Testimony submitted to the Office of the New York State Attorney General

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Access to mental health care for people with serious mental illness in the WNY region:

Access to mental health care for people with serious and persistent mental illness in WNY is grossly inadequate because of systemic failures. Multiple bureaucratic agencies work in silos that do not collaborate adequately in solving the problem of access for persons with severe and persistent mental illness.

- The lack of supportive services for families
- Lack of adequate supervised housing
- Lack of inpatient beds in long term facilities for a higher level of care
- CPEP (Comprehensive Psychiatric Emergency Program)is not staffed adequately to handle the number of patients who wait for hours and even days for an evaluation in inhumane conditions
- Criminalization of mental illness
- A revolving door experience- from hospital to homelessness to jail for so many people who live with incapacitating mental illness are all symptoms of **a broken mental health system.**

Families in Crisis

On our Helpline and while facilitating support groups, I have listened to hundreds of parents mostly mothers, tell their stories of caring for a loved one with mental illness, particularly those who refuse treatment and many of whom self-medicate with street drugs or alcohol. We have more than a few NAMI members who lost family members to suicide. Many families feel unsafe to have family members who refuse treatment living with them.

e.g. One mother who had her son living with her, could not receive information from his prescriber about his treatment but tried to share her concerns that her son was not taking his medications although he appeared to be keeping his appointments. She received no response. She felt afraid of her son as he became more psychotic and locked herself in her bedroom when she came home. She understood that the HIPPA form her son had signed made it illegal for the prescriber to share medical information with her, although she knew it was still legal for her to share her concerns with the prescriber, which she did through phone calls and a letter. While at home, she stayed in her bedroom because of her son's paranoid statements and behaviors. Her son became increasingly delusional about people trying to invade their home to the point where he set up booby traps and nailed a barricade to the door forcing his mother to climb from a window to go to work. When she returned she found that he had taken an ax to portions of her home making it unlivable.

Another parent, a father wept when he spoke about his dilemma of whether to evict his teenage son because of his risk of hurting his teenage sister.

One Buffalo mother reported that for many months she had spent every lunch hour at work making calls to agencies about housing, Medicaid, medical appointments or social services for her son. Upon learning of a first diagnosis for a loved one, many families plunge into crisis trying to navigate the mental health system maze, astonished and discouraged by how little support they can find within the system.

(NAMI focuses on education and support for these families as their primary objective.)

- At least 8.4 million people in the U.S. provide care to an adult with a mental or emotional health issue
- Caregivers of adults with mental or emotional health issues spend an average of 32 hours per week providing unpaid care

Suggestions:

- **Amend HIPPA laws** so that concerned family members may be able to receive necessary information e.g. about who their loved one's prescriber will be and date of appointments so that they can facilitate attendance and report concerns to the provider. The provider will see the patient once a month for ten minutes, the family in many situations will be caretakers for the remainder of the patient's life, often checking in on them and paying their expenses.
- **Psychiatric Advance Directives** should always be encouraged during the discharge process
- When possible, encourage providers to incorporate family members into provision of care plans. They should always be forewarned about any risk for violence that has been indicated.

Housing

The Erie County Department of Mental Health has mandated that family members seeking housing for their loved ones must apply through their SPOA (single point of access) line. The waiting list is long and once a rental is found, NAMI members have told us horror stories of inhumane living conditions in many of these apartments, some of which appear to be owned by negligent landlords. I have heard of assigned apartments: infested with roaches and rodents, one with black mold in bathroom and only 2 mattresses on the floor for 5 residents, another where a young man remained locked in his room because his cell phone was stolen by another resident. Reports from some family members indicate that patients are often expected to live independently when they lack the capacity to manage simple housekeeping tasks. Places like DePaul residences and (TSI) Transitional Services have a reputation for safe, supervised

housing with supports and are models of supervised housing. However, they are challenged in finding adequate funding and staff.

Decline of inpatient beds

Over the last 10 or 20 years, state mental health systems have been closing long term beds for the most severely mentally ill to reduce costs and encourage patient independence. The Strozzi Building at Buffalo Psychiatric Center (BPC) at one time had 800 beds and now is reduced to 100 beds. Psychiatrists who wish to find longer term treatment for their patients have no alternatives and often must release patients to the street or shelters for the homeless which cannot meet their complex needs. The unlocked RACCA residence on the BPC campus used to provide supervised housing for at least 120 patients that included provision of meals and medications.

It has recently been downsized and patients who lived in a community setting for years were moved to independent apartments. Several families called us concerned that this was not a good choice for their loved ones.

CPEP -other NAMI members will share personal stories of overcrowding, excessive wait times, lack of privacy, lack of chairs and one psychiatrist for 30 or more patients waiting to be evaluated.

Criminalization of Mental Illness

"*We have two mental health systems today, serving two mutually exclusive populations: Community programs serve those who seek and accept treatment. Those who refuse or are too sick to seek treatment voluntarily, become a law enforcement responsibility…Mental health officials seem unwilling to recognize or take responsibility for this second more symptomatic group.*"

Chief of Police (ret) Michael Biasotti , former President of the NYS Association of Chiefs of Police

DJ Jaffe, Insane Consequences: How the Mental Health Industry Fails the Mentally Ill ,p.43

Facts from nami.org

- 37% of adults incarcerated in the state and federal prison system have a diagnosed mental illness
- 70% of youth in the juvenile justice system have a diagnosable mental health condition.

This failure of the mental health system not only neglects the seriously mentally ill but threatens the function of the criminal justice system. Police and corrections officers are overwhelmed by responsibility for those with serious mental illness for which they have little to no expertise. Their mental health is at risk working in a stressful environment, sometimes (at ECHC) on 16 hour shifts, because of staff shortages. Individuals with serious mental illness fill our nation's jails and prisons where they are at increased risk of violence from some deputies and inmates alike. On the streets a mentally ill patient who is at risk for violence to self or others, has an increased risk of being shot by police who feel threatened by them.

In just over 17 years, between June 29, 2005, a total of 34 inmates have died while in custody at the Erie County Holding Center. Matt Spina, Buffalo News

A list of 34 Erie County inmates who have died since June 2005 (buffalonews.com)

Erie County Corrections Specialist Advisory Board (ECCSAB) was initiated in 2020 by Chair April Baskin of the Erie County Legislature to provide advice to, and oversight over the Erie County Sheriff Office's Jail Management Division which administers the Erie County Holding Center (ECHC)and the Erie County Correctional Facility (ECCF). The ECCSAB has worked with the Erie County Sheriff's Office (ECSO) and the Erie County Legislature:

- to purchase body and stationery cams for corrections officers following a tour of the ECHC by some Board members and interviews with three prisoners who alleged beatings by corrections officers
- After approval of purchase of body cams a year ago, they were accepted by corrections officers at ECCF in Alden but rejected by the Corrections officers' union at ECHC. Judge Thomas has been asked to rule on this issue.
- to fund MAT (Medication Assisted Treatment) which includes individual and group counseling in the Jail (ECHC) in the Fall 2022. The program began a few months ago and had 40 detainees volunteer for admission.
- Noting a significant number of detainees incarcerated for technical violations, Board sought information from Jail Administration. It was reported that jail administration has difficulty maintaining communications with the parole board.
- Board advocated during Covid for inmates and staff to have priority status in receiving Covid vaccines. Delays continued for a long time.

Right to Treatment and Right To Refuse treatment – families believe that the latter has the most power and often lament that pressure from well-intentioned disability advocates has resulted in more patients "dying with their rights on." Mental hygiene service employees visit inpatients and routinely advise them of their right to refuse treatment. It is one thing to respect the right to refuse treatment by someone who has intact cognition but those with serious mental illness suffer from a wide range of cognitive deficits. Anosognosia is a symptom of lack of awareness of illness. It occurs not only in serious mental illness but also in some strokes. Brain scans can confirm this frontal lobe malfunction and is the primary reason that patients refuse treatment. They do not believe that they are ill.

Some patients report that involuntary treatment in a hospital is just as traumatic as incarceration. Voluntary treatment is always preferred but there are situations where involuntary treatment is necessary. How can we make that outcome less traumatic for the patient?

How do we create the ideal therapeutic environment in hospital settings and employ staff who treat patients with compassion and respect?

Suggestions from D J Jaffe's book

1. **Consolidate and coordinate funding** – by combining the hundreds of discrete federal, state, county and local funding streams into one efficient department overseeing inpatient and outpatient treatment, case management, housing etc. p.222

2. **Make the sickest of those with a serious mental illness the target of most funding**.p.223

3. **Eliminate the IMD** (Institute for Mental Disease) exclusion which has been responsible for the closure of most long term hospital beds. Although only a small group require intensive long term hospitalization, it is almost impossible to find placements today for those that do. Community services will always be the ideal but it is inhumane to leave the most impaired of the seriously mentally ill, homeless without essential supports and resources. P.224

References

NAMI recommends the books:
Amador, Xavier (2007) I Am Not Sick and I Don't Need Help
to teach families communication strategies that will build trust.

DJ Jaffe (2017) Insane Consequences: How the Mental Health Industry Fails the Mentally Ill, Prometheus Books, Amherst, NY

Thank you for holding the hearing.