

## **Actual Examples of NAMI-NYS Members Telling Their Stories as Advocacy Tools**

### **Testimony by current NAMI-NYS President Ariel Coffman delivered to February 13, 2018 Joint Legislative Budget Hearing on Mental Hygiene**

I am proud to be here today representing NAMI NYS and the tens of thousands of NY state families and individuals who live daily with the devastating effects of serious and persistent mental illness.

Not only have I worked in the behavioral health system for nearly 20 years, I am also the caregiver and daughter of a father who lives with a serious mental illness so these issues truly mean more to me than just data, statistics, and politics. I ask all of you to envision a family member that you care deeply about struggling to recover from a life-changing illness that effects their ability to reason, their physical health and their ability to maintain the social ties that mean so much to them. This is what families and caregivers of people with serious mental illness face every day. We work tirelessly to trouble shoot a fragmented health system that lacks appropriate resources just to ensure that our loved ones get the medication, health care, and housing that they so desperately need in order to remain stable and connected to daily activities that many of us just take for granted like planning a meal, calling a friend or following up on our physical health needs.

As de-institutionalization has progressed families have been faced with the troubling reality of whether or not their loved one will be able to integrate into a community that they have limited ties to, in a world that frequently stigmatizes them fighting a day to day battle to recover from mental illnesses that they did nothing to cause.

My father lives in mental health housing and receives treatment at a community behavioral health clinic. Most recently he experienced a life changing event. In his mid-sixties he began to experience tremendous pain in his back, to the point where his 6'5 frame was literally bent over a walker for months. He couldn't get out of the house to shop and we needed an aide to come to his house just to complete simple daily tasks. His psychiatric symptoms began to increase due to his fears about surgery and his inability to fulfill his daily routine.

Fortunately, this story does not end in sadness like so many others because he lives in a permanently subsidized apartment on Long Island. He was able to have surgery, go to rehab, receive consistent psychiatric treatment, and return home to an apartment that was safe and supported. Without the mental health housing system, these triumphs would not have been possible. That is why funding existing mental health housing at sustainable rates is imperative.

When properly funded and staffed this type of housing allows people to focus on recovery in a supportive and safe environment. I believe that it is the duty of our legislature to set aside political discourse and achieve a moral imperative by ensuring people like my father do not lose their housing or face limitations on their opportunities to leave institutional settings because there are no appropriately funded community housing options with wrap around services that fulfill the obligation this state has to ensuring its disabled citizens receive the best quality care and treatment so that they can recover, grow and reconnect with their communities in a meaningful way.

NAMI-NYS calls upon the legislature to make our families a priority by funding mental health housing and services at a sustainable rate and by ensuring access to mental health services, properly prescribed medication and adequate resources such as psychiatrists, psychologists, and mental health professionals who specialize in treating co-occurring issues such as substance use and chronic medical conditions.

Adequately funded Mental Health Housing keeps people from falling through the cracks, helps avoid unnecessary incarcerations, hospitalizations, and repeated trips through the homeless system. We thank you for your motivation and desire to fix these long-standing issues that have created a crisis that is exacting its tolls on constituents, communities, and our families every day.

**Testimony by current NAMI-NYS Government Affairs Chair and past President Evelyne Tropper Ph.D delivered to December 6, 2018 New York State Assembly Hearing on Access to Mental Health and Developmental Disability Services and Supports**

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.

### **Tomorrow Could Be Just Around the Corner By Janet Susin**

The following story was written by past NAMI-NYS president Janet Susin and developed through Herstory Writer's Workshop.

"The sun will come out tomorrow. Bet your bottom dollar that tomorrow....There'll be sun!" We belt out this show tune from *Annie* every morning as we get close to home toward the end of our morning walk. Doug sings in his monotone and I croak out the tune, no longer able to make even a semblance of the high notes. This 2 ½ mile walk to and from the high-end shopping center a few blocks from our house, is the glorious way we start each day. As we reach the final leg of our journey Doug urges me on. "C'mon, Mom, you gotta get your miles in. Pick up the pace!" And so I do, enjoying every moment of this walk with my 47 year old, now mentally healthy, son.

These walks are especially sweet because I recall how different it was just over a year ago. After more than 30 years of relative stability on an antipsychotic medication, a year ago last September our son was admitted to a hospital on Long Island with a painful bowel impaction. For four days he was in agony, not just because of the discomfort of the tube down his throat draining his lower intestine, but also because that tube prevented him from swallowing his regular medications and keeping him stable.

By day 3 he was barely recognizable as our son, "Give me that phone", he demanded, as I tried to have a conversation with his older brother, Scott, who lives in Washington. "I want to talk to Len!" screamed Doug. Len? Why in the world was he bringing him up? An old friend of Scott's from his college days, they hadn't spoken in years. "Scott! I know Len is there with you, Let me talk to him," he demanded. "Tell him to get me out of here right now!"

I had long since forgotten what psychosis looked like, but by day three our even-tempered, sweetheart of a son had turned into a hallucinating bully. I got off the phone as quickly as possible and tried to explain to Doug that it was Scott on the phone, not Len. But he would have none of it.

And so it went until we brought Doug home from the hospital on the 4<sup>th</sup> day. At first things went astonishingly well. He went back on most of his old meds with the exception of three that his doctor felt were no longer needed. To our delight that brought expression back to Doug's face that we hadn't seen in years. He smiled, he laughed, he joked, and we were thrilled.

But that change was short lived. It didn't take long before he was doing very little except sitting stone faced in front of the television set. If we asked him what he was watching he looked blank. Responses were pretty much limited to grunts, and, if we were lucky, a yes or a no. Had he descended into dementia?

"Hey, mom. When we get home I'm going to play my Strat for two hours. Gotta get ready for my lesson." We often talk about music and his guitar when we take that invigorating morning walk. "You know playing the guitar is my life." "Yes, I know" I respond with a broad smile.

But I couldn't forget the torture of much of the past year with no guarantee of a happy ending. During the weeks leading up to his hospitalization guitar playing was limited to one or two horribly out of tune cordless whacks on his guitar, followed by frantic runs up and down the stairs and then around the house. This routine was repeated endlessly. And if it was a really bad day he added running up and down the driveway to his repertoire, sometimes accompanied by screaming and the final touch, pulling down his pants and urinating.

Clearly, we had no choice but to hospitalize him, his first mental health hospitalization in almost three decades. But to our great relief, despite our misgivings, it turned out to be the right thing to do. After seven weeks, stabilized on medications he emerged from his hospitalization as the new and improved Doug, the one who is bringing us so much joy today. .

"Just thinking about tomorrow, Clears away the cobwebs and the sorrow." We belt it out and pick up the pace singing and laughing as we make the final right turn toward home

But, in truth, we know that this can't go on forever. I am 79 and my husband is 84. What will happen when we're no longer around or able to care for our son?

My mind flashes back to an image that has stuck with me from ten years ago. A middle-aged man walks up and down the streets in the business district of our upscale community mumbling to himself. Tufts of hair have been pulled randomly from his blood shot scalp, his legs are scabby and swollen, and as he wanders aimlessly around the neighborhood he mumbles incomprehensibly to himself.

Concerned for his safety I call the police, but my well-meaning call is met with indifference. "How do you know he's mentally ill? If he needs to make the call himself." Frustrated I go into the bagel store where I'd recently seem him drinking coffee and ask the owner if he knows anything about him. What I learn gives me pause. For many years he'd lived in a multi-million dollar home with parents of means who cared for him. When his father died he continued to live with his mother, but then, suddenly, she died too. Without the support of his family, he decompensated, and, unable to make it on his own, joined the ranks of the homeless mentally ill, haunting many of our streets today.

Could that happen to our son? At a recent NAMI Queens/Nassau advocacy meeting with at least 60 people in attendance I took a poll. "How many of you have a loved one living in housing run by an agency?" 3 or 4 people raised their hands. But when I asked how many needed mental health housing for themselves or a loved one, at least half the hands shot up.

What will happen when my husband and I are no longer around to house Doug and take care of his daily needs? Clearly, like so many others with a loved one living at home, we have been abandoned by the mental health system and left to our own devices. But for now, I put that thought out of my mind knowing that there's no easy answer and just enjoy the moment. Bounding up our driveway in great

spirits we belt out the final words of what we now call our song, "Tomorrow! Tomorrow! I love ya tomorrow! You're always a day a-way!"