

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 live saving initiative.

Impossible is just a big word
thrown around by small men
who find it easier to live
in the world they've been given
than to **explore the power**
they have to change it.

– *Muhammad Ali*

AZ QUOTES

