

Submitted Testimony

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Joint Legislative Public Hearings

on the

2015-2016 Executive Budget Proposal

Mental Hygiene

National Alliance on Mental Illness of New York State

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Testimony delivered by:

Wendy Burch and Irene Turski

Good afternoon. My name is Wendy Burch. I am the executive director for the National Alliance on Mental Illness of New York State (NAMI-NYS). With me today is our president, Irene Turski. Thank you for this opportunity to provide testimony since this is a particularly crucial time in our state for the approximately 673,000 adult New Yorkers living with a serious mental illness whose very lives depend on the decisions made by this esteemed legislative body.

NAMI-NYS is the state chapter of NAMI, the largest family and consumer grassroots mental health organization in the country. We have more than forty affiliates in New York State. We offer support, education, and advocacy for both individuals and family members who have had their lives impacted by serious mental illnesses.

"Mental illness" is not a single illness. There are many types of psychiatric disorders. There are anxiety disorders, mood disorders, substance abuse-related disorders, obsessive-compulsive disorder, trauma and stress-related disorders, and psychotic disorders, among others. Most people who have a psychiatric disorder and receive the proper services to progress their recovery are able to live productive lives, exercise good judgment, seek employment, live freely in the community, and are willingly treated in office settings.

A very small subset of persons have the most debilitating forms of psychiatric diseases, which cause hallucinations, delusions, serious mood deregulations and impaired decision making. These people need more intensive care as their symptoms can cause an inability to care for themselves and they may demonstrate high risk behavior. Our society often fails to meet the needs of these people who have the most serious forms of mental illness.

We are here today to partner with you to maximize mental health in New York by ensuring that the necessary supports and services are in place and properly funded to progress the recovery of all people living with a mental illness, no matter where they are in the wide spectrum of psychiatric diseases.

Early identification, access to therapy and medications, a safe place to live and ensuring physical as well as mental wellness have proven to be effective in controlling symptoms, improving

quality of life, avoiding “self-medication” through the use of illegal drugs and alcohol and protecting against relapse. While we were encouraged that the Governor’s Executive Budget proposal will make some of the necessary investments to enact these crucial elements of recovery, there are still too many gaps in the Executive Budget, we humbly ask for your leadership in building the necessary bridges to address these holes.

NAMI-NYS priorities for 2015/2016 are:

- 1- Safe and Affordable Housing for People With Mental Illnesses:
- 2-Continued Support of Reinvestment in Mental Health Community Services:
- 3-Improving the Criminal Justice-Mental Illness Interface in New York State
- 4-The Reinstatement of Prescriber Prevalence.
- 5-The Incorporation of Mental Health Education in Schools
- 6-Increased Mental Health Services for Veterans and Military Families
- 7-Sustained Support of New York State’s Research Facilities

1-Safe and Affordable Housing for People With Mental Illnesses:

Since NAMI-NYS was incorporated safe, affordable housing has been an ongoing priority. As previously stated, a stable environment is vital and fundamental to the recovery from psychiatric disorders. Safe and affordable housing programs which incorporate recovery oriented support services are the cornerstone of successful recovery from a mental illness within the community setting.

The lack of availability to decent, safe, and affordable housing remains a tremendous challenge for adults with serious mental health disorders. It is important that appropriate services and supports are also provided so that our loved ones have the best chance possible to live in a residence that provides them with dignity and as much independence as possible.

In recent years, the Office of Mental Health has focused on reducing the number of people in the most expensive housing environments such as in-patient beds at state psychiatric hospitals, state operated supervised community residences, and other state funded residential settings. To

achieve this, OMH has given priority status in access to housing to individuals residing in these settings. While we acknowledge the necessity to reduce costs, we must ensure that housing opportunities are made equally available to individuals who do not come from these priority populations but are still in need of the housing supports and services. Additionally, we need to ensure that individuals who are being transitioned from these highly supervised settings are being moved to residential settings that adequately meet their high level of need for supports and services in order to maximize their recovery, avoid future hospitalizations, and ensure the best possible quality of life.

Our President, Irene Turski as a unique perspective on the challenges of finding appropriate housing for an adult loved-one living with severe mental illness:

I have a sister who is 64 years old with severe mental illness. Last year, I came here to plead for all involved not to allow too many inpatient beds to be closed too soon for people with serious mental illness. These are the people who have not or who might never be able to live more independently in the community. Unfortunately, my sister is one. Last year, my sister was at the Residential facility on the grounds of Buffalo Psychiatric Center but I am happy to report that my sister did leave the grounds in October of 2014 and is now living in a senior supervised community residence facility in Buffalo.

It was difficult getting her into this facility as I stated last year since it seems community residence facilities are very costly to operate. They require more funds than either supportive or supported housing so these types of housing units are scarce. This is the type of housing many people with serious mental illness will require in order to leave inpatient hospital facilities. Without this structure, many will not survive and wind up either in the hospital, in our criminal justice system, homeless or dead.

As family members, our loved ones are usually the most seriously mentally ill. We do not, as some may say, want our loved ones in a hospital for the rest of their lives. They are important and inclusive members of our families. We want them out in the community living life as fully as they are capable of. But... if they are not allowed to stay at an inpatient facility until the right

treatment or medicine stabilizes them, they will go out into the community destined for failure and even more horrific, further brain damage.

NAMI is asking everyone to take a step back and proceed with caution. In order for this transformation that OMH is initiating to work, there must be adequate supervised community residence facilities out there for the people with serious mental illness. If there are no funds for new builds, then retrofit existing facilities for this supervised community residence format. There are human lives at stake here and the decisions that are being made, may make and break many lives. You will not see many of our loved ones roaming the halls during our legislative days because they are either too sick or not capable of such advocacy. This is why you see me and other family members, here, advocating for them. They deserve to be considered and treated with dignity.

I propose that we do a study for the next year and for each patient that is released from an inpatient psychiatric facility out into the community, that we have a watchdog group that follows these individuals and reports back next year the success or stumbling blocks that occurred. And it cannot be someone on the payroll of the organization they may be reporting on. Because remember, it isn't how many beds are being closed, it is how many people with mental illness that have been released from inpatient facilities, that are living in the community successfully with the quality of life they deserve.

While NAMI-NYS is encouraged that the Executive Budget calls for a \$30 million investment in housing-through \$20 million in funding for additional supported apartments to facilitate the transition of 1,700 individuals from adult homes (400 individuals) and nursing homes (100 individuals) to the community as well as 1,200 additional congregate care beds primarily associated with the NY/NY III program to reduce homelessness, and \$10 million of the JP Morgan settlement funds to support approximately 13,000 supported housing units- a disproportionate amount of these funds will be dedicated to people previously residing in state hospitals and other state operated systems. We must ensure that housing opportunities are made equally available to individuals who do not come from these priority populations but are still in need of the housing supports and services.

When considering the transition of individuals to lower cost residential settings in the community, it must be noted that the funding for current housing resources such as Community Residences, Apartment Treatment Programs and Supportive Housing has remained flat for many years, while the need for the resources and the complex and increasing needs of the individuals served has grown. Because the funding has not kept up with increase in cost of living since 1990, programs are operating at 43% below where they should be today. To restore these crucial housing resources, \$82 million dollars is needed to replace the funds lost to flat funding as the cost of living has increased. The specific breakdown of necessary funds is as follows:

- \$29 million to the Supported Housing rate statewide in 2015 to make up for losses from inflation and to ensure that Supported Housing is sustained, basing future rates on a reasonable formula. Home Health care coordinators do not take the place of housing staff, while the new guidelines will place extra financial burdens on providers.
- \$23.2 million for Community Residencies (CR)-SROs to make up for losses from inflation and so that they can better serve those with challenging needs. These provide a high level of service and can be very long-term stay or permanent.
- \$17 million for the CR program (includes both CRs and Treatment Apartments) to make-up for losses from inflation and to incentivize providers to admit the most challenging clients safely. This would have the added value of ramping up the model's efficiency in rehabilitating people more quickly, most likely an outcome that the MCOs will expect when this model is moved into Managed Care. This number subtracts the estimated BIP revenue.
- \$12.7 million to SP-SROs, permanent housing with supports, to make up for losses from inflation and to better equip them to serve clients with more challenging service needs.

NAMI-NYS recognizes that in order to provide adequate services, providers must be able to recruit and retain qualified staff. This is not possible when staff have not been granted a cost of living increase (COLA) for the past 6 years. While we appreciate that this year's budget will provide a 2% increase to direct care staff, this is insufficient to keep up with inflation and staff are falling so far behind that they are often eligible for the same resources as those who are living

at or below the poverty level. The work these staff do is challenging, and requires a high degree of training, experience and education that is crucial to the success of the people they serve. Because of the low rate of pay and lack of cost of living increases, programs are not able to retain these qualified staff members.

It is imperative that we provide staff with a living wage that keeps up with the increases in the cost of living so that our family members have well trained and qualified people to provide their support and services. These are the people we depend on to ensure the health and safety of our loved ones. We need experienced and trained staff to provide the consistency necessary for a stable home environment. Dependable delivery of care is a critical element in the recovery of people living with a mental illness and is vital to the success of the transformation to community-based services that the Office of Mental Health is establishing. A lack of sustainable care can lead to decompensation and our loved ones going back and forth to the hospital, thus creating an increased financial burden to the state, as well as the potential for further brain damage which will diminish their chances for a life outside of a hospital setting.

NAMI-NYS applauds the Governor for including the COLA in the Executive Budget but we urge our legislators to support a greater commitment to these underappreciated workers.

NAMI-NYS is also encouraged that the Executive Budget included a new \$22 million investment to expand services to individuals at risk of violence. Part of this investment includes aggressive community services through the use of additional Assertive Community Treatment (ACT) teams and supported housing. NAMI-NYS believes this investment will advance the recovery of some of the most vulnerable people living with a mental illness. We urge the legislature to support this important initiative.

2-Continued Support of Reinvestment in Mental Health Community Services:

The methods for delivering mental health services are changing in New York State. The number of hospital beds dedicated to treating psychiatric disorders is shrinking. Though NAMI-NYS does not want to see beds reduced, we strongly believe that the savings from this reduction be reinvested into services that would afford those living with a mental health disorder the best

opportunity to advance their recovery in a community setting. We once again thank and applaud the legislature for fighting last year to ensure that \$110,000 per each bed reduced be invested in community services, after the Governor suggested a much lower number.

The FY 2015-16 Executive Budget proposes the reduction of an additional 136 psychiatric facility beds which translates into \$15 million dollars for community investment. This investment builds upon the \$44 million annualized last year's bed reduction. While NAMI-NYS has always opposed bed reductions we are encouraged that the full savings from these reductions will be invested to create community based recovery services. We urge the legislature to support this investment level.

NAMI-NYS believes that it is the responsibility of government at all levels to develop and maintain comprehensive community support systems that include treatment and services to guide people's recovery from mental illness and maximize their mental health.

NAMI-NYS wants to see community support services in New York State which ensure:

- Practices and services that are recovery, resiliency and wellness oriented, culturally competent and readily accessible
- Safe and affordable housing
- Residential support services with transportation services and intensive case management
- The availability of all appropriate and effective medications
- Access to both inpatient and outpatient treatment options
- Vocational Training
- Wellness
- Round-the-clock services that are available seven days a week
- That no one would have to travel more than an hour to get to a psychiatric emergency room or crisis service unit.

3-Improving the Criminal Justice-Mental Illness Interface in New York State

NAMI-NYS wants to see improvements and expansions to several facets of the criminal justice system to help ensure the best outcomes for people living with a psychiatric disorder who enter or exit the system as well as the dedicated law enforcement officers who may interact with people in the midst of a psychotic episode.

While the Executive Budget proposal contains several encouraging aspects, we want to begin with a glaring omission from the budget, the funding to sustain and expand Crisis Intervention Teams (CIT) in New York State. CIT is a proven effective program that has demonstrated the ability to reduce harm to both the dedicated law enforcement officers who respond to incidents involving people experiencing episodes of psychosis as well as those whose behavior and judgment is impaired by these disorders.

Police are often the first responders when a person is in psychiatric distress. Every community owes it to them to provide the knowledge and training to handle mental health crisis situations safely and compassionately."

Crisis Intervention Teams consist of law enforcement officers specially trained to deescalate situations and take appropriate action to assist an individual in the midst of a mental health crisis. Outcome research has shown CIT to be effective in developing positive perceptions and increased confidence among police officers; providing very efficient crisis response times; increasing jail diversion among those with mental illness; improving the likelihood of treatment continuity with community based providers; and impacting psychiatric symptomatology for those suffering from a serious mental illness as well as substance abuse disorders. Communities who have incorporated CIT initiatives have seen harm to their police force reduced by 80%ⁱ.

While CIT has proven to benefit both our law enforcement officers and people living with a mental illness, its incorporation can also lead to long-term savings generated by proactive measures that reduce emergency room visits and incarceration costs. A study published in the *Southern Medical Journal* examined the costs and savings associated with implementation of a police crisis intervention team. The costs and savings associated with the implementation of a CIT program were analyzed in a medium-sized city, Louisville, Kentucky, 9 years after the program's initiation. Costs associated with officer training, increased emergency psychiatry visits, and hospital admissions resulting from CIT activity were compared with the savings associated with diverted hospitalizations and reduced legal bookings.

The study found that based on an average of 2400 CIT calls annually, the overall costs associated with CIT per year were \$2,430,128 (\$146,079 for officer training, \$1,768,536 for hospitalizations of patients brought in by CIT officers, \$508,690 for emergency psychiatry evaluations, and \$6823 for arrests). The annual savings of the CIT were \$3,455,025 (\$1,148,400 in deferred hospitalizations, \$2,296,800 in reduced inpatient referrals from jail, and \$9825 in avoided bookings and jail time). The balance is \$1,024,897 in annual cost savingsⁱⁱ. While the study concluded that the net financial effect of a CIT program is of modest benefit, the effect the program can have on the mental health and safety of police and our loved ones living with a mental illness are immeasurable.

NAMI-NYS urges the legislature to continue your leadership in calling for the expansion of CIT throughout New York State. We thank and applaud you for including a \$400,000 investment in the 2014-2015 budget to form the Institute for Police, Mental Health & Community Collaboration, to advance CIT initiatives. We are disappointed to see the Executive Budget did not include funding to continue this program. We once again turn to you to lead the way in fully protecting the public by expanding your commitment to this crucial life-saving issue by allocating funding to sustain the program as well as well as expanding the funding to ensure that the streets in communities throughout New York are patrolled by CIT trained police officers. Since many first episodes of psychosis occur during the ages of 18-25, we also want to see that security officers on all State University of New York (SUNY) campuses are provided with CIT training. We also believe that correction officers should receive CIT training.

We are grateful that Senator Robert Ort, Chair of the Mental Health and Developmental Disabilities Committee is requesting \$450,000 to further fund the Institute for Police, Mental Health & Community Collaboration. We thank him for his leadership and urge you to follow his lead and call for the inclusion of this funding in the final budget.

While NAMI-NYS is disappointed that the Governor ignored CIT in his budget, we do strongly support two endeavors contained in the budget. We urge you to support the following initiatives:

1-\$22 million investment to expand services to individuals at risk of violence. We support this investment to provide enhanced services to at risk individuals with the goal of reducing recidivism and potential violence in the community. The New York State Office of Mental Health (OMH) will provide

additional in-prison assessments and treatment for high risk inmates, maintain individuals in OMH facilities when appropriate, and provide more aggressive community services through the use of additional Assertive Community Treatment (ACT) teams and supported housing and related services.

While we believe this investment will certainly lead to positive outcomes, we do believe this initiative lacks one vital component. In order to properly integrate someone with mental health issues coming out of prison there must be a presumption that these people are Medicaid eligible. Presumptive Medicaid eligibility will ensure these people who are among the most vulnerable people living with a mental illness receive quicker access to the services and medications which will advance their recovery and prevent their return to the criminal justice and reduce potential crisis episodes and emergency room visits.

2-Raising the age for criminal responsibility from 16 to 18. NAMI-NYS strongly supports this initiative as 70% of juvenile offenders have a mental health diagnosis. We also applaud Assemblyman Daniel O'Donnell for introducing a bill which would raise the age to 21. We urge the legislature to support this issue.

NAMI-NYS strongly believes that expanding CIT, investing to expand services to individuals at risk of violence, raising the age of criminal responsibility as well as the passage of bills introduced in the Assembly to reform the use of solitary confinement, will interject positive measures that will both maximize New York's mental health and ensure the public's protection. We appreciate your previous leadership on these issues and call for your continued support.

NAMI-NYS also strongly supports the Humane Alternatives to Long-Term (HALT) Solitary Confinement Act. This bill would restrict the use of segregated confinement and create alternative therapeutic and rehabilitative confinement options, as well as limiting the length of time a person may be in segregated confinement and excludes certain persons from being placed in segregated confinement.

4-The Reinstatement of Prescriber Prevails

The Executive Budget once again calls for the elimination of Prescriber Prevails. NAMI-NYS vehemently opposes this elimination. Medications that treat psychiatric disorders are not interchangeable and it should be up to a doctor and a patient to decide what their proper

medication should be. Eliminating Prescriber Prevails is a dangerous proposition, as not providing people living with a mental illness with the most appropriate medication can lead to more emergency room visits as well as possible interactions with the criminal justice system, these preventable outcomes would have a greater financial consequence than proactively allowing a trained medical professional to decide what medication is proper.

NAMI-NYS once again thanks and applauds the legislature for your constant advocacy for this issue. We ask you to once again serve as leaders on this and restore Prescriber Prevails in the final 2015-16 budget.

5-The Incorporation of Mental Health Education in Schools:

Education, early recognition and intervention as well as working on prevention are keys to minimizing mental health issues that are common in adolescents and hopefully, eradicating the long-term disabilities caused by mental illness. It is vital that New York's education system does a better job of creating a true comprehension of mental illness and mental health issues. Proper mental health is crucial to overall wellbeing, which is why it is necessary that mental health is incorporated into existing health education curriculums.

Administrators, teachers and students must be given the tools to identify the potential warning signs of mental illnesses which are prevalent in children and adolescents. The early recognition that mental health education provides can prevent our children from suffering the most debilitating long-term effects of serious and persistent mental illnesses. Integrating the proper supports can also lead to a better awareness of body image issues and a reduction in harassment and bullying both of which can contribute to an already high suicide rate in adolescents

The Executive budget does not include incorporating mental health education into existing school's health curriculums. NAMI-NYS has partnered with three other organizations, the Mental Health Association in New York State, Families Together in New York State, and the American Foundation for Suicide Prevention to promote the passage of legislation that would formally introduce mental health education into our state's health education curriculum, but that legislation does not have a financial mandate attached to it. Even though this issue does not impact the budget, we urge the legislature to support this crucial initiative.

6-Increased Mental Health Services for Veterans and Military Families

There is no mention of veterans' mental health programs in the budget. NAMI-NYS feels it is important to state our support for additional funding to expand the Joseph Dwyer Veteran Peer-to-Peer program and other support services to enhance veteran's mental health as well as mental health services for military families.

7-Sustained Support of New York State's Research Facilities

We are fortunate to have two of the world's most preeminent bastions of psychiatric research located right here in our own state: New York State Psychiatric Institute (NYSPI) and Nathan Kline Institute (NKI). While we were glad to see that the Executive Budget recognized the importance of psychiatric research by maintaining the same funding levels for these institutions, it is not enough for New York State to merely sustain funding, the funding must be increased. Research lines that have been frozen for years should finally be allowed to be filled. The cutting edge work being done at NKI and NYSPI not only provides jobs to thousands of New Yorkers, but brings enormous prestige to our state, as well. Support of neurobiological and clinical research into the causes of mental illnesses and other brain disorders is critically important so that scientists can develop improved medications and treatments, and eventually find a cure to prevent these devastating, disabling diseases. Not only is this the hope for patients who suffer and their families, but it is also the best hope we have to reduce the economic burden of illness on New York State in the long run.

NAMI-NYS also wants to state our support for the Executive Budget's inclusion of a \$68 million investment to improve community integration and services. This would be used to assist in the transition to managed care and the expansion of health home capacity; increase the number of children's community services with 250 additional Home and Community Based Services (HCBS) waiver slots; provide additional funding for community residences; and increase support for the Personalized Recovery Oriented Services program (PROS).

We are confident that the enactment and proper funding of the initiatives above will have a tremendous beneficial impact on the lives of individuals and families affected by mental illness as well as save New York's taxpayers millions of dollars in the long term.

We thank you for your time today and listening to the pleas of NAMI-NYS and the families we represent.

ⁱ According to CIT International

ⁱⁱ Peggy L. El-Mallakh, PhD, Kranti Kiran, MD, Rif S. El-Mallakh, MD, Southern Medical Journal,
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