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New York State Joint Legislative Budget Hearing

on

Mental Health and Developmental Disability Services and Supports

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

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Testimony delivered by:

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Good afternoon. Thank you Senator Krueger and Assemblywoman Weinstein for the opportunity to testify before you and provide our perspective on Governor Cuomo's budget proposal and the investments needed to create a fully functioning mental health system. My name is Wendy Burch and I am the Executive Director of the National Alliance on Mental Illness of New York State (NAMI-NYS) and with me today is Ariel Coffman, our board president. Along with serving as our board president, Ariel is also on the front lines in the battle for enhanced mental health services as she is both a mental health professional and a family member caregiver for her father who has a severe mental illness. These dual roles provide Ariel with a nuanced understanding of the fractures in the mental health system and how these fissures have left both family members and mental health providers struggling to provide adequate support services to the one in five New Yorkers living with a mental illness that we care for. In our testimony this afternoon, we will provide you with our recommendations on how to bridge these gaps in order to create a more mentally healthy New York State, one which offers all people across the spectrum of psychiatric disorders with the best chance to achieve recovery and live the best life possible.

NAMI-NYS is the state chapter of NAMI, the nation's largest grassroots organization dedicated to improving the lives of individuals and families affected by mental illness. For many years we have come before the legislature to testify on how too many New Yorkers are unable to access appropriate mental health services and unfortunately the struggle for access continues. Studies have concluded that on average it takes ten years from the time someone first notices psychiatric symptoms to when the person begins receiving treatment for these ailments.

For many years, the stigma that has long surrounded mental illness was blamed as the main culprit for this unacceptable situation. However, while we have made great strides in reversing the misconceptions of mental illness, people are still suffering for far too long, as accessing appropriate services and medications remains daunting, and once these recovery tools are located all too often health plans place another barrier to the road to recovery. This is why our top priority must be ensuring the ability of all New Yorkers to access person centered treatment designed to advance their recovery and having these live saving measures covered by healthcare plans.

Now is a crucial time for our population, many of whom, if provided with appropriate services in a timely manner, can live healthy and productive lives; for others, supports are needed to prevent them from living on the streets or being detained in a correctional system ill-designed to advance their recovery. NAMI-NYS understands that New York State is facing a difficult budget cycle, especially after the Governor's announcement earlier this week regarding the budget shortfall, however proactively investing in the full spectrum of necessary psychiatric services will save money by preventing costly outcomes such as reliance on emergency rooms, homelessness, long-term hospitalizations and criminal justice expenses. Proactively funding the mental health system, is a sound investment and will pay immediate dividends by saving the state from having to spend reactively on the costly alternatives mentioned above. More importantly, it will improve and save lives and ease the burden for the one in four New York families such as Ariel's who sacrifice a great deal to give their loved ones the best life possible.

The ability to deliver appropriate mental health services is impossible without a robust mental health workforce. NAMI-NYS estimates that 3,799,830 New Yorkers live in a mental health professional shortage area, that's roughly a fifth of our population¹. NAMI-NYS is very concerned about the lack of support for our mental health workforce. The Governor's budget proposal missed an opportunity to care for the dedicated mental health workers who care for our loved ones by not including a recommended 2.9% Cost of Living Adjustment (COLA) for non-profit human services agencies.

The entire behavioral health community stands together in support of a 2.9% COLA for the human services sector. Though the COLA is proposed in the budget every year, it ends up being rejected by the Executive for most of the last decade. This has resulted in a shortfall of over \$500 million dollars to that sector. The not for profits in the behavioral health community are on the front lines every day providing housing, treatment and support to over one million New Yorkers. In order to prevent the opioid epidemic, the increase in suicide completions and the increase in homelessness and incarceration, we need the valued support of the behavioral health sector. In addition, over 80% of the human service workforce is comprised of women and over 40% are individuals of color. Many of these individuals are working one or two

additional jobs. We urge your support to insure that there is \$140 million included in this year's budget to help provide the necessary funding to help support New York's not for profits

While a fully-funded workforce is the foundation for the delivery of services, the availability of services are of little benefit if people cannot afford them. NAMI-NYS is very concerned about health plans' continued lack of mental health parity and maneuvers to deny access to medications a person's doctor believes are best to address their individual set of symptoms. Fortunately, our leaders have the ability to remove these barriers to recovery. NAMI-NYS was extremely enthused that the Governor's budget proposal includes provisions to enhance the monitoring of compliance to mental health insurance parity and to hold the health plans accountable for failure to adhere to parity. We strongly encourage the legislature to support these investments. We also call on the legislature to ensure that prescriber prevails language remains strong in the state's Medicaid system. While not specifically budget related, it is important for us to state that the legislature has an opportunity to address the deceitful and dangerous practice of "Non-Medical Switching" used by private insurance providers, by passing A.2969/S.2849. Ensuring that people are able to obtain the medications their doctor believes are most effective for them will help avoid more costly options such as dependency on emergency rooms or entry into the criminal justice systems. Both these costly alternatives are being extremely over used to treat and house people with mental illness. This is why the lack of access to mental health services has become one of the major social justice issues of our time.

Our next concern revolves around the lack of mental health housing programs with full wrap-around support services. These programs when fully funded are tremendously beneficial and a major driver of recovery. These programs are more crucial than ever as hospital beds in both the public and private sector have been diminishing greatly for the past decade.

During the 2018 Democratic primary debate on August 29th, Governor Cuomo stated "We need more mental health beds. We need more community residences for people who are mentally ill on a permanent basis." The Governor is 100% correct; we do need more "mental health beds," both in the hospital and the community setting. NAMI-NYS has long called for increased investments in psychiatric beds in both the hospital and community setting to meet the wide-

gamut of needs of people living with psychiatric disorders, who at points in their recovery may require both services. We hoped Governor Cuomo's debate declaration would lead to his budget proposal addressing the disturbing trend that has made access to beds in both settings extremely difficult. While we are glad to see that the proposal does not look to reduce any further beds from the New York State Office of Mental Health (OMH) hospital system, we are disappointed that the proposal failed to address the quarter-century of flat funding to non-profit mental health housing providers, which has left them struggling to operate at 43% of where they should be when factoring the inflation during this time.

The lack of appropriate mental health housing is becoming a growing problem that is finally being scrutinized by the media. A few weeks ago, the New York Times reported on a lawsuit alleging that incarcerated people with mental illness are being held long past their release dates because there are no mental health housing programs in which to release themⁱⁱ. If these allegations are accurate they represent an unacceptable human rights violation. In December, Frontline and ProPublica, released a report that was also featured by the New York Timesⁱⁱⁱ on the difficulties assimilating the population coming out of adult homes due to the lack of investments in mental health housing and the staff needed to ensure these programs operate effectively.

For several budget cycles OMH had been directed to reduce 100 beds a year from the state psychiatric hospital system. During this time NAMI-NYS consistently called for these reductions to be paired with sufficient investments in mental health housing with wrap-around support services that would provide the type of recovery oriented care one would receive in a hospital. However, in examining the reduction of the OMH led hospital system, it must be noted that this process has been conducted without sufficiently investing in the mental health housing system.

As the media has explained, the mental health housing system is in serious crisis. The quarter century of flat-funding to non-profit mental health housing providers as detailed above has made hiring and retaining staff a difficult task and many housing providers are struggling to survive. Our colleagues at the Bring it Home-Better Funding for Better Care campaign estimate that

40,000 Mental health community-based housing units are in jeopardy due to years of inadequate funding.

Community based mental health housing programs with supports are the cornerstone of successful recovery for many people with serious mental illness. NAMI-NYS is distressed 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 news from the non-profit housing providers we work with that they are constantly struggling because they cannot continue to operate without proper funding. As Governor Cuomo clearly stated, we need more mental health beds, but the \$10 million included in the budget falls way short of the \$171 million the Bring it Home campaign estimates is needed to adequately fund the mental health housing system. The campaign is asking for a \$32 million investment each year for five years. We support this ask and hope that under your leadership and the leadership of our mental health chairs, Assemblywoman Gunther and Senator Carlucci, the legislature will work with the Governor to address his promise to solve this problem, as the time to act is now.

Earlier we mentioned the difficulties assimilating people with serious mental illnesses coming out of adult homes; we are enthused to see the budget include an additional \$10 million for specialized supports, such as peer support and in-reach, to engage individuals with mental illness who require a higher level of care to transition and live successfully in the community. These resources will be utilized for individuals currently residing in impacted adult homes.

NAMI-NYS has concerns regarding the transition out of adult homes. NAMI, NAMI-NYS and NAMI NYC-Metro recently sent a joint letter to Nicholas G. Garaufis, the United States District Judge for the Eastern District of New York (who presided over the adult home court ruling), expressing our viewpoint on how to best transition people out of adult homes and into the community.^{iv}

As the letter states: “NAMI (referring to National, NYS and NYC as one entity) believes there needs to be more emphasis placed in conducting thorough individualized assessments performed

by qualified licensed clinicians who know the strengths and limitations of the system before class members transfer to less restrictive settings to ensure that appropriate wrap around services and supports are in place with funding. We also believe that there must be recognition that some individuals leaving adult care homes may require twenty-four hour, seven day a week care and support in supervised settings.”

While the proposed investment in specialized supports appears to be a positive development based on our concerns, it is important to note that our letter also states: “A fully funded workforce is necessary for effective implementation of the adult home settlement. Unfortunately, New York State has continually failed to make necessary investments in recruiting and retaining qualified mental health professionals. We therefore urge that all mental health professionals engaged with adult home residents, including residential counselors, care managers and peer support specialists, be paid living wages and cost of living increases tied to the consumer price index (CPI) on an annual basis.”

While NAMI-NYS is glad to see that the community investments in this budget cycle are not being proposed vis-à-vis a further reduction in OMH hospital beds, we are disappointed that the investment is half of what it has been in prior years. We have long argued that making the necessary investments in community services should not have come at the expense of hospital beds which are equally important. We have continually protested that meeting the needs of people on one end of the spectrum by taking services from people on the other end of the spectrum is both dangerous and ill-advised. We must look for other ways to meet the needs of all people across the spectrum. Unfortunately, New York State missed an opportunity to do just this. In November, it was announced that New York’s hospitals and nursing homes will be receiving approximately \$675 million for Medicaid rate increases to cover workforce salary and benefits. NAMI-NYS believed this support should not be limited to in-patient facilities. We stood beside our colleagues in calling for 25% of the state’s share of the investment, roughly \$169 million be used to support community-based care.

We can ill-afford to continue to let other issue related funding opportunities pass our community by. One of the most needed types of community-based services is those that handle crisis

situations. NAMI-NYS believes that no one should have to travel more than an hour to access psychiatric emergency crisis services. Unfortunately, this goal is unattainable for far too many New Yorkers. We need investments to expand both mobile crisis services such as Assertive Community Treatment (ACT) Teams and Mobile Intervention Teams as well stationary options such as crisis stabilization centers and respite centers. While we are troubled that there are not enough psychiatric crisis services currently available, our ultimate fear is that there will be a much greater need for these services if the state legalizes marijuana.

Senator Krueger, as you are also the sponsor of the bill, we feel we must ensure that you understand the severe risk marijuana poses to those living with psychotic symptoms as well as to adolescents who are in the prodromal period, meaning the mechanisms for serious mental illness are already in their system even if the symptoms have yet to present themselves. Many studies have reached that conclusion, including one released by the National Academies of Science, Engineering and Medicine,^v which includes research by Ziva B. Cooper, Associate Professor of Clinical Neurobiology, Department of Psychiatry, Columbia University Medical Center, concludes that:

- Cannabis use is likely to increase the risk of developing schizophrenia and other psychoses; the higher the use, the greater the risk.
- For individuals diagnosed with bipolar disorders, near daily cannabis use may be linked to greater symptoms of bipolar disorder than for nonusers.
- Heavy cannabis users are more likely to report thoughts of suicide than are nonusers.
- Regular cannabis use is likely to increase the risk for developing a social anxiety disorder.^{vi}

It is clear that increased access to marijuana is going to have harmful results for people living with serious mental illness and that more crisis services will be needed to handle this outcome. This is why it is imperative that a portion of the tax-revenue generated by the sale of marijuana products be appropriated to OMH specifically to be used to increase the amount of integrated mobile and stationary crisis services in communities throughout the state. We also believe another smaller portion of revenue should be used for OMH to generate education materials specifically addressing how marijuana impacts people with mental illness. Two other measures

NAMI-NYS recommends for the most safe and responsible way to legalize marijuana are to have warning labels on products clearly stating the risk to people with psychotic symptoms and to limit the sale of products to those over the age of 26 as scientists at the National Institute of Mental Health estimate the brain finishes developing in the mid to late twenties.^{vii}

NAMI-NYS would also like to see New York State be more aggressive and creative in addressing the shortage of psychiatrists in the state, including introducing incentives to increase practicing psychiatrists in the state, especially in rural areas. We also would like to see programs that incentivize greater utilization of psychiatric nurse practitioners who can prescribe medicine and monitor patients as well as Licensed Mental Health Counselors to provide services under the OMH system. We also call for more investments in Telepsychiatry, as well as integrated psychiatric care in primary care settings and in schools.

Ariel will now share her experiences to illustrate the importance of all the community based services we want to see further investments in.

Thank you Wendy. I am excited and proud to be here today representing NAMI NYS and the tens of thousands of individuals and families living with serious mental illness in NYS.

The number one reason that brings me to Albany today is that my father lives with the effects of Bipolar Disorder along with several chronic medical conditions. We have a small family and I am his primary care giver. He is currently rehabbing after a knee replacement surgery that went very badly several month ago. His mental health has suffered and my family suffers along with him. My worries for his health extend in every direction but the one thing I haven't historically worried about is whether or not he will have a home when he gets out of the hospital. That's because he lives in one of the approximately 40,000 underfunded OMH mental health beds that we are advocating for along with the Bring it Home campaign. These beds are staffed by the same mental health workers who will not be receiving a COLA in 2019 if the governor and the legislature does not act. In my experience, a lack of properly compensated staff in mental health programs is dangerous to individuals and families living with serious mental illness. It creates

increased potential for a lack of experienced and qualified workers which leads to increased accidents, incidents and unnecessary heartbreak for people being served in these settings.

I am grateful every day that I don't have to worry about my Dad becoming homeless, sleeping in an unsafe shelter or on the streets, or ending up incarcerated without access to the vital mental health treatment he needs. I implore you to listen and extend the help that only you can regarding these very serious problems before more people with serious mental illness lose their housing, their stability, their freedom, or worst of all- their lives.

NAMI NYS is advocating so strongly for increased access to hospital beds, more mobile treatment options especially in rural areas, investment in the mental health work force, housing, and community mental health treatment because New Yorkers who fall through the gaping holes in this system are dying. The 30% rise in the suicide rate in NYS speaks clearly to this danger as does the high rate of re-hospitalization for those with co-occurring chronic medical and mental health conditions.

As you have just heard, NAMI's list of asks is extensive and wide reaching. It may sound like the ultimate mental health "to do" list for the governor and the legislature, but let me assure you that this all boils down to one issue. The matter at hand is whether this state truly values the health and welfare of its citizens.

I am sure each member of the legislature has a cause that is dear to their hearts, you wouldn't be here otherwise. In many ways our ask is not dissimilar to the asks of hundreds of groups that come through Albany each year, each one with a story and a struggle that seeks to move and elicit legislators to act in very personal and human ways. I implore you to see that the plea NAMI NYS puts forth for our loved ones, families and communities is a fundamental component of the health of our state. Without properly funded mental health care that abides by parity laws there is no functioning family or successful child, there are no healthy communities and there is little hope for recovery for New Yorkers who are struggling to get better and live fulfilling lives.

We urge you to act. Thank you for your time and for listening to me today.

Thank you Ariel, finally, NAMI-NYS has concerns in two other areas. First are investments to improve the way the criminal justice system interacts with people with mental illness. These include the expansion of Crisis Intervention Teams (CIT), making the investments needed to implement the passage of the HALT bill A.2500/S.1623 to reform the use of solitary confinement and investments for enhanced discharge planning for people living with a mental illness coming out of prisons. Finally, we would like to see continued investments in the Joseph P. Dwyer Vet-to-Vet mental health peer program.

Thank you again for your time today and including our insights. We look forward partnering with you to building a more mentally healthy New York State.

ⁱ www.nami.org/policystats.

ⁱⁱ New York Times, January 23, 2019, *Mentally Ill Prisoners Are Held Past Release Dates, Lawsuit Claims*,

ⁱⁱⁱ New York Times, December, 2018 *Living Apart, Coming Undone*

^{iv} <https://www.documentcloud.org/documents/5682677-Frontline-ProPublica-Letter.html>

^v The Health Effects of Cannabis and Cannabinoids THE CURRENT STATE OF EVIDENCE AND RECOMMENDATIONS FOR RESEARCH Committee on the Health Effects of Marijuana: An Evidence Review and Research Agenda. Board on Population Health and Public Health Practice Health and Medicine Division. A Report of the National Academies of Science-Engineering-Medicine, 2017

^{vi} The Health Effects of Cannabis and Cannabinoids THE CURRENT STATE OF EVIDENCE AND RECOMMENDATIONS FOR RESEARCH Committee on the Health Effects of Marijuana: An Evidence Review and Research Agenda. Board on Population Health and Public Health Practice Health and Medicine Division. A Report of the National Academies of Science-Engineering-Medicine, 2017. Page 289

^{vii} <https://www.nimh.nih.gov/health/publications/the-teen-brain-6-things-to-know/index.shtml#pub2>