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Joint Legislative Public Hearings

on the

2016-2017 Executive Budget Proposal

Mental Hygiene

National Alliance on Mental Illness of New York State

(NAMI-NYS)

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Testimony delivered by:

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Irene Turski

Good morning. 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 and Housing Committee chair, and the family member and caregiver of a loved one with a severe mental illness. Irene's family's story speaks to why our legislative leaders must take action for the approximately 673,000 adult New Yorkers living with a serious mental illness. This is a crucial time for this vulnerable population. Their lives and those of their families depend on the decisions made by the Legislature as 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 save these people from falling through the cracks and to create a truly mentally healthy and just New York State.

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 225 psychiatric beds in fiscal year 2017 and recommends reducing no more than 400. 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. This lack of capacity is greatly attributed to flat funding and the Executive Budget's lack of true investments to allow existing programs to operate at their full capacity as well as invest in new services. We urge you to examine and address this short fall as NAMI-NYS is only able to support any of these 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 to ensure that families are educated and have the opportunity to participate in a loved one's recovery.

These requirements can only be achieved through having housing and community services that are properly funded and have the full capacity to provide the specialized care this population needs and by enacting paid family leave, which will remove a tremendous barrier separating families from playing a role in a loved one's recovery.

Irene's experience caring for her sister will detail the struggles families of people living with a serious and persistent mental illness experience each day as they strive to find proper services and housing. She will detail the numerous problems that face the dedicated people who aim to provide the best housing conditions for our loved ones. Along with the housing obstacles Irene will detail, NAMI-NYS is also extremely disappointed that the Executive Budget proposal makes little significant investments in community support services.

Our colleagues have identified that "there are no commensurate longterm investments in community mental health services and have identified \$70 million in gross program funding that have unjustly been taken as savings in Reinvestment, the BHO HARP Investment Program and supportive housing instead of being kept in the service system." They argue that "monies should instead make up the initial installment in their \$90 million investment request." NAMI-NYS will work with these colleagues to learn more about these proposed investments, but one thing is obviously clear, the Executive Budget does not do enough to build an infrastructure of care suitable to advance the recovery of people with serious and persistent mental illnesses.

This short fall in funding for housing and community services has made the need for family involvement more important than ever. NAMI-NYS is very enthused to see Governor Cuomo speak passionately about the need to enact Paid Family Leave. Increasing family involvement in the recovery process has always been central to NAMI-NYS's mission. The shortages we mentioned coupled with the transformation of Medicaid services make family support crucial as it is needed to help provide an understanding of these changes and ensure people receive the proper services. Understanding these transformations can be a daunting challenge. As a professional, I struggle to keep up with the changes being implemented. I cannot imagine how difficult it must be for someone who is trying to overcome the obstacles which psychiatric disorders present, especially if a person's illness impacts his or her comprehension and cognitive ability.

NAMI-NYS has continually advocated for removing any barrier preventing family participation and establishing true recovery teams, consisting of someone living with a mental illness, along with his or her service providers and family members. When someone is experiencing a

psychiatric emergency or hospitalization due to a chronic illness, that individual's family members should not have to worry about losing their livelihood in order to be by their loved one's side. No family should have to experience regret or guilt produced by the feeling that they did not do everything they could to advance their loved one's recovery. While we applaud Governor Cuomo for sharing this priority and pushing for New York State to be a leader on Paid Family Leave, there are differences between his proposal and the one approved by the Assembly and before the Senate.

Under the Governor's proposal, employees could receive up to \$509 a week for twelve weeks depending on their wages. The program would be employee-funded, not to exceed a 60-cent weekly paycheck deduction. The bill passed for the Assembly would provide twelve weeks of paid leave through the state's temporary disability insurance system, and the employee contribution would be set at 45 cents a week. There is certainly room for negotiation on the deduction, but what is important is that an employee is eligible for up to twelve paid weeks. It is also crucial for workers who earn lower wages that they receive 2/3 of their weekly wage while on leave. At the 35-50% rate proposed, the wage replacement is too low and many workers will simply not be able to use the benefit. We will continue to have a system where only those with higher incomes are able to take time to care for their spouses, children, parents or siblings. We understand that the Governor has amended his proposal to include the 2/3 of the weekly wage and we hope the Senate does their part to give families the ability to help guide a loved one's recovery.

As Irene will detail, many of our NAMI-NYS families serve as the primary caregiver for their loved one living with a mental illness, in many cases with the loved one living in the same home as the caregiver. This also places an economic burden on our families and speaks to why it is so important they receive a suitable wage to provide this crucial care.

(Irene) I am an unpaid mental illness advocate with, unfortunately, a sister who has a serious mental illness. The only way she has been able to live in the community is due to a community residence that has the necessary support services to keep her healthy, but on many occasions despite this excellent care, I still have to play a large role in her recovery. I take her to weekly

appointments and I am the only one who can communicate with her and deescalate situations when her symptoms cause her to become distraught. Allowing family members to be included in our loved one's recovery will save tax dollars and more importantly, improve the mental and medical status of a person with a serious mental illness. No family member wants their loved one, if it can be avoided, in a hospital and will do all they can to prevent this situation.

The availability of a safe and appropriate place for our loved ones to live and advance their recovery remains the main priority for NAMI-NYS as well as for many of our not for profit colleagues who provide vital housing services. Proper housing and services are key to this. NAMI-NYS applauds the Executive Budget for not targeting the closure of any state funded psychiatric hospitals in FY 2017, which provide services for those with the most serious and persistent types of mental illness, but as Wendy detailed it does propose the reduction of 225 psychiatric beds.

These are human beings who are not equipped to go into the supported/supportive housing that are being targeted for them. 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 of these people from inpatient beds are also being sent to nursing homes for that type of structured care. How can we send these people to nursing facilities where there is no chance for them to learn how to advance their skills in order to have a chance at a meaningful and independent life?

NAMI-NYS is only able to support this reduction if the stipulations the budget calls for are put in place in advance to ensure that these people are relocated to a setting which will properly address their specialized needs. The Executive Budget stipulates that community services are sufficient to meet the needs of this population; people who had been long-term stay patients in Office of Mental Health facilities are placed in supported services appropriate settings; and

counties need to establish jail based restoration to competency programs thus reducing the need for State services.

NAMI-NYS is primarily concerned with the first two stipulations being in place. Currently, many of the supported housing providers who would be responsible for taking in this population simply do not have the capability to meet the myriad of challenges these people present. This is such a strong point that I cannot stress the importance of heeding their pleas. You have housing providers telling OMH, NAMI and anyone else who will listen that they are not equipped to take care of the people that are being released from the psychiatric hospital bed closures. History has shown us that this is a recipe for disaster, and it is at the expense of our most vulnerable human beings, those with serious mental illness who depend on others to take care of them in their compromised state of mind. How can these housing providers take care of our loved ones when they have been victims to flat funding which have failed to stay aligned with the cost of living increases since 1990? Because of this failure, programs are operating at 43% below where they should be today. This shortcoming would put an already vulnerable population at increased risk.

The budget also fails to address an increase in pay for those who work for non-profit housing providers. This is a critical issue for many of us with loved ones at housing facilities. NAMI-NYS and our families recognize the crucial roles qualified staff along with continuity of care play in the recovery of people in supported housing. This continuity is only achievable by hiring appropriately trained and caring staff as well as the ability to retain these staff members. This is impossible without a true living wage. Though the Governor calls for a \$15 minimum wage across the board, this could take years to achieve. If fast food workers are currently granted a minimum wage of \$15 an hour, why are those who have the challenging job of providing the best care possible for people with mental illness not given the same recognition?

Removing someone with serious and persistent mental illness from a highly supported setting and placing them in a facility with anything less can have disastrous results including homelessness, entry into the criminal justice system, over dependence on emergency rooms and in the most tragic situations, death from either suicide or the misuse of medication.

All of these enhancements are necessary if beds are to be reduced. We urge you to make sure that the transition from psychiatric hospitals is done as appropriately and responsibly as possible. As it is clear that many of these safety nets still need to be established, we also urge you to limit the reduction of hospital beds as suggested in the Executive Budget. We also hope you include the stipulation that a bed must be vacant for 90 days before it is targeted to for elimination.

The budget includes \$16 million from the state hospital bed reductions to fund a wide gamut of community services. These include mental health urgent care walk-in centers, mobile engagement teams, first episode psychosis teams, family resource centers, evidence-based family support services, community forensic and diversion services, tele-psychiatry, transportation services, family concierge services, and adjustments to managed care premiums. NAMI-NYS believes these are important investments that need to be fully funded.

As a family member whose loved one receives Medicaid services, I have many concerns about how the system is being transformed. To me, it appears that no one really has any idea how these changes will all work out. There seems to be a million questions, and not enough answers. From what I understand, the people designing and implementing the changes aren't even clear on how it will work. This is very scary to me.

My two primary concerns are: First, how will services get paid for? This potentially affects everything from housing to hospitalization and everything in between. Second, there is lots of money being spent helping providers make the transition, but I have seen no visible or widespread effort to help people living with a mental illness and their families understand the new eligibility requirements and changes in service delivery. As Wendy stated, it is difficult for professionals to stay abreast with these changes, we must invest money to make sure that the people directly impacted by these changes understand them

NAMI-NYS also applauds the Executive Budget's investment in six new State Plan Medicaid Services for Children, which would add \$7.5 million this year with a planned investment to expand to \$30 million by 2018. These are beneficial and necessary programs, as we know that early intervention can lessen the most debilitating symptoms that chronic and persistent

psychiatric disorders present. While we believe that it is vital that we make these investments that can improve the lives of the next generation of people who have a mental illness, we must not forget to invest in improving the lives of those not fortunate enough to be diagnosed at a time when these early intervention strategies were in place.

NAMI-NYS was disappointed to see that the Executive Budget does not include prescriber prevails language to ensure that people receiving Medicaid are provided with the most clinically appropriate medications. The Legislature has always corrected this omission and we hope that you once again rise to the occasion and add this important inclusion.

Improving the Criminal Justice–Mental Illness Interface in New York State is also important to NAMI-NYS . While the Executive Budget contains some positive inclusions including a million dollar investment to raise the age of criminal responsibility and another million to invest in Alternatives to Incarceration for high-risk, high-need populations, it fails to address many of NAMI-NYS’s concerns.

The budget does include the creation of an Independent Special Counsel to review cases of police-involved civilian deaths; too often these tragedies involve people living with a mental illness. This is certainly a positive development, but the budget had the opportunity to attempt to proactively prevent such police involved incidents by increasing funding for Crisis Intervention Training (CIT). However, expansion of CIT funds was not included and NAMI-NYS believes this is a glaring omission that must be rectified to protect both our loved ones as well as our dedicated law enforcement officers and generate the most positive outcomes.

Last year, New York State made positive strides in supporting the recovery of people living with a mental illness who are being released from jail. NAMI-NYS would like to see the inclusion of funds to create a presumption of Medicaid eligibility for this vulnerable population. NAMI-NYS has made presumptive eligibility a priority and we encourage the Legislature to explore ways to introduce this much needed reform. One way to do this is to expand the grant program through the Office of Mental Health, which allows this population to receive medication for 90 days while their Medicaid is being reestablished. While medication is an important part of recovery, it is not the only part and for these people to have the most successful reentry and advance their

recovery, doctor visits and other Medicaid funded treatments must be made available through this program.

NAMI-NYS urges the Legislature to sustain funding to the two world-class research facilities funded through the Office of Mental Health, New York State Psychiatric Institution and Nathan Kline Institute. It is imperative that you continue to support both research institutes in their efforts to develop better treatments and in their service to OMH in providing their expertise to help shape the delivery of care in the state. We believe that new approaches for early intervention and personalized medicine may make a major difference in the near future. We also urge the Legislature to continue to provide funds to OMH for the further expansion of OnTrackNY the evidence-based early intervention program which has had tremendous success in getting young people diagnosed with schizophrenia on a path of recovery that includes higher education and employment.

One final investment that is lacking in the Executive Budget proposal is the continued commitment to supporting Veterans' mental health programs. NAMI-NYS was disappointed to see that funding for the successful Joseph O'Dwyer veteran peer-to-peer program was not expanded in the Executive Budget proposal. We must increase funding for mental health and medical treatment for veterans with serious mental illness. 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 a moral 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.