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New York State Assembly
Standing Committee on Mental Health and
Developmental Disabilities Hearing

on

Access to Mental Health and Developmental
Disability Services and Supports

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

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Good Morning. Thank you chairwoman Gunther, for holding this hearing and for the opportunity to testify on the crucial topic of access to appropriate psychiatric services. My name is Matthew Shapiro, I am the Associate Director for Public Affairs at the National Alliance on Mental Illness of New York State (NAMI-NYS) and with me today is Dr. Evelyne Tropper, our board member and Government Affairs chair. Dr. Tropper is a family member and is the caregiver for her adult daughter with severe mental illness. Evelyne and her husband have struggled to find appropriate community-based services to provide treatment for their daughter who is living with schizophrenia. While the Tropper's quest to find help for their daughter is magnified by the fact that they live in a rural area, their 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 psychiatric disorders.

The statistics surrounding mental health are alarming, suicide is the only major leading cause of death that continues to increase, one factor in this is that on average it takes someone ten years from the time they begin noticing psychiatric symptoms to when they begin to receive help. While stigma is often blamed as the main culprit for this, we will testify today that far too many New Yorkers experiencing mental illness cannot find services to help them recover.

Now is a crucial time for this 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, 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., More importantly, it will improve and save lives and ease the burden for the one in four New York families such as the Troppers who sacrifice a great deal to give their loved ones the best life possible. NAMI-NYS has identified a serious lack in funding in the state hospital system, in community-based psychiatric programs and in mental health housing.

During the 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 hope Governor Cuomo will follow his debate declaration with action and that he will lead the way in addressing a concerning trend that has made access to beds in both settings extremely difficult.

For several years now, the New York State Office of Mental Health (OMH) has been directed to reduce 100 beds a year from the state psychiatric hospital system. We also believe that if more costly hospital beds need to be reduced those reductions must 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.

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. The mental health housing system is in serious crisis. Non-profit mental health housing providers have received flat-funding from OMH for 25 years. Due to the rates of inflation these providers are operating at 43% of where they should be. This 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 with out proper funding. As Governor Cuomo clearly stated, we need more mental health beds, we hope that under your leadership, the Standing Committee on Mental Health and Developmental Disabilities and the Legislature will work along side the Governor to solve this problem as the time to act is now.

Our deep concerns about the community-based mental health house system are magnified due to the changing systems which deliver mental health care in New York State. Earlier, I mentioned the administration's desire to reduce 100 psychiatric beds from the New York State Office of Mental Health (OMH) hospital system annually. The State estimates this will save \$11 million-at a value of \$110,000 per bed- and these savings are earmarked to be spent in more affordable community-based care. NAMI-NYS is advocating to make sure those investments are spent on community services that will enhance overall access.

In the current fiscal year, Governor Cuomo called for investments in Assertive Community Treatment (ACT) Teams and respite centers. While NAMI-NYS applauds the increased availability of these vital programs, however we are deeply concerned about the diminishing amount of psychiatrists and a reduction of the mental health workforce in our state. Evelyn's family's story highlights how challenging it often is for families to get care for their loved ones. This is especially true for those living with the most serious and persistent forms of psychiatric disorders and the struggle is magnified many fold if you live in a rural or inner-urban area. We hope that this problem is looked into more closely as we cannot have a community based system of care without providers. Evelyn will now explain the arduous task families have in finding services for their loved ones.

Good morning. Thank you chairwoman Gunther for the opportunity to tell my story. Matthew and other advocates have provided you with the statistics on the profound issues with access to mental health treatment in the state of New York. My family's personal story illustrates how significant and destructive this problem is.

My daughter is 43 years old and lives with schizophrenia. She has been hospitalized multiple times after suicide attempts in Montreal, Ohio and Plattsburgh, NY. Each time she was

hospitalized in Plattsburgh she was under the care of a retired psychiatrist doing a 3-months stint to supplement his/her retirement income. The in-patient psychiatrist would refuse to talk to her out-patient psychiatrist and subjected her to different meds, even though the out-patient doctor had experimented with a multitude of meds, none of which really worked except for one. The average time a new medication kicks in is 6 weeks, yet Medicaid typically only pays for a 10-day period for an acute care hospital stay. She would be discharged after she was asked if she still had some suicidal ideation. She knew the right answer to get out. HIPPA laws prevented doctors from asking us.

The last time she was hospitalized, she was declared ready for discharge (even though we knew she was still suicidal) to a group home where patients could sign themselves out for 29 days with no reason or forwarding address. The meds would be given each day but not monitored, so that patients could throw them out or accumulate enough to overdose. I asked one of the aides if that had happened and what they did then. The answer was that they brought them to the hospital.

We knew she would not survive there. She did not want to come home with us so we hired a lawyer to put a restraining order on the hospital to prevent their discharging her and putting her life at risk. They kept her until there was a long-term bed at St Lawrence Psychiatric Center which, at one time, had thousands of beds, and now has 108 beds, and those are mostly for the Sex Offender Treatment Program. We were forced to send her to a psychiatric facility in Vermont in order to get decent treatment and to keep her alive.

After being there for a couple of years, she was much better and seemed to understand she has a problem. We are now trying to repatriate her home to NYS. To our great surprise and consternation, all the psychiatrists we knew had retired. The ones left (from Albany to the Canadian border) did not take Medicare/Medicaid and some took no private insurance. When we offered to pay out of pocket, we were told that when you sign up for Medicare/Medicaid you agree not to seek privately paid doctors. We were now left with two community health centers, one in Plattsburgh another in Saranac Lake. Both had a waiting period of many months to get in. I also had Matthew assist in our search for adequate outpatient care and even with all his NAMI contacts, after weeks of searching, he too was unable to identify a provider for us. It became all

too clear that providers do not or cannot deliver care to people like my daughter who have serious mental illnesses, many of whom also have co-occurring physical ailments and need more intense monitoring. Using my daughter as an example, the medication that is most effective in treating her psychosis requires a blood test every month and she cannot be without medications for her psychiatric symptoms while we search to find a provider that can monitor her.

She also has a thyroid problem and psoriasis. Taking her to a doctor is always a struggle. However, taking her to a psychiatrist as opposed to an endocrinologist is more than twice as hard. There are close to zero case workers and therapists, no Mobile Intervention Team, no Crisis Response Center, no tele-psychiatry, and no incentive for qualified psychiatrists and other psychiatric providers to move to a rural area.

We feel stymied and let down that psychiatric patients are the last frontier of discrimination. There are now more people with psychiatric disorders in jails, prisons and on the streets than in treatment. We as a society should be ashamed by this and no family should have to struggle and watch their loved ones suffer the way we have. It is heartbreaking and it is wrong and I know we can do better, we must do better, my daughter and the thousands like her deserve the care needed to live happy and healthy lives.

Despite my family's experience, I remain optimistic; New York has shown that it can be a leader in introducing mental health reforms such as enacting mental health education, Kendra's Law and Timothy's Law. Please help lead people with neurobiological disorders and their families out of this wilderness and ensure that we no longer have to name laws after people failed by the mental health system.

Evelyne and her family's story is all too common and the state must make the proper investments to meet the need of all New Yorkers impacted by mental illness. ACT Teams and respite centers are a good starting point, but we need to invest in other community services as well.

Evelyne also detailed the lack of Mobil Intervention Teams and ACT teams in her area. NAMI-NYS is calling for increased utilization and funding for these teams and for innovative programs such as of crisis response centers to help individuals during their most vulnerable periods especially in rural areas. NAMI-NYS has long testified that no one should have to travel more than an hour to access psychiatric crisis care.

NAMI-NYS also wants to see expanded use of Certified Community Behavioral Health Clinics (CCBHCs). These clinics prove particularly valuable for individuals with serious mental illness, those with severe substance use disorders, children and adolescents with serious emotional disturbance (SED), and those with co-occurring mental, substance use or physical health disorders. Access to such a service provider would be extremely beneficial for families such as the Troppers.

NAMI-NYS would also like to see New York State be more aggressive and creative in addressing the shortage of psychiatrists in the state, introducing incentives to increase practicing psychiatrists in the state, especially in rural areas. We also would like to see programs that generate more psychiatric nurse practitioners who can prescribe medicine and monitor patients. Telepsychiatry, as well as integrated psychiatric care in primary care settings and in schools are essential.

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 believes this support should not be limited to in-patient facilities. We stand beside our colleagues who are calling for 25% of the state's share of the investment, roughly \$169 million be used to support community-based care.

NAMI-NYS has one more serious concern about the availability psychiatric services in the community. We have detailed how services are difficult to locate and many people across the state have found the ability to access the limited services available extremely difficult due to the lack of insurance parity as many providers do not accept insurance for psychiatric care. NAMI-NYS is grateful to the Legislature for adding \$1.5 million in this year's final budget in order to

create a statewide behavioral health ombudsman to monitor behavioral health parity violations. This is a very positive development, as ensuring adherence to parity by insurance plans is critical. We call on the legislature to continue a dedicated effort monitor and enforce parity through ensuring that insurance companies are consistently addressing issues with network access..

We thank you for your time today and listening to the pleas of NAMI-NYS and the families we represent. We wish you a joyous holiday season and look forward to working with you to create increased access to mental health services during the upcoming session.