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Joint Legislative Public Hearings

on the

2017-2018 Executive Budget Proposal

Mental Hygiene

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

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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 was encouraged by elements of the Executive Budget proposal, however we have also identified serious gaps that must be bridged in order to prevent these people from falling through the cracks and to create a truly mentally healthy and just New York State.

Before we detail our budget concerns, we would be remiss not to acknowledge Senator Young and extend our deep gratitude to you for your championing the step-therapy reform bill which Governor Cuomo signed into law. The fight for this regulation was ardous and it could not have happened without your dedicated support. Ensuring people with a mental illness get the medication their doctors believe to be most appropriate for them is a key component to recovery, which is why this was a crucial victory for all of us who care for people with chronic diseases. Equally as important is having 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.

The spectrum of psychiatric disorders is quite broad and while NAMI-NYS firmly believes that investments need to be made to advance the recovery of all people impacted by mental illness, no matter where they lie on the spectrum, today we want to detail the needs of those with serious mental illness. These are the sickest of the sick and most likely to suffer the worse negative consequences from a lack of proper funding, including homelessness, incarceration, or in the most tragic cicumstances, death.

There are two elements that must be properly funded to address the needs of this vulnerable population and to keep them as healthy as possible, off the streets and out of jails and prisons. The first is the continuation of Kendra's Law, New York's Assisted Outpatient Treatment program, and the other is access to housing with wraparound support services.

Funding for Kendra's Law is set to expire this year and it is crucial for the state to continue investing in this important and successful initiative. While there are a lot of misunderstandings surrounding the initiative, one thing that is inarguable is its success. Kendra's Law has been subject to many studies and each has found that is has substancially reduced long-term hospitalizations, homelessness, incarcerations, suicide and harm to self as well as dependency on drugs and alcohol. Everyone testifying this afternoon will tell you about the shortage of mental health services; Kendra's Law ensures that the ones who need the services the most have first access to the limited services that do exist, which includes housing which we will detail in a moment.

NAMI-NYS was encouraged to see that the Executive Budget proposal contains almost $7.6 million for services and expenses related to adult mental health services, including assisted outpatient treatment. We urge our legislators to support this funding and we also encourage you to vote to make the law permanent. Once again, Senator Young, you have been a leader on this and we deeply appreciate your advocacy.

The systems which deliver mental health care in New York State are currently going through a radical overall at a very rapid pace. The Executive Budget proposes the reduction of another 100 psychiatric beds in fiscal year 2018. NAMI-NYS understands the benefits of community based housing and care, but we cannot fully support the reduction in beds when it involves releasing people with highly specialized needs into a system, which despite its best intentions, does not have the capacity to provide the necessary care for this vulnerable population. The capacity to care for those with serious mental illness in the community setting is impossible without funding housing programs that offer wraparound support services and the type intensive care a person would receive in a hospital.

This lack of capacity is greatly attributed to years of flat funding, and while the Executive Budget does contain small investments, it fails to offer the amount of funding desperately needed to provide the support and continuity of care required to advance recovery of those with serious mental illness. The $10 million contained in the Executive Budget proposal for supported housing and single residence occupancy programs is a small investment which does not address the multiple housing needs for people with serious mental illness.

Because the funding has not kept up with the increases in cost of living since 1990, programs are operating at 43% below where they should be today. To restore these crucial housing resources, NAMI-NYS and our advocacy partners are calling for $38 millon annually for the next three years ($115 total for the three years) in order to keep the programs sustainable.

Equally important to recovery in the community housing setting is ensuring continuity and quality of care. This pillar is impossible if a housing provider is unable to hire and retain competent staff, and this necessity is only possible if staff are compensated at a proper rate. 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. The work 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. Irene will detail the consequences of what happens when someone does not receive true continuaity of care.

NAMI-NYS was very disappointed to see that the COLA for this type of staff has been deferred to the 2018-19 budget. The funding in the Executive Budget proposal to address the direct cost of FY 2018 minimum wage increases for direct care, direct support, and other workers at not-for-profits that provide services on behalf of OPWDD, OMH, and OASAS and for health care

workers that provide services reimbursed by Medicaid on behalf of the Department of Health are simply insufficient to provide our loved ones with continuaity of qualified care. This workforce short-fall must be addressed.

NAMI-NYS is only able to support any of these bed reductions if the necessary safety-nets are put in place to ensure that these people are relocated to a setting which will properly address their specialized needs and ensure that families are educated and have the opportunity to participate in a loved one's recovery.

Irene will now explain the human costs of the housing issue:

Thank you, I speak to you today, not solely in my role as Government Affairs Chair, but as a family member and an unpaid advocate for those with serious mental illness. This is an advocacy role I did not choose, the decision was made for me upon witnessing the experiences of my sister who has schizophrenia. She has lived within the state hospital system and is now in a community residence program. I assure you, the only reason she has been able to live in the community is because she resides in a program that incorporates the necessary support services to keep her healthy.

Despite the excellent care she receives, the transition from the hospital to the residential program was challenging. One of the many obstacles was ensuring she took her medicine properly; the lack of adherence to her regimen led to exacebation of her symptoms and additional acute hospital stays. It is important to remember that each relapse someone with a serious mental illness experiences is a major detrimental occurrence and it can take a lot of work and time to stabilize them, even once stabilized the effects from the episode can linger and they may never return to their previous level of stability.

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. They must have the necessary support services which are

provided in a community residence type of housing to teach 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 them 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, lips, face, trunk, and extremities. Tardive dyskinesia must be addressed as early as possible as the effects can be permanent.

As Wendy stated earlier, continuity of care for this population is essential. Only someone providing continual care would be able to notice slight changes in a person which could indicate serious ailments. Trust is also crucial in the caregiving relationship and this takes a long time to develop. 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 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 also important to note that continuity of care goes both ways and a recent episode with my sister demonstrates another challenge to continuity. Despite the excellent care she received in her residential program, she recently required a short inpatient stay in a hospital. While hospitalized, the residency tried to give her bed to someone else. Luckily this was worked out and she was able to return to the place she views as her home. As anyone impacted by psychiatric disorders knows, the road to recovery is rarely straight and hospital usage is sometimes needed. Those who need short-term hospital stays should not have to worry about losing their home. Hospitalizations can be traumatic by themselves and this should not be compounded be the fear of not being able to return to the home you are comfortable in. Being released into a new housing program and the requirement to form new relationships with caregivers can be a serious deterrent to recovery. This is why I beg you to have OMH address this practice and introduce stipulations that a person’s bed in a residential facility be held for them for an agreeable amount of time if they need short-term care in a hospital or CPEP.

I understand that I have detailed a multitude of needs to address the necessary improvements housing programs with support services require to help them maintain the best staff possible to provide care, case management and create a true home geared towards recovery. My sister who has suffered a great deal throughout her life deserves nothing less. Thank you!

NAMI-NYS also has questions concerning the Executive Budget's proposal to call on OMH to reconfigure 140 state operated residential beds, which are less integrated and more costly to operate. This would create $5.25 million in savings. The proposal would invest $2.3 million of the savings to develop 280 community-based, scattered site supported housing units in the same geographic area. The proposal states that these new units, when provided in tandem with access to other existing community services, will ensure the continued support and care of all individuals transitioning into less restrictive settings while keeping them close to their families.

While this seems to be a positive development, there a several aspects we ask the legislature to investigate. Will the new beds be available as soon as the old beds are removed to ensure a smooth transisition? We are concerned that more clinically oriented and case management services will be needed for this transition and scattered bed plan, is funding for this included? Why is not even half of these savings being reinvested in housing to serve those with mental illness? Where is the remaining $2.95 million going? Is it staying in the OMH budget?

Our final concern regarding housing is that the Executive and Legislature agree to sign the memo of understanding detailed in the 2016-2017 budget that would release the $2.5 billion which was targeted for for 6000 new units of new supportive housing over the next five years.

NAMI-NYS also has questions about the proposal to inclusion of a reduction of $3.97 million related to an evaluation of all State-operated clinics. OMH will review clinic treatment services at all 85 State-operated facilities to reduce any overlap of services and ensure that clinics are operating at optimal patient capacity to address community need. This sounds good as we want the clinics operating efficiently and at maximum capacity. However, NAMI-NYS is always concerned when reductions are mentioned. For instance, clinics in low populated areas may not be deemed necessary since they are not utilized as much as those in larger areas, but for the

people in that area the clinics may be their only mental health resources and are of vital importance. We are concerned that the needs of those in under served populations and rural areas are not being met and this could make the gap in services even greater. We urge the funding to conduct outreach to these areas, to ensure communities are aware of the mental health services available.

Also while looking at services in rural and underserved areas, we note that the Executive Budget proposal contains initiatives to keep doctors in the field of psychiatry. We would like to see these initatives broaden to include to recruitment and support the education of psychiatric nurse practitioners as they play a vital role, especially in rural and underserved communities.

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 disportionate 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 progress this important issue. The Aid to Localities bill calls for $500k 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 it to increase the funding again this year.

NAMI-NYS was very encouraged to see that the Executive Budget would raise the age of juvenile jurisdiction to 17 in 2019 and to 18 in 2020, and would provide services for 16 and 17 year olds who are involved in the juvenile justice system. Under the Executive proposal, newly sentenced youth would be placed in Office of Children and Family Services (OCFS) facilities. The Executive Budget provides $110 million for additional OCFS facility capacity. We urge the legislature to follow this proposal and the funding around it. It is embarrassing that New York is only one of two states that still has such a low juvenile jurisdiction.

This is a concern for NAMI-NYS as the same disportionate amount of people with mental illness in the correction system is mirrored in the juvenile system. Too many in the juvenile system have mental health issues or developmental disabilities and come from underserved populations that do not have access to mental health care. Many others have been subjected to trauma. Studies such as the Adverse Childhood Experiences Study (ACES) have demonstrated that exposure to trauma impacts long-term mental health and decision making. The National Institute of Mental Health has also conducted numerous studies which show the human brain is not fully developed until the age of 25 and the part of the brain that dictates decision making is one of the last to develop. This is a major reason adolescents as a whole tend to make poor decisions; it's important that our criminal justice recognizes this scientific fact.

Finally, NAMI-NYS was disappointed to find that the Executive Budget Proposal does not include investments to support veteran's mental health programs. Services such as the Joseph O'Dywer peer-to-peer program have been tremendously successful and more needs to be done to address the complex mental health needs of veterans and military families. We must ensure that monies designated for mental health and substance abuse treatment for veterans are allocated to Veterans Medical Centers, Community-Based Outpatient Clinics (CBOCs) and other programs serving veterans with mental illness and utilized for the treatment of these individuals. We have an obligation to provide our veterans the best and most readily available services we can offer.

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