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Joint Legislative Public Hearings

on the

2015-2016 Executive Budget Proposal

Housing

National Alliance on Mental Illness of New York State

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Testimony delivered by:

Wendy Burch and

Denise Duncan, Chairperson of Government Affairs Committee

Good morning. My name is Wendy Burch. I am Executive Director for the National Alliance on Mental Illness of New York State (NAMI-NYS), with me today is Denise Duncan, chair of our Government Affairs Committee. Thank you for this opportunity to provide testimony today, since for many of the 673,000 adult New Yorkers living with a serious mental illness, accomplishing one of the most basic human needs...that of a safe, accessible and stable place to call home remains a tremendous challenge.

NAMI-NYS is the state chapter of NAMI, the largest family and consumer grassroots mental health organization in the country with more than 40 affiliates in New York State. Since our incorporation in 1982, establishing safe and affordable housing for people living with psychiatric disorders has been a major ongoing priority. I am sad to say that while we have made some inroads, far too many of this vulnerable and underserved population are still without proper housing, forcing them to live on the streets or finding shelter in what has become the state's largest asylum for mental illness, our prison system. Both of these avoidable outcomes leads to a greater burden on taxpayers. We must and can do better.

Mental illness is not a single illness. There are many types of mental illnesses. There are anxiety disorders, mood disorders, substance abuse-related disorders, obsessive-compulsive disorder, trauma and stress-related disorders, and psychotic disorders, among others. Most people with mental illness are nonviolent, exercise good judgment, move about freely in the community, are willingly treated in office settings, can find employment and live independently without support. However, for far too many housing has become unobtainable.

Many of our members serve as the primary caretakers for their loved ones with serious and persistent mental illnesses and as they grow older they have become increasingly concerned of who will take care of their adult children hampered by the debilitating effects of psychiatric disorders once they are gone. We hear their cries almost every day and we echo them today with you.

Denise is a member who has several unique perspectives on housing issues as both a family member and a clinician:

Good Morning. My comments today are informed by experiences as the daughter of a single-parent with Schizophrenia, director of housing provider for people with mental illness and as a licensed mental health clinician.

Housing and services for people with mental illness have been inadequately funded for too many years. Today I hope to illustrate for you the very real cost incurred- both financial and human-, that the continued flat funding of programs providing supports and services for people with Mental Health disabilities have and will continue to have in our communities.

It is beyond dispute that programs such as these are highly effective. I'd like to tell you about Mr. Kim, a man I first encountered when he was living in a homeless shelter struggling with mental illness and substance abuse. Because of his psychiatric instability and homelessness he was unable to care for his young son, who also resided in a different homeless shelter with his mother.

Mr. Kim's dream was to be able to establish a home for his son, go to college and maintain his recovery. Mr. Kim was working hard to obtain mental health services, but his local clinic had a 3 month long waiting list. Because of the rampant drug use in the homeless shelter, Mr. Kim often chose to leave the shelter to sleep on the streets. When that became untenable, he went back to social services to be placed in another shelter, where he would again apply to get on the waiting list for the clinic local to the new shelter. This cycle continued for years until Mr. Kim was offered an opportunity to reside in a local non-profit mental health housing agency which provided rent subsidy and weekly case management services.

Within several months the agency's case management staff was able to assist Mr. Kim in becoming stabilized, at which point he was able to obtain clinical services, address several chronic medical issues, and apply for disability benefits, enroll in a community college, and re-establish contact with his son- all of which had been an impossibility while living a transient life in and out of homeless shelters.

If we flash forward a couple of years to today, Mr. Kim has maintained his mental health treatment, and remains free of substance abuse. He has graduated from the local community college with a degree in broadcast media, and is on his way to earning his bachelor's degree at the local SUNY school. In addition, Mr. Kim was able to secure family housing within the same agency where Mr. Kim was reunited with his son and his son's mother. Staff were proud to stand behind the family as Mr. Kim married the mother of his son, and brought them out of the shelter system to live with him. Mr. and Mrs. Kim never miss an opportunity to express how grateful they are to have had the support and assistance that has allowed them to live together.

Mr Kim's story as well, as many others like his, clearly illustrate that the supports and services provided by programs like these are highly effective. These achievements would be impossible without the help of dedicated staff who deliver these life-changing supports.

I'd also like to share with you the story of one such committed employee. Shirley and others like her are the ones who work tirelessly to provide services to people such as the Kims. Their job is to promote recovery, enrich lives and reduce the burden on tax-payers by helping people maintain their independence in the community and reduce the use expensive alternatives such as ERs, shelters and hospitals.

To be effective in helping people obtain these goals requires not just dedication, but also clinical skills and expertise. Shirley has a bachelor's degree, and the student loans to go with it.

Shirley and her colleagues have not received a cost of living increase in their salary for six years. We are grateful that this year, direct care staff can expect a 2% cost of living increase. However that 2% across the last 6 years leaves staff significantly behind the actual increase in the cost of living. Shirley and almost all of her co-workers has a second job (some even have 3 jobs). She works all day, doing a difficult job with very challenged people giving them the help and hope they need to recover from mental illness. She makes sure people are safe, secure and have their complex needs met, providing services that help someone in the throes of psychosis gain stabilization, help someone without food to access a food pantry, help someone address a medical emergency, getting them connected with resources and services...the list is exhaustive, and the work is often exhausting. And at the end of her day, she heads out to her second job.

Shirley works very hard, in a demanding field that requires education and expertise, yet she only earns \$33,000 a year and her salary hasn't increased for 6 years. She knows the 2% increase, will not go far enough to sustain her as the costs of everything have risen 3 times higher than her pay has. Shirley hopes that this year she will be able to afford heating oil for her home, because last year she went several weeks without heat because she couldn't afford to pay for oil. Her health care costs and deductibles have skyrocketed way beyond 2% and her rent increases 5-10% annually.

Good and qualified people like Shirley are leaving the field in droves because they can't afford to do this necessary work anymore. By far the most consistent complaint of people who live with mental illness in the community and count on workers such as Shirley is: "They can't keep up with the constant change of staffing." No one can afford to do this work anymore. It is almost impossible to find educated, qualified staff willing to work for the salaries paid to them. And if we are lucky enough to get them, we can't keep them for very long.

Mr. Kim's experience is illustrative of the positive outcomes we can achieve when we allocate the necessary funds to the resources that exist to provide these life changing services. We spend roughly \$3,000 per month to keep people in homeless shelters when we could provide decent affordable housing for less than half of that amount. We have people using valuable Medicaid dollars to pay for emergency room visits and hospitalizations, many of which can be avoided by providing services, treatment, and housing that allow people to stabilize in the community before emergencies erupt. The services that allowed Mr. Kim to transform his life are vital for him, and they save the taxpayers a hefty sum as well. As a taxpayer, I appreciate that.

Unfortunately, Shirley's experience is illustrative of the impact that 6 years of flat funding has had. It is unconscionable to expect people who require the level of education, experience and motivation to maintain employment in a field where they can't even expect to earn enough to sustain themselves even with holding down 2 or 3 jobs.

We therefore implore you to consider the positive impact that community mental health services have on people who live with the challenges of severe and persistent mental illness, their families and the community as a whole. Please imagine what would happen if these services were unavailable. And please understand that the people who provide these services, the clinics, the housing agencies, the care managers, and others can't afford to do this work if funding is not restored to realistic levels. Housing agencies are closing their doors or are not willing to open new beds to keep up with the demand because the funding to run these programs is so inadequate. Staff can't afford to stay in the field. We must address the years and years of flat funding that has gotten us so far behind. We cannot continue to ignore the desperate cries for relief from the people we depend on who provide the services that benefit not only the most vulnerable among us, but our communities at large.

Our President, Irene Turski could not join us this morning as she had an emergency involving her sister who lives with a mental illness. But she wanted to detail the struggles her and her family have faced in trying to find housing for her sister:

My name is Irene Turski, president of the National Alliance on Mental Illness in New York State and I have a 64 year old sister who suffers from serious (severe) mental illness. I call my sister's affliction severe since I do believe all mental illness is serious. It has been a struggle to try to keep my sister both medically and mentally stable. I sometimes think we all need to step back and remember, all this talk of housing and services relate to one thing: A human life, a precious human life and making sure it is not wasted, that this one person of many has the best quality of life they can. The most severe people with mental illness cannot function without our help and support.

During the course of her 16 year struggle with severe mental illness, I have had to monitor closely the care she has received at many facilities. Her stay at some facilities unfortunately was horrible at times and lead to repeated hospitalizations due to medication errors, lack of daily well-being checkups and lack of experienced staff. Too many times, staff was not consistent, those with experience leaving and new staff without the experience necessary to detect the beginning of a resident decompensating to avoid hospitalization. At residential facilities, the

same scenario, staff not experienced or knowledgeable enough to detect when a resident is decompensating to prevent a hospitalization. How can we expect staff to do the necessary jobs that come with people who have many different medications that upset their medical and mental state? A staff member who is caring and efficient recently told me that she might do better if there is a minimum wage increase to go work at Walmart? So once again, we lose someone who cares and has the experience necessary due to finances.

The transformation that the Office of Mental Health is asking us to accept cannot be achieved unless we have the necessary housing facilities with adequate support services in place. Part of that equation is the trained, experienced staff that know enough to monitor residents especially when their medication has been changed and they begin to display decompensation. This is the crucial time that the psychiatrist or counselor needs to be called and make a decision if the medication given is working or if they need to reevaluate medication changes. Also for many of these residents, many of their medications can cause dehydration and other medical issues.

It is imperative that there is qualified staff to remind these people to drink enough water or wash or any of the needs that some medications cause such as mental confusion or forgetfulness. As family members, we do not want our loved ones hospitalized for the rest of their lives. There is nothing I want more than my sister out on her own, living independently but it hasn't happened.

Please, I beg you, allocate enough funds for the housing necessary with appropriate support services and qualified staff to stay in their jobs. Every time my sister decompensates, she has never come back to me in the same state of mind. Is it further brain damage? Every time one of our loved ones decompensates and goes into the hospital, they and we run the risk, they will never come back to a stable mental state which reduces their chances of going out into the community to live a satisfying life.

The need to create safe and affordable housing for people living with mental illness has intensified as New York reforms the way it delivers mental health care. In recent years, the Office of Mental Health has focused on reducing the number of people in the most expensive housing environments such as in-patient beds at state psychiatric hospitals, state operated

supervised community residences, and other state funded residential settings. To achieve this, OMH has given priority status in access to housing to individuals residing in these settings. While we acknowledge the necessity to reduce costs, we must ensure that housing opportunities are made equally available to individuals who do not come from these priority populations but are still in need of the housing supports and services.

Additionally, we need to ensure that individuals who are being transitioned from these highly supervised settings are being moved to residential settings that adequately meet their high level of need for supports and services in order to maximize their recovery, avoid future hospitalizations, and ensure the best possible quality of life. We learned a painful lesson from the last time OMH conducted such a reduction twenty-years ago. At that time, many people went from highly supported environments to single residency occupancy (SRO) apartments with no supervision. The results were disastrous as many people still ended up living in the streets and entering the criminal justice system. We cannot relive these mistakes of the past.

When considering the transition of individuals to lower cost residential settings in the community, it must be noted that the funding for current housing resources such as Community Residences, Apartment Treatment Programs and Supportive Housing has remained flat for many years, while the need for the resources and the complex and increasing needs of the individuals served has grown. Because the funding has not kept up with increase in cost of living since 1990, programs are operating at 43% below where they should be today. To restore these crucial housing resources, \$99 million is needed to replace the funds lost to flat funding as the cost of living has increased. The specific breakdown of necessary funds is as follows:

- \$43 million to the Supported Housing rate statewide in 2015 to make up for losses from inflation and to ensure that Supported Housing is sustained, basing future rates on a reasonable formula. Home Health care coordinators do not take the place of housing staff, while the new guidelines will place extra financial burdens on providers.
- \$24 million for Community Residencies (CR)-SROs to make up for losses from inflation and so that they can better serve those with challenging needs. These provide a high level of service and can be very long-term stay or permanent.

- \$19 million for the CR program (includes both CRs and Treatment Apartments) to make up for losses from inflation and to incentivize providers to admit the most challenging clients safely. This would have the added value of ramping up the model's efficiency in rehabilitating people more quickly, most likely an outcome that the MCOs will expect when this model is moved into Managed Care. This number subtracts the estimated BIP revenue.
- \$13 million to SP-SROs, permanent housing with supports, to make up for losses from inflation and to better equip them to serve clients with more challenging service needs.

NAMI-NYS is encouraged by the \$30 million investment in housing that is appropriated in the Executive budget for FY 2015-16, as well as the Governor's proposal to take \$10 million of the JP Morgan settlement funds to support approximately 13,000 supported housing units. However, this additional funding still falls short of the \$99 million needed to address the flat funding housing programs have received since 1990 and return the funding they have lost due to inflation, and a disproportionate amount of these funds will be dedicated to people previously residing in state hospitals and other state operated systems. We ask that the legislature join us in calling for an increased appropriation that would raise the funding to adequate levels.

NAMI-NYS was also encouraged that the Executive Budget included a new \$22 million investment to expand services to individuals at risk of violence. Part of this investment includes aggressive community services through the use of additional Assertive Community Treatment (ACT) teams and supported housing. NAMI-NYS believes this investment will advance the recovery of some of the most vulnerable people living with a mental illness. We urge the legislature to support this important initiative.

NAMI-NYS recognizes that in order to provide adequate services, providers must be able to recruit and retain qualified staff. This is not possible when staff have not been granted a cost of living increase (COLA) for the past 6 years. While we appreciate that this year's budget will provide a 2% increase to direct care staff, this is insufficient to keep up with inflation and staff are falling so far behind that they are often eligible for the same resources as those who are living at or below the poverty level. The work these 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.

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. Dependable delivery of care is a critical element in the recovery of people living with a mental illness and is vital to the success of the transformation to community-based services that the Office of Mental Health is establishing. A lack of sustainable care can lead to decompensation and our loved ones going back and forth to the hospital, thus creating an increased financial burden to the state, as well as the potential for further brain damage which will diminish their chances for a life outside of a hospital setting.

NAMI-NYS applauds the Governor for including the COLA in the Executive Budget but we urge our legislators to support a greater commitment to these underappreciated workers

NAMI-NYS believes it is the responsibility of government at all levels to develop and maintain comprehensive community support systems that include treatment and services, as well as short and long range plans for all those living with serious mental illness. Providing safe and affordable housing with the proper support services is essential to achieve this goal and maximize the mental health of New York State.

Thank you for your time today.