The Guide Features:

- Information on the 2019 NAMI-NYS Action Agenda
- How to tell your story as an advocacy tool
- How to have effective meetings with your legislators
- Contact Information for newly elected legislators
- How to advocate through social media
- How to advocate through traditional media

#TellYourStory
#Act4MentalHealth
#HopeStartsWithYou
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January 17, 2019

Dear NAMI-NYS Members and Mental Health Advocates,

Thank you for your willingness to enhance your advocacy skills and help NAMI-NYS strengthen our collective voice. As a grassroots movement, we are only strong and effective by having as many voices as possible come together to project our message on how to create a more mentally healthy New York State. As we commonly say at NAMI, “Hope starts with YOU.” Throughout the year, NAMI-NYS is going to focus on the importance of telling our stories, as our stories are our most powerful tool to bring about change. We need to use our stories and experiences to demonstrate why acting for mental health is so important.

This is a critical time for mental health advocacy in the Empire State. Changes in the New York State Legislature, specifically, the Senate changing hands, have presented us with an opportunity to make more positive change than we have in years. Reforms we have been advocating on behalf of our membership for several sessions (including making sure people get the appropriate medication, criminal justice issues and enacting Extreme Risk Protection Orders) which passed the Assembly, only to die in the Senate, now have a real chance of being enacted. While this is a time of great optimism, it is also a time of grave concern as the lack of funding for the mental health workforce and mental health housing programs has continued to fracture our mental health system, and too many New Yorkers are struggling to find the services needed to best advance their recovery. Our voice is needed more than ever. Included in the guide are two of our very own personal stories demonstrating the importance of community mental health support programs and the difficulties families are experiencing in accessing psychiatric services.

This advocacy guide is designed to ease anxieties people have about advocacy and help you both understand our 2019 Action Agenda and how to most effectively use your story to bring about positive change. Just quick notes about the Action Agenda: while we have provided you with all the details for each of our issues, do not feel as though you need to memorize all the facts and figures, as along with the in-depth information on the issues, we also have provided you with brief talking points. What’s most important is learning to tell your story to explain why these issues are important.

If you have any questions about our advocacy issues, please contact Matthew Shapiro at 518-462-2000 or Matthew@NAMINYS.org. We look forward to seeing you at our Legislative Advocacy Day on February 12th.

In solidarity,

Wendy Burch  Ariel Coffman, LMSW  Evelyne Tropper, Ph.D
Executive Director  President  Government Affairs Chair
**2019 Legislative Action Agenda**

**Access to Appropriate Services and Medication**
- Ensure prescriber prevailing language for Medicaid services in final budget.
- Support investments in Departments of Finance and Health for monitoring insurance parity violations.
- Ensure the availability of inpatient hospital beds for those with serious mental illness and crisis beds.
- **Support Legislation (Bill#TBA)** - Regulating private insurance providers making changes to prescription drug formulary during a contract.
- **Support Legislation (Bill#TBA)** - Expanding a pharmacy to administer injectable medications.
- **Support Legislation (Bill#TBA)** - Amending the public health law and the education law, in relation to generic drug products.

**Mental Health Housing With Wraparound Support Services**
- Housing programs incorporating recovery support services are crucial to successful recovery from a mental illness within the community setting.
- Investing in mental health housing saves taxpayers money as programs are 40% - 94% less expensive (depending on housing model) than the alternatives: state psychiatric institutions, other hospitals, ERs, nursing homes, jails and prisons.
- The state has not kept its promise to fund the system adequately.
- 25 years of flat-funding have led to housing providers to operate at 43% below where they should be, causing access to be a serious challenge.
- 40,000 Mental health community-based housing units are in jeopardy due to years of inadequate funding.

**Improve the Criminal Justice – Mental Illness Interface**
- More than 60% of those incarcerated have a diagnosable mental illness. We must do better to divert people with mental illness from jails and into treatment and improve interactions between police and people with mental illness.
- NAMI-NYS supports the expansion of Crisis Intervention Teams (CIT) which would save lives, reduce harm, and result in better outcomes for the individuals and the police.
- **Support the HALT Bill** to reform the use of solitary confinement. Cap the amount of time someone serves in solitary and ensure people with mental illness are not put in solitary.
- Enhanced discharge planning for people living with a mental illness exiting jails and prisons and connecting them to Medicaid and appropriate services. This will help ensure they engage in recovery and prevent recidivism.

**Enact Extreme Risk Protection Orders (ERPO)**
- NAMI-NYS supports the enactment of an ERPO law which would remove guns from the homes of people with mental illness during vulnerable times of crisis.

**Expand Joseph P. Dwyer Veteran’s Mental Health Program**
- Expand NY’s innovative veteran’s peer support program to more counties.
NAMI-NYS firmly believes in a person centered approach to treating psychiatric disorders. Integral to the goal of person centered care is the ability of people living with a mental illness to access the most appropriate treatments to advance their specific recovery. Though this sounds obvious, too many people are facing a myriad of obstacles to accessing services and medications.

Though medication is not needed for everyone living with a psychiatric disorder, for those who do require medication, it is of the utmost importance that they receive the medication their psychiatric provider determines to be most appropriate for their individual recovery.

**Prescriber prevails is especially important in treating psychiatric disorders.** Specific mental illnesses can impact each person differently. Each case must be viewed and handled uniquely with doctors reviewing specific symptoms and other medications that person is taking. This is crucial as antipsychotic and antidepressant medications are not clinically interchangeable and many people with a mental illness also have co-occurring physical ailments, and drug-to-drug interactions also must be considered when changing medication for someone with mental illness. Both private insurance providers and the Medicaid system are threatening “prescriber prevails.”

NAMI-NYS is extremely concerned by these threats, which include the practice of drug formulary switching by insurance providers during a contract year, as well as the continued weakening of prescriber prevails language under Medicaid.

Drug formulary switching, also known as *Non-Medical Switching* (NMS), is when a private insurance provider changes what prescription medications they cover during a contract year. This is not only dangerous, but it is deceitful to consumers. **This is why NAMI-NYS has long supported legislation (Bill number pending) which would regulate drug formulary switching.** Last year, legislation to regulate NMS passed unanimously in the Assembly, but the chair of the Senate Insurance Committee would not bring the legislation up for a vote. You can [click here](#) to watch NAMI-NYS discuss this issue on the Capital Tonight program. **The Governor’s budget proposes eliminating prescriber prevails from all medication including psychiatric medication.** We urge the legislature to reinstate this in the final budget.

It is also crucial that people have the easiest access to the treatments that best advance their recovery, this includes **injectable psychiatric medications which are especially beneficial as they make adherence easier.** This why NAMI-NYS supports legislation (Bill number pending), which expands the scope to allow a pharmacy to administer injectable medications.

Finally, it is also critical that people know what’s in the generic medication they are taking. **This is why NAMI-NYS supports legislation which amends the public health law and the education law, in relation to generic drug products.**
Continued Investments in the Mental Health Workforce and Community Services

The methods for delivering mental health services in New York State are changing. The number of hospital beds dedicated to treating psychiatric disorders is shrinking. This is very concerning to NAMI-NYS as many of our members have experienced both the tremendous benefits that hospital care has for our loved ones with serious mental illness, as well as the tragic and heart-breaking results of what happens when someone with the most debilitating forms of mental illness do not receive the housing and services they need. Too many of our members have seen their loved ones end up on the streets, stranded in emergency rooms and complete suicide.

Once again the Governor’s budget proposes investing in $11 million from the savings of eliminating 100 inpatient beds into community services. Though NAMI-NYS does not want to see beds reduced, we strongly believe that the savings from these reductions be reinvested into services that would afford those living with a mental health disorder the best opportunity to advance their recovery in a community setting.

It is impossible to deliver appropriate sustained care without a robust mental health workforce. The state has failed to invest in the dedicated and compassionate workers who provide care for people living with mental illness. This lack of investment has led to difficulty in mental health providers’ ability to hire and retain staff. NAMI-NYS is alarmed by the high turnover and vacancy rates among providers. This is why we are calling for a 2.9% Cost of Living Adjustment (COLA) for non-profit human services agencies. We are disappointed this was not included in the Governor’s budget proposal.

In November, it was announced that NYS’s hospitals and nursing homes will receive $675m for Medicaid rate increases to cover workforce salary and benefits. NAMI-NYS is calling for 25% of the state’s share of the investment, roughly $169m, be used to support community-based care. Click here to watch NAMI-NYS discuss community investments on Capital Tonight.

NAMI-NYS wants to see community support services in New York State which ensure:

- Practices and services that are recovery, resiliency and wellness oriented, culturally competent and readily accessible
- Residential support services with transportation services and intensive case management
- The availability of all appropriate and effective medications
- Access to both inpatient and outpatient treatment options
- Vocational Training
- Wellness
- Round-the-clock services that are available seven days a week
- That no one would have to travel more than an hour to get to a psychiatric emergency room or crisis service unit.
A stable environment is vital and fundamental to the recovery from psychiatric disorders. Safe and affordable housing programs which incorporate recovery oriented support services are the cornerstone of successful recovery from serious mental illness (SMI) within the community setting, yet accessing these essential programs remains a tremendous challenge.

Community based mental health housing providers have received flat-funding from New York State since the early 1990’s. Since the funding has not kept up with the rates of inflation and the increases in the cost of living since 1990, these programs are operating at 43% below where they should be today. It will take $120 million to simply close that gap and allow mental health housing providers to operate with a budget that is reflective of today’s economic structure.

The $10 million contained in the Governor’s budget proposal falls way short of what is needed to deliver the type of mental health housing needed to best drive recovery.

In recent years, the Office of Mental Health (OMH) 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. This is why NAMI-NYS believes that a large part of the savings from hospital bed reductions must be invested in more beds and staffing support in the community based mental health housing system.
New York State
2019 Legislative Action Agenda

Improve the Criminal Justice – Mental Illness Interface

It is estimated that more than 60% of those incarcerated have a behavioral health issue. Improvements and expansions to several facets of the criminal justice system are necessary to help ensure the best outcomes for people living with a psychiatric disorder who enter or exit the system. NAMI-NYS is calling for the following measures to be enacted:

1-Expansion of Crisis Intervention Teams: Contacts between law enforcement officers and individuals experiencing mental health disorders can be deadly, dangerous or result in poor outcomes for the individual. NAMI-NYS supports the expansion of Crisis Intervention Teams (CIT) which would save lives, reduce harm, and result in better outcomes for the individuals and the police. Crisis Intervention Teams consist of law enforcement officers specially trained to deescalate situations and take appropriate action to assist an individual in the midst of a mental health crisis. We want to see further investments in this vital program.

2-Abolish Long Term Solitary Confinement: NAMI-NYS strongly supports reforming the use of solitary confinement, capping the amount of time someone serves in solitary and restricting the use of solitary confinement for juveniles under the age of twenty-one and any person with a mental illness or a developmental disability. NAMI-NYS is calling on legislators to support the HALT Bill (Bill # Pending) to reform the use of solitary confinement by capping the amount of time someone serves in solitary and ensure people with mental illness are not put in solitary.

3- Enhanced discharge planning for people living with a mental illness exiting jails and prisons. Along with reinstating Medicaid benefits 30 days prior to discharge, people with a mental illness need to be educated on their Medicaid benefits and connected to appropriate services. This will help ensure they engage in recovery and prevent recidivism.

4- Improve Mental Health Treatment and Family Engagement in the Correctional and Forensic System: Too many people living with a mental illness have entered the correctional system. New York must improve mental health care in prison and encourage communication with families so they can voice concerns about their loved one’s mental health.

5-Expanded Mental Health Courts: Mental Health Courts are crucial in generating the most successful outcomes for people living with a mental illness. Mental Health Court judges evaluate each case individually to determine the best plan for each offender. If that person lives with a mental illness, recovery oriented treatment programs are often deemed to be better alternatives than incarceration. Mental Health Courts can be an essential point of entry to recovery services that can contribute to a reduction of arrests, recidivism, emergency room visits and long term in-patient care. Mental Health Courts are a sound investment as they can save the state money by proactively addressing issues that often lead to potential long-term expenses such as hospital stays and prison sentences.
Enact Extreme Risk Protection Orders

NAMI-NYS supports the enactment of an Extreme Risk Protection Orders (ERPO) law which would remove guns from the homes of people with mental illness during vulnerable times of crisis. Under the law family members, friends and caregivers could petition a court and express their concerns about someone living with a mental illness who they know has a gun and they fear is in crisis and could harm themselves or others. If the court grants the order, trained professionals would be sent to remove the gun from the home. The gun would be returned once the crisis is determined to be over. An ERPO law will help save lives by preventing suicide and other tragic outcomes.

Expand Joseph P. Dwyer Veteran’s Mental Health Program

Supporting those who have served our country must be a top priority. Returning combat veterans are experiencing very high rates of serious mental health disorders, suicide, addiction, homelessness and incarceration related to posttraumatic stress disorder and traumatic brain injury. More must be done in New York to provide services to America’s returning heroes of combat. This is why NAMI-NYS supports the continued investments and expansion of the innovative Joseph P. Dwyer veterans peer support program to more counties throughout the state.

Proper Education Regarding the Legalization of Marijuana

NAMI-NYS has serious concerns about Governor Cuomo’s intention to legalize the recreational use of marijuana. Many studies have demonstrated the damaging effects of marijuana for people with psychotic disorders and young people in the prodromal period. If the state does move forward with legalization it must be done responsibly. NAMI-NYS is calling for warning labels on marijuana products that detail the hazards to those with psychosis. NAMI-NYS also wants a portion of the tax revenue generated from sales of legalized marijuana to be earmarked for the New York State Office of Mental Health to both be able to expand crisis services to address negative outcomes that could arise from people with psychosis having access to marijuana, as well as additional educational resources for schools and families.
Key Talking Points on 2019 Action Agenda Issues

ACCESS TO PROPER TREATMENT

People must be able to have access to services and medications most appropriate for their recovery

- Support investments for insurance parity oversight
- We need to regulate the practice of Non-Medical Switching by insurance providers, support bill number:
- We need to strengthen prescriber prevails language under Medicaid.
- Support bill # which expands the ability for a pharmacy to administer injectable medications.

INCREASED COMMUNITY SERVICES

Too many people cannot access mental health services which is why we call for:

- Support of a 2.9% COLA for Mental Health Workforce
- Investments in broad community services.
- 25% of the Centene settlement ($169m) should go to community-based care.

HOUSING WITH WRAP AROUND SERVICES

Housing with wrap around mental health support services is essential to recovery.

- If NYS insists on decreasing psychiatric hospital beds, it must replace those beds with mental health housing.
- Community based mental health housing providers have received flat-funding from New York State since the early 1990’s making it hard to hire and retain staff.
- NAMI-NYS and the Bring it Home campaign are calling for...

ENACT EXTREME RISK PROTECTION ORDERS

- ERPO laws have the power to save lives by removing guns from the homes of people in crisis.

EXPAND JOSEPH P. DWYER PROGRAM

- NYS can increase mental health among veterans by expanding this innovative veteran peer support program.

CRIMINAL JUSTICE REFORMS

We must initiate reforms to divert people living with a mental illness from the criminal justice system and towards recovery.

- Support investments in Crisis Intervention Teams (CIT) programs to generate better interactions with police and first responders.
- Support the HALT Bill to reform the use of solitary confinement.
- Enhanced discharge planning for people with mental illness.

RESPONSIBLE MARIJUANA LEGALIZATION

- Warning label on products detailing the risk for people with psychosis.
- Earmark portion of tax revenue for the NYS Office of Mental Health.
As grassroots advocates our greatest tool to communicate and resonate with elected officials is telling our stories. Our stories and experiences demonstrate how the lack of appropriate mental health services is negatively impacting New Yorkers. Success stories also demonstrate the positive outcomes that are generated when proper mental health services are available.

By telling your story, you are putting a human face on these issues. This is crucial as elected officials and their staffs are constantly inundated with special interest concerns. Lobbyists provide facts and figures, but advocates tell our stories and demonstrate how these issues are actually impacting people.

This message is especially important to legislators to help them understand what is taking place in their districts and how their constituents’ lives can be improved. In many cases, the legislator may not be aware of the shortage of mental health services, not because they do not care, but because they have yet to be properly educated on the issue. Hearing from their constituents demonstrates that these issues matter and more must be done. By telling your story, you become the face for the issue and can be the reason an official decides to take action.

While the details of your story are important, you also want to remember that people’s attention spans are short, so telling your story succinctly is also crucial to successful advocacy. The following resources, as part of the NAMI Smarts for Advocacy program, are designed to help you most effectively tell your story in order to enact positive change.
# Seven Steps to Telling Your Story

The following seven steps will help you craft a succinct and powerful story.

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<tbody>
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<td>1.</td>
<td><strong>Introduce yourself</strong></td>
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<td></td>
<td><strong>Give your name and city or town.</strong> Include your organization. We encourage you to describe yourself as “a member of [NAMI State Org or NAMI Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.”</td>
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<td><strong>Share how you are affected by mental illness.</strong> Are you living with mental illness, a family member, a caregiver? This brings a &quot;real face&quot; to mental illness.</td>
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<td><strong>State your issue and position.</strong> Let your listener know what you want them to support or oppose (or do). This helps your listener focus.</td>
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<td>2.</td>
<td><strong>What happened?</strong></td>
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<td></td>
<td><strong>What happened before you received the help you needed?</strong> Keep this brief—think about the most important thing you’d like your listener to know.</td>
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<td>3.</td>
<td><strong>What helped?</strong></td>
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<td></td>
<td><strong>Describe what helped in your recovery (or would have helped).</strong> This adds a hopeful tone and helps show the value of services and supports.</td>
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<td>4.</td>
<td><strong>How are you different today?</strong></td>
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<td><strong>Share what is going right in your life or how you are experiencing recovery.</strong> This concludes your personal story on a positive note that inspires.</td>
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<td>5.</td>
<td><strong>What is the need or problem?</strong></td>
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<td><strong>Mention the problem or need you want addressed.</strong> Transition to the challenge(s) faced by people living with mental illness.</td>
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<td>6.</td>
<td><strong>What will help others?</strong></td>
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<td><strong>Talk about what will help.</strong> Let your listener know what will address the need or problem you described.</td>
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<tr>
<td>7.</td>
<td><strong>Make your &quot;ask&quot;</strong></td>
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|   | **Ask your policymaker if you can count on their support (or opposition).** Include a bill number, if possible. Thank your policymaker for his or her time.
Sample Family Member Story

1. My introduction
Hello, I'm Jenny Jones from Springville. I'm a member of NAMI Springville, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I'm also the proud mother of a 23-year-old son who lives with bipolar disorder. I'd like to share my story with you and ask for your support of mental health services.

2. What happened
When my son was still a toddler, I had a thought that no mother should have: I wondered if my beautiful boy would be in juvenile detention on his 16th birthday. He just did not respond the way other children did to requests, to routines, to daily life and love.

As he grew, we never knew what would be broken, who might be hurt or when it would happen.

3. What helped
In fifth grade, my son's teacher said, "Jenny, honey, I've taught hundreds and hundreds of kids. I know when a boy is misbehaving and I know when something is wrong. And something is wrong. You just keep looking for help."

When Andy was finally diagnosed with bipolar disorder, our lives changed. With treatment, he started smiling, enjoying school and making friends.

4. How I'm different today
On his sixteenth birthday, Andy wasn't in juvenile detention; he was creating art. Today, he's enjoying life, working hard and making me proud.

5. What is the need or problem
My son is proof that treatment works. But, not everyone gets the help they need.

6. What will help others
A strong mental health system will help children and adults get the right care at the right time.

7. My "ask"
Thank you for meeting with me and listening to my story. Can I count on you to protect mental health services—and give families the hope of recovery?
Sample Peer Story

1. My introduction

Hello, I’m Shannon Johnson from Springville. I’m a member of NAMI Springville, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.

As a person who lives with schizophrenia, I’d like to share my story with you and ask for your support of mental health services.

2. What happened

I was married and had a successful career in business. I worked hard and never imagined I would experience a mental illness. But, I did.

I started seeing a therapist after experiencing nightmares, nervousness and problems going to work. I thought that with a few visits to a therapist, these problems would be over. But, my symptoms got worse and worse. Eventually, I lost everything.

3. What helped

With the help of a psychiatrist who diagnosed me with schizophrenia, I found my way back again. I will always remember him telling me that having schizophrenia did not mean life was over. He gave me hope.

4. How I’m different today

Today, I’m proud to be working again and volunteering with NAMI’s In Our Own Voice program.

5. What is the need or problem

Many people have mental illnesses like mine, but not everyone gets the help they need.

6. What will help others

A strong mental health system helps more people get the right care at the right time to experience recovery.

7. My "ask"

Thank you for meeting with me and listening to my story. Can I count on you to protect mental health services?
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. They 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 2½ 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 4th 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!”
Examples of Using Personal Stories to Explain the NAMI-NYS Action Agenda

Access Issues:

Hello, thank you for time this morning, my name John Smith and I live in Albany. I am a member of NAMI Capital Region, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I’m here to talk to you today about my 32-year brother, Mark, who lives with bi-polar disorder. I’d like to share our story with you and ask for your support of mental health services.

My brother first started showing symptoms of bi-polar while he was at college. It was a difficult time for Mark and our family. Finding the right medication for him took a really long time and he had to take an extended break from school and move back home. After a year, Mark finally found a medication that worked for him. It was such an incredible relief for my family as we felt we got our Mark back. He returned to school, got his degree and started a successful career.

About a year ago, his insurance provider stopped covering his medication without notice during a contract year. He went to the pharmacy and was given a totally different medication and it wasn’t until he called his insurance company to ask about the switch that he was informed of the formulary change. He had no choice but to take the medication the provider would cover. Almost immediately he began to decompensate. He became so depressed that he could not get out of bed and began missing work. I cannot fully describe the heartbreak my family felt seeing a decade of progress erased and watching him erode. Luckily, his work was understanding of the disease and his doctor was dedicated enough to challenge the insurance provider and got him back on the original medication.

Despite his struggles, I know Mark is one of the lucky ones. This practice of non-medical switching is not only deceitful to consumers, but it is extremely dangerous. Mark is an example that on the right medication people with bi-polar can live healthy productive lives, but that not all medications work for all people, which is why it is essential that people with mental illness receive the medication their doctors believe to be most appropriate for them.

This is why I am asking you to support legislation that would regulate non-medical switching. I don’t want to see other people suffer the way Mark had to suffer. His ordeal could have been avoided if his provider simply stuck with the medication that was proven to work best for him. I know not everyone has the same support system Mark had that’s why I’m here to speak for them.

Thank you for taking the time out of your busy day to listen to my story. Can we count on your support for the legislation?
Community Investments/Mental Health Workforce:

Hello, thank you for time this morning, my name John Smith and I live in Albany. I am a member of NAMI Capital Region, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I’m here to talk to you today as someone who has lived with schizophrenia for the last twelve years. I’d like to share my story with you and ask for your support of mental health services.

As you can imagine living with schizophrenia can be very challenging, it took me a long time to get to the place I am today and be the person you see in front of you. I was diagnosed in college and had to drop out of school. I thought my life was over and I admit there were several times I thought about ending my life. I was fortunate to find a mental health program which provided me with both a case manager and peer services. I cannot say enough good things about my first case worker Juan. He was amazing and we developed a strong relationship. Without his caring support I don’t know where I’d be today. About a year ago, Juan had to leave the agency as he wasn’t being paid enough to support him and his family. In my peer support groups, I have heard similar stories from my peers, some have told me that their case managers keep changing. This is very frustrating as each time we get a new case manager, it’s like starting from the beginning and I have to rehash my experiences which can be very emotionally painful. I would give anything to have Juan back.

I am sad that Governor Cuomo did not include a cost of living adjustment for the mental health workforce in the budget. I know firsthand how hard these caring individuals work and they deserve to be paid a living wage. I am urging you to help get a 2.9% COLA in the budget and care for those who care for us.

Thank you for taking the time out of your busy day to listen to my story. Can we count on your support?

Criminal Justice Reforms

Hello, thank you for time this morning, my name John Smith and I live in Albany. I am a member of NAMI Capital Region, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I’m here to talk to you today as a concerned parent of a son with a serious mental illness. I’m alarmed by the estimates that approximately 60% of those incarcerated have a diagnosable mental illness or intellectual disability. Unfortunately my son David was one of them so I know firsthand how the failure to properly recognize mental illness in the criminal justice system impacts both individual and families.
David is a good person; however a psychotic episode led to him damaging some property. The bad situation was made worse as the officer who intervened did not recognize that David was in a psychotic state and his interaction with David exasperated David and he attacked the officer. I am thankful neither David nor the officer was hurt, but this incident resulted in more charges being brought up against him.

He ended up having to serve time in prison where his situation took another turn for the worse. My wife and I would travel almost two hours each way to visit David every weekend. When we arrived one weekend, we were told that we couldn’t visit with David because he was in solitary confinement. We asked why and for how long and no one would answer our questions. I cannot explain how scary and frustrating this was. My wife couldn’t sleep with the thought of David in solitary and not knowing when he would get out. He was in solitary for three weeks and we still don’t know why. When we finally saw him after he was removed from solitary we were horrified by how much he had decompensated. He has been released from jail for almost a year and has lived at home with us and we take care of him. He is still traumatized from his experience and in much worse condition than before he entered prison. Honestly, despite our love, support and best efforts we are not sure if he will recover as other people with a mental illness can.

I want to make sure that others don’t have to experience the nightmare that David and our family have had to endure. This all could have been avoided if proper protections were in place. An officer who had taken Crisis Intervention Team or CIT training may have been able to de-escalate the situation and brought David to a crisis center instead of have him arrested. This is why expanding CIT is so important, every community needs trained officers. CIT has been proven to increase the safety of both offenders and officers. We were also shocked to see how David was treated in jail. Not only was he not provided with the tools to manage his illness, but he was subjected to solitary confinement which only made his symptoms worse. I understand that solitary is a necessary tool but it must be used responsibly. This is why I urge you to support the Humane Alternative to Long-Term Confinement or HALT bill. The bill would regulate the use of solitary by ensuring that no one is in solitary for more than two weeks and that it wouldn’t be used for people living with a mental illness and other vulnerable populations.

Thank you for taking the time out of your busy day to listen to my story. Can we count on your support of the HALT bill and CIT funding?

**Mental Health Housing**

Hello, thank you for time this morning, my name John Smith and I live in Albany. I am a member of NAMI Capital Region, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I am here today as a proud parent of daughter living with a serious mental illness. My daughter Samantha began showing signs of psychiatric issues while still in elementary school and her symptoms caused years of struggle which impacted our entire family. However today, she is
doing extremely well and the key to her recovery was participating in a mental health housing program with wraparound services.

The housing program not only provided Sam with psychiatric supports but other wellness and vocational skills to fully help her meet the challenges posed by mental illness. I cannot say enough good things of the skillful, patient and caring staff who supported Samantha every step of the way. She is now working and living independently. Our pride in Samantha is equaled by our gratitude to the staff who helped get her to where she is today.

We know how essential housing programs can be and I want all people living with a mental illness to have the same opportunities Sam had. I am very concerned that the state is not investing enough in these programs, in fact non-profit mental health housing providers have received flat funding for a quarter century and are operating at 43% of where should be due to inflation over that time. It disturbs me to hear that these providers are struggling to hire and retain staff and simply keep their doors open.

I urge you to help increase the funding for these life changing programs and give others the same chance at a happy and healthy life. Can we count on your support?

**Extreme Risk Protection Orders**

Hello, thank you for time this morning, my name John Smith and I live in Albany. I am a member of NAMI Capital Region, part of America's largest grassroots mental health organization, the National Alliance on Mental Illness.

I am here today as a suicide survivor as almost two years ago my son Andrew, who lived with bi-polar disorder, lost his battle against the diseases and took his own life by using a gun. Nothing I can say to you today can bring Andrew back, but I hope by telling his story, I can help spare other families the pain that our family has endured.

For many years, Andrew experienced the highs and lows associated with bi-polar disorder and had to be hospitalized several times, including a short stay shortly before his death. My family, expressed our concern upon his last discharge, as we knew he was not ready to be released, but the hospital let him go home despite our protests. We begged Andrew to stay with us following the discharge but he refused. In the final weeks of his life, Andrew was very withdrawn and did not answer our calls. The only way we knew he was alive was by seeing his posts on Facebook, which became increasingly darker. My wife and I were very concerned by this as we knew Andrew had a gun in his home, as when he was well he enjoyed hunting and some of my best memories are from our hunting excursions. Once we stopped seeing posts on Facebook, we called the police where he lived to do a safety check on him. Our worst fears were realized when the police found Andrew dead from a self-inflicted gun-shot wound.
As hard as it is losing our son, what makes our experience even worse is being powerless to do anything to prevent it, despite the fact that all the warning signs were clearly evident to us. The hospital ignored our pleas not to release Andrew and once he was released he shut himself off to us. Often family and friends have more insight on a loved one’s mental illness and as with the hospital, our insights are often ignored. However there is a measure before the legislature that would take family’s concerns into account and that is Extreme Risk Protection Orders. This would allow family, friends and caretakers to petition a court to have guns removed from the home of people living with a mental health who are believed to be experiencing a time of crisis. The guns would be returned once it was determined the crisis had passed.

As I explained, I am a hunter and a gun rights supporter, but I also understand that there are times when vulnerable people should not have access to guns. I also know that something needs to put in place to not only listen but to take seriously the concerns families have. If an Extreme Risk Protection Order was in place, my wife and I would have made a petition upon seeing the first of his problematic Facebook posts and Andrew might still be with us today.

I thank you for listening to my story and I hope we can count on your support for this life saving initiative.
Story Practice Sheet

1. My introduction

Include your name and city and organization, if applicable. We encourage you to describe yourself as a member of [NAMI State Org or NAMI Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness. Add how you are affected by mental illness and your issue and position.

2. What happened

Aim for 3-9 sentences. Briefly describe the most important and compelling thing(s) about your situation.

3. What helped

Aim for 1-5 sentences. Briefly describe what helped in your recovery (or what would have helped). Aim for a hopeful tone that helps show what is helpful.
How to Make the Most Impactful Legislative Visits

Preparing for Your Meetings

Many people find speaking to their legislators intimidating and this section is designed to help relieve the stress about advocacy meetings and provide tips to successful meetings.

Key things to remember which will demystify advocacy meetings:

- Legislators work for us, we are their boss, and they are accountable to us. So you shouldn’t be intimidated by them.
- You are an advocate, not a lobbyist. You are only an expert in your own experience, so no one expects to be an expert on all these issues and know all the facts and figures. We will provide you with a folder with all the detailed information to give to whomever you are meeting with. We want you to use your story to explain these issues. We don’t expect you to be a policy expert, so you should not expect that for yourself.
- Don’t feel you need to answer every question. It’s perfectly ok to say, “I’m sorry, but I don’t know the answer to that question. I will relay your question to NAMI-NYS staff and have them follow-up with you.”
- Don’t play party politics. Do not assume because your representative is a member of a certain party that they do not care about our issues. Mental health is truly an issue that crosses party lines. We have had tremendous legislative champions on both sides of the aisle.
- Not everyone in the meeting needs to speak or tell their story, in fact in most cases you won’t have time for everyone in a group to tell their stories. So you can be effective just by showing up and demonstrating that there are many people impacted by our issues.
- People are embarrassed if they don’t know who their legislators are or how to schedule a meeting. That’s ok, many people don’t know who their state legislators are. NAMI-NYS can help you identify your legislators and schedule visits.

Tips for successful meetings:

Since your legislative meetings are generally less than ten minutes, you want to ensure that you have time to make your advocacy visits as effective as possible.

1-The smaller the group the better: Bringing too many people can get chaotic. Remember you only have a limited amount of time and you don’t want to waste that time by having to organize everybody and finding seats. More people also lead to longer introductions which again takes time away from our message. Ideally, you want no more than four to six people at a meeting. If you plan on having a large contingent from your affiliate attend, break into smaller groups and try to set up meetings with all the legislators who represent the area your affiliate is located in. Remember not every affiliate member’s Assemblymember and Senator will be the same.
2-Plan ahead: Before your meetings your group should decide who is going to say what. Ideally in each meeting two people should tell their stories. Before your meeting, NAMI-NYS will provide you with a folder for the meeting with information on the legislator you are meeting with and what type of stories are needed to sway them on an issue. It is also important to remember that you may not get to every issue in every meeting. So predetermine what issues are priorities. Again, NAMI-NYS may explain what issues to focus on for particular meetings. It is also important to designate a lead person and a time keeper in advance.

3-Do not be disappointed if you do not meet with your representative themselves: We know that ideally you would like to meet with your representative, but often times it is actually more beneficial to meet with a legislative director or staff person as they are the ones who shape the policies that the legislator supports. It is vital that we educate these decision makers on why these issues are important. It also important to remember that while legislators change, the professional legislative staff remains after a legislator leaves Albany and many staffers go on to work for different legislators. So by influencing a staffer today can actually impact several legislators.

4-Know when to advocate and when to thank. It’s important to do a little homework before your meetings. Again NAMI-NYS will provide you with a folder with information on your legislator. It will tell you if they already support the issues NAMI-NYS is advocating for. If they are a supporter, be sure to thank them. If they are not supporting one of our issues, you need to explain why it is important to you as their constituent. It is also important to know if a bill has passed the branch of the legislator you are meeting with.

5-Tell your story: When meeting with your legislators or members of their staff you DO NOT WANT to read the action sheets verbatim. Here is how a successful meeting should flow:

The lead person should confirm the name of the staff person you are meeting with. Thank them for their time and exchange business cards so a follow up can take place and hand them a folder.

The lead person should then make a quick introduction such as: My name is John Smith, I live in Albany and I here because (state relationship to mental illness or NAMI). I am a member of NAMI Capital Region, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness. With me today is:

All the other group members will introduce themselves, say where they live and state the relationship.

After everyone has introduced themselves, the lead person will take over and transition to the action agenda:

“We’re here today to discuss the NAMI-NYS Action Agenda to create a more mentally healthy New York State. Our main issues are:

Access to proper treatment as too many people are not receiving the services and medication they need to advance their recovery. We are very grateful for all your support on the insurance parity issues as that is a main barrier to care. Another insurance issue we’re concerned about is the practice of non-medical switching, essentially when a provider switches what medication
they cover during a contract year. Which is why we support bill #____ which would regulate this practice.

Community Services, which begin with a strong mental health workforce. We are disappointed that the Governor’s budget did not include a 2.9% COLA for the mental health workforce.

Mental Health housing, Laura is going to explain how mental health housing helped her and her family.

Laura would than tell her story.

The lead person continues: “One other priority we want to bring to your attention is the need to make criminal justice reforms. Unfortunately, Charles’ family’s story will explain why this is so important.”

Charles tells his story.

The lead person continues:

“Our other priorities include enacting Extreme Risk Protection Orders and expanding the Joseph P Dwyer veterans’ peer-to-peer program. All of which are detailed in your packet.”

6-Do not try to answer questions you do not know the answer to. We mentioned this before, but we cannot emphasize this point enough. If the person you are meeting with asks a question you that you cannot answer, don’t make up an answer. It’s okay to say, “Honestly, I do not know the answer to that, I will check with the NAMI-New York State office and get back to you on that.

7- Offer our services. Also ask if there is anything we can do to help their member (this could be an opportunity to build a positive partnership) you can also let them know of community events coming up (such as a NAMI Walk) where they can come speak to your membership. The lead person should then thank the staff person for their time (usually everybody shakes hands) and then everyone should leave as quickly and politely as possible since other groups are probably waiting to come in.

8-Follow up. After the meeting be sure to follow up with a thank-you letter addressing specific items discussed. Here is an example of a thank you letter:

Dear______,

Thank you again for taking the time out of your busy schedule to meet with me and my fellow members from NAMI_______, to discuss issues important to us as people impacted by mental illness. Again I want express my appreciation to Senator/Assembly Member__________ for his/her support of (list bills they support) and we urge him/her to support (list bills we are looking to have them support).
Please do not hesitate to contact either myself or NAMI-NYS at 518-462-2000 if you have additional questions about the legislation or issues we discussed. We look forward to working with you and Senator/Assembly Member__________ to create a mentally healthier New York.

**Information on Newly Elected Legislators**

One of the other things that makes this legislative session so unique is that this is the largest freshman class of legislators in 50 years. This means there are many new legislators who need to learn about NAMI and the issues that are so important to us. The earlier we can begin to establish relationships with our new legislators the stronger those relationships will be.

Below you will find a list of all the newly elected legislators, what area they serve, what party they belong to (remember, mental health cuts through party lines) and who had the seat before them. We also provided you with some background on the newly elected Senators.

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<th>House</th>
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<td>Cayuga, Onondaga</td>
<td>John A. DeFrancisco</td>
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<td>Senate</td>
<td>Rachel</td>
<td>May</td>
<td>D</td>
<td>53</td>
<td>Madison, Oneida, Onondaga</td>
<td>David J. Valesky</td>
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<td>Joseph</td>
<td>DeStefano</td>
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<td>Michael</td>
<td>LiPetri</td>
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<td>Nassau, Suffolk</td>
<td>Christine Pellegrino</td>
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<td>Assembly</td>
<td>Taylor</td>
<td>Raynor</td>
<td>D</td>
<td>18</td>
<td>Nassau</td>
<td>Earlene Hooper</td>
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<tr>
<td>Assembly</td>
<td>Judy</td>
<td>Griffin</td>
<td>D</td>
<td>21</td>
<td>Nassau</td>
<td>Brian Curran</td>
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<tr>
<td>Assembly</td>
<td>Catalina</td>
<td>Cruz</td>
<td>D</td>
<td>39</td>
<td>Queens</td>
<td>Aridia Espinal</td>
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<tr>
<td>Assembly</td>
<td>Mathylde</td>
<td>Frontus</td>
<td>D</td>
<td>46</td>
<td>Kings</td>
<td>Pamela Harris</td>
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<tr>
<td>Assembly</td>
<td>Simcha</td>
<td>Eichenstein</td>
<td>D</td>
<td>48</td>
<td>Kings</td>
<td>Dov Hikind</td>
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<td>Charles</td>
<td>Fall</td>
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<td>61</td>
<td>Richmond</td>
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<td>Karines</td>
<td>Reyes</td>
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<td>87</td>
<td>Bronx</td>
<td>Luis Sepulveda</td>
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<td>Assembly</td>
<td>Nader</td>
<td>Sayegh</td>
<td>D</td>
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<td>Colin</td>
<td>Schmitt</td>
<td>R</td>
<td>99</td>
<td>Orange, Rockland</td>
<td>James Skoufis</td>
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<tr>
<td>Assembly</td>
<td>Jonathan</td>
<td>Jacobson</td>
<td>D</td>
<td>104</td>
<td>Dutchess, Orange, Ulster</td>
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<td>Mark</td>
<td>Walczyk</td>
<td>R</td>
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<td>Jefferson, St. Lawrence</td>
<td>Addie Jenne</td>
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<tr>
<td>Assembly</td>
<td>Robert</td>
<td>Smullen</td>
<td>R</td>
<td>118</td>
<td>Fulton, Hamilton, Herkimer, Oneida, St. Lawrence</td>
<td>Marc W. Butler</td>
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<tr>
<td>Assembly</td>
<td>Marianna</td>
<td>Buttenschon</td>
<td>D</td>
<td>119</td>
<td>Herkimer, Oneida</td>
<td>Anthony Brindisi</td>
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<tr>
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<td>John</td>
<td>Salka</td>
<td>R</td>
<td>121</td>
<td>Madison, Oneida, Otsego</td>
<td>William Magee</td>
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<tr>
<td>Assembly</td>
<td>Brian</td>
<td>Manktelow</td>
<td>R</td>
<td>130</td>
<td>Cayuga, Otsego, Wayne</td>
<td>Bob Oaks</td>
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<tr>
<td>Assembly</td>
<td>Marjorie</td>
<td>Byrnes</td>
<td>R</td>
<td>133</td>
<td>Livingston, Monroe, Steuben</td>
<td>Joseph A. Errigo</td>
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<tr>
<td>Assembly</td>
<td>Jamie</td>
<td>Romeo</td>
<td>D</td>
<td>136</td>
<td>Monroe</td>
<td>Vacant</td>
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<tr>
<td>Assembly</td>
<td>Patrick</td>
<td>Burke</td>
<td>D</td>
<td>142</td>
<td>Erie</td>
<td>Erik Bohen</td>
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<tr>
<td>Assembly</td>
<td>Karen</td>
<td>McMahon</td>
<td>D</td>
<td>146</td>
<td>Erie, Niagara</td>
<td>Raymond Walter</td>
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Some background on new Senators

<table>
<thead>
<tr>
<th>District</th>
<th>Counties</th>
<th>Current</th>
<th>New Members</th>
<th>Background</th>
</tr>
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<tbody>
<tr>
<td>3</td>
<td>Suffolk</td>
<td>Tom Croci</td>
<td>Monica R. Martinez</td>
<td>School administrator. Was recruited by Governor Cuomo to run.</td>
</tr>
<tr>
<td>5</td>
<td>Nassau, Suffolk</td>
<td>Carl L. Marcellino</td>
<td>James F. Gaughan</td>
<td>Gaughan is an attorney by trade and has been practicing in Suffolk County for over 80 years.</td>
</tr>
<tr>
<td>6</td>
<td>Nassau, Suffolk</td>
<td>Kemp Hannon</td>
<td>Kevin M. Thomas</td>
<td>Attorney and appointee on the US Commission on Civil Rights to the New York State Advisory Committee.</td>
</tr>
<tr>
<td>7</td>
<td>Nassau, Suffolk</td>
<td>Elaine R. Phillips</td>
<td>Anna M. Kaplan</td>
<td>Kaplan is a Town Boardmember from North Hempstead.</td>
</tr>
<tr>
<td>11</td>
<td>Queens</td>
<td>Tony Avella</td>
<td>John Liu</td>
<td>Liu is the formerly Comptroller of New York City, as well as a former NYC Council Member.</td>
</tr>
<tr>
<td>13</td>
<td>Queens</td>
<td>Jose Peralta</td>
<td>Jessica Ramos</td>
<td>Strong union advocate. Ran on issues such as MTA, rent control, labor and healthcare.</td>
</tr>
<tr>
<td>18</td>
<td>Kings</td>
<td>Martin Dilan</td>
<td>Julia Salazar</td>
<td>Salazar is a community activist, staff organizer and Democratic Socialist of America member.</td>
</tr>
<tr>
<td>20</td>
<td>Kings</td>
<td>Jesse Hamilton</td>
<td>Zellnor Myrie</td>
<td>Lawyer by trade who ran on affordable housing, LGBTQ rights, women’s health, and criminal justice reform.</td>
</tr>
<tr>
<td>22</td>
<td>Kings</td>
<td>Martin Golden</td>
<td>Andrew Gounardes</td>
<td>Lawyer and activist, serves as Counsel to Brooklyn Borough President Eric Adams and a trustee of the NYC Employee’s Retirement System.</td>
</tr>
<tr>
<td>31</td>
<td>New York, Bronx</td>
<td>Marisol Alcantara</td>
<td>Robert Jackson</td>
<td>Former NYC Council Member, previously ran unsuccessfully for this seat in 2014 and 2016. He ran on issues such as education, protecting small businesses, housing, and tenant protections.</td>
</tr>
<tr>
<td>34</td>
<td>Bronx, Westchester</td>
<td>Jeffrey Klein</td>
<td>Alessandra Biaggi</td>
<td>Biaggi is a lawyer and community activist, the granddaughter of Mario Biaggi a former NY congressman. She previously worked as deputy national operations director for Hillary Clinton’s 2016 presidential bid and as counsel to Governor.</td>
</tr>
<tr>
<td>39</td>
<td>Orange, Rockland, Ulster</td>
<td>Bill Larkin</td>
<td>James Skoufis</td>
<td>Skoufis has been in the State Assembly for six years. As an Assemblymember he served as Chair of the Task Force on People with Disabilities and was a member of the Insurance committee.</td>
</tr>
<tr>
<td>40</td>
<td>Dutchess, Putnam, Westchester</td>
<td>Terrence Murphy</td>
<td>Peter Harckham</td>
<td>Harckham is a four-term Westchester County Legislator.</td>
</tr>
<tr>
<td>42</td>
<td>Delaware, Orange, Sullivan, Ulster</td>
<td>John Bonacic</td>
<td>Jen Metzger</td>
<td>Rosendale Town Councilwoman and Director and Co-founder of the not-for-profit Citizens for Local Power.</td>
</tr>
<tr>
<td>43</td>
<td>Columbia, Rensselaer, Saratoga, Washington</td>
<td>Kathleen Marchione</td>
<td>Daphne Jordan</td>
<td>Jordan is currently the Legislative Director and Senate Local Government Committee Director for Senator Kathy Marchione.</td>
</tr>
<tr>
<td>50</td>
<td>Cayuga, Onondaga</td>
<td>John DeFrancisco</td>
<td>Robert Antonacci</td>
<td>Antonacci is currently the Onondaga County Comptroller.</td>
</tr>
<tr>
<td>58</td>
<td>Madison, Oneida, Onondaga</td>
<td>David Valesky</td>
<td>Rachel May</td>
<td>Faculty member at Syracuse University.</td>
</tr>
</tbody>
</table>
Communicating Our Message Through Traditional Media

Letters to the Editor and OP/ED Pieces

Along with meeting with you legislators there are other ways for you to project your advocacy voice. Letters to the editors of local newspapers can have a powerful impact and create more support in your community on behalf of the issues so important to NAMI-NYS. We are supplying you with templates for letters to editors on the behalf Action Agenda issues. Feel free to edit and personalize these letters to explain why they are important to you and your community. Please remember though these letters should not exceed 250 words.

Community Services/Mental Health Workforce:

As a person living with a mental illness

(or)

As a family member of someone living with a mental illness,

I am extremely concerned about the lack of investments in our state mental health system. Recovery from psychiatric issues is impossible without a broad mental health system providing a wide range of services to meet the needs of people on all points of the spectrum of psychiatric disorders. These services begin with a robust, skilled and caring workforce. New York has failed to care for the dedicated people who care for people living with mental illnesses and provide them with a sustainable living wage.

I know firsthand how hard mental health professionals work every day to drive recovery for the one in five New Yorkers living with a mental illness. I was disappointed to learn that Governor Cuomo did not include a 2.9% cost of living adjustment for non-profit human service agencies. The lack of support for these vital agencies and their programs has led to difficulties hiring and retaining staff and their ability to deliver the type continuity of care that is integral to recovery. The staff they do have is overburdened with unmanageable caseloads which has led to far too many vulnerable people falling through the cracks of our fractured system.

It is time for New York to bridge the cracks in our mental health system and that starts by supporting the mental health workforce. Our recovery depends on them.

Mental Health Housing With Wrap Around Services:

A safe and secure place to call home is essential to everyone, but a home is also the foundation to successful mental health recovery. Too many people living with mental illness are homeless in the streets, in hospitals or incarcerated. We must do better to support them and give them a proper starting point to advance their recovery. That starting point is mental health housing with wrap around support services.
Mental health programs are becoming more important as the state continues to reduce psychiatric hospital beds, putting more of a burden on housing programs that are already overstretched. If New York is determined to reduce beds it must do so responsibly and with the proper safety nets in place. Mental health housing programs can be that safety net, but only if they are properly funded.

As someone who has benefitted from these programs I am very concerned that community based mental health housing programs are reaching a breaking point as they are being asked to meet the needs of a more specialized and challenging population while being grossly underfunded. Non-profit housing programs have received flat funding for a quarter century, resulting in providers doing their best to offer essential services despite being unable to keep up with the rates of inflation; in fact housing programs are operating at 43% of where they should be due to failure to stay aligned with inflation rates.

It is long overdue to properly support these life changing programs.

**Non-Medical Switching:**

Decisions on a person’s medical care should be made by themselves and their doctor, based on what is believed to be most appropriate in advancing their recovery. People paying for medical insurance should expect their coverage to honor and subsidize the medication their doctor prescribed. However, too often decisions on what medications to cover are based on profit margins and not sound medical recommendations.

Many patients have been betrayed by their insurance providers who switch what medications they cover during a contract year. This practice known as non-medical switching is both amoral and hazardous.

As a person living with a mental illness

(or)

As a family member of someone living with a mental illness,

I am particularly worried about non-medical switching. People who have psychiatric disorders need to have access to the medications their doctor believes are the most appropriate for them. Anti-psychotic and anti-depressants are not interchangeable and prescribing someone with severe mental illness the wrong medication can be very dangerous. Improper use of medication can lead to negative and expensive outcomes such as emergency room visits, hospitalizations and possible entry into the criminal justice system. The most tragic results can include suicide.

A bill before the New York State Legislature ______, would regulate the practice by making it easier for doctors to override insurance company's decision not to approve prescribed medication. I urge our representatives to support this bill.
Using Social Media as an Advocacy Tool

Social Media has become an increasingly powerful tool to project your advocacy voice. In today’s world, to be a strong grassroots advocate it is an absolute necessity to have a presence on social media

We strongly encourage all of our NAMI-NYS affiliates and members to have Twitter handles and Facebook pages. If you don’t already follow NAMI-NYS on social media our handles are:

Twitter: [@NAMINEWYORK](https://twitter.com/NAMINEWYORK)

Facebook: [NAMI NEW YORK STATE](https://www.facebook.com/NAMI-New-York-State/)

Please follow us as we use social media for breaking news and advocacy efforts.

Social media is how a majority of people now communicate and get their news and information.

It lets you share news links, pictures and advocacy issues. It also allows you to “tag” your representatives which ensures they or their staff and all their followers will see your advocacy message. It also allows you to tag other NAMI-NYS affiliates and advocacy partners so they and their followers will see the message and resend it.

**Examples of Using Twitter as an Advocacy Tool**

![Example Tweet](https://example.com/example_tweet_image.jpg)

*Congratulations to NYS Senator @DavidCarlucci for being named the new Senate #MentalHealth Chair. We are grateful for your past leadership of the committee and continued advocacy on mental health. We look forward to working with you. #Act4MentalHealth #HopeStartsWithYou*
Thank you Assemblywoman @HeleneWeinstein for taking the time to meet with us to discuss the #HALTBill and the need to reform solitary confinement.

#Act4MentalHealth #HopeStartsWithYou

Thank you Assemblywomen @EllenJaffee for being a champion for mental health, solitary reform and your constant friendship to @NAMIRockland &

@NAMINEWYORK #Act4MentalHealth #HopeStartsWithYou
@NYGovCuomo - We need a NY/NY4 Agreement NOW: 35,000 new supportive housing units statewide! #NY4SupportiveHousing thndr.me/E52YZn

Yes! Insurance companies must be accountable to cover #mentalhealth treatment and medication. NYS must pass S-3419A

"Too many Americans suffering from mental illness are unable to access the treatment they need because their insurance company refuses to cover it."

U.S. Representative Joe Kennedy III

The Kennedy Forum @kennedyforum

We agree with @JoeKennedy. Let's make 2016 the year Americans get the access they need. bit.ly/1PmkFHs

NAMI New York State @NAMINEWYORK Jan 4

Thank you @RepTimMurphy for explaining why 2016 must be the year for #mentalhealth reform & compassion washex.am/1OuOdUs

NAMI New York State @NAMINEWYORK 28 Dec 2015

Good 2 see the fight for #FamilyLeaveInsurance getting more coverage. @NAMINEWYORK is proud to be in this coalition. bit.ly/1ZxFZ6i

NAMI New York State @NAMINEWYORK 23 Dec 2015
Action needed! @NAMI_QN @NAMIWalksRocNY @namiwestwalk @NAMI_NYC
support the @4NYNYHousing campaign at thndr.me/46A138

NAMI New York State @NAMINEWYORK 17 Dec 2015 New York, USA
Excited to participate in a press conference along with @AARP to call for family leave insurance. #Recoveryteam

NAMI New York State @NAMINEWYORK 12 Dec 2015 Delmar, NY
LEGISLATIVE VICTORY! @NYGovCuomo signs S633 to protect most vulnerable people with #mentalillness. Thank you to all who advocated for this!

Here are examples of how using Twitter has helped deepen our relationship with NYS Senator David Carlucci

NAMI New York State Retweeted David Carlucci
TY @davidcarlucci we deeply appreciate your leadership to protect the most vulnerable people with mental illness.
NAMI New York State added,
David Carlucci @davidcarlucci

Great job Matthew, proud to stand with @NAMINEWYORK @NAMICommunicate and I urge @NYGovCuomo to sign this bill .twitter.com/NAMINEWYORK/st……..

NAMI New York State Retweeted

David Carlucci @davidcarlucci 7 Dec 2015

Joined by @NAMINEWYORK @CANY_1844 and @nyaprs at Sing Sing, we urge @NYGovCuomo to expand MH training in NY prisons.
Have you called @NYGovCuomo to tell him to sign S633/A836? Please make your voice heard on this important issue!!!. conta.cc/1N8DIIP.

Thanks to the leadership of @AileenMGunther & @davidcarlucci A836 passed the Legislature. Tell @NYGovCuomo to sign it & expand MH training

How to use # and @

People new to social media are often confused about what the symbols # and @ mean and how they should properly incorporate them in their messages.

Using #

The # (or hashtag) allows you to tag a subject, campaign, issue or event. Hashtags with multiple uses will generate a page where you can see everyone who has used that hashtag.
An example of using the hashtag for an event was the NAMI-NYS Education Conference. For that event, we used the hashtag #NAMIEDCON15, if you went on to Twitter and searched for #NAMIEDCON15 it would take you to this page of everyone who posted about the conference on Twitter and used the hashtag.

An example of using the hashtag for a campaign would be how our NAMI-NYC Metro affiliate or @NAMI_NYC, as they are known on Twitter, uses #IWillListen for their awareness campaign. Again if you went on Twitter and searched #IWillListen it would take you to this page where you can see everyone who has participated in the campaign.

Hashtags are also good to use when discussing advocacy issues as seen in the examples above #NY4SupportiveHousing and #FamilyLeaveInsurance. This allows you to connect with everyone discussing this issue, thus creating an advocacy network on the issue.

Hashtags also allow you to connect and network with other people and organizations concerned about the same issues as you are. Examples of this would be #MentalHealth #MentalIllness #NAMI #MentalHealthEducation #Schizophrenia #Bipolar #Depression #SuicidePrevention

**Using @**

The @ indicates a specific Twitter handle (in other words, an account) and allows you to tag specific people and organizations. This is especially effective in advocacy when you want to guarantee someone sees your message and you want them to take action. For example, in the tweet below, we wanted to make sure that our affiliates participated in an advocacy campaign so we used their handles to make sure they saw the message and a link to the campaign.

@NAMI New York State @NAMINEWYORK 23 Dec 2015

Action needed! @NAMI_QN @NAMIWalksRocNY @namiwestwalk @NAMI_NYC support the @4NYNYHousing campaign at thndr.me/46A138

Another way using specific handles are important in advocacy is when you want to get your message across to a certain elected official. You can see the use of this in many of the examples above. Again, as mentioned in the legislative meeting section, it is important to both ask and thank when an official supports an issue we are advocating for.
Click here to register for the 2019 NAMI-NYS Legislative Advocacy Day