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Joint Legislative Public Hearings

on the

2014-2015 Executive Budget Proposal

Mental Hygiene

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

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Testimony delivered by:

Sherry Janowitz Grenz, Chair of the Government Affairs Committee

Barbara Biasotti, Board Member

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Good afternoon. My name is Sherry Janowitz Grenz. I am chairperson of the Government Affairs Committee for the National Alliance on Mental Illness of New York State (NAMI-NYS). Board Members Irene Turski and Barbara Biasotti are here with me today. Thank you for this opportunity to provide testimony since this is a particularly crucial time in our state for the approximately 673,000 adult New Yorkers living with a serious mental illness whose very lives depend on the decisions made by this esteemed legislative body.

NAMI is the largest family and consumer grassroots mental health organization in the country with 48 affiliates in New York State. We offer support, education, and advocacy for family members of those who have serious mental illnesses, as well as for those who suffer with mental illnesses themselves.

"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, and are willingly treated in office settings.

A very small subset of persons who have a mental illness experience hallucinations and delusions. They may not attribute their unusual beliefs, experiences, and behavior to a mental disorder. This lack of awareness/insight is called anosognosia; people with dementia and Alzheimer's sometimes also experience anosognosia. From the person's point of view, if nothing is wrong with them, why should they accept treatment of any kind? About half of people living with schizophrenia have this clinical feature.

This group of persons with serious mental illness does not endorse the benefits of treatment because they do not see themselves as having one of the serious mental illnesses. Their high risk

behaviors are informed by their auditory hallucinations and false beliefs. Use of alcohol and other drugs of abuse compounds their impaired judgment. They do not want to be symptomatic, but a brain disease affects them in ways that lead to impaired ability to care for themselves safely in the community. Our society often fails to meet the needs of these people. They need and will benefit from intensive state-of-the-art treatment that is available only in hospital settings which keep them safe and from harming themselves and/or others. Medications have proven to be effective in controlling symptoms, improving quality of life, and protecting against relapse. On becoming less symptomatic and more able to live safely in the community, they can then move to a less restrictive setting. Even then, a small number will benefit from Assisted Outpatient Treatment that is court-ordered and known as Kendra's Law so they can remain safely in the community.

NAMI-NYS board member, Barbara Biasotti, describes her daughter's experience and how her life was saved by AOT. Barbara's daughter was afflicted with schizophrenia soon after her college graduation. Barbara was able to access some of the best psychiatric care for her that is available in the New York City area, but her daughter could not and still does not recognize her own psychiatric diagnosis that she has had for almost 19 years now. She has almost consistently been non-compliant with her prescribed treatment and medications simply because she is unable to recognize that she has a psychotic disorder due to anosognosia. Her delusions and hallucinations are completely real to her. The voices have instructed her to act in harmful and dangerous ways to herself and others. Some examples are: she ran into oncoming traffic on numerous occasions, attempted to apply for a gun permit, and attacked random people on the street whom the voices deemed to be dangerous to her. She has been involuntarily hospitalized about 25 times because she was determined by two psychiatrists to be dangerous to herself and/or others.

At a tearful conference with her daughter's psychiatrist at a major medical center, Barbara expressed her deep concern about what her formerly gentle and kind daughter might do to harm herself or others when she was discharged and once again became non-compliant with treatment.

The psychiatrist agreed with Barbara. Barbara asked what could possibly be done and the psychiatrist explained Kendra's Law and that her daughter met the very stringent criteria for a petition for Assisted Out-Patient Treatment. Since that time, Barbara's daughter has not had any arrests and is not aggressive. She is even gainfully employed at times, enjoys her family, and makes social connections while living safely in the community. Barbara is convinced and very thankful that AOT has saved her daughter's life.

In the best of all worlds treatment would be non-coercive and informed. On rare occasions, society will need to overcome a person's failure to acknowledge his/her mental illness and offer treatment in an environment that preserves both the safety and the dignity of an impaired individual. Anything less is inhumane and risky to the individual and the community.

Many of our relatives have complex mental illnesses that sometimes *do* require hospitalization. As it is, there are not enough inpatient psychiatric beds available in New York State to meet these needs: What will happen when even more beds are cut as recommended in the New York State Office of Mental Health's Regional Center of Excellence (RCE) report? These recommendations would reduce the number of state-run psychiatric hospitals from 24 to 17, thus eliminating 400 beds. An Op-Ed piece in the January 25, 2014, edition of The New York Times states that according to E. Fuller Torrey, M.D. (author of *Surviving Schizophrenia*); today there are only 14 beds for every 100,000 citizens. Dr. Torrey estimates that we need at least 50 beds per 100,000 people. As of July, 2013, the population of New York State was 19.6 million people. When psychiatric beds go down, incarceration goes up. The justice system is not equipped to treat people needing psychiatric hospitalization. Will our relatives wind up in jails or in prisons, or homeless? Now is the time to do the right thing and return the care of the severely mentally ill to the health professionals so that lives can be saved.

NAMI-NYS priorities for 2014/2015 are:

1-Support Reinvestment in the Mental Health Community:

Money saved from any closures must be reinvested in the mental health community. Such reinvestment should be a dollar-for-dollar reinvestment and align with our belief that all publicly funded community service providers must offer practices and services that have evidence based effective results.

2-Support Safe and Affordable Housing for People With Mental Illnesses:

Access to decent, safe, and affordable housing remains a tremendous challenge for people with serious mental illness. Appropriate supports and services are necessary so that our family members live in a residence that provides them with as much dignity and independence as possible. Housing with adequate special services will prevent our loved ones from multiple emergency room visits, living homeless or being incarcerated which, ultimately, ends up costing taxpayers more money.

3-Support Government Sponsored Research of Mental Illnesses:

We are fortunate to have two of the world's Crown Jewels of psychiatric research located right here in our own state: Psychiatric Institute (PI) and Nathan Kline Institute (NKI). It is not enough for New York State to merely sustain funding to these institutes, the funding must be increased. Research lines that have been frozen for years, should finally be allowed to be filled. The cutting edge work being done at NKI and PI not only provides jobs to thousands of New Yorkers, but brings enormous prestige to our state, as well. Support of neurobiological and clinical research into the causes of mental illnesses and other brain disorders is critically important so that scientists can develop improved medications and treatments, and eventually find a cure to prevent these devastating, disabling diseases. Not only is this the hope for patients who suffer and their families, but it is also the best hope we have to reduce the economic burden of illness on New York State in the long run. RESEARCH IS OUR HOPE FOR THE FUTURE...and the future is now!

4-Support Expansion of Crisis Intervention Teams:

Contacts between law enforcement officers and individuals experiencing mental illness can be deadly, dangerous or result in poor outcomes for the individual. This is why NAMI-NYS supports the expansion of Crisis Intervention Teams (CIT), which consists of trained law enforcement officers and mental health professionals working together as first responders to deescalate situations and take appropriate action to assist an individual in the midst of a mental health crisis. Several organizations have passed resolutions to endorse CIT: New York State Association of Chiefs of Police, New York State Sheriffs' Association, New York State Defenders Association, New York State Catholic Conference, and New York State Association of Counties. Out of over 550 police departments in New York State, only 10 have CIT. NAMI-NYS supports the statewide expansion of CIT using the CIT Core Elements program which saves lives, reduces harm, and results in better outcomes for the individuals.

5-Support Veteran's Mental Health Initiatives:

Returning combat veterans are experiencing high rates of serious mental illness, suicide, addiction, homelessness and incarceration related to posttraumatic stress disorder and traumatic brain injury. More must be done in New York State to provide these courageous men and women with the full range of services and supports they need.

NAMI-NYS calls for the inclusion of mental health education into school's already existing health curriculums. All children and adolescents should have available to them mental health programs that provide prevention, identification, and treatment for all mental illnesses. We also call for the expansion of mental health courts throughout the state.

NAMI-NYS supports the modification of HIPAA rules which will allow providers to be more responsive and more helpful to family members who are first-responders to their loved ones' unusual beliefs and actions. Providers will be relieved to know that they can be protected by fewer restrictions in regard to what information can be disclosed and what guidance can be

offered. Families will be less frustrated, more collaborative, and better informed. Their loved ones will be better served by informed family interventions.

Although NAMI-NYS respectfully opposes OMH's recommendations regarding closures of state-run psychiatric hospitals and reduction of psychiatric hospital beds, in the event that the state moves forward in spite of our opposition, it is essential that savings from every bed and/or facility closure and consolidation as well as monies from the sales of property be reinvested into community support mental health services. Many mental health advocates remember the first reinvestment initiative in 1993 when there were significant cuts to OMH facilities. We were promised that these savings would be reinvested into community mental health services. They were not. An oversight committee comprised of stakeholders, including representatives from NAMI-NYS, should be formed to insure that this does not happen again.

NAMI-NYS board member Irene Turski has been caring for her older sister Christina for 15 years who, after spending the past 15 years in a state hospital, was told she was going to be discharged. According to Irene: "I have been through hell trying to find a more suitable inpatient hospital facility for my beloved sister. Over and over again I would be told there were no openings and the only choice I had was to have her live with my elderly, ailing parents or have her sent to a nursing facility with no mental health professional to monitor her; both unacceptable choices. Mental illnesses are a spectrum of illnesses and many people with mental illness lead full productive lives in society with minimal special services, but please do not forget or neglect the others who are too sick to advocate for themselves.

Media coverage in recent months has highlighted the horrors of mall shootings, school shootings, and even shootings of politicians by those with serious mental illness. However, the overwhelming majority of people with mental illnesses are not violent and are more often the victims of crimes than the perpetrators. But when an incident of such magnitude occurs, the public doesn't differentiate between the very few who, if untreated, might be violent and the rest of the seriously mentally ill who are never violent. This has a negative impact on all those with neurobiological brain disorders and reinforces stigma...stigma that could be eliminated if those

who have a severe mental illness and who might be at risk for being violent are properly stabilized, initially in a hospital and then continue their treatment in the community.

Those of you who watched Virginia Senator Creigh Deeds' story on 60 Minutes, no doubt, share the Senator's pain and sorrow. But Senator Deeds did not have to suffer the physical harm he did and Senator Deeds' son Gus did *not* have to die. The system failed them both. How many more tragedies will it take, how many more lives will be lost, and how much more human suffering has to be endured until cuts to mental health stop! You, our government officials, have a responsibility to protect those with serious mental illnesses, to protect their families...and to protect the public at large.

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. We need to offer an array of services that range from inpatient to outpatient, that includes effective medications and therapy, that offers safe, supported housing, that provides vocational and socialization opportunities, and that offers improved quality of life so that everyone has the best chance possible for recovery.

"...the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped." (Hupert Humphries)