancer. In Ohio, mental illnesses and emotional and behavioral disorders are major barriers to school success, employment, housing and quality of life, and a leading contributing factor to poverty.

Failure to provide timely treatment can destroy individuals and families. Untreated mental illness is the leading cause of disability and suicide and imposes high costs on state and local government. Many people left untreated or with insufficient care see their illnesses worsen. Children left untreated become unable to learn or participate in a normal school environment. Adults lose their ability to work and be independent; many become homeless and are subject to frequent hospitalizations or jail.

No parent should have to give up custody of a child and no adult or senior should be forced to go on disability or become homeless to get mental health services as too often happens now. Those are the terrible realities that too many Ohioans face. Lives can be devastated and families financially ruined by the costs of care.

For too many Ohioans, also, mental health care and supports remain fragmented, disconnected and inadequate—frustrating opportunity for recovery. The grim reality is that in many communities in the state, treatment is non-existent and in others extremely difficult to access.

Mental illness is expensive. Nationally, direct treatment (public and private) costs an estimated \$69 billion in 1996, translating into over \$3 billion in Ohio alone. Indirect costs for untreated

mental illness such as lost productivity were estimated at \$79 billion. In Ohio, indirect costs were estimated at more than \$3.5 billion.

Overall, the total national cost of mental illness was estimated at \$148 billion annually. In Ohio, that figure translates to more than \$6.5 billion per year.

Untreated mental illness also involves other costs, costs that are shifted to other sectors of society, including county systems and budgets. State and county governments are forced to pay millions of dollars each year in emergency medical care, education interventions, long-term nursing home care, unemployment, housing, and law enforcement, including juvenile justice, jail and prison costs. Everyone ends up being affected.

Spending \$\$ in All the Wrong Places -- The Unintended Consequences of Untreated Mental Illness in Ohio

- **Children with mental illness often do not graduate. Over half (58%) of children with severe mental illnesses do not graduate from high school.**
- **Children with parents with mental illness are over represented in the child welfare system. Only one-third of children with a parent who has a serious mental illness are being raised by that parent.**
- **Lost productivity not only robs people living with mental illnesses of a measure of dignity, but also reduces the community tax base. More than 90 percent of adults with severe mental illness end up unemployed.**
- **Individuals with mental illness frequently end up homeless. Over 30 percent of homeless Ohioans have a mental illness.**
- **Adults with untreated mental illness often end up in jails and prisons. The Ohio Department of Rehabilitation and Correction estimates that 12 percent of inmates are diagnosed as “seriously mentally ill.” Many children with mental illnesses end up in the juvenile justice system. Nearly 75 percent of children in the system have a mental disorder.**
- **Almost all suicides are the result of mental illness, with impacts that extend throughout families and communities. Among young people ages 15 to 24, suicide is the third leading cause of death today.**

III. IMPACT ON CHILDREN

Ohio is home to nearly three million children and youth. Of these, about 175,000 were under age five and living in poverty in 1996. Research suggests that as many as 20 percent of these young children are at high risk for being unable to relate to other children, poor academic performance, •

developmental delays, and post traumatic stress disorders. They are also usually more sad, anxious, aggressive, and impulsive than their peers. In addition, they are at a higher risk to use alcohol, drugs and tobacco, and to engage in other risky behaviors as they get older.

About 1.8 million children and youth are enrolled in Ohio's public schools. Of the 432,000 students in 21 urban school districts, the graduation rate is only 43 percent. More and more students statewide are being suspended and expelled for disruptive behaviors in the classrooms. There is a significant increase in alcohol use among children under age 13 (30 percent in 1993, 37 percent in 1997, and 45 percent in 1999). Drug use, teen sexual activity, and low passage rates on school proficiency tests also contribute to a dismal picture for many of Ohio's children and youth. About 23 percent of all high school students report having considered suicide.

The Surgeon General's Report suggests that as many as 400,000 Ohio students (21 percent) may suffer from a diagnosable mental or addictive disorder, and 198,000 (11 percent) may have a mental illness that significantly impairs their daily functioning. Other studies indicate that only about one percent of children and adolescents with a serious emotional disturbance are in special education courses. Of the 21 percent of children and adolescents with a diagnosable illness, less than half receive any type of treatment and less than a quarter receive specialty mental health care. In Ohio, in fiscal year 1997, approximately 47,600 children (about 1.5 percent of all children in Ohio) received community mental health services. Of those, 22,975 (48.2%) were severely emotionally disturbed.

The idea of being forced to decide between the custody of a child and accessing critically needed services for a child with severe mental illness is unspeakable -- but a stark reality for too many families. As a result, far too many families are forced to do the unthinkable - relinquish custody of their child to the state to access services to treat the child's mental illness. According to Community Service Board reports, over 1,000 families relinquished custody of their children to the state of Ohio in order to secure needed mental health treatment for them as these children do not have access to the treatment and services they need.

This happens in Ohio for several reasons: (1) Private health plans either limit the number of hospital days and therapy visits or fail to provide for intensive services, (2) Publicly funded services are insufficient or unavailable, or (3) Intensive treatment, whether at home, in the hospital, or in residential treatment facilities, is very expensive or not available. As a consequence, families are shattered and forced to abandon their children to the custody of the state, unthinkable for most parents.

IV. STATUS REPORT: BASIC SERVICES IN OHIO

The U.S. Department of Health & Human Services (HHS), Substance Abuse & Mental Health Services Administration (SAMHSA) and experts in the field are promoting services and supports for people with serious mental illness from community living, including the implementation of evidence-based practices (EBPs) – proven interventions that are shown by research and implementation to work and promote recovery.

These interventions, together with stable housing, really work at helping people 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, Ohio must go farther in implementing EBPs. Unfortunately, the vast majority of individuals who need these services and can benefit from them are not receiving basic, core interventions.

Although Ohio has made an effort to implement evidence-based practices to assist adults with mental illness, including those adults most severely in need of these services, there remain significant gaps between the number of programs and the needs of people with mental illness. We want to work with all stakeholders to close those gaps.

“Intensive case management, a service badly needed by patients whose lives are in upheaval, is a thing of the past in our part of the state.”

NAMI Ohio – Mental Health Safety Net Survey

Access to the multiple services described below is frequently impeded because responsibility for providing them is vested with different providers who are administered by different systems and are subject to different funding streams and rules. Additionally, the boundaries between public and private sector services have been increasingly blurred as public sector agencies have contracted with private organizations to provide and/or manage services. We are prepared to work with all stakeholders to assure close collaboration and coordination among diverse systems and providers to achieving cost effective and positive outcomes for the treatment of people with severe mental illnesses.

A Snapshot of Implementation of Evidence Based Practices (EBPs)

According to the 2000 U.S. Census, the state of Ohio has a total population of 11,353,140; 74.6% of this population or 8,469,442 is 18 years of age or older.

It is estimated that 2% of the adult population has persistent and severe mental illness – 2% of Ohio’s adult population is 169,388 – it is thus estimated that this is the number of adults in Ohio with severe and persistent mental illness.

Ohio has made an effort to implement evidence-based practices for assisting adults with mental illness. Below is a brief summary of progress based on self-reported data for FY ‘04 from Ohio government agencies:

- **ACT:** ACT is defined as a multi-disciplinary clinical team approach to provide intensive community treatment, support and rehabilitation services on a time unlimited basis to

individuals who experience the most intractable symptoms of severe mental illness and who often experience the greatest functional deficits. Statewide implementation is underway with a target date of July 2005. In the first year of establishment, 1,000 persons were served by ACT services. As statewide implementation occurs, the number of people using the services should increase drastically.

NAMI Expectations: 16,940 persons served

- **Supported Employment:** Supported employment programs typically assist people in obtaining competitive employment—that is, community jobs paying at least minimum wage for which any person can apply—in accord with client choices and capabilities, without requiring extended prevocational training. Four programs were established in FY 2004, expanding to 10 in FY 2005, with statewide services offered by 2006. Thus far, 125 persons have been served. This program has yet to reach many people in need.

NAMI Expectations: ~42,350

- **Family Psychoeducation:** Offered as part of an overall clinical treatment plan for individuals with mental illness to achieve the best possible outcome through the active involvement of family members in treatment and management and to alleviate the suffering of family members by supporting them in their efforts to aid the recovery of their loved ones. Forty eight (48) programs have been established. Annually, 800 persons are served – significant expansion is required to fully meet the needs of Ohio family members of people with severe and persistent mental illness.

NAMI Expectations: Minimum 42,350 family members

- **Integrated MH/SA Services:** Dual diagnosis treatments combine or integrate mental health and substance abuse interventions at the level of the clinical encounter. Hence, integrated treatment means that the same clinicians or teams of clinicians, working in one setting, provide appropriate mental health and substance abuse interventions in a coordinated fashion. Currently, there are 24 such programs. These programs reach 400 participants annually. Programs need to expand in order to serve the population as needed.

NAMI Expectations: N/A

- **Illness Self-Management:** Includes a broad range of health, lifestyle, and self-assessment and treatment behaviors by the individual with mental illness, often with the assistance and support of others, so they are able to take care of themselves, manage symptoms, and learn ways to cope better with their illness. Six programs are in existence. Only 250 persons have been served. This program is not reaching an appropriate portion of the community.

NAMI Expectations: Accessible to 84,694 persons with severe and persistent mental illness in Ohio

Other efforts, such as 7 mental health courts have been established and have assisted 800 people with mental illnesses. Additionally, the 28 jail diversion programs in the state have been used by 1,400 Ohioans and the 50 supported housing rental assistance programs have assisted 4,700

people with disabilities in the state.

V. TREATMENTS THAT WORK

Thanks to advances in medical science, treatment for people living with mental illnesses have become more specialized and effective, on par with, and often more successful than, treatments for “physical” ailments.

The U.S. Surgeon General has documented the efficacy of treatments. Progress is the result of increased knowledge of the brain and the development of new and improved psychotropic medications, and use of research-based, evidence-based psychotherapies.

Despite these advances, nearly 50% of all people with a serious mental illness do not get the treatment they need. There are many reasons: lack of or inadequate health insurance coverage, stigma associated with mental illness, financial disincentives to treatment and lack of qualified mental health professionals. In Ohio and across the country, too many people who do seek treatment do not receive the right services or ones with appropriate frequency and quality.

In cost cutting moves 25 years ago, Ohio began drastically reducing its services in state hospitals for people with severe mental illness. Thousands ended up on the streets homeless, in the state’s jails and prisons or back with their families who are ill equipped to care for them. **Today thousands of suffering people remain without adequate care and have been abandoned and forgotten in deplorable conditions or on the street because they are afflicted with untreated severe mental illness. We can and should offer these people the care they need to lead more productive lives.**

“It is disturbing and disappointing to learn from NAMI families that their consumer rarely, if ever, has access to newer, more effective medications.”

NAMI Ohio – Mental Health Safety Net Survey

With effective treatment and support, recovery from mental illness is feasible for most people. For the most severely disabled, effective treatment often means access to the newest medications, such as atypical antipsychotic and anti-depressant agents. **Correctly prescribed, these miracle medications have proven to be successful tools to help the sickest citizens reclaim their lives free of the debilitating symptoms of a serious mental illness.** With access to the same level of care afforded sufferers of heart disease, the success rate could be significantly higher for people suffering from a biological brain disorder. Access to the medications that make this possible is essential if we are going to commit to the best, most cost effective strategy of treating the most severely mentally disabled. NAMI Ohio is indebted to the Ohio Department of Job and Family Services for their commitment to ensuring access to all medications for the treatments of severe mental illnesses in Ohio.

VI. PRIORITIES FOR THE STATE OF OHIO

NAMI Ohio and The Campaign for the Mind of America strongly believe that advocating for access to treatment and support services is our top priority. As a state organization, the NAMI Ohio Board of Directors has identified areas that they believe can have the biggest impact in addressing this priority.

PRIORITY ISSUE! **Mental Health Parity in Ohio**

After successfully moving H.B. 225 (Mental Health Parity) through the House and securing the support of a clear majority in the Senate, mental health advocates were disappointed to lose the final battle to the powerful business and insurance lobby. Despite this setback, significant progress was made in educating the members of the Ohio legislature. At every point in the process, legislators who were once staunch opponents changed their position to that of vocal supporters as a result of the passionate testimony on the part of the families and consumers in this state coping with a serious mental illness. While most of the same obstacles stand in our way again in 2005, the family and consumer movement in Ohio seems to have the momentum in this battle and has shown the tenacity to achieve success in the coming year. However, stigma and misunderstanding still abound.

NAMI Ohio supports mental health parity in private individual and employer-based and public insurance coverage for mental illnesses. Central to an understanding that mental illnesses are both “blameless” and treatable is non-discriminatory coverage for the necessary medical care for these illnesses. One key to unlocking the prisons of these illnesses is research, and research is driven by funding. The discrimination in access to care is evidenced by limited coverage, punitive co-pays and restricted access to hospitalization during acute episodes and what one would logically conclude would occur for other untreated or under-treated serious illnesses. That is to say: the outcome for people with untreated or under-treated illnesses are disastrous and too frequently results in death or permanent disability. To that effect NAMI Ohio has been actively pursuing non-discrimination clauses in Ohio’s state insurance laws.

- There is no medical or economic reason for health insurance plans to discriminate between mental illnesses and other illnesses.
- Mental illnesses such as schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder and severe anxiety disorders are real illnesses.
- There is simply no scientific or medical justification for insurance coverage of mental illness treatment to be on different terms and conditions than other diseases.
- Discriminatory insurance coverage of mental illness bankrupts families and places a tremendous burden on taxpayers.
- Parity is affordable - the Congressional Budget Office (CBO) estimates that S 543 will increase insurance premiums by less than 1% (a finding that is consistent with numerous previous studies that demonstrate how non-discriminatory coverage is economical and results in better treatment outcomes).
- 35 states have enacted parity laws.

PRIORITY ISSUE!
Access to Medications

In response to runaway Medicaid budgets and partially as a result of the breakthroughs (and therefore, higher costs) in the treatment of biological brain disorders, there is a quickly growing threat of significantly reduced funding for, and access to the medications that have shown to have the greatest impact on the symptoms of the most seriously mentally ill. Mental health advocates must convince the legislature that Line 419 needs a significant increase so that communities can provide the medications that are essential to recovery. Proposed cuts to the Medical Disability Benefits, increased funding for Line 419 becomes more urgent. Advocates also must address the findings in the Medicaid Reform Commission’s Report that threaten to limit access to medications through limited formularies, prior authorization, “fail first” requirements and tiered co-payments for any medications prescribed to treat a serious mental illness. The recent agreement between Jobs and Family Services and NAMI Ohio prohibits restrictive policies such as limited formularies, prior authorization, “fail first” requirements and tiered co-payments for any medications prescribed to treat a serious mental illness. ODJFS Director Barbara Riley’s commitment to ensure access to these life-saving medications is a significant part of NAMI Ohio’s campaign to protect access to medications for the most severely mentally disabled.

NAMI Ohio and the Partners of the Campaign for the Mind of America strongly urge the state to reconsider the proposed cuts of the Disability Medical Assistance Program. However, if this program is indeed cut, NAMI Ohio and its Campaign Partners are advocating for a \$3 million increase to cover the costs of making medications available to the most severely mentally ill who are currently unable to access these life saving medications. This life saving program, Disability Medical Assistance, provides medications for the most poor and must be supported even if in modest terms.

Limiting access to necessary medications negatively impacts on productivity and the economy. With appropriate treatment, many people with mental illness are able to work and contribute as tax paying members of society. The denial of appropriate treatment impairs the ability of people with these disorders to maintain employment and fosters dependency on publicly funded benefits such as Supplemental Security Income and Medicaid. Restricting access is “risky business” for states.

It is critically important to maintain choice in order to find an effective treatment, as quickly as possible, thus achieving the best possible clinical outcome and avoiding much higher health care costs downstream in the form of emergency department visits, hospital stays and crisis management, as well as avoiding additional budget costs due to increased homelessness and involvement with criminal justice systems.

What are the Positive Effects of Access to Medications?

Enhanced productivity – With appropriate treatment, most people with serious mental illness are capable of working and contributing to the American tax base. In fact, a recent survey found

that the majority of the costs of treating depression are offset by the increased productivity of the individuals who received treatment.

Decreased public expenditures for hospital based services – The provision of appropriate treatment for these disorders decreases the necessity of crisis-oriented psychiatric services in inpatient treatment settings, the costs of which are frequently financed by publicly funded programs such as Medicaid and state mental health funds.

Lower burdens on law enforcement, courts and corrections – Police have become front line responders to people experiencing psychiatric crises in the U.S. Correctional facilities have become the largest de-facto psychiatric treatment facilities. The availability of timely and appropriate treatment for people with mental disorders will lessen significantly the considerable financial and human resource burdens that these roles entail. And, while people with serious mental illnesses are generally no more violent than the rest of society, the availability of appropriate treatment will also have a positive impact on public safety.

Healthier and more productive families – The availability of appropriate medications for people with these disorders decreases burdens on family members to provide constant care, and thereby allows family members to work and contribute more meaningfully to society.

PRIORITY ISSUE!
Appropriate Funding for Mental Health Services

As it is all over the country, state support for the public mental health care system in Ohio has been under serious attack since 2001. While the situation here is no different than what the rest of the country is facing, mental health advocates are in a markedly better position to defend themselves against the disastrous cuts being threatened elsewhere. In spite of a fiscally conservative leadership in Columbus, NAMI Ohio and our advocacy partners have successfully educated the Governor and the General Assembly on the absolute necessity of maintaining adequate funding for the core services relied upon by the communities serving the most serious mentally disabled.

The state budget process for the FY 06-07 plan will be every bit as brutal as the last two budgets, but we have achieved a certain amount of credibility with our case as a result of our persistent message of need over the past 4 years. That said, this will still be the most bitterly fought budget battle in the state's history. NAMI Ohio will need to utilize every education and advocacy weapon in our arsenal to make our voice heard on behalf of those we represent over the next 5 months. NAMI Ohio will advocate for adequate funding to maintain the access to mental health services in community and state hospital settings.

The Governor's budget recommendations for the next two fiscal years are as good as we could possibly expect given the state's current fiscal crisis. Therefore, NAMI Ohio

will be supporting the Governor’s budget proposal and will advocate in the House of Representatives and the Senate to ensure that it remains intact. NAMI Ohio also advocates for a \$3 million per year increase in Line 419 (medications) and will advocate for continued open access to the medications prescribed for the most severely mentally disabled.

NAMI recommends core community-based mental health services for Ohioans with severe mental illness; those who are covered by the public system and those who are not. Essential services include: crisis response, inpatient and residential treatment, psychiatric medication, intensive case management, psychotherapy for specified diagnoses, and support services.

Eligibility for core services should be based on functional assessment, so as to allocate scarce resources to the most disabled. Multiple funding streams should be crafted into a seamless system of care for this priority population, allowing for consistent service provision, quality assurance and cost effectiveness.

These basic investments could yield huge savings by preventing unnecessary incarcerations, chronic homelessness, overcrowding in emergency departments and reliance on social services, and most importantly help people with serious mental illness live independent lives and contribute to their communities.

Crisis Response

Community based crisis response services prevent suicide, unwarranted criminalization and costly hospitalization of people with mental illness. To realize these savings, Ohio must maintain round the clock psychiatric crisis response teams for telephone and face-to-face intervention in every county. Where insufficient mobile crisis teams exist we recommend psychiatric triage centers that operate on a walk-in basis. On-site security would allow law enforcement officers to transport consumers for evaluation, then return to protecting their communities.

Inpatient and Residential Treatment

When people with mental illness need acute inpatient care, we prefer small, local facilities. Regional Mental Health Centers should be the fall-back strategy for individuals with complex needs, not the first line of intervention. Unless people with severe mental illness can get rapid crisis response and short term local inpatient care, they will end up in the Behavioral Healthcare Organizations (state hospitals) at state expense, or in jail, on the street or in the morgue.

Residential treatment for co-occurring mental illness and substance abuse should be available along with inpatient and outpatient detoxification services. Strong evidence supports the use of integrated treatment to promote and sustain recovery for people with chemical dependency and mental illness.

Psychiatric Medication

To reduce the number of psychiatric prescriptions, we recommend using evidence-based medication algorithms, drug utilization review and physician-to-physician education. We are

gravely concerned that people with co-existing psychiatric and medical conditions may need more than four prescriptions per month, and therefore request a process to appeal medication limits for people with complex conditions. When general medical physicians prescribe psychiatric medications, the provision of psychiatric consultation will help physicians prescribe in a more effective and frugal manner.

Case Management

Consumers who are severely disabled require intensive case management to organize the resources necessary to support recovery. Since public dollars must be prioritized, we recommend focusing case management on those who need it most, rather than providing a little service to many people as we do now. The Program of Assertive Community Treatment (PACT) has proven over 30 years of research, to be the most effective method for stabilizing people who are extremely disabled in the community, thus avoiding long-term, costly hospitalization. We only have 17 PACT programs in Ohio at the present time. We need more.

Psychotherapy

Research shows that specific types of psychotherapy are the treatment of choice for disorders such as clinical depression, personality disorders, co-occurring mental illness and substance abuse and post-traumatic stress disorder (U.S. Surgeon General Report).

Psychosocial Rehabilitation

While standard methods of vocational rehabilitation have not generally been effective for people with severe mental illness, psychosocial rehabilitation has a proven track record of 40 years. Psychosocial clubhouses across Ohio provide pre-vocational training, transitional employment and supports to help people with serious mental illness get a job and keep a job.

Consumer and Family Education

An essential component of disease management is education of the patient and family about disease states and preventive strategies

There is widespread agreement in the mental health field that close collaboration and coordination among diverse systems and providers is essential to achieving good outcomes in the treatment of people with severe mental illnesses. NAMI Ohio is prepared to work with all parties to weave these core services into a tapestry that addresses the needs of vulnerable people with serious mental illness.

PRIORITY ISSUE!

Child Custody Relinquishment

Something must be done to stop custody relinquishment and the anguish it causes families and their children. No parent or caregiver should face the unthinkable prospect of choosing between the custody of their child and accessing critically needed services.

NAMI Ohio applauds the Governor's efforts at directing administrative policies that begin

to address the issue, specifically through the Access to Better Care Initiative. The 126th General Assembly, however, must pass S.B. 63 to move further to eliminate the practice in counties across the state and require county systems to develop processes for alternatives to this unthinkable consequence.

State policymakers and legislators must support the change that is needed to fix the problem and eliminate the practice of custody relinquishment by expanding mental health services and supports, particularly home- and community-based services for families and children while at the same time prohibiting agencies from requiring caregivers of children to relinquish custody solely for the purpose of obtaining necessary supports and services for the life of their children.

The cumulative efforts of Ohio’s child serving agencies, the state administration, the 126th General Assembly, and families must remain constant in their mission to enable families to remain intact while children living with mental illness receive the care they need.

PRIORITY ISSUE!
Housing

For too long, the state legislature has turned a blind eye to the deplorable condition and choices afforded consumers of mental health services when it comes to independent or supportive housing options. The tired excuse of not being able to afford to improve the standards for this basic necessity must be addressed. The reality is that recovery is nearly impossible without stable, affordable, safe housing and that without it the community mental health model cannot succeed. NAMI Ohio must raise the awareness of this important issue and provide the leadership to address the inexcusable lack of viable options for this basic human need. During the next biennium, NAMI Ohio advocates for the creation of 2,000 new housing options for persons with mental illness.

According to Ohio’s Mental Health Commission, access to adequate, decent and affordable housing is a key element to recovery for people with a serious mental illness. Unfortunately, the amount of housing available for people with a serious mental illness does not meet the need, and the quality of the housing that is available is often substandard. Adults with a mental illness are at the bottom of the housing marketplace and at great risk for homelessness.

“My son has been ill for years and has not been able to get housing.
Most housing I am aware of is in totally unsafe areas.”

NAMI Ohio – Parent

At the same time, the burden of providing housing for people with a mental illness is growing significantly for state and local authorities. Federally-funded production of low income housing has plummeted. Federal Section 8 housing vouchers have not kept pace with the demand or the marketplace, and Medicaid will not pay for residential care for persons with a serious mental

illness. Additionally, federally funded lower-income housing is being converted to market-rate housing as the initial 20-year obligation and financing commitment expires. Ohio leads the country in potential exposure to this problem. All of this is occurring in an environment in which rental and housing costs are rising substantially.

State and local officials must also do more to focus on housing stability, quality, and safety issues. The Ohio Department of Mental Health (ODMH) awarded more than \$6.5 million in community capital grants to local communities in 2000. The mental health system has also worked with the Departments of Aging and Health and their local systems on a program to tighten the requirements for Adult Care Facilities that provide care for people with mental illness, many of whom receive Residential Support Supplement funds from the Department of Aging. But in many neighborhoods, the housing that is available for people with a mental illness is deplorable. Housing is in fact a key component to recovery, but it must be decent, livable, and affordable. The mental health system has a responsibility to improve the current conditions.

PRIORITY ISSUE!

Employment

Every adult served in the mental health system and every young person with serious emotional disturbances making the transition from school to work must have access to employment services if they are to participate fully in society. NAMI Ohio believes that people with disabilities are entitled to the same rights and opportunities as all people to make decisions about where, how and with whom they will live and work as full and equal members of their communities.

NAMI Ohio advocates for the implementation of the Medicaid Buy-in Program as part of a comprehensive program to provide protection and advocacy services to SSI and SSDI beneficiaries who are working or returning to work.

Access to employment is a critical issue affecting adults with a serious mental illness. Mental illness often leads to lifelong joblessness, homelessness, and poverty. More than 90 percent of people with a serious mental illness are unemployed, despite the fact that many consumers themselves say that employment is their primary recovery goal. Severe mental illness often causes people to lose their job and their health insurance coverage or never have the opportunity to pursue employment or a career. The result is a downward social and economic spiral that makes recovery difficult. To continue receiving publicly funded services like Medicaid, the person often must remain poor and jobless.

Medicaid eligibility helps an individual pay for the mental health services he or she needs. But it also perversely forces the person to stay poor in order to continue receiving benefits. The Medicaid spend-down provision, which charges some consumers a portion of the cost of care (in theory increasing the number of people that can be covered), creates an unintended obstacle to employment. For people who are looking for work, supportive services are scarce and getting

scarcer.

Significant work must be done to remove all barriers to employment, but the work must start within the public mental health system, which itself does a poor job of promoting employment for the people it serves. Mental health services are often inflexible and difficult to access for individuals who are working. ODMH and others within the mental health system have a very low rate of hiring consumers. Employment must become a key recovery goal of the system.

VII. ALTERNATIVE PROPOSALS FOR MEDICAID COST SAVINGS AND FUNDING STRATEGIES – IDEAS THAT DO NOT INVOLVE DRASTIC REDUCTIONS IN ELIGIBILITY OR MEDICAL SERVICES.

NAMI Ohio believes that the core, community-based services described in the previous section are critically important so that people who have serious mental illness are able to live and become productive members of their communities. To fund these services and programs involves implementing new approaches to control the rate of escalation in health care spending but at the same time ensuring quality of care for consumers.

The National Association of State Budget Officers reports that “Medicaid spending continues to hound state budgets”, with all fifty states reporting that they have been forced to take aggressive measures to contain costs. States have looked at a variety of means to cut costs while seeking to protect the health and mental health of their people.

The National Conference of State Legislatures (NCSL) reports that all 50 states and the District of Columbia have worked to control the rate of escalation in health care costs and slow growth over the past couple of years. NCSL has provided a list of ten “fixes that work” for provider payments and prescription medication expenditures. NCSL cautions that restricting eligibility, reducing benefits and increasing co-payments, while having a short term impact can, “trigger costly consequences”.

To avoid that pitfall, states are employing other strategies. The NAMI Ohio and the Campaign for the Mind of America and its partners stand ready to assist the state in finding those strategies that meet the needs of the state and its citizens. We believe these approaches and examples will inform all parties on trends and provide for a consideration and conversation on a range of approaches implemented by other states.

Illinois

Illinois was recently successful, with the support of the Illinois Hospital Association, in getting the Bush administration to sign off on a hospital tax levy that will allow the state to capture \$450 million in extra federal Medicaid money. The hospital tax will bring an additional \$560 million to the state. The state will then use this revenue to boost Illinois’ share of federal matching dollars for Medicaid. Much of this will then be returned to hospitals in the form of increased payments for treating Medicaid patients.

Michigan

A 75 cent-a-pack increase has been added in the state's cigarette tax which generates an additional \$300 million annually into the state's Medicaid program.

Missouri

Missouri formed the Missouri Mental Health Medicaid Pharmacy Partnership (MHMPP) in March of 2003. MHMPP retained the services of Comprehensive Neuroscience, Inc. (CNS) to evaluate mental health medication prescribing practices focusing on improving patient care by educating doctors regarding best practices standards of mental health medications and reviewing, identifying and analyzing problematic prescribing patterns of physicians who frequently deviate from those guidelines (Alternatives to Restricting Access to Mediations).

This program analyzes pharmacy claims data on a monthly trend basis for better behavioral pharmacy management, identifies prescriber outliers based on deviations from nationally recognized best practice Guidelines, engages outlier prescribers through targeted educational messages, benchmarking and peer review consultations, tracks changes in outlier prescribing practice over time, tracks high-risk patients' failure to refill antipsychotic medications and reports to physicians, and identifies patients receiving current same-class medications from multiple prescribers and alerts all involved prescribers. It is estimated that Missouri saved nearly \$9 million under the first year of the program.

NAMI Ohio recognizes and applauds ODJFS Director Barbara Riley's commitment to ensure access to these life-saving medications through recent agreements that include the prohibition of restrictive policies such as limited formularies, prior authorization, "fail first" requirements and tiered co-payments for medications for people living with mental illness. At the same time, NAMI Ohio and its partners must remain vigilant to ensure that this life saving measure remains as part of Ohio policy long term.

Louisiana

A 22-page "plan for immediate action" by the Department of Health and Hospital is calling for a change in the way nursing homes are paid under Medicaid. They are advocating for one long-term Medicaid unit that will oversee all services for the elderly, disabled, nursing home and waiver people who want home and community-based care. Home and community-based care services are currently handled by separate agencies with separate budgets.

The state currently collects a provider tax from nursing homes that is based on the number of patients they serve. Proposals have been made to charge a tax on the number of beds, rather than the number of patients, as an incentive for nursing homes to cut back on their number of beds and to steer nursing homes into the business of providing community-based services.

New York

The Health Care Reform Working group, headed by Stephen Berger, proposed reducing Medicaid reimbursements to hospitals on certain "high end" treatments like transplants and cardiac care, and give savings to more basic services like emergency room care and treatment for asthma.

Vermont

About two-thirds of Vermont's Medicaid spending is financed from their Health Access Trust Fund (HATF). Revenues for the trust fund come from tobacco (taxes as well as part of the settlement from cigarette manufacturers), provider taxes on hospitals, nursing homes and home health agencies, and an annual transfer from the General Fund.

Washington State

The state's Department of Social and Health Services has created a "No Wrong Door" program to coordinate services across various programs. Three specific groups were recognized as key targets for program coordination: people with multiple disabilities including mental illness; troubled youth and their families; and long-term welfare recipients, many of whom were dealing with chemical dependency or mental illness.

IX. CONCLUSION

We recognize that the state government continues to face acute financial pressures. But caring for people with mental illnesses is also a critical issue for state government. Understanding mental illness, patient needs, and how services are currently provided are important steps in determining what actions the state of Ohio can take to improve access to quality treatment and services. Because of the nature of mental illness, individuals often require a multi-faceted approach to care. Meeting the needs of people with mental illness means addressing their "total care" needs, and that includes job training, access to medications and other services described as part of our "core services" strategy.

Given today's budgetary difficulties in Ohio, ensuring that patient needs are met through an array of services can appear challenging. Yet, the fiscal risks to the state of drastic cost containment actions, or inaction, i.e, not addressing the medical and social needs of people with mental illness – can result in greater financial costs, but most notably, can ultimately put individuals at risk.

NAMI Ohio and the Campaign for the Mind of America are prepared to work with all stakeholders to develop common goals and solutions to help to ensure that systems of care and social supports are designed efficiently and effectively and aid recovery and life in the community for people with mental illness.

We have highlighted several strategies that states have adopted or are considering in order to enhance revenue streams through hospital tax levies, financing reforms and additional "sin" taxes. Additionally, we have identified several strategies that preserve access to medications while protecting quality that have been adopted by states around the country. Restricting access to medications will not result in real cost savings – just cost shifting and ultimately affecting other state budget silos in a negative way.

It is incumbent that all concerned with the welfare of people with mental illness, develop strategies to provide quality health care that is both medically sound and cost-effective. Working together we can improve patient outcomes and save money in the short and long run.

- OHIO MUST JOIN 35 OTHER STATES AND PASS A MENTAL HEALTH PARITY LAW TO END THE DISCRIMINATION IN INSURANCE COVERAGE FOR THE TREATMENT OF MENTAL ILLNESSES.
- DOCTORS MUST BE ALLOWED TO UTILIZE THE LATEST BREAKTHROUGHS IN MEDICAL SCIENCE TO TREAT THE MOST SEVERLY MENTALLY DISABLED WITHOUT BUREACRATIC RESTRICTIONS TO THE ACCESS OF LIFE-SAVING MEDICATIONS.
- OHIO MUST FULFILL ITS PROMISE TO ITS MOST VULNERABLE CITIZENS AND FULLY FUND THE COMMUNITY MENTAL HEALTH CARE SYSTEM IN THIS STATE.
- OHIO MUST ENSURE THAT FAMILIES AND CAREGIVERS OF CHILDREN WITH MENTAL ILLNESS DO NOT HAVE TO RELINQUISH CUSTODY OF THEIR CHILDREN TO THE STATE IN ORDER TO ENSURE APPROPRIATE SERVICES AND TREATMENTS.
- SAFE AND AFFORDABLE HOUSING OPTIONS ARE ESSENTIAL TO ENSURE THAT RECOVERY FROM A SERIOUS MENTAL ILLNESS IS ATTAINABLE.
- EVERY OHIOAN MUST HAVE THE OPPORTUNITY TO FULLY PARTICIPATE IN THEIR COMMUNITY AND SHOULD BE SUPPORTED AND ENCOURAGED TO FIND AND MAINTAIN EMPLOYMENT.

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