



NAMI in Buffalo & Erie County
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“One person with a belief is equal to a force of ninety-nine who have only interests.”
~ Peter Marshall



the challenger

A Publication of the NATIONAL ALLIANCE on Mental Illness in Buffalo & Erie County

vol. 5 - Number 1
February 2013



NAMI Happenings: Kendra's Law Improved

The Holidays were marred by sad and tragic occurrences in Connecticut and close to home as, once again, untreated mental illness was the cause of deaths and serious injury. When a person with a mental illness lacks capacity to understand that they are ill, someone needs to take notice and care. Kendra's Law has been a means to accomplish just that—within limitations. Needed improvements to Kendra's Law once again came up for legislative consideration. A few of them were approved, but it is unfortunate that they were buried in gun legislation.

Kendra's Law allows for Assisted Outpatient Treatment (AOT) for those who refuse help for mental illness but repeatedly relapse in the community, or for those who are a danger to themselves or others. A 2009 study by Duke University showed AOT significantly reduces harm to others and vastly improves quality of life for people with severe mental illness by reducing suicide, hospitalizations, incarcerations, homelessness, and drug and alcohol abuse. This also reduces cost to taxpayers. Across the state from New York City to Western New York, there have been hundreds of cases of untreated mental illness with tragic consequences.

New improvements strengthening Kendra's Law are:

- Maximum length of an initial AOT order has been changed to a year, from six months, as studies have shown longer periods of treatment are more effective.
- Where there is reason to believe that a person under AOT has moved or will move to another

(Kendra's Law, cont'd. pg. 2)

Mark Your Calendar

All educational and family support meetings are held at St. Paul's Evangelical Lutheran Church, 4007 Main Street, Amherst (near the intersection of Main and Eggert Rd.) Educational meetings are held on the second floor (main entrance at the back of the church). Support meetings are held on the first floor (church entrance at ground level at left rear of the building.) All Board meetings are held at 636 Starin Ave., Buffalo, 1st floor and members are welcome.

March

NAMI Board Meeting, Thursday, March 7th, 7 p.m.

NAMI Monthly Educational Meeting, Thursday, March 14th
Library and Coffee Hour: 7 p.m. Program: 7:30 p.m. Guest:
Karl Shallowhorn, MS, CASAC: "The Journey to Wellness: Keys to Recovery"

NAMI Family Support Meeting, Wednesday, March 20th, 7 p.m.

April

29th Annual Celebration Dinner, Wednesday, April 3rd, 6:30 p.m.,
Sean-Patrick's, 3480 Millersport Hwy., Amherst. Keynote: we are honored to present E. Fuller Torrey, M.D.

NAMI Board Meeting, Thursday, April 4th, 7 p.m.

NAMI Monthly Educational Meeting, Thursday, April 11th
Library and Coffee Hour: 7 p.m. Program, 7:30 p.m. Film showing: PBS special documentary, "The Released," is about what happens when mentally ill prisoners are released and how they access jobs, housing, and care.

NAMI Family Support Meeting, Wednesday, April 17th, 7 p.m.

May

NAMI Board Meeting, Thursday, May 2nd, 7 p.m.

NAMI Monthly Educational Meeting, Thursday, May 9th
Library and Coffee Hour: 7 p.m. Program, 7:30 p.m. Guest:
R.J. Bradley-Ortiz, Public Policy and Education Fund. Topic: "The Effect of the Affordable Health Care Act on the Treatment of the Chronically Mentally Ill"

NAMI Family Support Meeting, Wednesday, May 15th, 7 p.m.

June

NAMI Board Meeting, Thursday, June 6th, 7 p.m.

NAMI Monthly Educational Meeting, Thursday, June 13th
Library and Coffee Hour: 7 p.m. Program, 7:30 p.m. Guest: Dr. Beth Allen, veterinarian and sexual abuse trauma survivor, leads a bi-polar support group and is a trainer/facilitator of WRAP (Wellness Recovery Action Plan) with the Genesee County Mental Health Association.

NAMI Family Support Meeting, Wednesday, June 19th, 7 p.m.

Mailing Address • P.O. Box 146 • Buffalo, NY 14223 • 716.226.6264
Website: www.NAMIBuffaloNY.org NEW! E-MAIL: namibuffalony@gmail.com

county of New York State, county mental health officials are required to notify their counterparts in the new county of residence. Responsibility for overseeing enforcement of the order transfers to mental health officials of the new county of residence.

• A state forensic correctional facility releasing a mentally ill inmate into the community is required to first assess whether the inmate meets AOT criteria. If the assessment finds that criteria are met, the director of the facility must either petition the court for AOT or refer the matter for investigation in writing to the mental health authorities of the county of the inmate's expected residence.

• Prior to the expiration of an AOT order, county mental health officials are required to evaluate the need to petition for renewal and to report the result of such evaluation and consequent actions to the state Office of Mental Health.

• County mental health officials are explicitly authorized to petition for renewal notwithstanding the failure of appropriate attempts to examine the person (i.e., when the person cannot be located).

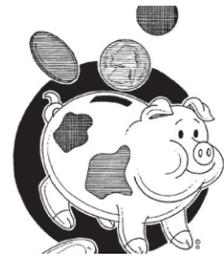
• The "sunset date" of Kendra's Law (the date by which it will expire if not re-authorized) is deferred from June 30, 2015 to the same date in 2017.

A measure similar to Kendra's Law failed to pass in the Connecticut Legislature earlier in 2012. We will never know if it could have helped Adam Lanza's mother get him the care he needed. She reportedly told friends and family she was increasingly worried about Adam's deteriorating mental condition.

It is critical that those who are most ill receive the care and attention they need. Too often, families try desperately to get care for a relative who is continually relapsing, refusing care, or for whom needed hospitalization has been denied.

The "system" that is being blamed for not responding is made up of individuals who are aware of what has been happening—lack of housing, lack of adequate hospital care, long waits to see a psychiatrist, people who are too ill to know they are and so don't get treatment, families who want to help being silenced by "HIPAA" confidentiality claims. These individuals, whether professionals, legislators, families, or consumers are responsible for taking action so that the victims, who are mentally ill, do not become scapegoats for a "system" only too willing to blame and punish the ill person.

Marcy Rose,
President



End to Physical Benefit Checks

Social Security recipients who still get their checks by mail have been put on notice: Starting on March 1, benefits will be issued only electronically.

The U.S. Treasury Department says 5 million paper checks still are mailed to beneficiaries.

Beginning on March 1, beneficiaries of Social Security and other federal programs will receive payments through direct deposit or through the government's Direct Express debit card.

Most people have made the switch, but paper checks for U.S.recipients still represent 7 percent of all payments nationwide.

"We're dealing with people who might be procrastinating a bit," said Walt Henderson, director of the Treasury's Go Direct program, which is designed to educate beneficiaries about making the switch to direct deposit or the debit card.

Some beneficiaries also might not feel comfortable with using direct deposit, he said.

The government began offering direct deposit in the 1990s. It wasn't until 2010, though, that the government decided to phase out paper checks for all federal benefits, not just Social Security payments.

Since May 1, 2011, people signing up for federal benefits have been required to receive them through direct deposit or the debit card.

The conversion to electronic payments will save the government \$1 billion over the next 10 years, Henderson said. It costs about a dollar to produce and mail each check.

(Benefit Checks, cont.'s on pg. 3)



New or Renewing Members

- Beth Andersen
- Jon (and Diane) Baker
- Eileen Boland
- Mary Lou Bond
- Joanne Brooks
- Tom (and Marlene) Donohue
- Nancy Gawdowski
- Janice (and Nick) Gagliardi,
in memory of Lois Dubin
- Harry (and Marie) Guildford
- David Isbell
- Susan Jesella
- Carol Moscati
- Ted Pietrzak
- Mary Ellen Rubin, PhD
- Dolores (and Thomas) Santa Lucia
- David Stebbins

*Not what we give,
But what we share,
For the gift
without the giver
Is bare.*
~James Russell Lowell



Christmas is for Kids
thanks going out to...

Christmas Angels (\$500-999)

- Katie Evans
- Brian Moore
- Friends at Per Niente Club
- Suburban Psychiatric Associates

Circle of Light (\$250-499)

- Dr.'s Gayle and Terry O'Connor/
O'Connor Medical Group

Santa's Circle (\$100-249)

- Brenda Battleson
- Bry-Lin Hospitals
- Bry-Lin Medical Staff
- Marilyn and Edward Green
- Joyce and Phillip Orłowski

Friends (\$1-99)

- Darci Brasch
- Mickey Delaney
- Brian Gallagher
- Diane and Mark Graziano
- Harry and Marie Guildford
- Karen and Jack Krnjaich
- Margaret Neenan Leahy
- Kathy Nealy
- Eleanor Nixon
- Mary Beth O'Neill
- Marie and Robert Terreri
- Lorie Ann Wagoner

*We invite you to join
NAMI Buffalo &
Erie County*

*in helping us make a difference for people
with mental illness and their families*

Mail to:

NAMI in Buffalo & Erie County
P.O. Box 146, Buffalo, NY 14223

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

E-Mail _____

Membership \$35

No one will be denied membership due to financial hardship. For those in financial need:

"Open Door" Membership - \$3

NAMI in Buffalo & Erie County Associates or Other Donation

Benefactor - \$100 - \$250

Patron \$75 - \$99

Sustainer - \$50 - \$74

Advocate - \$26-\$49

Friend - \$1-\$25

\$ _____ Donation (other)

In Memory of -OR- In Honor of

**Please keep my membership/
contribution anonymous.**

I'd like to help with the following:

Fund/friend Raising Office & Clerical

Phone Tree Legislative Advocacy

Support Letters Speakers Bureau

Other _____

I'd like to be put on the phone tree/e-mail
list to receive legislative or other alerts.

Yes No

Please send a copy of the newsletter to:

Memberships, contributions, and donations
are tax deductible.



NAMI Future Fund Contributors



Your support is "heart-warming!"

President's Circle (\$1,000 and +)

Katherine Evans
Darlene and Bryan Schaefer

Circle of Hope (\$500-999)

Cynthia Connine
Eli Lilly and Company Foundation
Matching Gifts Program & Susan Minotti
Anne & Herman Szymanski

Rainbow Circle (\$250-499)

Cheryl Brendle
Radhika & Dharma Iyer, *in honor of Lynne Shuster & Mary Kirkland*

Benefactors (\$100-249)

Dr. Horacio Capote
Ravinder Dua, *in honor of Veena Dua & Happy Holidays!*

Benefactors (\$100-249) cont'd.

Ann Ezzo
Beth Lombardo
Judith Quinn
Barbara Utter

Builders (\$61-99)

Harry and Marie Guildford
in honor of Marcy Rose

Friends (\$1 - 60)

Mary Lou Bond
Patricia DiVito
Arthur Efron
Susan Friedhaber-Hard
Dr. Abel Fink
Neil & Julie McGillicudy
Marlene Schillinger
Jane Urbanski

Did you know?

You can donate to NAMI in several ways. Mailing a check still works, of course--or cash!

Other options include:

- the "Donate Now" link on our website at www.NAMIBuffaloNY.org
- designated giving through United Way by payroll deduction--just note "NAMI in Buffalo & Erie County" on your annual pledge card with the amount per pay that you want withheld and donated
- through United Way-administered SEFA, Combined Federal Campaign, or Donor Choice programs
- planned bequest giving in your will

Also, ask your employer if there is a giving match program for charitable donations at your work place, and specify your donation amount to be matched.

We can provide proof of charitable, tax deductible status on request. Now you know!

I would maintain that thanks are the highest form of thought, and that gratitude is happiness doubled by wonder.

- Gilbert K. Chesterton



Member and Associate Donors

Founders' Circle (\$500-1,000)

Niagara Frontier SEFA friends

Benefactor (\$100-249)

First Presbyterian Church of Clarence
Thomas Hays, MD
Thomas Miller
Wm. C. Rott & Son, *in honor of Random Acts of Kindness*
Dennis Sadjak, *in honor of Lynne and Mary...for all they have done to improve the lives of the mentally ill*
Dolores Santa Lucia, *in honor of Thomas J. Santa Lucia*
David Stebbins & Elizabeth Taylor

Sustainer (\$50-74)

Elizabeth J. Andersen
Jonathan Baker, *in memory of Casper*
Rev. Daryl Bennett
Marguerite Mohr
Josie Olympia, *in honor of the Angrisano family*
Harry & Marie Guildford, *in honor of Mary and Lynne*

Advocate (\$30 - 49)

Niagara Frontier Combined Federal Campaign friends
Carrie Rose
Imogene Wager

Friend (\$1 - 29)

Sharon Augustyn, *in honor of Tracy Livia & Vince Cammarano, in the name of Jesus of mercy and thanksgiving*
John and Eileen Grimaldi
Shamin Iyob
Mary & Jim Kirkland, *in memory of Katherine Vertino*
Marion Liberati
Stephanie Maines, *Happy New Year!*
Mary Beth O'Neill
Dorothy Taylor

Benefit Checks, (cont'd from pg. 2)

The conversion also is about convenience for recipients, advocates say.

Recipients no longer have to be at home to get access to their money, or worry about theft of a check. Direct deposit also is easier for people with disabilities who might have trouble getting to a bank, or those who have gone through a disaster such as super-storm Sandy.



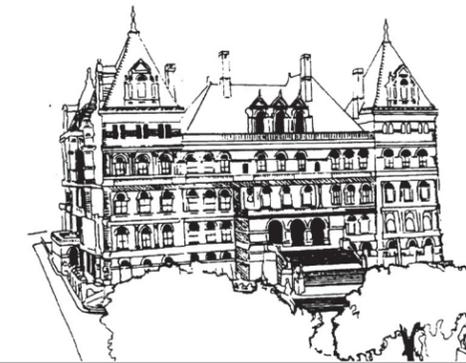
"We really think it is the way to go," said Kathy Keller, spokeswoman for AARP Ohio.

Recipients who miss the March 1 deadline won't lose their payments. Henderson said government officials will communicate directly with them about the need for direct deposit or getting the debit card.

For more information about converting to direct deposit, recipients can call 1-800-333-1795 or go to <http://GoDirect.org>.

mawilliams@dispatch.com

Buffalo News
1/20/13



Cuomo Budget limits choice of anti-psychotic drugs

ALBANY — Buried in New York Gov. Andrew Cuomo's proposed budget is a cost-cutting measure that would empower the state and health insurance companies to deny low-income mental patients the specific brand-name anti-psychotic drugs their doctors prescribe, in favor of less expensive versions.

Some care providers worry that some of those patients could be dangerous without an effective drug or if they stop taking it. The proposal would cover anti-psychotic drugs for patients suffering from an array of mental illnesses including schizophrenia, bipolar disorder, personality disorders and deep depression.

"The additional hoops we have to go through may mean their symptoms go on longer," said Dr. Anna Lamb, a primary care physician in Batavia and president of the New York State Osteopathic Medical Society.

"They may become less functional," Lamb said. "In the mental health world, it can be very frustrating because you run the risk that the drugs may not be effective, or have side effects ... the idea is to help them become productive members of society."

Cuomo insists that eliminating the "prescriber prevails" power wielded by physicians will pose no public threat, noting that the state's preferred list of anti-psychotic drugs includes 13 brand names.

The state already requires less-expensive generics when they are proven to work as well as brand names, but in the anti-psychotic drug class there are few generics. The New York conflict is between competing brand-name drugs, some of which are cheaper. If the cheaper drug fails first, a patient could appeal for his or her preferred drug.

The Cuomo administration and the medical experts serving his Medicaid "redesign team" say each is effective for the poor and elderly patients served by the government health care system. And the anti-psychotic drugs are also prescribed for less serious disorders, such as insomnia, dementia and mild depression.

The measure would save \$9 million in state funds. It's part of Cuomo's \$143 billion budget proposal, which also includes spending increases such as an extra \$420 million in tax breaks for movie productions through 2019.

(Cuomo budget, cont. 's on pg. 4)

NAMI Local Chapter Doings

Thanks to...

Judy Capodicasa, for updating the phone tree and contact list, taken over from **Mary and Jim Kirkland**. Thanks, too, to call volunteers **Nancy Brown** and **Joan Snyder** who are stepping down.

Tom McNulty and **Mary Kirkland**, the heroic co-chairs of Christmas Is for Kids. The project was a huge success again this year!

Jackie Thompson who will be co-teaching the next Family-to-Family outreach course with **Marcy Rose**.

Dennis Harkawik, our hard working chairperson for the 29th Annual Dinner.

Welcome and thank you to:

- new phone tree volunteers, **Renata Decarolis** and **Nora Roberto**; and to continuing call volunteers **Ann Ezzo Sue Keppel**, **Esther Trachtman**, and **Roger Watkins**

- new Niagara County partner, **Josh's Journey**, our sponsor for the next Family-to-Family course.

- **Canisius College** marketing professor, **Dr. Sauer**, and upperclassmen who are helping us through **United Way and Joe Roccisano's office** to prepare a survey to help us with planning, programs and services for our members and supporters.

Congratulations to Irene Turski on her election to the NAMI New York State board where she'll serve as the board secretary.

Our heartfelt sympathies to...

Kathleen Thill and the family of **Joseph Thill**, who recently passed away.

Kathy Vertino, who lost her mother, Katherine.

Our thoughts and prayers are with you.

(Cuomo budget, cont.'d from pg. 3)

It follows another cost-cutting attempt from last year's budget in which some female Medicaid patients were told they had to switch from their preferred brand of contraceptive to lower-cost options unless the cheaper measures failed, resulting in pregnancy, bleeding or nausea.

After protests by women, the administration reversed itself and ordered insurers to cover preferred contraceptives.

Health insurers, industry experts on the redesign team and more than a dozen other states see such changes as not just cost-effective, but also better for patient care. Cuomo is also concerned about the inappropriate prescribing of anti-psychotic drugs, which can have serious side effects. Officials said as many as half the prescriptions for anti-psychotic drugs are done by general practitioners, not psychiatrists.

Cuomo doesn't want primary care physicians to overrule the choice of managed care companies that use experts in the field.

Lamb, however, said primary care physicians are often charged with the care of patients after they leave psychiatric hospitals, especially in rural areas with few psychiatrists.

The governor is expected to address that concern. He is planning to propose a "gold card" program in which highly trained psychiatrists could make quicker decisions from a remote location if there is a conflict in an area without psychiatrists to consult.

In the meantime, patients would be able to appeal to get the specific drug they prefer, but that could take weeks.

Cuomo's proposal "conforms Medicaid-eligible drugs with the federal guidelines and accepted science," said Cuomo spokesman Rich Azzopardi. "This will protect patients while also removing opportunities for waste and abuse in the system."

Cuomo's proposal comes a week after a new state law was enacted that requires therapists to more aggressively report any dangerous comments by mental health patients involving guns.

"It's very frustrating to me after we just spent time on how important the mental health issue is in the big picture of gun violence," said Kathe LeBeau, a patient advocate who has experience as a care provider for mentally ill patients. "This seems to be diametrically opposed to that effort."

LeBeau is part of an effort by health care providers to persuade Cuomo to eliminate the proposal during a 21-day period to amend his budget. The group is also lobbying legislators who will negotiate a final budget by April 1.

"From a patient's perspective, you are not as invested in your therapy because you lose confidence — you already are taking something your doctor doesn't think is best," LeBeau said. "In a crisis, it's hard enough to get people to take medication. ... This is a class of drugs specifically for patients who are probably the most vulnerable."

*Michael Gormley
Associated Press
January 26, 2013*



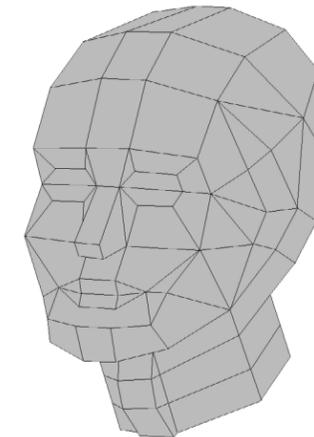
Topics, cont'd. from pg. 8

Brain Circuits Link Schizophrenia to High Risk of Smoking

Schizophrenia is associated with a high prevalence of smoking. It has long been established that smoking helps diminish the amount of "noise" in the brains of people with schizophrenia and allows an improvement in the ability to focus.

Now researchers have established connectivity between certain areas of the brain and a nicotine addiction-related circuit which influences the severity of smoking behavior. These connections were significantly impaired in schizophrenic non-smokers but overlapped in people with schizophrenia who smoke, indicating a biologically defined brain circuit mechanism that contributes to the high prevalence of smoking.

<http://library.constantcontact.com/download/get/file/1110032941273-250/brain+circuits+that+link+schizophrenia+to+high+risk+of+cigarette+smoking.pdf>



New NIMH Study Participation Opportunity

Schizophrenia: Can Cognitive Function Be Enhanced?

NIMH looks at the effects of medications on the way the brain works

People with schizophrenia often have problems concentration and remembering. Sometimes they find it hard to make a plan or follow it through step by step. Doctors at the national Institute of Mental Health (NIMH) believe these problems are related to the way the brain functions after becoming ill.

NIMH is testing:

- Modafinil (FDA-approved for daytime sleepiness)
- Tolcapone (FDA-approved for Parkinson's disease)
- Atomoxetine (FDA-approved for Attention Deficit Disorder)

Doctors are testing whether these drugs could improve memory and the way the brain works in people with schizophrenia. NIMH is also studying how genes may make a difference in how these drugs work.

In these research studies, people do not stop taking their current medication(s). The study drug is added to the drugs they take now. The research study includes tests that assess participants' ability to remember, focus and concentrate, and a brain-imaging study called a functional MRI (fMRI). These will measure how well the drug may work and record changes in brain activity.

People may stay up to 12 weeks at the NIMH Schizophrenia Research Program. Tests that include medical, psychiatric, neurological and pharmacological tests are done to see whether a person can be part of this study. The medication phase of the study lasts 3 or 5 weeks. Once the research is completed, the person stays in the inpatient research program so that the clinical team can complete all evaluation, treatment assessments and discharge planning.

Participants must:

- be 18 to 50 years old
- Have schizophrenia or schizoaffective disorder
- Not have serious alcohol or drug problems
- Not have a history of major medical problems

This inpatient research program is at the NIH Clinical Center in Bethesda, Maryland. There is no cost for taking part in this study. There is compensation for research study participation.

For more information, call NIMH Schizophrenia Program Referral Line at 1-888-674-6464 or 301-435-8970 (TTY:1-866-411-1010) or email Schizophrenia@mail.nih.gov. The National Institute of Mental Health (NIMH) is part of the National Institutes of Health (NIH) of the Department of Health and Human Services.

NAMI Advocate, Winter 2012

Current Topics in Treatment

Exercise and schizophrenia

Studies have shown that regular exercise improves cardiovascular and mental health in schizophrenia. However, people with schizophrenia appear to have decreased physical capacity and autonomic imbalances (the autonomic nervous system regulates functions such as heartbeat and breathing) which might predispose to arrhythmia (irregular heartbeats) during exercise. The vagus nerve is involved in this regulation. There appears to be a connection with an inflammatory process causing the reaction which needs to be taken into account when assessing the effects of exercise on people with schizophrenia.

(Schizophrenia Bulletin, 9/20/2012)

<http://www.medlinx.com/psychiatry/print-preview.cfm/4203494>



Nutrient-Based Therapies for Bipolar Disorder:

As an adjunct to treatment for bipolar disorder, promising research shows that the use of nutritional supplements could be effective in combination with prescribed medications.

Preliminary data show positive evidence for use of omega 3's and chromium for bipolar depression. Limited evidence found inositol may be helpful in bipolar depression, but larger samples are needed for confirmation. Preliminary trials show that choline, magnesium, folate and tryptophan may be beneficial for reducing symptoms of mania. Note that these are preliminary findings and were studied in combination with prescribed medication, not alone.

(Psychotherapy and Psychosomatics, 11/12/2012)

<http://www.medlinx.com/psychiatry/print-preview.cfm/4278525/bipolar-disorder>



Use of ginkgo as adjunct therapy in schizophrenia

A study aimed to review the roles of antioxidants in schizophrenia has found that ginkgo as an add-on therapy to antipsychotic medication for schizophrenia produced moderate improvement in negative symptoms (lack of feeling, slowness, lack of speech or thought, etc.) of chronic schizophrenia. Ginkgo as add-on therapy improves the symptoms of chronic schizophrenia.

(International Journal of Neuropsychopharmacology)

www.ncbi.nlm.nih.gov/pubmed/19775502

(Topics, cont's., pg. 9)

NAMI Members, Associates, and Friends! Ways of Giving to NAMI in Buffalo & Erie County

Several folks have asked recently about why donation designations are important for us, and what they mean. Here is a quick snapshot on the topic:

Membership - is for one person for \$35 (or \$3 for Open Door, low-income) and confers local, state and national voting rights and communication as well as resources. A portion of dues is split among the three levels, and members all receive the local newsletter, event information, and can attend meetings of the board. A spouse may be added as an Open Door member for an additional \$3. You may also write a check for membership plus a donation.

Associates are non-voting members that wish to maintain a relationship only at the local level, not national and federal information (and donor solicitations). These are primarily local professionals and agencies that support our work but don't want "extra" paperwork and mailings. Associates do receive our local newsletter and event information.

Several "special" annual events and projects (these funds remain local as long as they are donated to our local office directly, not through the National website or address):

- **The Future Fund** is NAMI's long-term capital trust. Future Fund designated gifts are put in a permanent fund, and the interest earned helps support our operations, programs and projects, while ensuring NAMI will be financially stable for the future.

- **Christmas is for Kids** donations support this special project that provides holiday gifts and cheer for 600 young people who are receiving mental health care and treatment.

- **The annual dinner** receives donations and ticket proceeds to help underwrite event costs and to cover the expenses of our speakers, honorees, and invited guests.

Our local chapter's fundraising mail and other outreach information to you will always say "NAMI in Buffalo & Erie County" in the heading and include our Buffalo return address. Membership renewal reminders only come from the NAMI in Buffalo & Erie County office.

When you designate and return your contribution directly to us at P.O. Box 146, Buffalo, NY 14223, the maximum amount of your donation will do the most continuing good locally.

We are grateful for your support of our local efforts and hope helps to clarify how to handle your donation memo. As always, thank you for your generosity. Still have questions? Contact the office at 226-6264 or namibuffalony@gmail.com.

The Tragedy of Mental-Health Law

After Newtown, there is widespread concern that laws regarding mental-health services need reform. Two places to start are the laws governing involuntary hospitalization, and the restrictions placed on communication with a patient's family.

Across the U.S. today, federal and state laws give people with mental illness the right to decide when, where, how, and if they will receive care. Yet some serious mental illnesses (such as schizophrenia or mania) can make it difficult for those affected to assess the reality of their own experiences or their need for treatment.

An individual with a mental illness that interferes with his judgment, self-interest, self-preservation and safety represents a profound challenge for families and clinicians. Doctors have remarked that when patient rights exceed truly necessary protections, individuals with mental illness can "die with their rights on." Sometimes they may harm others along the way.

Many mental-health laws are prohibitive in nature—they describe what cannot be done in certain situations. This is important but comes at a cost. The 1996 federal law known as HIPAA (the Health Insurance Portability and Accountability Act) is meant to protect the medical information of individuals, but it has also come to limit what a doctor can say to a patient's family (with the exception of unemancipated minors).

State laws vary, but all set strict controls regarding involuntary hospitalization, limiting it to circumstances when a person is an imminent danger to himself or others, or likely to become so. State laws also limit involuntary hospital stays to a few days, unless a court orders otherwise based on continued evidence of imminent danger to self or others. Another court order is necessary for doctors to treat hospitalized patients against their will. In other words, we may be able to drag a horse to water but we cannot make him drink unless a judge says so.

Consider the young man in his 20s brought to an emergency room by the police after harassing a bus driver and initially acting aggressively with the officers who arrived on the scene. The young man had never been to this particular ER, so there was no record of any previous treatment he may have received or any medical or mental conditions he may have had. In the presence of the police and hospital security, he appeared quiet and cooperative, even saying he regretted losing his temper.

(Tragedy of Law, cont. 's on pg. 5)

**Please join us
to welcome special guest
E. Fuller Torrey, M.D.
at NAMI's 29th anniversary dinner
and awards celebration!**

**Wednesday, April 3rd at Sean-Patrick's
3480 Millersport Highway, Getzville
at 6:30 p.m.**

In the mailbox...



Dear Marcy,

I know I haven't been in touch, but when I got your e-mail, it reminded me of my time in need and how the family-to-family meetings helped me. I attended two years ago and you may not remember me, but I surely remember you.

I have a daughter who struggles with depression and anxiety...I have been her whipping post over the years. It has been a struggle for me also and I am thankful that you gave me some tools to work through dark times. Even though I think I will never forgive her for the darker times, she is my shining light at the end of the dark tunnel. How strange, but true.

Keep up your good works. It doesn't go unnoticed!

-P



Dear NAMI Members and Friends,

We send our heartfelt greetings from afar. We miss the NAMI meetings and all the information they provide. NAMI Buffalo is a jewel. We so appreciate all the hard work and time-consuming effort that Mary and Lynne gave unselfishly to NAMI for so many years. We are grateful to Marcy Rose, the officers and the Board who are now continuing the excellent work.

We will continue to support NAMI with our membership and contributions. There is a NAMI chapter in our new town, but it is too far away for us to attend, unfortunately.

I am enclosing an article from our paper which we consider excellent. The author is an active NAMI member. We very much appreciate receiving "The Challenger." Thank you so much for mailing it to us. It makes us feel part of NAMI!

We wish all of you a safe and Happy New Year, and continued success with NAMI.

Warmest wishes,

- H& M



Tragedy of Law, cont'd from pg. 4

But his disheveled and fearful look prompted a nurse to call for a psychiatric consult. The consultation revealed that while he lived with his parents, he didn't want the hospital to contact them. He said he'd never had any such outbursts before, and that he had never received mental-health care. The psychiatrist continued to request permission to call his family, but he continued to refuse adamantly.

Had the call been made, the young man's parents would have volunteered that this was their son's third emergency-room visit in four weeks, and that he had been involuntarily hospitalized six months earlier after hitting a stranger in a supermarket during an acute episode of psychotic illness.

In another instance, a middle-aged woman with a serious mental illness was involuntarily hospitalized after a very high-risk suicide attempt was accidentally discovered in time. She was diagnosed with a major depression and offered medication and therapy, which she refused.

She could not leave the hospital (for days initially, then for a few weeks after a court order), but she had the right to refuse treatment. In response, the treating psychiatrist had to go to court to obtain a judge's order for "treatment over objection." This resulted in several weeks of delay, but after the order came down the patient agreed to accept treatment the next day.

The law arguably plays a more prominent role in psychiatry than in any other field of medicine. Issues of personal and public safety, civil rights, accountability, privacy, confidentiality and competency are woven throughout the practice of psychiatry. But today's laws were mostly written decades ago, in response to an era when doctors and hospitals had almost unbridled control over patients and their treatments.

What began as patient protections have in many instances become rigid rules and procedures that seem to exceed patient needs and even common sense. Good intentions spawned these laws, but in practice they can interfere with or delay the delivery of necessary care and crucial communication between caregivers and families—as families of people with serious mental illnesses can attest in often heartbreaking detail.

Families are—or can be—our early-warning system: They see the fuse burning months before the bomb goes off. Yet when mental illness produces troubled behavior, families are too frequently sidelined by the refusal of their ill relative to involve them in the considerations about treatment.

No one thing can completely eliminate the risk of tragic events such as those we have witnessed in Newtown, Aurora, Columbine and elsewhere, or the risk of the suicides and violent acts that occur by the tens of thousands nationwide each year. But we can reduce risk through early identification and intervention if families are equipped to highlight problems and mental-health professionals are permitted to do the tough work of responding to those whose serious mental disorders have them refuse help that can be lifesaving.

Many successful industries employ "user-driven design," and laws are made to serve the people. Let's ask the families of people with serious mental illnesses what changes in law and clinical practices could better help their family members.

Lloyd I. Sederer

Dr. Sederer, the medical director of the New York State Office of Mental Health and an adjunct professor at Columbia University's Mailman School of Public Health, is author of "The Family Guide to Mental Health Care," forthcoming in March from W.W. Norton. The views expressed here are his own.

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Opinion Feature: Action Plan for Obama to Reduce Violence by Mentally Ill

President Obama said the federal government has to do something meaningful to prevent future shootings like the one in Newtown, Connecticut that killed 26 people. Though mental illness is as yet unconfirmed in the Newtown killer's case, here is what the federal government can do to prevent violence related to mental illness.

1) Start demonstration projects of Assisted Outpatient Treatment (AOT) - Kendra's Law in NY, Laura's Law in Calif. -- throughout the country. AOT allows courts to order certain individuals with mental illness to stay in treatment as a condition of living in the community. It is only available to the most seriously ill who have a past history of violence, incarceration or needless hospitalizations. AOT is proven to keep patients, public, and police safer. The Department of Justice certified AOT as 'effective crime prevention program.' But mental health departments are reluctant to implement because it forces them to focus on the most seriously ill. Demonstration projects would help them see the advantage of the program.

2) End the Institutes for Mental Disease (IMD) Exclusion in Medicaid law. This provision encourages states to lock the front door of psychiatric hospitals and open the back regardless of whether the community is an appropriate setting. Sometimes, these discharged individuals become homeless, suicidal, sick and even violent. If you have a disease in any organ of your body, other than the brain, and need long-term hospital care, Medicaid pays. Failing to pay when the illness is in the brain is federal discrimination against persons with mental illness. Thirteen years ago I wrote on Medicaid discrimination for the mass market in the Washington Post, and more recently in Huffington Post. But John Edwards wrote a more

scholarly paper on ending the IMD Exclusion.

3) Create a federal definition of serious mental illness, and require "x" percent of all existing mental health funding go to it. Most mental health funding currently goes to the highest functioning, not most seriously ill. There is more than enough money in the mental health system provided it was spent on people truly ill. I wrote on this for a mass market on Huffington Post, but a much more scholarly paper was written by Howard H. Goldman and Gerald N. Grob. With the fiscal cliff approaching,

prioritizing the most seriously mentally ill for services is more important than ever. We have to end mission creep in mental illness programs and send the seriously ill to front of line, rather than jails, shelters, prisons and morgues. This failure to fund serious mental illness is most acute in California, where they taxed millionaires to provide services to the mentally ill, and then used the money for the highest functioning.

4) Eliminate the Substance Abuse and Mental Health Services Agency (SAMHSA). SAMHSA is the epicenter of what is wrong with the American Mental Health System. SAMHSA actively encourages states to engage in mission creep and send the most seriously ill to the end of the line. They provide massive funding to organiza-

tions that want to prevent mentally ill individuals from receiving treatment. They have little positive to show for their efforts. I wrote on this for a mass market in Washington Times and Huffington Post. But Amanda Peters wrote a terrific scholarly piece on SAMHSA for a law journal.

If Obama is serious about wanting to do something -- and I believe he is -- the suggestions above would be the best first step. True, the mental health industry may throw a hissy fit as they find themselves obligated to serve the most seriously ill, but it's the right thing to do.

DJ Jaffe

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The Huffington Post Blog
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Note: Our readers' thoughts on this piece are welcome. We will publish replies as space is available in the next newsletter issue.

