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New York State Assembly Mental Health Committee

Public Hearings

on the

Access to Housing Services for People with Mental Illness

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

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Assemblywoman Gunther, thank you for holding this hearing focusing on the crucial issue of housing for people living with a mental illness and I deeply appreciate the opportunity to participate in this discussion. I speak to you today, not solely in my role as the NAMI-New York State Government Affairs Chair, but as a family member and unpaid advocate for those with serious mental illness. I traveled from Buffalo to be here and offer the experiences of families. While many of our colleagues testifying before you today will detail the financial specifics necessary to provide appropriate housing services, I am not an expert in these numbers, my expertise lays in being a caregiver of a loved one with a serious mental illness. While others will be providing the specific statistics detailing the housing needs, I want to speak about the human impact of the decisions your esteemed committee will be making today.

As many of those testifying today, my words are drawn from being on the front lines of the epidemic caused by insufficient housing resources and imsufficient psychiatrists in the community. NAMI-New York State speaks for families of those with mental illness and I want to explain to you how the inappropriate under funding of housing programs with wrap-around services impacts the one in four families in New York State with a loved one with mental illness. My testimony today is based on witnessing the experiences of my sister who has schizophrenia. She has lived within the state hospital system and in a community residence program. I assure you, the only reason she was able to live in the community is because she did reside in a community residence that incorporated the necessary support services to keep her healthy.

Many of the people like my sister going into the community were institutionized for years and haven't had to make decisions for themselves. Their mental and physical health are fragile and require the necessity of seeing a psychiatrist, psychologist or mental health counselor frequently. We can bring people into the community but it is inhuman to do so without the appropriate amount of doctors to monitor their recovery. My experience has been once out of an inpatient setting, they see their psychiatrist once a month or if lucky, once every two weeks. When someone like my sister is given a new medication, this should be monitored very closely for adverse reactions. In my case, my sister had a horrible reaction to a new medication called lamictal and was literally burning from the inside out. I have the pictures and emails to

prove this. She went through hell and only because of the attentiveness of the community residence staff who knew her along with my repeated emails to her psychiatrist, did we finally get her slowly titrated off this medication. Even with all this, my sister is back as an inpatient (by her own decision) and still unfortunately not stabilized, so please be careful about allowing inpatient bed closures. I have heard that OMH is offering housing providers incentives for a certain period of time, to take people from inpatient beds to their facilities . OMH can permanently close an inpatient bed if it is not occupied for a 90 days period I believe. What happens after the additional funds are no longer given to housing providers for these people? Many housing providers I have spoke to have said some of these people in the community belong in a hospital setting for proper care. Is anyone keeping track of where these people end up if they are removed from the housing they were put in? What happens to those who don't have a family advocate out there raising hell for their loved one?

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.

Housing programs for those such as my sister must include full wrap-around staff support services. These includes the ability to get residents to doctor and therapy appointments, teaching 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 the people who need these services 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, face, trunk, and extremities. In order to address the complex needs of this population housing programs must be able to provide caring and attentive support along with mental health professionals .

This type of attentive support can only be achieved through having continuity of care delivered by qualified and compassionate staff. Only someone providing continual care would be able to notice slight changes in a person which could indicate serious ailments. 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 essential and it 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 a common myth that families turn to housing programs because we don't care about our loved ones. Nothing could be farther from the truth. The sad reality is, despite our best efforts most of us are simply unable and unqualified to provide the intensive type of care necessary to help our loved ones achieve recovery. This is not out of a lack of want or lack of love, the challenges of providing full-time care are just too great. Many of us have tried and many of us have painfully failed. We turn to housing providers as a last resort, but we do so expecting those dear to us to receive the type of support they would get at home along with skilled expertise to help advance their recovery. This can only happen by relying on competent staff that can combine compassion and clinical knowledge.

I have gotten to know many of the staff people who have literally cared for my sister throughout the years. They are committed to not only caring for a challenging population, but willing to work long hours and spend too much time away from their own families to tend to our family members. Many have taken the time to get to know me as well and listen to my own concerns and insights about my sister. A firmly held belief by NAMI-New York State is that recovery happens best when individuals with a mental illness, their families and their providers work together as a team with open communication and shared goals. We view this much like three legs holding up a stool. As you know, a stool cannot stand if one of the legs is broken. I am here today to testify; that despite the best intentions of some the most dedicated people I have ever met, one of the legs of our recovery stool is broken. I ask for your help in repairing that leg.

If New York State is determined to reduce the use of hospitals and deliver care in the community setting, the state must help housing providers deliver the most appropriate form of care. Recovery in community housing is unachievable without the ability to maintain the best staff possible to provide care, case management and create a true home geared towards recovery. This

is way NAMI-NYS is proud to participate in the Bring it Home campaign. The state must also allocate funds to OMH to provide the necessary psychiatrists and therapists to monitor the recovery of our loved ones. My sister who has suffered a great deal throughout her life deserves nothing less. Thank you!