**February 13, 2018**

# Joint Legislative Public Hearings

**on the**

## 2018-2019 Executive Budget Proposal

# Mental Hygiene


## National Alliance on Mental Illness of New York State (NAMI-NYS)

**99 Pine Street, Suite 105**
**Albany, New York 12207**
**(518) 462-2000**

**Evelyne Tropper, Ph.D, President,**

**Wendy Burch, Executive Director**

**Irene Turski, Government Affairs Chair**


**Testimony delivered by:**

**Wendy Burch**
**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 Irene Turski, our Government Affairs chair. Irene is a family member and serves as a caregiver for an adult with severe mental illness. Irene's family's story is all too similar to that of many families who have a loved one with serious mental illness and speaks to why our legislative leaders must take action for the approximately 673,000 adult New Yorkers living with such psychiatric disorders. This is a crucial time for this vulnerable population. NAMI-NYS understands that New York State is facing a difficult budget cycle and we were encouraged by elements of the Executive Budget proposal. However, we have also identified a serious lack in funding for our priority advocacy issue: community-based mental health housing with wrap around services.

Community based mental health housing programs which incorporate recovery oriented support services are the cornerstone of successful recovery from serious mental illness and has long been NAMI-NYS's top advocacy priority.NAMI-NYS is very concerned that community based mental health housing programs are reaching a breaking point as they are being asked to meet the needs of a more specialized and challenging population while being grossly underfunded. It is difficult to express how scary it is to hear grumblings from the non-profit housing providers we work with that some of them are ready to call it quits and close their doors, because they cannot continue to operate with the meager funding they receive. We need more housing services, not less.

In his executive budget proposal Governor Cuomo proposes including $10 million for community based mental health housing programs. This falls way short of what is necessary to meet the needs of this crucial system and the providers who deliver this all-encompassing type of care. A big part of the reason this system is in such dire straights is because community based mental health providers have received flat-funding from New York State since the early 1990's. Since the funding has not kept up with the rates of inflation and the increases in the cost of living since 1990, these programs are operating at 43% below where they should be today.

NAMI-NYS joins our colleagues from the Bring it Home: Better Funding for Better Care campaign in asking the legislature to address this lack of funding. The campaign has stated that $120 million is needed just in order to close the gap that formed from decades of flat-funding. We endorse their recommendation that the Governor's proposed $10 million investment be moved to the fourth quarter of the budget cycle (Janurary 2019) along with the legislature contributing an additional investment of $10 million and having the figure annualized. This $20 million to utilized at the start January 2019 for mental health housing would annualize to $120 million while mitigating the impact on this fiscal year.

Our deep concerns about the community-based mental health house system is magnified due to the changing systems which deliver mental health care in New York State. The Executive Budget proposes the reduction of another 100 psychiatric beds from the New York State Office of Mental Health (OMH) hospital system in fiscal year 2019. NAMI-NYS is worried that the Article 7 language in the Governor's budget proposal does not specifically link the bed closures to an exact dollar amount. We are advocating that this loophole end during budget negotiations and that there is specific reference to a value of $110,000 a bed for each bed that is reinvested.

Even with the $110,000 per bed rate solidified, NAMI-NYS still has apprehensions about the bed reduction. The $11 million savings from the proposed bed reductions would be reinvested into community services. While NAMI-NYS is gratified to see the Governor calling for investments in Assertive Community Treatment or ACT Teams and respite centers, two services NAMI-NYS believes to be vital for comprehensive mental health treatment in the community setting, we are concerned about the diminishing amount of psychiatrists and mental health professionals in our state. We hope that this problem is looked into more closely as we can't have a community based system of care without providers. We are also troubled with how the reductions will not only impact our loved ones who require hospitalization, but also place more of a burden on a mental health housing system that is already stretched way too thin.

In order to achieve the hospital bed reduction, OMH has been forced to give priority status in accessing housing to individuals residing in these hospital settings. While we are grateful that people who have received all-encompassing care in a hospital would theoretically be released

into a housing system that could meet their wide gamut of needs, there are two problems that must be addressed in order for this to happen successfully. The first problem, which we and our colleagues have detailed, is that these housing providers are not adequately funded to provide the type of wrap-around services this population who have serious mental illnesses such as schizophrenia and bi-polar need. In order to address this more challenging population, increased funding is needed for the community-based mental health system.

The second problem is that many of our members have loved ones who have not required long-term hospitalizations but still desperately need mental health housing. Even before the hospital reductions there were long waiting lists to access the limited amount of housing services available. Now that OMH has established a new priority population, these people who are no less deserving and in need of housing are placed in the back of the line. NAMI-NYS believes that we need a community mental health system (which includes housing) that meets the needs of all people living with a mental illness, no matter where on the spectrum they are. This is why we must also ensure that housing opportunities are made equally available to individuals who do not come from these priority populations.

The failure to make appropriate investments to allow both the community mental health system as a whole and the mental health housing system to address the needs of people across the spectrum of psychiatric disorders will lead to more dangerous, tragic and financially burdensome results. Preventable outcomes that can be reduced by making the necessary investments include homelessness, dependency on emergency room visits, suicide and entry into the criminal justice system. We also want to see more investments in programs such as supported employment which will help advance both recovery and independence.

I am joined today by our Government Affairs chair, Irene Turski, who would like to share the personal impact the lack of funding has on families:

*I speak to you today, not solely in my role as the NAMI-New York State Government Affairs Chair, but as a family member and unpaid advocate for those with serious mental illness. I traveled from Buffalo to be here and offer the experiences of families. While many of our*

*colleagues testifying before you today will detail the financial specifics necessary to provide appropriate housing and mental health services, I am not an expert in these numbers, my expertise lays in being a caregiver of a loved one with a serious mental illness. While others will be providing the specific statistics detailing the many needs of New York's mental health system, I want to speak about the human impact of the decisions your esteemed committee will be making today.*

*As many of those testifying today, my words are drawn from being on the front lines of the epidemic caused by insufficient housing resources and insufficient psychiatrists and other mental health services in the community. NAMI-New York State speaks for families of those with mental illness and I want to explain to you how the inappropriate under funding impacts the one in four families in New York State with a loved one with mental illness.*

*My testimony today is based on witnessing the experiences of my sister who has schizophrenia. She has lived within the state hospital system and in a community residence program. I assure you, the only reason she was able to live in the community is because she did reside in a community residence that incorporated the necessary support services to keep her healthy. Many of the people like my sister going into the community were institutionized for years and haven't had to make decisions for themselves. Their mental and physical health are fragile and require the necessity of seeing a psychiatrist, psychologist or mental health counselor frequently. We can bring people into the community but it is inhuman to do so without the appropriate amount of doctors and mental health providers to monitor their recovery.*

*My experience has been that once out of an inpatient setting, they see their psychiatrist once a month or if lucky, once every two weeks. When someone like my sister is given a new medication, this should be monitored very closely for adverse reactions. In my case, my sister had a horrible reaction to a new medication called lamictal and was literally burning from the inside out. I have the pictures and emails to prove this. She went through hell and only because of the attentiveness of the community residence staff who knew her along with my repeated emails to her psychiatrist, did we finally get her slowly titrated off this medication. Even with all this, my sister is back as an inpatient (by her own decision) and still unfortunately not stabilized, so*

*please be careful about allowing inpatient bed closures without the necessary housing and community-based supports.*

*I have heard that OMH is offering housing providers incentives for a certain period of time, to take people from inpatient beds to their facilities, which is another example of the priority populations Wendy detailed. OMH can permanently close an inpatient bed if it is not occupied for a 90 day period I believe. What happens after the additional funds are no longer given to housing providers for these people? Many housing providers I have spoken to have said some of these people in the community belong in a hospital setting for proper care. Is anyone keeping track of where these people end up if they are removed from the housing they were put in? What happens to those who don't have a family advocate out there vigorously advocating for their loved one?*

*People such as my sister are often looked upon as mere statistics, but let me remind you, they are not statistics or patients; they are human beings with complex needs who are not equipped to go into supported/supportive housing programs that do not offer the level of intensive care they would receive in a hospital setting. Housing programs for those such as my sister must include full wrap-around staff support services. These include the ability to get residents to doctor and therapy appointments, teaching them how and when to take medications and in the most serious cases, basic needs such as personal hygiene and how to feed themselves.*

*On top of this, some of the people who need these services are suicidal and a danger to themselves. Some suffer from Anosognosia and do not know they are ill. Many who have been on anti-psychotic medications may also be suffering from tardive dyskinesia which causes involuntary movements of the tongue, face, trunk, and extremities. In order to address the complex needs of this population housing programs must be able to provide caring and attentive support along with mental health professionals .*

*This type of attentive support can only be achieved through having continuity of care delivered by qualified and compassionate staff. Only someone providing continual care would be able to notice slight changes in a person which could indicate serious ailments. Communication and de-*

*escalation strategies are also necessary in treating people with serious mental illness and learning the proper techniques that resonate with an individual is also a long-term process. Continuity of care is essential and it is only possible if providers can hire and retain qualified and caring staff members who build the types of relationships necessary to drive recovery. It is impossible to form these relationships if staff is constantly changing.*

*It is a common myth that families turn to housing programs because we don't care about our loved ones. Nothing could be farther from the truth. The sad reality is, despite our best efforts most of us are simply unable and unqualified to provide the intensive type of care necessary to help our loved ones achieve recovery. This is not out of a lack of want or lack of love; the challenges of providing full-time care are just too great. Many of us have tried and many of us have painfully failed. We turn to housing providers as a last resort, but we do so expecting those dear to us to receive the type of support they would get at home along with skilled expertise to help advance their recovery. This can only happen by relying on competent staff that can combine compassion and clinical knowledge.*

*I have gotten to know many of the staff people who have literally cared for my sister throughout the years. They are committed to not only caring for a challenging population, but willing to work long hours and spend too much time away from their own families to tend to our family members. Many have taken the time to get to know me as well and listen to my own concerns and insights about my sister. A firmly held belief by NAMI-New York State is that recovery happens best when individuals with a mental illness, their families and their providers work together as a team with open communication and shared goals. We view this much like three legs holding up a stool. As you know, a stool cannot stand if one of the legs is broken. I am here today to testify that despite the best intentions of some the most dedicated people I have ever met, one of the legs of our recovery stool is broken. I ask for your help in repairing that leg.*

*Thank you for listening to our concerns.*

NAMI-NYS has one more serious concern about the availability psychiatric services in the community. Though services are available, many people across the state have found the ability to

access them extremely difficult due to the lack of insurance parity and the many providers who do not accept insurance for psychiatric care. A recent report titled *Project Access* details the difficulty of accessing services in Long Island. These difficulties are mirrored throughout the state. We applaud Senators Phillips and Kaminsky for sending a letter asking the New York State Department of Finance to look into the lack of partity and the barriers to access this has caused. Additionally, to address this growing epidemic, NAMI-NYS is urging the Senate and Assembly to allocate $1.5 million in the one-house bills and final budget in order to create a statewide behavioral health ombudsman to monitor behavioral health parity violations.

Along with housing and community services we have a few additional concerns about aspects of the Executive Budget proposal. As we explained, the spectrum of psychiatric disorders is quite broad and NAMI-NYS firmly believes in person centered care to advance each indivdual's unique recovery. Though medication may not be necessary for everyone, for those who do require medication, a crucial element of the person centered approach is the ability to access the medications their mental health provider believes to be most appropriate for them. This is why NAMI-NYS believes it is vital to have prescriber prevails in place for those treating people through the Medicaid system. Once again, the Executive Budget omits this and we encourage the legislature to restore prescriber prevails in the final budget. This is especially integral to our concerns, as psychiatric medications are not interchangeable and many living with serious mental illness have their health care met through Medicaid.

As we mentioned earlier, one of the most negative outcomes of not providing the necessary support services for people living with serious mental illness is a disproportionate amount of people with these disorders entering the criminal justice system and being incarcerated in a system not designed to address their illness. We urge you to invest in improving the criminal justice-mental illness interface and work to decriminalize mental illness. The Executive Budget Proposal makes some investments to advance this important issue. There is an investment in the Aid to Localities bill for Crisis Intervention Teams. More funding is needed for this vital program which helps generate the most positive outcomes when police and first responders interact with people with mental illness and their families. In last year's budget, the legislature

was able to secure $1.5 million for CIT and we encourage you to match the funding again this year.

Finally, NAMI-NYS wants to state our support for the Governor's initiatives addressing children's mental health and school-based mental health programs. In the State of the State Governor Cuomo discussed $250,000 to create enhanced mental health support grants. Community schools programs would be eligible to include mental health activities in wrap-around services. NAMI-NYS supports this. There are now 745 school-based mental health clinics licensed by the New York State Office of Mental Health to help students better access services. NAMI-NYS would like to see this expanded especially in underserved areas, where school-based mental health clinics may be the sole provider of pediatric psychiatric services in that community.

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