

STATEMENT

of

THE NATIONAL ALLIANCE ON MENTAL ILLNESS
OF NEW YORK STATE (NAMI-NYS)

before

THE SENATE FINANCE COMMITTEE

and

THE ASSEMBLY WAYS AND MEANS COMMITTEE

at the

BUDGET HEARING ON MENTAL HEALTH SERVICES

February 7, 2007

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MURIEL SHEPHERD (Co- Chair)
ROY NEVILLE (Co-Chair)
Government Affairs Committee
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My name is David Seay and I am Executive Director of the National Alliance on Mental Illness of New York State, also known as NAMI. With me today is our President, Sherry Grenz, and Roy Neville, Co-Chair of our Government Affairs Committee.

NAMI-NYS this year is celebrating 25 years of families helping families. We are a grassroots organization whose mission is to improve the lives of all New Yorkers affected by the brain disorders known as mental illness. We accomplish this through carefully crafted programs of support, education and advocacy. Our membership consists of thousands of families and friends of persons with serious mental illness and their ill loved ones statewide in 60 local affiliate organizations across the state. We are part of the national NAMI movement which is the nation's largest mental health advocacy organization.

We thank you for the opportunity today to comment on the Executive Budget submitted to the Legislature by Governor Spitzer.

First off, we want to applaud – no wait – we want to give a standing ovation to Governor Spitzer for crafting a proposed budget that does what this budget does for the Office of Mental Health and for all New Yorkers who struggle to live with and strive to recover from serious mental illness. Sherry and Roy will highlight some of the details contained in our written Statement, but I will begin by saluting the Governor for his bold initiative on housing – with support services – for persons with mental illness. His inclusion of funding for 2,000 more beds is most positive and reverses a trend in recent years to back-pedal on the state's commitment to provide adequate housing and services to these vulnerable citizens. Although we are a part of and endorse the Campaign for Mental Health Housing's call for a long-term commitment to build at least 35,000 more such beds, we are most heartened by the message Governor Spitzer has sent on housing. Similarly in the area of research into the causes and treatments of mental illness, the Governor has included funding for 15 new research positions for our two world-class mental illness research centers – the Nathan Kline and New York State Psychiatric Institutes. This reverses efforts in recent years to close or starve these precious state assets. We thank the Governor for this message also.

We are also very pleased to see that he has fully funded the first year of implementation of Timothy's Law, included funding for the treatment of seriously mentally ill prisoners as an alternative to the Special Housing Units, and has funded the Geriatric Mental Health Act.

Sherry Grenz and Roy Neville will now cover a few details of our Statement while adhering to our time limit.

HOUSING

"The road to recovery starts with a good home." "Preserve, Reform, and Develop" were the chants of eighteen hundred advocates at the recent rally of the New York State Campaign for Mental Health Housing at the capitol last month. Consumers, family members, providers and advocates, including the League of Women Voters, were there.

Since then we have all applauded Governor Spitzer's funding for 2,000 more beds of mental health housing in his first budget and we hope the momentum will continue in order to solve the longstanding housing crisis.

Presently, state assisted housing is available to only 13.7 percent of New Yorkers with serious mental illnesses. Badly needed is a viable long-term program to provide at least 35,000 more units of housing with support services and to improve housing that already exists as proposed by the Campaign for Mental Health Housing. It is needed upstate and on Long Island as well as in New York City. To meet the ten year goal the state should develop 3,500 units per year.

Full funding is also provided in this year's budget for continuation of last year's New York/New York III agreement expected to provide an additional 5,000 units of supportive housing for individuals with serious mental illnesses in ten years.

This really is spending money in the right places as housing is basic to improving the quality of life and to recovery and it is prudent. The recent landmark University of Pennsylvania study of 5,000 homeless adults with mental illnesses in New York City showed that it costs little more to provide supportive housing and group homes than to leave people homeless. A startling high cost was found for maintaining them in a state of homelessness, as they used \$40,500 worth of publicly funded services annually, such as psychiatric hospitals, Article 28 hospital beds and emergency room services, shelters and prisons, not counting the costs of courts, police, soup kitchens, private shelters and outreach services. Savings in these areas offset the cost of supportive housing.

It should be noted that a recent study of homeless individuals in New York City showed that their physical health is much worse than that of others.

Consumers need a broad range of housing options to meet their individual needs: Apartment or single-room occupancy (SRO) buildings, townhouses or single family homes that exclusively house homeless individuals with serious mental illness or ones that mix special needs housing with general affordable housing; rent-subsidized apartments leased in the open market; and long-term set-asides of units within privately owned buildings. Flexibility and reform of existing models created in the eighties is necessary as some are no longer responsive to all of today's consumers. Most important is whether support services are linked to housing in a way that accommodates the varying needs of consumers over time.

An increase in rent stipends were provided in the budget for the third and last time, unless a decision is made to continue them. Continuation will be essential in order for providers to cover their costs.

Funding is needed this year for improvements for adult home residents: \$5 million for nonprofit agency case management services and \$3 million for legal advocacy.

Finally, a chief concern of NAMI families is that the Office of Mental Health's Single Point of Access regulation does not assign any priority to adult children who are living with their aging parents. According to an OMH study requested by the State Senate, the mortality rate of parents providing housing to their psychiatrically disabled loved ones ranges up to 1,200 per year. The greatest fear of families is that their adult children will become homeless. The State needs to do its share when families can no longer do theirs.

According to NAMI's 1998 survey of families, "A Crisis in Housing", 55% of the adult children were not living in preferred situations. The largest percentage of those who preferred their current situations--83%--were in apartment programs; and the smallest percentage of those preferring their current situations--18%--lived with their families because there were no other choices. Parents were also unhappy because they prefer that their adult children move toward independence.

Safe, decent, stable, affordable housing must be available to all persons living with mental illness who need it.

MEDICAID

For hundreds of thousands of New Yorkers with serious mental illnesses, Medicaid is the lifeline for access to life-saving, recovery-fostering treatment, medication, housing and support services. The advent last year of the Medicare Part D prescription drug "benefit," under which primary drug coverage for "Dual Eligible" New Yorkers shifted from Medicaid to Medicare, added yet another safety net role to the program through its "Wraparound" drug benefit.

In its efforts to rein in the costs of this vital program, New York State must ensure that cost-containment not lead to "care containment." It must ensure the health and safety of our most vulnerable citizens not be placed at the mercy of for-profit HMO's, an area of particular concern to us with the advent of mandatory enrollment for the previously exempt Serious and Persistent Mental Illness (SPMI) population into Medicaid Managed Care for health services.

In addition to ensuring adequate access to specialty care providers, our chief concerns with Medicaid Managed Care for the SPMI population are the potential rationing of care for individuals with multiple complex medical conditions and further bifurcation of health and mental health services, an issue we'll talk about later on in our testimony.

The state must also ensure that prescribing decisions under Medicaid be made by physicians and their patients, not HMOs or bureaucrats in Albany. We believe the

Executive Budget's proposal to add the currently-exempt antidepressant class of medications to the Medicaid Preferred Drug Program to be a step back for New Yorkers struggling to recover from serious mental illnesses, including not only depressive disorders, but mood, anxiety, and thought disorders as well, since many individuals suffer from more than one psychiatric condition. Despite the welcome inclusion of the "Physician Prevails" patient protection for this class, we believe the savings achieved by placing another administrative burden on physicians and their patients will be dwarfed by increased crisis contacts and hospitalizations, not to mention the incalculable loss of lives and human potential.

Continuing on the subject of access to medications under Medicaid, we cannot fail to mention the importance of the Medicaid Wraparound for Dual Eligible New Yorkers subjected to the Medicare Part D Drug Benefit. Last year, New York State did the right thing by ensuring access to all necessary medications for Dual Eligibles getting the runaround from their Part D plans. The reduction of the Wraparound benefit to four classes of medications at the beginning of this year – while anticipated – was disappointing. NAMI-NYS agrees with and wholeheartedly supports the efforts of the state to ensure that Part D plans honor their primary coverage obligations to Dual Eligibles, but at the same time we ask the state to remember its own obligations to the safety and welfare of its most vulnerable citizens.

True Medicaid reform must begin with creating a system of care that is coordinated, accessible, and based on evidence-based practices such as the Disease Management approach successfully utilized by other states to serve high-need, at-risk populations, improving lives while saving money without scrimping on care.

The consequences of uncoordinated care for individuals with co-occurring mental health, substance abuse, and/or physical disorders go far beyond repeat trips to the emergency room and disproportionate expenditures. They extend to repeat visits to inpatient settings, shelters, the streets, jails, prisons, and in far too many cases, premature death, not to mention the vast loss of human potential.

For far too long, a good deal has been spoken about the need for coordination of care, but with little in the way of substantive steps to tackle the issue. Therefore, we are heartened to see in this year's Executive Budget funding for collaborative care demonstration projects involving OMH, OASAS, and DOH. Such efforts are long overdue.

RESEARCH

NAMI-NYS strongly supports Governor Spitzer's initiative to expand research at New York State's two world renowned Psychiatric Research Institutes--New York State Psychiatric Institute in Manhattan (PI) and Nathan Kline Institute for Psychiatric Research in Rockland County (NKI). Specifically, he has added \$1.5 million in the Executive Budget to fund 10 new research positions at NKI and 5 at PI.

The Executive's proposed new funding will allow NKI to continue its investigation into adult disorders such as schizophrenia and Alzheimer's disease, and the opportunity

to investigate mental illness beginning in childhood and adolescence in collaboration with NYU and the new Rockland Children's Psychiatric Center.

PI is currently doing research on the treatment and etiology of eating disorders, depression and suicide, and early signs of schizophrenia in children and adolescence. This funding will provide them the opportunity to extend its investigations to include the genetic etiology of these disorders for the ultimate benefit of both children and adults.

Please continue to support NKI and PI... RESEARCH IS OUR HOPE FOR THE FUTURE.

COMMUNITY MENTAL HEALTH—SAFETY NET SERVICES

According to state Office of Mental Health figures, more than 90 percent of the persons with serious mental illness in New York State reside in our local communities. The rest are in state hospitals, jails and prisons, nursing facilities, adult homes and other institutions. Despite the preponderance of the numbers, this locally-based population receives 44 percent of state spending for mental health, under the Aid to Localities budget. The state hospital system with its 4,030 adult in-patient beds makes up much of the State Operations budget which controls 56 percent of total mental health spending.

State hospitals have drastically reduced their census over the past 50 years while resources meant to offset these losses and buttress the community mental health system have not kept up. The federal dream of the Kennedy years to put a mental health center in every city or county fizzled badly in the 60s and 70s as the money ran out.

Our community mental health systems do not stack up well— they are under-funded and thinly staffed, with waiting lists and missing services. Too many people with serious mental illness do not have access to community mental health services. A 2003 Office of Mental Health patient characteristics study showed only 22 percent of individuals with serious mental illness receive any of the main community support services available such as vocational, case management, self-help and housing services. And that figure is probably lower today.

We need to shore up the services that are the safety net for the majority of the people with mental illness, now in our communities. The Governor has recognized this disparity and has authorized some \$175 million more dollars in the Aid to Localities budget for 2007-08. We are very pleased with that -- for the increases in housing beds, which have already been discussed, and for gains in community based services for children and families, promoting public health by reducing the risk of suicide, enhancing community-based program models, and providing access to efficient and high quality mental health services.

Regarding community-based programs, we have a few priorities. First, continuation of the three year cost-of-living adjustment (COLA) for community service workers is most important for recruitment and retention of the workforce and we are pleased to see that. The allocation of \$2 million to continue to fund demonstration projects to address the

mental health needs of older New Yorkers is an important source of support for that age group, although we would like to see \$3 million in additional funds added to the budget for the Geriatric Mental Health Act.

Community mental health has medical care at its core. General hospitals that have psychiatric beds, the Article 28 hospitals, become the main treatment venues now that the state psychiatric hospitals have dropped to a thin line of patients – 4,030 adult beds statewide. General hospital beds for psychiatric care must not be reduced in the process of hospital consolidations ordered by the Berger Commission.

Outpatient mental health clinics, sometimes tied to these hospitals and often county-operated, face a crisis of understaffing and over-demand. As one corrective, the Medicaid reimbursement schedules need to be reviewed for these services so the clinics can increase capacity and meet the higher workloads imposed on them. To show how bad this situation is, in one upstate city the mental health clinic a wait of six weeks is required to gain a clinic interview. And some of those seeking services never get them. The delays have impact throughout the system -- affecting the hospital emergency room and its inpatient psychiatry unit, the county social services department which authorizes Medicaid payment, and even the fledgling mental health court in this particular county where clinic treatment personnel cannot be freed up to take those leaving jail.

Similarly, continuing day treatment services, supplementing the outpatient clinics, often face the same heavy demand, backed up schedules and overworked staffs. The day treatment places teach independent living skills to fragile patients, some of whom are recently released from a hospital, enabling them to survive in the community. The centers need to be bolstered with funds and added capacity.

Besides these there are many rehabilitation programs like supported employment, affirmative businesses, consumer clubhouses, drop in centers and peer support programs that may or may not be folded into a new initiative of the state Office of Mental Health called PROS -- Personalized Recovery-Oriented Services. This is a program that the previous administration pursued in order to qualify these so-called softer services for Medicaid reimbursement. However, the smaller, more independent programs, some of them with excellent track records for the mentally ill, will not qualify and be dropped. We think this is wrong.

We support the governor's initiative to include \$574,000 in annual funds for additional supported employment slots which will assist persons with mental illness to become engaged in employment. Innovative supported employment programs must be available to help those who want to work. Services that will help families help their mentally ill loved one are needed, too, such as family education. We urge OMH to continue and expand the Spectrum of Family Services initiative which was begun under the previous administration.

We need more Assertive Community Treatment (ACT) teams. These outreach teams provide comprehensive treatment to our most at-risk individuals in their homes, reducing preventable and costly hospital readmissions and relapses.

More intensive case management (ICM) services are needed to focus on the high risk populations that are the most likely to be re-hospitalized. The ICMs are supposed to carry smaller caseloads than other clinic workers and be higher credentialed. They are particularly needed where mentally ill persons reside in housing that does not have built-in counseling. ACT, ICM and family education are evidence-based practices that work. We need more of them.

Greater coordination is needed between staff in the mental health clinics and workers in supported employment so the referrals run smoothly. The newly nominated state mental health commissioner, Michael Hogan, has set supported employment as a priority, contending that it is better to train someone with a disability and see that he or she has a job rather than pay endlessly for their disability payments such as SSI and SSDI. We agree.

We need to give more attention to the problems associated with co-occurring disorders. Large numbers of people diagnosed with a serious mental illness are found to also have a substance abuse disorder. Estimates for the jail population of mentally ill persons with an overlapping substance abuse history run as high as 50 percent. And there are large numbers of people with multiple disorders that include mental retardation, a form of developmental disability, as well as mental illness and sometimes a physical disability as well. This population has created agonizing problems for caregivers. We seek more training funds and more service workers to address the needs of these individuals.

Moreover, transition services are needed for adolescents who have been treated for mental illness, so there is continuity of care as they enter adult services in their community. The Governor's budget has addressed this population with new funding.

INTEGRATION OF PHYSICAL AND MENTAL HEALTH CARE

The diabetes epidemic is striking people with serious mental illnesses in disproportionate numbers. Studies show that people with schizophrenia are up to four times more likely to develop diabetes than the general population--and they are less likely to be diagnosed and treated. Left untreated, diabetes has devastating consequences: heart attacks and strokes, blindness, kidney failure, and amputations.

Investing in diabetes prevention and management programs for people with mental illnesses makes good sense. Many studies show that psychiatric patients are very interested in their physical health and are as motivated as the rest of the population in maintaining it.

- Integration of physical and mental health care requires:
- Universal screening for diabetes

- Treatment of all psychiatric patients with diabetes, heart disease, and metabolic disorders according to the same standards that apply to the general population
- Medical risk management
- Medicaid funding for the preventive care of psychiatric patients at high risk of diabetes, heart disease and obesity
- Medicaid coverage of the American Diabetes Association Recognized Program of Diabetes Self-Management Education--a 10 hour course for patients and family members covered by Medicare
- Investment in a highly trained staff to achieve the behavioral modifications that result in lowering the risk of diabetes
- Investment in cross-training of primary care physicians, nurse practitioners, diabetologists, cardiologists, and other specialists to raise their level of understanding of psychiatric illnesses and treating medications.
- Investment in cross-training of mental health professionals to raise their level of understanding of diabetes, metabolic disorders and heart disease
- Investment in peer- counseling programs
- Investment to support psychiatrist leadership of patient-centered wellness programs to allow extra time for patients, for improved communication and consultations with primary care physicians and other medical specialists
- Investment in the creation of wellness clinics in mental health centers as this is where the highest standards of diabetes prevention and treatment can be obtained at the best price and where the highest success rates for prevention and treatment can be achieved. NAMI-NYS specifically calls for the additional of \$2 million in the budget for this purpose.

We hope that these steps to integrate physical and mental health care will be started now. Governor Spitzer said recently, "Medically complicated Medicaid patients make up 20 percent of beneficiaries but account for 75 percent of Medicaid spending. With coordinated care, medically complicated patients get better care, their diseases are better managed--and we estimate, taxpayers will save tens of millions of dollars from greater efficiencies over the next four years." We agree.

PRISON MENTAL HEALTH

The \$2 million appropriation in the OMH budget—eventually going to \$9 million when fully annualized--- to expand mental health services in state correctional facilities is indeed welcome news. Particularly encouraging is the language in the Department of Correctional Services and OMH budget documents, which state that these agencies will collaborate to develop “specialized residential mental health programs as an alternative to SHU placement for persons with a serious mental illness.” Those of us in the mental health advocacy arena applaud this administration’s commitment to abolish the egregious practice of locking up persons with a serious mental illness in solitary confinement for months and years at a time.

Now, more than ever, NAMI-NYS believes that the legislature should again pass the Aubry-Nozzolio SHU bill and Governor Spitzer should sign it since this legislation gives

the Governor the legal framework and programmatic structure needed to best carry out this historic budgetary initiative.

While this budget represents a clear statement that “Day One” is a good beginning for those who suffer from a serious mental illness and their families, NAMI-NYS is disappointed that there is little indication that persons who suffer a dual disorder, i.e., those who suffer from a serious mental illness as well as serious substance abuse problem, can look to any additional treatment resources. The number one criminal justice-related issue facing our families and their loved ones is the dearth of treatment beds for persons with a dual disorder who find themselves incarcerated.

Despite the fact that integrated treatment programs for persons with a dual disorder are considered an “evidence-based practice,” we have made little, if any, progress in this state since identifying this population and referring to them as the “quadrant four” population some ten years ago. Addressing the needs of this population can go a long way toward decriminalizing many of our young persons with a mental illness whose attempts to “self-medicate” get them into trouble.

TIMOTHY’S LAW

We also thank the Governor for putting \$100 million in the Department of Insurance budget to fully implement Timothy’s Law for mental health parity in its first year. In our 2007 Legislative Action Agenda, NAMI-NYS calls for speedy and full implementation of Timothy’s Law and for the Legislature to improve and expand the law to get closer to full parity and to apply the law to more New Yorkers.

PSYCHIATRIC CENTER CAPACITY AND “REINVESTMENT”

According to the Office of Mental Health’s budget overview, OMH will be “seeking out opportunities to eliminate unnecessary state inpatient capacity.” According to the agency’s 2006 Statewide Comprehensive Plan for Mental Health Services, there is no unnecessary state inpatient capacity.

On page 72 of the Comprehensive Plan, OMH states the following: “The ability to further close or consolidate state psychiatric center inpatient capacity does not appear warranted at this time due to the leveling off of previously declining demand for inpatient services, utilization of current inpatient capacity, and the need to evaluate future inpatient capacity requirements.”

This is a tremendous understatement. The truth is that those who need this level of care are being turned away on a routine basis. The City of New York’s 2006 Local Governmental Plan for Mental Health Services reported waiting periods as long as 200-300 days for patients to be admitted into state psychiatric hospitals. Mental health care consumers and their families have reported long waiting periods throughout the state.

Nationally recognized expert opinion recommends that about two percent of adult individuals with serious and persistent mental illness (SPMI) need long-term or

intermediate care. In New York State, there are approximately 390,000 adults living with SPMI; this translates into 7,800 people in need of such care. Currently there are 4,030 adult care beds in the system. The disparity between the beds we now have and the number we should have is even worse for children and individuals who have a dual diagnosis of a serious mental illness and chemical dependency.

The point is that actual need exceeds available resources. We need more beds, not fewer. What's at stake is the integrity of the entire mental health system as well as the lives of countless individuals. Many improvements have been made in outpatient services, but even the best of outpatient programs cannot substitute for inpatient stabilization, which is what the intensive therapy in these hospitals provides. Without effective stabilization, individuals cannot successfully participate in community services designed to help them recover, and they often get stuck on our streets, in our jails and prisons and in the revolving door of our acute care wards. Even Assisted Outpatient Treatment and Assertive Community Treatment can have little or no success with individuals who are not stable enough to take the next step.

Seeking to eliminate unnecessary capacity will not save the state any money because, again, there is no unnecessary capacity left in the system. If the state were to focus on the capacity that it has already eliminated, however, it could garner significant savings. According to OMH, the average number of beds in an adult psychiatric center has declined from 5,200 to 250. The state is spending a lot of money to maintain large buildings for a relatively few beds. That's the problem. In this case, right-sizing means more contents in smaller containers.

We could support hospital consolidations if they were done right, with the tradeoff being an actual increase in total beds for persons with serious mental illness -- not violent sexual predators -- more community services such as Assertive Community Treatment teams, and creative ways to deal with the gap in intermediate care in the service areas where hospitals are closed, such as having intermediate care wards in Article 28 hospitals with a shared staffing arrangement.

As an organization consisting of family members and consumers, we are heartened by OMH's statement that "right-sizing" the state psychiatric hospital system will require the full cooperation of all key stakeholders, most importantly the patients and their families, and we are ready to play a constructive role in making this a more effective as well as a more efficient system. The problem is not simple, and it requires a deliberate, thoughtful and comprehensive approach. Rushing to get on the reinvestment bandwagon without such an approach could make things much worse for people with serious mental illness in New York State.

VIOLENT SEXUAL PREDATORS

We note with grave concern that the Executive Budget has proposed an additional \$19.2 million for 335 additional full-time employees to confine violent sexual predators where they do not belong: our state psychiatric hospitals. This would bring the number of staff members employed in civil commitment to 782 at a total cost of \$46 million.

This, of course, is only the tip of the iceberg when it comes to the actual cost of civil commitment in state hospitals, conservatively estimated to be \$250,000 per predator per year.

We would not be doing our job if we didn't object to this very bad idea. Arbitrarily lumping together mental illnesses with sex offenses is scientifically, practically and morally baseless and wrong. The confinement of violent sexual predators in these hospitals is not only costly, it does not make New Yorkers significantly safer. It does endanger our most vulnerable population, however, as well as those who care for them.

Instead, we advocate that the entire \$46 million be set aside to create a new, separate Office of Sex Offender Management to study and plan a comprehensive and cost-effective approach to protecting our families and our communities.

NAMI-NYS and our thousands of members and 60 local affiliate organizations across the state of New York thank you for the opportunity to present our Statement for the record. We appreciate your willingness to listen to our concerns about the sickest of the sick – New Yorkers with serious mental illness, and their families – who we represent.

Respectfully Submitted,

THE NATIONAL ALLIANCE ON MENTAL ILLNESS OF NEW YORK STATE
(NAMI-NYS)

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