



**MESSAGE FROM THE PRESIDENT**

Dear Members,

By now, I am sure you know that I have resigned as president of NAMI Syracuse. I am so pleased that Karen Winters-Schwartz has accepted the position. You will be in very capable hands with someone who, through her books, has worked with other NAMI affiliates across the United States.

I have been pleased and proud to serve as president of NAMI Syracuse. I am grateful to all of its members and families. The common bond of our members is the unique challenges we have gone through over the years having a family member with a mental illness. We have supported one another, taught each other, fought for new and improved treatments in our area and across the state and nation, and worked hard at attempting to bring down the stigma of mental illness. I have worked with so many wonderful persons and families over the years. Thank you for enriching my life and teaching me so much.

I also want to say thank you to all those who have sat on our Board of Directors over the years and will continue to do so. Please know that all you in this volunteer role are so important, and that we do make a difference!

To all, please know that I am not saying good-bye, but plan to be a part of the board and work closely with all of you.

Respectfully,  
Judy

**NAMI Syracuse Officers**

Karen Winters Schwartz.....President  
Spencer Plavocos..... Vice-President  
Frank Mazzotti.....Treasurer  
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**Consultant to Board**

Dr. Mantosh Dewan

**Supportive Family Training Classes**

Sheila Le Gacy, Director of the Family Support & Education Center is taking registrations for the Spring 2014 session of Supportive Family Training. Supportive Family Training is an educational and support program for relatives and concerned friends of persons diagnosed with serious psychiatric disorders.

The 12 week course is *free* and classes are held at Transitional Living Services, 420 East Genesee Street, Syracuse.

For more information or to register, call Sheila Le Gacy, 315-478-4151 ext.152 or Vanessa Watts, 315-478-4151 ext. 177.

For the latest happenings at NAMI Syracuse visit us on **Facebook** and **LIKE** our page.



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**NAMI Homefront Coming Soon & NAMI Family to Family Classes expected to start in Spring 2014 at the Syracuse VA Medical Center!**

NAMI Homefront will be a six-session adaptation of Family-to-Family intended specifically for the families of service members and veterans living with mental illness. New York State is one of six pilot states who will be introducing this program to families across the U.S. While further details are pending, we know that the program's initial teachers will be currently-trained NAMI program leaders who will participate in a web-based training process to become familiar with the new curriculum.

For more information about these two programs, contact Ann Canastra, MS, NCC, LMHC, ACS at the Syracuse VA Medical Center (315) 425-4400 x 5271 or [Ann.Canastra@va.gov](mailto:Ann.Canastra@va.gov).

**NAMI SYRACUSE ELECTS  
KAREN WINTERS-SCHWARTZ  
AS PRESIDENT**

Hello fellow NAMI members!

I am honored that NAMI Syracuse members have entrusted the "leadership" of this wonderful organization to me. Six years ago, NAMI became my family. As a family, it supported me, listened to me, and gave me strength and hope and knowledge. And unlike many families, it never criticized or judged me-at least not openly! NAMI Syracuse also gave me solidarity; I wasn't alone.

In her 14 years as president, Judy Bliss-Ridgway has given to NAMI Syracuse more than we as members can ever repay. I can't say that Judy has provided tireless leadership, because it wasn't tireless. Running a not-for-profit organization, without any sort of compensation other than a pat on the back now and then, is an awful lot to ask of any individual. "Thank you, Judy!" seems so inadequate. As scary as change can be, it's time to give Judy a break!

I have been asked to step up to the plate. I have accepted this challenge, but I do not expect to be standing there alone.

Even though I'm speaking of NAMI Syracuse as an entity, we all know that what gives NAMI Syracuse its breath and heart and voice, is its members-all of you help make NAMI what it is.

None of what we do can be done by one or two or three individuals-or even by hard-working board members. What we do-what our mission statement entails-takes a community. It takes all of us to fulfill our purpose which is to:

- 1.Promote, support, and foster shared feelings and experiences.
- 2.Work for quality treatment, emergency, and rehabilitation services.
- 3.Educate the public, mental health professionals, and government officials.
- 4.Work to eliminate unjust stigma.
- 5.Encourage, promote, and support policies at local, state, and federal levels.
- 6.Encourage dissemination of information regarding patient and family rights.
- 7.Solicit, receive, and contribute funds.

8.Encourage development of community advocacy and support groups.

Blatantly stealing from some past leaders:

I have a dream-a dream that entails a community effort of all our members and all our future members. Over the next year, I will be reminding our members of our mission, of our goals, of the good we do, and most importantly of the better that we can do. Ask not what NAMI Syracuse can do for you, but what can you do for NAMI Syracuse. And not just for NAMI Syracuse, but for our human community.

Let's set our 2014 goals to include increasing awareness. We need to let the community know who we are and what we do. Let's work on increasing our membership. We are strength in numbers. If each member just told three people who we are and what we do, what a difference that could make.

Let's reach out to the community, especially to our educators and medical professionals. Family members and recipients of services should not have to find out about NAMI through a friend of a friend of a friend as I did. Every school counselor, every teacher, every pediatrician, every clergy leader, every family doctor, every psychologist, every social worker, every psychiatrist needs to know who we are, what we do, and then readily refer people to us. If each of us just talked about NAMI with our own family doctor or our kid's school counselor or our clergy, or even our extended family members-if we handed them a stack of our pamphlets to disperse-what a difference it could make.

No one should stand alone.

As we enter into this New Year, let's all work together, let's all have a dream to fulfill the NAMI Syracuse mission statement and make NAMI Syracuse all that it was ever meant to be-and more.

~~Karen

*Snowflakes are one of nature's  
most fragile things,  
but just look what they can do  
when they stick together.*

*Vesta M. Kelly*

**Hutchings Psychiatric Center  
Family and Community  
Education Schedule**

**January through March 2014**

All classes are **free** and open to the public, and held in the H.P.C. Education and Training Building, 545 Cedar Street, Syracuse, NY. Paid parking is nearby. To register for classes please call the Education and Training Department at **315-426-6872**. Please register at least 1 week in advance.

**1/14/14 10am to 12 noon**

Mental health and residential resources: Information for consumers, families and caregivers.

Presenter: Patricia Moore, LCSW-R, HPC Director of Social Work and Outpatient Clinic Coordinator

**2/11/14 10am to 12 noon**

The Impact of Trauma: A discussion on Post-Traumatic Stress Disorder for consumers, families and caregivers.

Presenters: Ross Loucy, LCSW-R, HPC Team Leader  
Jim Riter, LCSW, HPC Outpatient Program Director

**3/11/14 10am to 12 noon**

Overview of Medications

Presenter: Dr. Sunny Aslam, MD, HPC Outpatient Psychiatrist



## I THINK ABOUT MY BROTHER EVERYDAY

from the *Treatment Advocacy Center*,  
*Personally Speaking*

Every day I think of our family's story and the loss of my brother due to his lack of treatment for his mental illness.

I lost a brother who for over 40 years was like any other member of our family. He was a college graduate, business owner and father who enjoyed spending time with his family. He was a regular guy.

Until he wasn't.

Ten years ago he started getting off track and began to say things I had never heard him utter before. He was someone I had known my entire life and suddenly he started taking on a new persona. For over a year there were gradual changes and then a spiral out of control.

I am a nurse, and I had absolutely no idea what mental illness truly encompassed until we were faced with his ultimate diagnosis of bipolar disorder. For my brother it was terminal.

His last manic period began when he was in Costa Rica in the spring of 2012. Somehow we were able to get Brad hospitalized in Costa Rica. Even being in another country this was easier than at any time back in the states.

Unfortunately, once he was deported back to the United States all medical care immediately ceased. His illness became worse and his path took him to jail. This was not the first time jail became his only way of being locked up and kept from making more acts of poor judgment.

He was in and out of jail and in and out of mental institutions where he was usually only kept for three days. The social workers never listened, meanwhile his symptoms and his behavior worsened. All the while we stood by helplessly.

I constantly discussed with my brother, what goes up, must come down. And with time, we all realized the further up, the further down. He came down very fast and hard in the end. When he was discharged from the hospital, the doctors told him, "There is nothing more we can do for you here that you can't do

at home." But he can commit suicide at home.

Faced with moving into a group home, my brother who had run his own business couldn't face the humiliation and he committed suicide the night before being placed.

Do I think that laws need to be changed? For the severely mentally ill, for those loved ones that have lost the ability to make proper decisions, have had multiple hospitalizations with their illness, absolutely someone needs to be their advocate.

For those of us who know the person best, who can be their ally, we are relegated to a back seat position and absolutely no ability to help during times of crisis.

While my brother had lost many things along the path of his illness, treatment would have helped him regain some of his dignity. There could have been a place for him in society, rather than a burden to it.

Untreated severe mental illness will never have a positive outcome, both for the stability of the illness, and ultimately for the life of the person suffering.

Please, we need to change the laws. We need to change the perception of these illnesses. Without this, there will continue to be stories like my brother's, and families like mine will continue to mourn their loss.

Denise Schmitt

Wisconsin

Schmitt's brother lived in Florida

## HOW YOU CAN HELP PREVENT DISCRIMINATION AGAINST PEOPLE WITH MENTAL ILLNESSES

by *John M. Grohol, Psy.D.*

Stigma discrimination remains a hot topic in mental illness circles. In fact, at the National Conference on Mental Health in June 2013, President Obama singled stigma out as one of the major problems facing people with a mental health concern:

"... [we] whisper about mental health issues and avoid asking too many ques-

tions. - And there should be no shame in discussing or seeking help for treatable illnesses that affect too many people that we love. We've got to get rid of that embarrassment. We've got to get rid of that stigma.

Too many Americans who struggle with mental health illnesses are still suffering in silence rather than seeking help, and we need to see to it that men and women who would never hesitate to go see a doctor if they had a broken arm or came down with the flu, that they have that same attitude when it comes to their mental health."

Inadvertently, and perhaps even unconsciously, mental health professionals sometimes contribute to that stigma, the foundation of which is prejudice and discrimination.

Professionals do this by sending the message that a person with mental illness is less than someone without. This is especially true for people who grapple with serious mental illnesses, such as schizophrenia or bipolar disorder. In the past, well-meaning professionals and therapists often told people things like

"You can't hold down a job, it requires a regular commitment."

"You'll never be able to live on your own."

"You can't go back to school and get a degree-it's too stressful."

This is the language of defeat and imprisonment, not that of hope and positive change. **What Can We Do to Prevent Such Discrimination and Prejudice?**

Professionals in the mental health field often learn such language from their schools, colleagues, and even the people they serve. Because it is a simple learned response, it can also be unlearned. Here are some tips to help change this behavior.

1. Each person is unique. While professionals often fall back on their experience with other service users who have similar concerns to help guide them with a new person, everyone is different. No two people with schizophrenia are any more alike than two people with asthma or diabetes. We need to remember the individuality each of us brings to each interaction and not use labels as generalizations that predetermine our expectations for each person. Just because a previous service user couldn't make independent living work doesn't mean the next person won't be able to.

2. Emphasize the possible. Sometimes therapists and other well-meaning professionals get bogged down by the details or specifics of a problem or plan. A professional's job is not to problem solve for the person, but to act as his or her guide, helping the person problem solve for him or herself. As far as a professional should be concerned, all things are possible. One of the most valuable assets a professional can bring to the recovery relationship is hope. Hope is such an important component of treatment and recovery.

3. Watch your language. How we talk about something is often more important than what we say. Nonverbal communication is picked up just as readily by a person as anything else you say, so it helps to remember people are not the sum of their diagnostic labels. Use language and words that respect the individual and his or her life struggles, strengths, and experiences.

4. Stop using shorthand with colleagues and demand the same from them. Sometimes when colleagues talk with each other, they'll inadvertently reinforce prejudices against people with mental illness by using demeaning language or shorthand labels. "Oh, I saw this borderline today who -" People receiving mental health care deserve the same respect after they leave the office as they do while inside it.

5. Encourage reasonable goal setting without trampling the dream. A professional can become distracted by a person's "big dream" and quickly label it unrealistic. Instead, focus on small steps toward that dream-reasonable goals the person can readily attain with some effort and changes to his or her life.

6. Get involved. Preventing discrimination and prejudice can be as easy as writing a letter to your local newspaper when a publication uses stigmatizing language or repeats falsehoods about people with mental illness. Another option is to become more active in an advocacy organization focused on changing the conversation about mental illness.

Discrimination and prejudice can be prevented by employing these kinds of strategies as early as possible in a profes-

sional's career and training. However, even older professionals can change their attitudes toward the people they serve. All it takes is awareness and a dedication to change.

*Dr. Grohol is the founder, editor in chief, and CEO of PsychCentral.com. Please contact him at grohol@psychcentral.com.*

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### **MOST TEEN PSYCHIATRIC DISORDERS GO UNTREATED**

*Duke Today, November 18, 2013*

More than half of adolescents with psychiatric disorders receive no treatment of any sort, says a new study by E. Jane Costello, a Duke University professor of psychology and epidemiology and associate director of the Duke Center for Child and Family Policy. When treatment does occur, the providers are rarely mental health specialists, says the study, which was based on a survey of more than 10,000 American teenagers.

The country's mental health system has come under scrutiny in recent years, following a string of mass shootings, such as the murders at Columbine High in Colorado, in which mental illness seems to have played a role. The new study underlines the need for better mental health services for adolescents, Costello said.

"It's still the case in this country that people don't take psychiatric conditions as seriously as they should," Costello said. "This, despite the fact that these conditions are linked to a whole host of other problems."

Costello noted that not all teens in the study fared the same. Treatment rates varied greatly for different mental disorders, for instance. Adolescents with ADHD, conduct disorder or oppositional defiant disorder received mental health care more than 70 percent of the time. By contrast, teens suffering from phobias or anxiety disorders were the least likely to be treated. Results also varied greatly by race, with black youths significantly less likely to be treated for mental disorders than white youths.

The care that teenagers received also varied greatly. In many cases, care was provided by pediatricians, school counselors or probation officers rather than by people with specialized mental health training. There simply are not enough qualified child mental health professionals to go around, Costello said.

"We need to train more child psychiatrists in this country," Costello said. "And those individuals need to be used strategically, as consultants to the school counselors and others who do the lion's share of the work."

The study draws on data from the National Comorbidity Survey Adolescent Supplement, a nationally representative face-to-face survey of 10,148 adolescents between the ages of 13 and 17. It was published online Nov. 15 in *Psychiatric Services*.

The research was supported by NIDA (grants U01-DA024413, DA011301, and DA022308), NIMH (grant MH083964), and the NIMH Intramural Research Program.

~~Editor's Note: The survey is available online at:

<http://ps.psychiatryonline.org/data/Journals/PSS/0/appi.ps.201100518.pdf>

*Congratulations to  
**Karen Winters-Schwartz,**  
elected President of NAMI Syracuse*

*Thank you to **Judy Bliss-Ridgway** for  
all you have done and will continue  
to do for NAMI Syracuse*

*Welcome to the newly elected 2014  
NAMI Syracuse Board Members:*

***Susan Bonzagni**  
**Carol Sheldon-Brady**  
**Ray Hart**  
**Monica Lamont***

*Thank you to **Ann Canastra** whose  
term ended in 2013, for your  
commitment and dedication  
to NAMI Syracuse*

## WHY GUS DEEDS WASN'T HOSPITALIZED

by Michael Tomasky, November 20, 2013

Why couldn't they find a psych bed anywhere in southwestern Virginia for Gus Deeds?

It's quite rare that a public tragedy allows us to connect dots this clearly, but the horrifying case of Gus Deeds stabbing his father, Virginia politician Creigh Deeds, is one such case. We begin with this sentence, from the Richmond Times-Dispatch account of the incident:

The son was evaluated Monday at Bath Community Hospital, Cropper said, but was released because no psychiatric bed could be located across a wide area of western Virginia.

Hmmm. And why would that be so? Just one of those things? The usual pre-Thanksgiving rush? Not really. As Think Progress notes, the likely culprit here is that Virginia cut funding for psychiatric beds by 15 percent between 2005 and 2010. Certainly, 2005 would mean the cuts started under Democratic governors-first Mark Warner, and then Tim Kaine. They continued under current GOP Governor Bob "Rolex" McDonnell, who then proposed even deeper cuts last year.

What's going on in Virginia is going on nationally. Try this statistic on for a shocker. ***The per capita state psychiatric bed population in 2010 in the United States was identical to the figure for 1850. Yes, 1850, around when the very idea of caring for mentally ill people first started! Then and now, the number 14.1 beds per 100,000 population.***

Between 2009 and 2012, states cut \$4.35 billion from mental health services, which eliminated nearly 10 percent of all beds in just those three years. This is while 10 percent more people have been seeking services. I remember when I covered state and local politics in New York, mental health services were always among the first things on the chopping block. No

constituency with any political power at all, just a bunch of do-gooders pleading for officials to do the right things. Which in fairness a lot of them want to do, but most don't end up doing.

Now let's bring in the reviled Obama-care. It requires for the first time in American history that mental illness treatment of some kind will be included and covered in all plans. Such coverage has been a comparative rarity until the ACA. There's more good in the law for people who live in the states that have accepted the Medicaid expansion, as it will provide funds for treatment for many people who haven't qualified up to now because of extremely strict eligibility requirements, which will be loosened under the expansion. I've written on this before. It's not going to fix everything, because no system devised by human beings ever does, but these two changes will help millions of suffering people.

We have a long way to go on mental health in this country. I don't know if Republicans quite think that the mentally ill, like the poor, are enfeebled through some fault or moral flaw of their own, and if they just collected themselves and started thinking sensibly about things they wouldn't need all this "help." What I do know is that they somehow end up opposing most things government and mental-health professionals support. I'll leave you to speculate on the why.

But this morning, we know this. Gus Deeds should have been in a psychiatric ward yesterday. That he was not, as I noted above, was a bipartisan failure. But it sure would be nice to see a bipartisan success for a change-Republicans joining Democrats to do more for mentally ill people. They could start with the new law that's doing more on this front than pretty much any in our history, but of course they're just going to vote another 50 times to repeal it.

~~Michael Tomasky is a liberal American columnist, journalist and author. He is the editor in chief of *Democracy*, a special correspondent for *Newsweek* / *The Daily Beast*, a contributing editor for *The American Prospect*, and a contributor to *The New York Review of Books*.

## RICHARD DREYFUSS REVEALS BIPOLAR DIAGNOSIS "TOOK AWAY ALL OF MY GUILT"

Actor Richard Dreyfuss has struggled with bipolar disorder since childhood, but for many years, he didn't know what was behind the intense emotions that filled much of his life.

"I didn't know it was a manic state," he explained during a recent interview on the TODAY Show. "I just thought I was really happy, and everything that was bad, I turned to good."

But what seemed good to him sometimes seemed odd to those around him.

"Every once in a while, when I was talking, I would find myself getting up and talking louder and faster and louder and faster and louder and faster, until my friends would say, "OK, OK. Let's get the big circus cables and throw them around his ankles and pull him gently back to Earth," Dreyfuss recalled.

The star realized those actions were beyond his control, and eventually, he learned what was really behind it all.

"It took away all of my guilt because I found out it wasn't my behavior - it was something I was born with," Dreyfuss explained of his bipolar diagnosis. "I didn't feel shame or guilt. It's like being ashamed that you're 5-foot-6 or something. It's just part of me."

And yet, others living with bipolar disorder often still feel shame, and that's something Dreyfuss, who first spoke publicly about his diagnosis in the 2006 documentary "The Secret Life of the Manic Depressive," hopes will become a thing of the past.

"Stigma is silly; stigma is stupid; stigma is what other people think about you," he said. "I, first of all, don't know anyone who's normal. Everybody's got something, and I come from Hollywood so no one even argues the point. 'Stigma' is a word that should be kicked away - and 'shame' and 'guilt' - because it's a condition."

Now the actor - best known for big-screen blockbusters "Jaws," "Close Encounters of the Third Kind" and "Mr. Holland's Opus" - is working with Hope for Depression Research Foundation and speaking out to help those who want help.

"I'm, personally, not in a hurry to get rid of my condition, but most people are," he said.

## IMMUNE SYSTEM MAY PLAY CRUCIAL ROLE IN MENTAL HEALTH

USA Today, Karen Weintraub, 12/1/13

*Considering inflammation has helped neuroscientists cast a broader net when searching for causes of and possible treatments for mental illness, mood disorders and neurodevelopmental conditions.*

Last time you had a bad cold, you likely had less energy than usual. You lay around and didn't have any enthusiasm for your usual activities. After it dragged on for a day or two, a sense of helplessness probably set in. It was hard to remember what feeling good felt like or how you could ever bound off the couch again.

In short, for a few days, you probably felt a lot like someone with depression.

And increasingly, scientists think it's no coincidence that a mental illness feels like a physical one.

A growing body of research on conditions from bipolar disorder to schizophrenia to depression is starting to suggest a tighter link than was previously realized between ailments of the mind and body. Activation of the immune system seems to play a crucial role in both.

"We just didn't understand how much of a role the immune system plays in how we think and feel and act," says Andrew Miller, a professor of psychiatry at Emory University. "An overactive immune system or when there's something going on in the immune system, it can have consequences on the brain."

An immune response, including inflammation, new research suggests, may help explain why:

- Brain conditions such as multiple sclerosis, Parkinson's and Alzheimer's disease all affect mood;
- About one in four people hospitalized with schizophrenia had a urinary tract infection when admitted to the hospital;

- Mothers with auto-immune conditions such as lupus are more likely to have a child on the autism spectrum;
- People with higher rates of inflammation are more likely to show signs of depression than those with healthy immune function. A study in mice presented earlier this month at the Society for Neuroscience's annual convention showed that the immune changes came before the emotional ones.

"One of the things we need to stop thinking is that mental health is just a disorder of the brain," says researcher Georgia Hodes, of the Icahn Medical Institute at Mount Sinai Hospital, who conducted the mouse study. "There's plenty of evidence in a number of different mental illnesses that they have components to them that relate to the entire body."

Merely adding inflammation to their thinking has helped neuroscientists cast a broader net when searching for causes of and possible treatments for mental illness, mood disorders and neurodevelopmental conditions such as autism, researchers say.

And this mind-immune system connection might help explain why mental health treatments don't work for some people. Perhaps, researchers now think, those people would be better off with approaches that target their immune systems rather than their brain chemicals.

For those with schizophrenia and urinary tract infections, for instance, acute psychotic symptoms often improve after a few days on antibiotics, according to Brian Miller, an assistant professor of psychiatry at Georgia Regents University in Augusta, who is studying the connection between the conditions. This isn't to suggest that all people with schizophrenia should be on antibiotics, Miller says, but patients with both might get as much or more relief from antibiotics as antipsychotics.

Other studies show that the level of an inflammatory protein called interleukin - may help predict someone's emotional state. Manipulating the levels of this protein changes behavior on depression and anxiety tests in mice, says Larry Swanson, a neuroscientist at the University of Southern California, and immediate past president of the Society for Neuroscience.

Researchers are still working out the connection between the immune system and autism, says Judy Van de Water, an immunologist at the MIND Institute at the University of California-Davis. There is some indication, she says, that the people with autism who have the most behavioral problems, such as irritability and hyperactivity, also show the highest levels of inflammation. She says she hopes that better understanding the role of inflammation in autism will lead to treatments.

The immune system's role might also fit into the "second-hit" idea of mental illness, where two or more factors, such as genetics, immune challenges and, say, a hit to the head, combine to cause brain problems. That may explain why traumatic brain injuries often lead to depression, says Jonathan Godbout, a neuroscientist and associate professor at the Institute for Behavioral Medicine Research at The Ohio State University Wexner Medical Center.

A serious infection during pregnancy or early in life might make someone more vulnerable to problems later, says Godbout. "It's like a priming or sensitization. There are secondary triggers that can reactivate something and make it worse."

What is clear, says Andrew Miller of Emory, is that the body and mind both influence one another. "It's a two-way street - what happens psychologically can affect you physiologically and then feed back and affect you psychologically. The brain and immune system - their interactions are quite meaningful for health and illness."

Tips for keeping down inflammation, which might help promote good mental health:

- Keep stress to manageable levels (inflammation probably causes stress and stress can cause inflammation; both are bad for the body and the brain.)
- Exercise.
- Maintain a healthy weight (excess fat leads to inflammation).
- Get adequate sleep - 7<sup>3</sup>/<sub>4</sub> to eight hours a night, on average.
- Avoid serious infections while pregnant and in early childhood.
- There is a little evidence that anti-inflammatory drugs, including aspirin, might help improve mood, though that research is very preliminary and these drugs are probably not strong enough to treat full-blown illnesses, say researchers.

## **SUPPORT THE HELPING FAMILIES IN MENTAL HEALTH CRISIS ACT!**

On December 12, U.S Representative Tim Murphy (who is also a psychologist) introduced *The Helping Families In Mental Health Crisis Act*. The act comes after a year of Rep. Murphy holding investigations on how the mental health system in America is broken and the bill aims to fix many of the fractures in the system.

Of the bill Rep. Murphy says, "More than 11 million Americans have severe schizophrenia, bipolar disorder, and major depression yet millions are going without treatment and families struggle to find care for loved ones. The federal government's approach to mental health has been a chaotic patchwork of antiquated programs and ineffective policies across numerous agencies. Sadly, patients end up in the criminal justice system or on the streets because services are not available. *The Helping Families In Mental Health Crisis Act* fixes the nation's broken mental health system by focusing programs and resources on psychiatric care for patients and families most in need of services."

NAMI-NYS strongly supports *The Helping Families in Mental Health Crisis Act*.

NAMI-NYS President Thomas Easterly says, "NAMI-NYS applauds Congressman Murphy for introducing this landmark legislation. I am extremely encouraged by the scope of the bill. I also deeply appreciate the fact that it acknowledges and addresses the struggles families face when trying to get the proper care for our loved ones living with a mental illness."

NAMI-NYS Boardmember Steve Dvorin, MD, says, "All features of the proposed legislation appeal to me, but a couple of elements that especially resonate with me are:

Modification of HIPAA rules will allow providers to be more responsive and more helpful to family members who are first-responders to their loved

ones' unusual beliefs and actions. Providers will be relieved to know that they can be protected by fewer restrictions in regard to what information can be disclosed and what guidance can be offered. Families will be less frustrated, more collaborative, and better informed. Their loved ones will be better served by informed family interventions.

In a time of great concern about health-related issues, our community is particularly deficient in their knowledge and understanding of serious mental illness. Anti-treatment advocates should not confuse the issue with idiosyncratic, scientifically unfounded information that only serves to delay effective treatment. SAMHSA and related agencies should have no role in supporting non-evidence based practices or the recommendations of anti-treatment groups. Knowledge is mastery. Let's ensure that government sponsors of information will only promote information that is based on high quality studies and research."

NAMI-NYS First-Vice President Paul Capofari says, "There are many aspects of the bill to support, but I would say that the reform of HIPAA would get my vote. Family members who are actively trying to get their loved one into treatment are often prevented from doing so by the hospital or Doctor refusing to speak to the family due to HIPAA."

NAMI-NYS Board Member Barbara Biasotti says, "Exceptions to HIPAA are so necessary to help people get treatment that they are too sick to access themselves while wandering the streets in a psychotic state of mind. There's nothing better than evidence based programs to ensure success in our nation's goal to improve the lives of people suffering so much from severe mental illness through treatments proven by replicated studies done by our nation's higher education institutions!"

For a summary of the bill, go to:  
<http://murphy.house.gov/uploads/Summary.pdf>

**CALL YOUR HOUSE REPRESENTATIVE TODAY AND ASK THEM TO SUPPORT THE HELPING FAMILIES IN MENTAL HEALTH CRISIS ACT**

## **MENTAL HEALTH PEER SPECIALISTS REPORT THEIR WORK IS BENEFICIAL TO THEM**

*Newsworks, Maiken Scott, 12/30/13*

The Department of Veterans Affairs has hired more than 800 mental health peer specialists over the past year. The VA joins other service providers across the country that have staffers who have dealt with their own mental health challenges.

Previous research has found that receiving services from a peer specialist helps those in treatment, but new research finds that the benefits are mutual.

Dr. Mark Salzer, who heads Temple University's department of rehabilitation sciences, recently surveyed more than 150 peer specialists working in Pennsylvania.

"People said they felt better about themselves. They felt that providing peer services to others facilitated their own recovery and wellness," explained Salzer.

Peer specialists also reported using fewer services once they started working, he said.

"For some people who had been unemployed, they were able to go back to work, which is good for people's mental health, and hopefully has an impact on people's receipt of entitlements," Salzer said. "And we also found that people reported decreasing their use of mental health services."

Salzer said that previous studies have shown that people who are receiving peer services are more engaged in their mental health treatment and recovery.



**"What the New Year brings to you will depend a great deal on what you bring to the New Year."**

**~~Vern McLellan**

## A PSYCHIATRIST THINKS SOME PATIENTS ARE BETTER OFF WITHOUT ANTIPSYCHOTIC DRUGS

*Sandra Steingard, The Washington Post, 12/9/13*

What does it mean that the man who killed 12 people at the Washington Naval Yard had told people that he was “hearing voices”?

I have spent 30 years as a psychiatrist treating people who are psychotic. Almost every day I meet with individuals who hear voices that no one else hears, are sure the TV or radio is talking to them or have such confused thinking that it is hard to understand what they are trying to tell me.

Sometimes these patients lead quiet lives. But not uncommonly these voices get them into trouble. I've had patients who call the police repeatedly, demanding that they stop bugging their phone. And others who stay up all night talking back at the voices. Some accuse family members of being involved in the torment.

In many cases, this is a frightening experience - for the people I see and those who love them. And the labels we use - “schizophrenia,” “bipolar disorder,” “psychosis” - only crudely capture these experiences.

About 60 years ago, a group of drugs was discovered that appeared to quiet the voices, improve the clarity of thought and lessen the preoccupation with delusion beliefs. Originally called major tranquilizers and later renamed antipsychotic drugs, these have been considered essential for the treatment of people with schizophrenia.

Once it was clear that these drugs were helpful in the short term, questions arose over how long people should remain on them. Studies done in the 1970s and 1980s looked at people who were stabilized after being treated with antipsychotic drugs for several months and then followed them for up to two years. Some continued on the drugs, while others stopped taking them. The relapse rate was much higher in the group that stopped the medications.

Based on these studies, treatment guidelines now state that people should stay on anti-psychotics indefinitely.

The problem with “indefinitely” is that antipsychotic drugs have many troubling side effects. They can cause muscle stiffness, tremor and something called tardive dyskinesia, where muscles in the face or limbs move uncontrollably. But the belief - my belief - was that this was the unfortunate price paid to help people who were suffering.

Many people do not want to take these drugs because of the side effects or because they do not think of themselves as ill. After all, if the government is using telemetry to transmit messages into your brain, the solution is to turn off the source of the transmission, not to take a pill. I considered myself a successful psychiatrist when I was able to use my powers of persuasion to convince a reluctant patient to stay on the drugs.

Yet, over the past 15 years, my attitude has shifted. I have become deeply disturbed by the marketing practices that many pharmaceutical companies began to use in the 1990s to push their new medications.

Like many of my colleagues, I awaited the new drugs with enthusiasm, hoping that they would have fewer terrible side effects. Leading psychiatrists who had worked on the development of the drugs also said that they not only were less likely to cause neurological problems but also were more effective.

Quickly, though, I started to think that their benefits were being inflated and their side effects minimized. With one drug in particular, it was clear after a year that my patients were gaining weight at alarming rates: 20, 30, even 100 pounds in a matter of months, a real threat to their health.

Researchers test such new drugs on people for years before they reached the market, but little attention was focused on this issue and only then in the context of a product war - i.e., whether one drug caused more weight gain than others. Only a decade after they were released to the market was it widely acknowledged that severe weight gain was common with many of the newer anti-psychotics, increasing the risk of diabetes. Given

that people may take these drugs for decades, the health consequences are serious.

Yet until 2 1/2 years ago, I still thought that prescribing antipsychotic drugs was necessary. After all, a good number of my patients ended up in the hospital or, worse, the police station, when they stopped taking their medications. I did not think I had any other option than to continue to employ my now well-honed powers of persuasion to convince them to stay on their drugs.

And then I read Robert Whitaker's “Anatomy of an Epidemic,” in which he wondered why, if these new drugs were so great, we were seeing increasing numbers of people on disability for psychiatric conditions. He looked at the studies of long-term outcomes, and what he found surprised me and many of my colleagues: Although it is very hard to do a definitive study that follows people for many years, the research suggested that, over time, the people who remain on these drugs do worse than those who stop using them.

Those who remained on the drug were less likely to return to work or develop meaningful relationships. Of equal concern, it appeared that brain shrinkage - thought initially to be due to the illness itself - was in fact caused by the drugs. Even when monkeys took these drugs for a period of months, their brains shrank.

If Whitaker was right, everything I had been doing for 20 years was wrong. Many psychiatrists have accused him of cherry-picking the data or distorting the findings of the studies. I have spent much of my time rereading the articles and studies he cites, looking for others, talking to colleagues and reading as much criticism of his work as I can find.

And what I concluded is that Whitaker is probably right.

The dilemma.

This created a dilemma for me: If the drugs that are helpful in the short run may be harmful over time, what do I do for the person who is unable to have a conversation because the voices in his head are so loud?

If the medications stop the voices, do I suggest he come off the drugs and risk relapse? Or do I suggest he stay on them and reduce his chances for a full recovery? If I suggest that he stop the drugs and then something bad happens, I may be blamed for his relapse, while I am unlikely to be blamed 30 years from now when he has diabetes.

Doctors are held to a standard of "accepted community practice." What if my own research has led me to a conclusion that is at odds with accepted community practice? What if accepted community practice is so distorted by pharmaceutical advertising in favor of these drugs that it is suspect and unreliable?

Two years ago, I decided to invite my patients into this conversation. I explain to them what I have read and what conclusions I have drawn, as well as the conflicting views of other psychiatrists.

I have been monitoring those who have chosen to wean themselves from the antipsychotic drugs they have been taking, in some cases for 20 years or more. What has been most striking is that my patients make careful and deliberate decisions. Many psychiatrists fear that having this conversation will lead to massive dropping of the drugs, but this has not been my experience. Some do - most often, the ones who have stopped them multiple times in the past - but most are cautious. Of the 64 people I have tracked, 40 decided to try a dose reduction, 22 chose to remain in their current dose and only four abruptly stopped taking their medications.

Some might think my approach cavalier. When we read about Aaron Alexis, who heard voices and shot 12 people before being killed at the Washington Navy Yard, it raises our fears. However, it is important to keep in mind that the problems I describe are common and that the vast majority of people who experience psychosis are not likely to be violent toward others. One study found an increased risk of violence only among those with mental illness who also abuse drugs or are young men. Such risk factors and an individual's history would, of course, be a part of any decision about whether to wean someone off medication.

In this context, a blog post by Thomas Insel, the director of the National Institute of Mental Health, received much attention. This year, Insel described a Dutch study involving 103 people treated for schizophrenia and related disorders. The participants were randomly assigned to one of two groups: Half

remained on drugs continuously; the others stopped taking drugs when they became well but restarted them if symptoms emerged. After seven years, the researchers found that those who were not continuously on drugs had a much greater likelihood of getting a job and resuming their regular life activities than those who remained on medications. Remember that people who stop drugs have a higher rate of relapse? It turns out that over the seven years, those who remained on the drugs relapsed as often as the others.

"For some people, remaining on medication long-term might impede a full return to wellness," Insel wrote. "For others, discontinuing medication can be disastrous."

The problem is that we do not know who is in which group.

A slow reduction.

A man I have known for many years has had some serious bouts with psychosis. He has been hospitalized multiple times, and his thoughts have put him - though not others - at personal risk. However, the medications have also put him at risk. He is now overweight and has diabetes and his kidneys are not working well. He spends a good part of his day sleeping and the rest watching TV.

We have tried in the past to reduce his dose, but these efforts have never gone well. Within days he would be hallucinating and delusional. However, recently we found that with a very slight reduction in dose, he would relapse for about a month but then improve. Perhaps it was his age or greater experience, but he was able to get through the bad days without getting into trouble, and once things quieted down in his mind he felt better. We have agreed to slowly proceed.

His family supports his choice. We all understand the risk of dose reduction, but we see it in the context of all of the risks. Maintaining his current dose is not without consequence. I have known him for a long time, but the problems of schizophrenia tend to start early and he is still a young man. Even if it takes five years to get him on a significantly lower dose, we have the opportunity to improve the long-term quality of his life.

The Dutch study shifted the focus away from the belief that we need to eradicate all symptoms of schizophrenia to a focus on

improving the quality of patients' lives and health, the relationships they have, the work they do. Some people can learn to live with voices. Some people find that the voices have a significant meaning for them and that communicating with them is what is most important. Some people can learn to talk themselves down from delusional thoughts. And some people might choose hearing voices over being 30 pounds overweight and tired all of the time. The point is that this is not a choice I should be making for my patients; it is a choice I need to make with them.

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## FIRST UP IN 2014, MENTAL ILLNESS

*New York Times, Nicholas Kristof, January 4, 2014*

My own suggestion for a systematically neglected issue: **mental health**. One-quarter of American adults suffer from a diagnosable mental disorder, including depression, anorexia, post-traumatic stress disorder and more, according to the National Institutes of Health. Such disorders are the leading cause of disability in the United States and Canada, the N.I.H. says.

A parent with depression. A lover who is bipolar. A child with an eating disorder. A brother who returned from war with P.T.S.D. A sister who is suicidal.

All across America and the world, families struggle with these issues, but people are more likely to cry quietly in bed than speak out. These mental health issues pose a greater risk to our well-being than, say, the Afghan Taliban or Al Qaeda terrorists, yet in polite society there is still something of a code of silence around these topics.

We in the news business have devoted vast coverage to political battles over health care, deservedly, but we don't delve enough into underlying mental health issues that are crucial to national well-being.

Indeed, when the news media do cover mental health, we do so mostly in extreme situations such as a mass shooting. That leads the public to think of mental disorders as dangerous, stigmatizing those who  
*(continued on page 11)*

# Seeds Of Hope

*a poem by: Tanisha Wiggins  
inspired by: Nicole Semmens*



One **beautiful** night

A seed was planted that shined so **bright**

This seed had so many qualities that it took time to grow

With each gardener leaving something felt from deep below

Some nights was nice some nights was **warm**

And some nights was **windy** which brought on **storm**

But through it all the seed still grew

With marks **imprinted** if only you knew

Sprinkles of **life**, sprinkles of **joy**

Sprinkles of **love** felt from up above

This seed was surely admired

Had **courage** and **strength** even through fire

Every season it was there, every season it was **nourished**

through the gardeners who watered it and let it **flourish**

And who is this seed

The seed is **you**

With **gardeners** who want to see you **through**

Each one of us started off as a seed

Its up to us to allow in what we need

We can take in the mess that the world ditch out

Or we can leave it and decide to **sprout**

Life can be cold and filled with pain

And we couldn't of grown without the rain

Little sprinkles of **hope** is coming your way

Its up to you to **blossom** each and everyday

You have a **purpose** and your purpose may be

**To plant a seed in someone else in need**



are mentally ill and making it harder for them to find friends or get family support.

In fact, says an Institute of Medicine report, the danger is “greatly exaggerated” in the public mind. The report concluded: “although findings of many studies suggest a link between mental illnesses and violence, the contribution of people with mental illnesses to overall rates of violence is small.”

Put simply, the great majority of people who are mentally ill are not violent and do not constitute a threat - except, sometimes, to themselves. Every year, 38,000 Americans commit suicide, and 90 percent of them are said to suffer from mental illness.

One study found that anorexia is by far the most deadly psychiatric disorder, partly because of greatly elevated suicide risk.

Mental illness is also linked to narcotics and alcoholism, homelessness, parenting problems and cycles of poverty. One study found that 55 percent of American infants in poverty are raised by mothers with symptoms of depression, which impairs child rearing.

So if we want to tackle a broad range of social pathologies and inequities, we as a society have to break taboos about mental health. There has been progress, and news organizations can help accelerate it. But too often our coverage just aggravates the stigma and thereby encourages more silence.

The truth is that mental illness is not hopeless, and people recover all the time. Consider John Nash, the Princeton University mathematics genius who after a brilliant early career then tumbled into delusions and involuntary hospitalization - captured by the book and movie “A Beautiful Mind.” Nash spent decades as an obscure, mumbling presence on the Princeton campus before regaining his mental health and winning the Nobel Prize for economics.

Although treatments are available, we often don’t provide care, so the mentally ill disproportionately end up in prison or on the streets.

One example of a cost-effective approach employs a case worker to help mentally ill people leaving a hospital or shelter as they adjust to life in the outside world. Randomized trials have found that this support dramatically reduces subsequent homelessness and hospitalization.

Researchers found that the \$6,300 cost per person in the program was offset by \$24,000 in savings because of reduced hospitalization. In short, the program more than paid for itself. But we as a society hugely underinvest in mental health services.

Children in particular don’t get treated nearly often enough. The American Journal of Psychiatry reports that of children ages 6 to 17 who need mental health services, 80 percent don’t get help. Racial and ethnic minorities are even more underserved.

So, mental health gets my vote as a major neglected issue meriting more attention. It’s not sexy, and it doesn’t involve Democrats and Republicans screaming at each other, but it is a source of incalculable suffering that can be remedied.

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