



# NAMI SYRACUSE

National Alliance on Mental Illness

## Newsletter

MARCH/APRIL 2015

### Meeting Schedule

**NAMI Syracuse - Support & Sharing Meeting**  
**Third Tuesday of each month**

**ACCESS-CNY**

**420 East Genesee Street, Syracuse 13202**

*(parking and entrance in rear of building)*

NAMI Syracuse is a not-for-profit, self-help organization of active and concerned families and friends of people who suffer from serious and persistent psychiatric illnesses, most commonly schizophrenia, bipolar disorder (manic depression), and severe depression.

**CARING**

**SHARING**

**EDUCATION**

**ADVOCACY**

### *Events Calendar*

- March 17, 2015     **Support & Sharing Meeting**  
7:00pm - AccessCNY
- April 21, 2015     **Support & Sharing Meeting**  
7:00pm - AccessCNY
- May 2, 2015         **NAMIWalksRochester/Syracuse**  
9:00am - Village Gate,  
N. Goodman St., Rochester  
*(see page 3)*
- May 6, 2015         **NAMI Syracuse**  
**Children's Conference**  
Empire Room, NYS Fairgrounds  
*(see page 9)*
- May 19, 2015       **Support & Sharing Meeting**  
7:00pm - AccessCNY

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**MESSAGE FROM THE PRESIDENT**

Dear members:

It's been another brutal winter, and for those of us who were not able to escape to warmer climates it's been very very long. Remember what they say: In like a lion, out like a lamb.

We at NAMI Syracuse are looking forward to spring and to the many things we have coming up this year. First up on the agenda is our partnership with the **NAMIWalks Rochester** on May 2nd. As a participating affiliate, NAMI Syracuse will receive a portion of all funds we raise which will go directly to continuing our many services. Please consider getting involved. We're hoping to get a group together to join NAMI Rochester for this fun event. You don't need to walk, or even make the trip to Rochester. You just need to get involved by joining a team, forming your own team, or just spreading the word about all the wonderful things we do at NAMI. This is your organization, let's get talking and WALKING! Please see page 3 on how to help with this fun event.

We are very excited about this year's children's conference, **New Options for Treatments, Research and Education on Mental Illness in Children** on May 6th. This year it will be held in the Empire Room at the New York State Fairgrounds and will provide critical information for professionals as well as family members. See page 9.

Also, get your creative juices flowing as we are planning another **“SEE ME” Art Show** this summer. Keep checking our Facebook Page or website for information about submissions.

As you all know we put on two large educational conferences every year. We feel this is an important community service for our family members and our local professionals. Right before each conference we're always running around asking who we can borrow AV equipment from-which doesn't help decrease our overall stress level! If anyone would like to donate these items or funds earmarked for purchasing a projector, mic, and an inexpensive laptop to NAMI Syracuse, it would be greatly welcome. And remember, all donations are tax deductible!

Also remember: THINK LAMBS!

~~Karen Winters Schwartz

**NAMI Syracuse Officers**

- Karen Winters Schwartz.....President
- Spencer Plavocos.....Vice-President
- Frank Mazzotti.....Treasurer
- Marla Byrnes .....Recording Secretary

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**Consultant to Board**

Dr. Mantosh Dewan

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



[facebook.com/NAMISyracuse](https://www.facebook.com/NAMISyracuse)

Follow us on **twitter**:



<https://twitter.com/NAMISyracuse>

**“SEE ME” Second Annual Art Show**

All you creative types get busy!

We will be sponsoring the second annual “SEE ME” art show in June. It will be held courtesy of the Community Folk Art Center, 805 East Genesee St., Syracuse NY. We are hoping for another great turnout of artists, poets, and photographers.

All artwork must be framed and ready for display. Poetry must fit on an 8x10 page and we will frame. Consider doing a reading of your poetry at our reception (no date set yet).

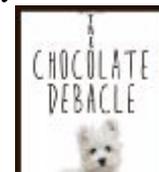
We will send out an application form with our next newsletter in May.

Any questions, please call NAMI Syracuse 487-2085.

Author Karen Winters Schwartz and other authors will be at the River’s End Bookstore, 19 West Bridge Street, Oswego on May 2nd at 2:00pm for **Independent Bookstore Day**.

Karen will be signing her new book, *The Chocolate Debacle*, along with *Where Are the Cocoa Puffs?* and *Reis’s Pieces!*

Support your local booksellers!





## **Get involved with NAMI Rochester/NAMI Syracuse partnered NAMIWalks**

NAMI Rochester is pleased to be hosting the 3rd NAMIWalks Rochester and this year NAMI Syracuse is partnering with them! As a participating affiliate, NAMI Syracuse will receive a portion of all funds we raise through our teams and our direct sponsorship.

Location: Village Gate, 274 North Goodman Street, Rochester, NY 14607

Date: Saturday, May 2, 2015

Distance: Distance (1.5 miles)

Check-in: 9:00 am

Start Time: 10:00 am

We need your help! We are looking for all of our members to get involved in this big undertaking. Companies, organizations and families are encouraged to organize teams of walkers made up of employees, organization members, relatives and friends. We are in need of sponsors, team leaders, team participants. For more information or to volunteer, please contact NAMI Board Member Susan Zdanowicz at [susanz@sbh.org](mailto:susanz@sbh.org) or contact the NAMI Syracuse office, Telephone #315-487-2085, e-mail: [namisyracuse@namisyracuse.org](mailto:namisyracuse@namisyracuse.org)

If you are willing and able to support Team NAMI Syracuse in the 2015 NAMI walk, please donate online using the secure payment address below:

<https://securewalks.nami.org/registant/TeamFundraisingPage.aspx?teamID=596001#&panel1-1>

Also, a direct link for more information and to donate can be found on our website: [namisyracuse.org](http://namisyracuse.org) or the NAMI Syracuse Facebook Page.

Or you may call or send your pledge directly to the NAMI Syracuse office, 917 Avery Avenue, Syracuse, NY 13204, 315-487-2085.

**Changing minds one step at a time!**

## RESEARCHERS SHOW HOW YOUR THOUGHTS CAN INDUCE SPECIFIC MOLECULAR CHANGES TO YOUR GENES

With evidence growing that training the mind or inducing specific modes of consciousness can have beneficial health effects, scientists have sought to understand how these practices physically affect the body. A new study by researchers in Wisconsin, Spain, and France reports the first evidence of specific molecular changes in the body following a period of intensive mindfulness practice.

The study investigated the effects of a day of intensive mindfulness practice in a group of experienced meditators, compared to a group of untrained control subjects who engaged in quiet non-meditative activities. After eight hours of mindfulness practice, the meditators showed a range of genetic and molecular differences, including altered levels of gene-regulating machinery and reduced levels of pro-inflammatory genes, which in turn correlated with faster physical recovery from a stressful situation.

“To the best of our knowledge, this is the first paper that shows rapid alterations in gene expression within subjects associated with mindfulness meditation practice,” says study author Richard J. Davidson, founder of the Center for Investigating Healthy Minds and the William James and Vilas Professor of Psychology and Psychiatry at the University of Wisconsin-Madison. “Most interestingly, the changes were observed in genes that are the current targets of anti-inflammatory and analgesic drugs,” says Perla Kaliman, first author of the article and a researcher at the Institute of Biomedical Research of Barcelona, Spain (IIBB-CSIC-IDIBAPS), where the molecular analyses were conducted.

The study was published in the *Journal of Psychoneuroendocrinology*.

Mindfulness-based trainings have shown beneficial effects on inflammatory disorders in prior clinical studies and are endorsed by the American Heart Association as a preventative intervention. The new results provide a possible

biological mechanism for therapeutic effects.

### Gene Activity Can Change According To Perception

According to Dr. Bruce Lipton, gene activity can change on a daily basis. If the perception in your mind is reflected in the chemistry of your body, and if your nervous system reads and interprets the environment and then controls the blood's chemistry, then you can literally change the fate of your cells by altering your thoughts.

In fact, Dr. Lipton's research illustrates that by changing your perception, your mind can alter the activity of your genes and create over thirty thousand variations of products from each gene. He gives more detail by saying that the gene programs are contained within the nucleus of the cell, and you can rewrite those genetic programs through changing your blood chemistry.

In the simplest terms, this means that we need to change the way we think if we are to heal cancer. “The function of the mind is to create coherence between our beliefs and the reality we experience,” Dr. Lipton said. “What that means is that your mind will adjust the body's biology and behavior to fit with your beliefs. If you've been told you'll die in six months and your mind believes it, you most likely will die in six months. That's called the nocebo effect, the result of a negative thought, which is the opposite of the placebo effect, where healing is mediated by a positive thought.”

That dynamic points to a three-party system: there's the part of you that swears it doesn't want to die (the conscious mind), trumped by the part that believes you will (the doctor's prognosis mediated by the subconscious mind), which then throws into gear the chemical reaction (mediated by the brain's chemistry) to make sure the body conforms to the dominant belief. (Neuroscience has recognized that the subconscious controls 95 percent of our lives.)

Now what about the part that doesn't want to die - the conscious mind? Isn't it impacting the body's chemistry as well? Dr. Lipton said that it comes down to how the subconscious mind, which contains our deepest beliefs, has been programmed. It is these beliefs that ultimately cast the deciding vote.

“It's a complex situation,” said Dr. Lipton. People have been programmed to

believe that they're victims and that they have no control. We're programmed from the start with our mother and father's beliefs. So, for instance, when we got sick, we were told by our parents that we had to go to the doctor because the doctor is the authority concerning our health. We all got the message throughout childhood that doctors were the authority on health and that we were victims of bodily forces beyond our ability to control. The joke, however, is that people often get better while on the way to the doctor. That's when the innate ability for self-healing kicks in, another example of the placebo effect.

### Mindfulness Practice Specifically Affects Regulatory Pathways

The results of Davidson's study show a down-regulation of genes that have been implicated in inflammation. The affected genes include the pro-inflammatory genes RIPK2 and COX2 as well as several histone deacetylase (HDAC) genes, which regulate the activity of other genes epigenetically by removing a type of chemical tag. What's more, the extent to which some of those genes were downregulated was associated with faster cortisol recovery to a social stress test involving an impromptu speech and tasks requiring mental calculations performed in front of an audience and video camera.

Biologists have suspected for years that some kind of epigenetic inheritance occurs at the cellular level. The different kinds of cells in our bodies provide an example. Skin cells and brain cells have different forms and functions, despite having exactly the same DNA. There must be mechanisms - other than DNA - that make sure skin cells stay skin cells when they divide.

Perhaps surprisingly, the researchers say, there was no difference in the tested genes between the two groups of people at the start of the study. The observed effects were seen only in the meditators following mindfulness practice. In addition, several other DNA-modifying genes showed no differences between groups, suggesting that the mindfulness practice specifically affected certain regulatory pathways.

The key result is that meditators experienced genetic changes following mindfulness practice that were not seen in the non-meditating group after other quiet activities

- an outcome providing proof of principle that mindfulness practice can lead to epigenetic alterations of the genome.

Previous studies in rodents and in people have shown dynamic epigenetic responses to physical stimuli such as stress, diet, or exercise within just a few hours. "Our genes are quite dynamic in their expression and these results suggest that the calmness of our mind can actually have a potential influence on their expression," Davidson says. "The regulation of HDACs and inflammatory pathways may represent some of the mechanisms underlying the therapeutic potential of mindfulness-based interventions," Kaliman says. "Our findings set the foundation for future studies to further assess meditation strategies for the treatment of chronic inflammatory conditions."

### **Subconscious Beliefs Are Key**

Too many positive thinkers know that thinking good thoughts - and reciting affirmations for hours on end - doesn't always bring about the results that feel-good books promise.

Dr. Lipton didn't argue this point, because positive thoughts come from the conscious mind, while contradictory negative thoughts are usually programmed in the more powerful subconscious mind.

"The major problem is that people are aware of their conscious beliefs and behaviors, but not of subconscious beliefs and behaviors. Most people don't even acknowledge that their subconscious mind is at play, when the fact is that the subconscious mind is a million times more powerful than the conscious mind and that we operate 95 to 99 percent of our lives from subconscious programs.

"Your subconscious beliefs are working either for you or against you, but the truth is that you are not controlling your life, because your subconscious mind supersedes all conscious control. So when you are trying to heal from a conscious level - citing affirmations and telling yourself you're healthy - there may be an invisible subconscious program that's sabotaging you." The power of the subconscious mind is elegantly revealed in people expressing multiple personali-

ties. While occupying the mind-set of one personality, the individual may be severely allergic to strawberries. Then, in experiencing the mind-set of another personality, he or she eats them without consequence.

The new science of epigenetics promises that every person on the planet has the opportunity to become who they really are, complete with unimaginable power and the ability to operate from, and go for, the highest possibilities, including healing our bodies and our culture and living in peace. *This article was originally featured on Prevent Disease.*

### **HUTCHINGS PSYCHIATRIC CENTER OFFERS FAMILY CARES**

**Family Cares** is a psychoeducational group designed to support families with loved ones suffering from mental illness.

Many of the topics will be determined by our group members to ensure we are targeting areas of importance. Examples include, but are not limited to - psychotropic medications, substance abuse, diagnosis, supportive techniques, navigating/understanding the mental health system and coping.

Presenters are: Sean Ahern, LCSW-R and Shannon Kelley, LCSW.

Every Tuesday for four weeks we will convene from 5:30pm to 7:30 pm.

- 5:30-6:00 - Food & Refreshments
- 6:00-6:30 - Networking
- 6:30-7:30 - Psychoeducational Presentation

**May 5th, May 12th, May 19th and May 26, 2015**, we will meet at Hutchings Psychiatric Center, Education & Training Building, 545 Cedar St., Syracuse, NY 13210.

Please call by March 27th and ask for Sean or Shannon with questions and/or to register, 315-426-7680. E-mails also available at [Shannon.Kelley@omh.ny.gov](mailto:Shannon.Kelley@omh.ny.gov) or [Sean.Ahern@omh.ny.gov](mailto:Sean.Ahern@omh.ny.gov)

*When the world says "Give up."  
Hope whispers, "Try it one more time."*

### **FAMILY LEADERSHIP ACADEMY**

SATURDAY, MARCH 14TH &  
SATURDAY, MARCH 28TH

10:00am - 2:30pm

Institute of Technology at Central  
258 E. Adams Street, Syracuse

### **YOUTH MENTAL HEALTH FIRST AID**

With the recent rise in juvenile suicide, learn how to identify early warning signs of declining mental health in your child and/or his/her friends. Includes light breakfast, lunch and childcare.

**Classes are free.** You can register on the Syracuse City School Parent University website or respond to Marla Byrnes at 720-2838.

### **Hutchings Psychiatric Center Family & Community Education**

Tuesday, April 14th 10am-12noon

### **Therapeutic Interventions and Treatment of Psychosis**

Information for consumers, families, caregivers and friends.

Presenter: Catherine Baggett, PsyD  
Associate Psychiatrist, HPC

This class is free and open to the public, and held in the HPC Education and Training Building, 545 Cedar St., Syr. Paid parking is nearby. To register, call the Education and Training Department at 315-426-6872.

Hutchings Psychiatric Center presents its 2nd annual recovery conference:

### **Recovering in the hospital; creating a healing experience**

*Wednesday, April 29th,  
HPC Auditorium,  
Cedar St., Syracuse, NY*  
**Full schedule to come!**

Sunny Aslam, MD  
Washington Street Clinic

Recent reports from **The Bipolar Network News, Vol. 18, Issue 5, 2014** edited by Sheila Le Gacy, Director of the Family Support & Education Center, AccessCNY.

More arguments for the use of large doses of fish oil for persons diagnosed with bipolar disorder. "A 2014 article in *Neuropharmacology* reported that levels of inflammation predict depression persistence. Researchers suggest that inflammatory and metabolic dysregulation worsens the course of depression.

### **High risk of Suicide Attempts in Bipolar Disorder with Substance Abuse**

Researchers report that 60% of bipolar patients with comorbid alcohol abuse have attempted suicide, and 48% of bipolar patients with cocaine abuse have attempted suicide. The most promising treatments, based on data in patients with primary addictions, are the nutritional supplement N-Acetylcysteine and Topiramate, which have both performed better than placebo in studies of alcohol and cocaine abuse disorders.

N-Acetylcysteine may also improve preliminary symptoms of schizophrenia.

Subjects in a recent study were given 2000mg/day of NAC for 12 weeks and their subthreshold symptoms of psychosis improved.

### **Memory Tips for Bipolar Disorder**

Like cancer patients undergoing chemotherapy, patients with bipolar disorder often have memory problems, particularly if they have had prior episodes. Some tips from CancerCare's Chemobrain Information Series may help patients remember things better and keep their memory sharp.

- Make lists
- Use a paper or electronic day planner

- Carry a notebook
- Leave yourself a voice mail message to remember something important
- Organize your home or office
- Avoid distractions
- Have conversations in quiet places
- Repeat information aloud and write down important points
- Tell your loved ones that you are having memory problems

### **from The Daily Beast, 11/9/14**

Beware of Big Pharma!

The best-selling drug in America is worth \$6.9 billion a year. And it is not Prozac, Viagra or something for heart disease. It is Abilify, the powerful anti-psychotic that's now widely used to treat depression. From April 2013 through March 2014, sales of Ability (official name aripiprazole) totaled almost 6.9 *billion dollars*.

That's more than all other major anti-depressants combined. And yet, the FDA says that the way Abilify works is "unknown." Unknown! As in, we have no idea why this medication seems to help people with bipolar disorder. But go ahead and try it anyway, since it seems to work somehow.

*Sheila Le Gacy, Director of the Family Support & Education Center at AccessCNY (formerly TLS) will be on medical leave from January 15th through April 15th. Patricia Hetrick, the capable and experienced Assistant Director of the Center, can be reached at 315-218-0816.*



*The following letter appeared in the Ask Amy column written by Syndicated Columnist Amy Dickinson on Sunday March 1, 2015*

Dear Amy,

Several weeks ago I read a letter in your column that broke my heart. This young woman had been adversely affected by her sister's instability and her frequent and disruptive moves back to the family home. She asked if she is a terrible person, No!

I grew up with a sibling who is mentally ill and is now considered disabled. With community support my sib lives in an apartment, with visits from our family members who help with housework.

At times we have had a strained relationship, until a year ago when I attended a Family-to-Family 12 week program provided by NAMI (National Alliance on Mental Illness).

The volunteer facilitators have family members who also are ill, and the support was overwhelming. This led to my understanding, and brought both of us so much healing. There is no charge for this valuable program. You will do your readers a great service by providing this information: **nami.org**.

Grateful

Dear Grateful,

The family support offered through NAMI is excellent - I should have recommended it. Thank you for following up.

If any of our NAMI Syracuse members and readers haven't taken the **Supportive Family Training Classes**, a *free* 12 week course that teaches communication, coping and management skills and practical problem solving, contact Patricia Hetrick at 315-218-0816.

The training includes information about schizophrenia, depression, bipolar disorder and other serious psychiatric disorders, with an emphasis on current research.

## ADVOCACY OUTCRY OVER NEW YORK TIMES OP-ED TOUTING RETURN TO INSTITUTIONS

*Mental Health Weekly, March 2, 2015*

Members of the mental health and disability communities are up in arms over comments in a **New York Times** op-ed and in **Journal of the American Medical Association** that suggest a solution for patients with mental illness and developmental disabilities who cycle between emergency hospitalizations and inadequate outpatient care is to be cared for in “modern asylums.” Many have followed up with letters to the **New York Times**.

In the February 18 **New York Times** op-ed, “Modern Asylum,” Christine Montross, M.D., Rhode Island Butler Hospital staff psychiatrist, writes in response to a **JAMA** article by Dominic A. Sisti, Ph.D.; Andrea G. Segal, M.S.; and Ezekiel Emanuel, M.D., Ph.D., ethicists from the Department of Medical Ethics and Health Policy in the Perelman School of Medicine of the University of Pennsylvania.

In **JAMA**, the aforementioned authors write that well-designed community-based programs are often inadequate for a segment of patients who have been deinstitutionalized. “For severely and chronically mentally ill persons, the optimal option is long-term care in a psychiatric hospital, which is costly,” Sisti, Segal and Emanuel wrote.

“For persons with severe and treatment-resistant psychotic disorders, who are too unstable or unsafe for community-based treatment, the choice is between the prison-homelessness acute hospitalization-prison cycle or long-term psychiatric institutionalization,” they wrote. “The financially sensible and morally appropriate way forward includes a return to psychiatric asylums that are safe, modern and humane.”

Montross in her **NYT** op-ed said that “the movement to deinstitutionalize the mentally ill has been a failure.” Patients with chronic, severe mental illnesses are still in facilities - only now they are in medical hospitals, nursing homes and, increasingly, jails and prisons, places

that are less appropriate and more expensive than long-term psychiatric institutions, Montross wrote.

Montross said a new model of long-term psychiatric institutionalization, as the **JAMA** contributors suggested, would help patients with mental illnesses. She noted that group homes for the mentally disabled are established to provide long-term housing while preserving community engagement. Rigorous regulations evolved to ensure patient safety and autonomy have “backfired,” Montross wrote.

“Modern asylums for the severely mentally disabled would provide stability and structure,” she wrote, adding that sensory issues often accompany severe intellectual disability, so rooms with weighted blankets, relaxing sounds and objects to squeeze would help patients calm themselves.

### Advocates respond

The **Bazon Center for Mental Health Law**, in response, issued policy alerts February 20 urging the field to write 150-170 words to the **NYT** editor to oppose those ideas espoused in the op-ed. “It’s important for the editorial board to hear from a ton of people in order to understand how far out of the mainstream and widely rejected the idea of expanding long-term institutionalization is,” the **Bazon** alert stated.

Among the points to be made is that public policies should emphasize proven treatment that promotes recovery and services and support that empower people to make their own life choices and to participate fully in their communities, according to the alert.

“We think it’s a bad idea for people with mental health and developmental disabilities to go to long-term institutions,” John Head, spokesperson for the **Bazon Center**, told **MHW**. “It’s a policy that failed in the past.”

Despite the authors’ discussion of a “modern asylum,” the problem is the very nature of these large institutions that keep people there in the long term, Head said. “The institutions don’t provide individual care,” he said, adding that the problems there include overmedication, seclusion and abuse, he said.

The **JAMA** contributors would have one believe that institutions can provide

patients with mental illness peace and rest, he said. Those are “idealized versions” of what large scale institutions are like, said Head.

He pointed to the **JAMA** article, which referenced the **Massachusetts-based Worcester Recovery Center and Hospital** - a “transformed” state hospital with 320 rooms that provides treatment services, psychiatric research and medical education programs. The hospital costs \$300 million to build and \$60 million a year to operate, said Head.

How many states, noted Head, could afford that amount to build and \$60 million annually to operate it? The discussions do not indicate the need for investments in community-based services, said Head. Community-based mental health services continue to be underfunded, said Head. “We’re not stepping back,” he said. Head noted the recently established **Recovery Now! Campaign**, formed to advance recovery-focused care and supported by such organizations as the **National Coalition for Mental Health Recovery**, the **Bazon Center** and **Mental Health America**. “We had a discussion among coalition members about what a bad idea this is,” he said. If there are enough comments on this perspective, the **New York Times** will feel it should publish the letters from this perspective, Head said. Calls to the **NYT** editorial department went unreturned.

The **Bazon Center** wants the letters to point out that the field has years of experience with community services that work, and the problem is that they are underfunded and in short supply, not that people with disabilities belong in institutions.

### NYAPRS

Bazon officials believe it would be more effective for organizations and individuals to submit their own letters to the **NYT** rather than sign on to one letter as a coalition, said Head. “The number of letters from a broad spectrum of organizations will provide the **New York Times** with a better sense of how strongly people feel about it,” said Head.

Alison Carroll and Carla Rabinowitz, providers and co-presidents of the **New York Association of Psychiatric Rehabilitation Services (NYAPRS)**, told **MHW** they are very concerned over the “disturb-

ing” articles calling for the establishment of “modern asylums” and increased use of court-ordered treatment.

“We are also very troubled that these regressive trends are also extending to Congress, where proposals to build more institutional beds are joined with those to erode personal rights, including a push to expand coercive community treatment and near-elimination of Protection and Advocacy Organizations - the administrative and legal recourse for allegations of abuse, neglect and violation of the civil rights for individuals with disabilities,” they said. “We must not support taking away both a person’s community and their voice.”

Carroll and Rabinowitz added, “The answers don’t lie in rebuilding institutions or forcing the same care that has failed people in the first place: they are to be found by directing the resources necessary to better deploy and train our staff and to create a more adequate and innovative continuum of community options.”

#### **Disability rights**

“As a disability legal organization, so often our main response is to protect individuals from abuse and neglect, including individuals with live-in facilities,” Elizabeth Priaulx, senior disability legal specialist at the **National Disability Rights Network (NDRN)**, told **MHW**. Montross’ assertion that institutions can provide security and stability is wrong, she said. “The “modern asylums” are no panacea to abuse and neglect,” said Priaulx. “It comes down to neglect.”

David Card, **NDRN** spokesperson told **MHW** that the organization submitted a response to the **Times** but has not received word if they plan to run it. “We are also encouraging all of our member protection and advocacy agencies to respond. We are coordinating with like-minded organizations like the **Bazon Center**,” he said.

The **NYT** op-ed can be viewed here: [http://www.nytimes.com/2015/02/18/opinion/the-modern-asylum.html?\\_r=1](http://www.nytimes.com/2015/02/18/opinion/the-modern-asylum.html?_r=1)

## **“I DON’T WANT TO WORK:” THE CHALLENGE OF EXPLORING PERSONAL RECOVERY GOALS**

*Steve Harrington, 2/5/15*

“I don’t want to work. Why does everyone want me to get a job?” Those words came from “John,” a 30-year old man who lived with his brother and rarely left the home. I was asked to “engage” him in services because he refused to come to an agency for meetings with his case manager. “So, what is it that is important to you?” I asked. “Having a quart of beer every day. I don’t want to have to worry about not having a beer when I watch TV.” When I reported John’s goal to his case manager, she rolled her eyes and spoke sternly. “That’s not a goal. He needs to get a job, come in for appointments and take his medication. Those are goals.” “Those are goals you may value but they are not John’s goals. He has a right to decide for himself what is important to him,” I told her. “Let’s give it some time and see where it goes.”

Together, we explored ways John could ensure his daily beer. Options were somewhat limited because John didn’t want to use the bus. And a social phobia also made it difficult for him to relate to people. Still, he was interested in achieving his only life goal-having that quart of beer each day.

Ultimately, John decided the only way he could attain his goal was with some sort of income. That, he reluctantly decided, was the only answer. But how could he realize that income? Again, we explored possibilities. After many trips to his modest home in the city, I had come to know John fairly well. My job was not to find John a job but to help him decide what HE wanted and how he might fill his needs.

Through our visits, John became increasingly comfortable in our relationship. He freely shared his thoughts and feelings and I could see a flicker of hope when he talked about cars and television shows. After several months of weekly visits, John met me at his door obviously excited. “I got a job!” he announced before I got to the door. “I got a job next door.”

John lived next to a lumber yard. He shared his news telling me he had gone on his own to the lumber yard and asked about a job. The manager hired him on the spot to

load lumber on trucks. John would have limited contact with others and could easily walk to the worksite. It was a perfect way for him to achieve his goal. John started working part-time and proved himself a hard worker. He was soon hired full-time and it wasn’t long before he left Social Security benefits in favor of a regular paycheck. Last I knew, John was saving for a car. Perhaps his most meaningful accomplishment was rejoining his community where he has formed relationships and learned to step outside his comfort zones.

When people with physical or mental health challenges engage in human services there are often two responses: 1) You aren’t capable of working so learn to live on entitlements, or 2) You need to get a job. Both responses reflect value-based judgments on the part of human service workers. A better approach is to explore the values of the individual and encourage him/her to create goals important to THEM and help them find their own ways to achieve those goals. Recovery goals must be based on an individual’s values; not the values of service providers who often see work as one of a few “legitimate” goals. Indeed, work can bring much meaning to our lives. In the U.S., when we meet someone new and ask, “What do you do?” the expected response is a vocational occupation. But in some European countries, the question elicits a much different response. A person may say, “I garden,” “I write poetry,” “I cook for my children.” The difference is values; what an individual finds meaningful in their lives.

In the U.S., we have come to link our work with our life meaning. Consider the fact that U.S. workers, on average, rarely use all their vacation time while workers in many countries enjoy considerably more vacation time and use it all. One of the highest suicide rates in the U.S. is among recently retired men. Presumably, they are unable to find meaning beyond the workplace. Unfortunately, I have seen this among people who graduated high school in my class as they consider or begin retirement. “What are you going to do when you retire?” I asked a friend preparing for retirement from a police department. “I have no idea. The kids are grown. I never had time for a hobby. I just don’t know,” he said.

Instead of that “Get a job” knee-jerk reaction, let’s help those we support explore a broader sense of life meaning. Let us reject the notion that our life’s meaning is solely linked to our work. Let us instead focus on personal growth and life in a community of our choice.

Save the Date! NAMI Syracuse Children's Conference

## New Options for Treatment, Research, and Education on Mental Illness in Children

Wednesday, May 6, 2015, 9:00am-3:00pm

Empire Room, New York State Fairgrounds, Syracuse

~presenters~

**Kevin M. Antshel, PhD**, Associate Professor of Psychology and Director of the Clinical Psychology program at Syracuse University. Dr. Antshel's research and clinical interests both focus on developmental psychopathology, with particular emphasis on ADHD.

*Evidence Based Non-Pharmacological Treatments for ADHD in Children and Adolescents*

**Stephen J. Glatt, PhD**, Associate Professor of Psychiatry & Behavioral Sciences and of Neuroscience & Physiology, Associate Director Psychiatry Research, and Director of the Psychiatric Genetic Epidemiology & Neurobiology Laboratory at SUNY Upstate Medical University in Syracuse. The ultimate objective of his research is to facilitate earlier identification, intervention, and prevention.

*New Research on Childhood Development and Psychiatric Disorders*

**Wanda Fremont, MD**, Associate Professor of Psychiatry, is currently the Division Chief of Child and Adolescent Psychiatry at SUNY Upstate Medical University in Syracuse. Dr. Fremont's professional interest include child and adolescent mental health, multicultural issues, family systems, post traumatic stress disorder, and collaboration between psychiatry and primary care medicine.

*Depression in Children and Adolescents*

**Teresa Hargrave, MD** is a Child and Adolescent Psychiatrist and Assistant Professor of Psychiatry at SUNY Upstate Medical University. Her special interests are fostering the development of Integrated Health Care, Preventive Mental Health, Early Childhood Development and Mental Health issues, and advocacy for larger societal support to young families and their children.

*"S(he) Hurt Me!"*

In addition there will be a Panel Presentation to *Update Families & Providers on New Programs*

**John R. Cook, ACCESS**

**Kristin Russell-Miller, CTRS, Child & Adolescent Respite Program**

**Seetha Ramanathan, MD. OnTrack CNY**

### New Options for Treatment Research, and Education on Mental Illness in Children

Registration Fee \$35.00

Become a member of NAMI Syracuse & attend conference \$60.00

Name: \_\_\_\_\_

From: (Agency, NAMI, School, etc.) \_\_\_\_\_

Address: \_\_\_\_\_

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Registration includes Lunch

Display Table Requested

## WHEN IT COMES TO GETTING HELP, CULTURE COUNTS

by Valerie Denis, February 20, 2015  
from NAMI Now

A friend of mine once told me, "Black people don't get depressed."

Even within my own family, mental distress was perceived as a weakness, something to "snap out of" or "get over." I didn't think that there was anyone who would understand my experiences and so I was afraid to ask for help. I felt hopeless and alone, ashamed that I wasn't strong enough to shoulder life's difficulties.

Many believe that mental illness only affects others - other people, other families, other ethnic groups. In reality, mental illness affects indiscriminately. One in five adults in America experience symptoms of a mental health condition each year. Although the rates of mental health conditions are similar between different cultural groups, the impact is not. But the truth is, when it comes to mental illness, culture counts.

Stigma is a big reason why many people belonging to a minority group do not receive the psychiatric treatment they need. Individuals from racial and ethnic communities with mental health symptoms experience vastly different, and sometimes disastrous, results. For example, according to the Health and Human Services Office of Minority Health, African Americans are 20% more likely to experience serious mental health problems than the general population. We are also more likely to receive a misdiagnosis.

The lack of access to mental health information and services - or access to only inferior information and services - can compel African Americans to mask or ignore their issues. Add to that the fact that African Americans face discrimination and biased attitudes in other spheres, including other areas of the health care system, it's no wonder silence and stigma surround mental health in this community.

Considering the huge costs associated with untreated mental illness, this gap needs to be addressed. Improving mental

health wellness in diverse communities means fighting stigma while increasing both awareness of recovery and access to culturally competent services, education and support.

Growing up, I almost never encountered positive portrayals or shining examples of African Americans with mental health conditions - not on television or in movies, not at the schools I attended, not in the books I read. What I wish I'd known then, what I know to be true now, is that if you have a mental health condition you are not alone.

Depression and other mental disorders are extremely common. There should be no shame in seeking help; social and psychological supports and services can truly be salvation. It doesn't matter what you look like, there are millions of people who are facing similar problems. And millions - like me - find their way to recovery and a path back to hope.

## FIVE POINT PLAN TO IMPROVE THE NATION'S MENTAL HEALTH

by Pamela S. Hyde, J.D., Administrator, Substance Abuse and Mental Health Services Administration and Paolo Del Vecchio, M.S.W., Director, Center for Mental Health Services, Substance Abuse Administration

In the 50 years since the implementation of the Community Mental Health Act, we have learned a great deal about how to improve the mental health of the nation, particularly for those of us with serious mental illnesses. The solutions to improving mental health care in America are clear and have been demonstrated repeatedly by presidential commissions, federal agencies, states, providers, the Surgeon General, the Institute of Medicine, foundations, nonprofit organizations, and others over the last several decades. However, as a nation we continue to lack the economic and political will to put these solutions into place, despite the fact that they would greatly reduce the economic burden of mental illness; increase productivity, achievement, and independence; and improve the lives of millions of Americans and their families.

The following are 5 steps America could take that would immediately and greatly improve the existing overburdened mental health system and would help ensure delivery of effective, high quality, coordinated, and evidence-based care for Americans with mental illnesses.

### 1: Increase Prevention, Treatment, and Recovery Services

Despite the ongoing knowledge that 1 in 5 Americans experience a mental illness each year, and that many Americans with serious mental illness die years earlier than other Americans from treatable medical conditions, our nation is often reluctant to make the investments necessary to provide effective prevention, treatment, and recovery services for mental illness as it does for other health conditions. These investments - personal and public - would improve care coordination and save money by preventing the use of costly crisis care and hospitalizations, and preserve these resources for when they are truly needed. America should invest in increased 1) prevention - that includes reducing the tragedy of suicide; 2) integrated treatment and early intervention; and 3) recovery services - such as supported employment, supportive housing, and peer-operated services - and target much of these efforts for people with serious mental illnesses and their families.

Similar to the disparities in the overall healthcare system, disparities based on culture, race and ethnicity, gender and gender identity, disability, and sexual orientation have an impact on the delivery and quality of care and outcomes in mental health. We need to target outreach and engagement strategies and treatment and services that are tailored to the backgrounds of individuals, families, and communities. In so doing, individuals and families should have access to and choice of both evidence-based medical supports as well as efficacious complementary and alternative services.

While the implementation of the Affordable Care Act and the Mental Health Parity and Addiction Equity Act will help, more resources are required at both the state and federal levels to adequately provide needed quality mental health services.

2: Expand the Mental Health Workforce  
Workforce shortages continue to burden an already underfunded and fragmented

mental health system. A trauma-informed, recovery-oriented and culturally competent workforce in numbers and locations adequate to meet the need is essential for increased service delivery capacity and system improvement. The delivery of safe, effective, and high-quality coordinated care is dependent on workforce competencies. America should invest in training and education of the mental health workforce including evidence-based and effective clinical and psychosocial innovations that incorporate medications, counseling, crisis prevention and intervention strategies, engagement techniques, community support services, and use of peer and family providers.

### 3: Widen the Use of Health Information Technology

New information technologies are revolutionizing health and behavioral healthcare and exponentially expand the outreach and engagement of populations into mental health treatment and services via electronic health records, telepsychiatry, self-care applications, on-line psychotherapies, and many other approaches. Such technologies can help to achieve needed efficiencies to address gaps in care availability and accessibility that will enable individuals to attain help in a confidential, easy-to-access manner. Use of these technologies can also help to support the workforce stay abreast of the most recent developments and training opportunities in the behavioral health field.

### 4: Educate the Public

Negative attitudes, beliefs, and behavior about mental illness and prejudice and discrimination toward individuals with mental illnesses and their families continues to be one of the greatest barriers to improving mental health care and helping those in need. Negative beliefs deter the public from wanting to pay for care, despite the prevalence and impact of mental illness on the lives of Americans. Public rejection often prevents individuals from seeking care. America should invest in multiple, evidence-based public education and awareness strategies, campaigns, and engagement activities to reduce prejudice and discrimination. Such efforts should be done

in schools, workplaces, faith communities, and other settings until mental disorders are understood and treated the same as any other set of health conditions, and emotional health development is considered just as important as exercising and resting to take care of our bodies, and preventing death by suicide is just as important as preventing death from cancer.

### 5: Invest in Research

Despite the gains in our knowledge about mental illness and what works best to ameliorate symptoms, restore and improve functioning, and assist persons with mental illness to live successfully in the community, we still have much to learn. We are just beginning to understand how the brain functions and how our genes and the environment - including trauma - impact our emotional well-being. Bio-markers for mental illnesses are not yet available, making the assessment and treatment of mental illnesses often less precise than other health conditions. Our ability to identify and practice early intervention to prevent long term disability or death from these conditions needs to be further developed. The research about which services and supports work best for different kinds of people and in a variety of circumstances deserves more attention in and from the research community. We also need to understand more about moving what we do know into practice more quickly with a much wider reach. Evidence-based care is possible and more evidence is needed.

## THE THREE R'S TO RECOVERY

Some mental illnesses tend to shut us down, cause us to feel listless and not wanting to do much of anything. And if we are taking medication to treat that illness it might even add to our indifference to participating in activity of any kind, even those activities which are extremely important to our well being. There are few activities as essential in our daily lives as recreation, relaxation and rest. This may be especially true for those of us dealing with the effects of having a mood disorder. Let's take a look at just some of their many benefits.

Recreational activities should do what the word suggests--refresh our body as

well as our spirit. Moderate to vigorous activity and exercise that we enjoy can have a number of positive benefits by:

*Strengthening and energizing our body.*

*Building confidence and improving our mood.*

*Having social involvement.*

*Helping to control our weight.*

*Reducing stress and helping us relax.*

Relaxation is essential for everyone although the techniques or activity one chooses may differ. Some people especially find music beneficial while others enjoy reading or a movie. Whatever helps us to relax and refresh our mood and senses is a positive undertaking. Specialists tell us that relaxation can:

*Release our body's feel good hormones and lower stress hormones.*

*Help relieve anxiety, lower blood pressure and reduce our heart rate.*

*Help lower stroke risk.*

*Make better decisions.*

*Boost our memory.*

*Help us with better rest and sleep.*

We all should be aware of how important rest is to each one of us. Sleep is essential to the continuance of a healthy and high functioning daily life, especially when we already have the added effects brought on by a brain disorder. Sleep, we should know:

*Helps our brain work properly.*

*Helps our immune system keep us healthy.*

*Improves learning and making better decisions.*

*Helps us to be creative in solving problems.*

*Controls our emotions and risk taking behavior.*

*Helps with our interpersonal relations.*

When we are able to allow these activities to work together in our life we stand a better chance of making real progress on our personal path to recovery. All three areas, however, are necessary to be attended to, each in their own way.

Your doctor, therapist, support group, DBSA, NAMI or other community service providers can give you some ideas on maximizing the benefits you can achieve in these areas. The ideas are there for the asking. Ask today.

~~Jerry Malugeon, Author, "The Black Dog and the Cyclone Racer" (Available on Amazon)

## SEND YOUR MEMBERSHIP TO NAMI Syracuse TODAY

\_\_\_\_ Individual Membership (\$35.00)

\_\_\_\_ Open Door Membership (\$3.00 for Individuals on a limited income)

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### What are the benefits of NAMI membership?

- Membership at all three levels of the organization: NAMI National, NAMI-NYS & NAMI Syracuse
- Eligibility to vote in all NAMI elections
- A subscription to The Advocate, NAMI national's quarterly magazine, as well as access to optional subscriptions to specialty newsletters and information at the national, state and local levels
- Discounts on publications, promotional items, and registration at NAMI's annual convention, state and local conferences
- Access to exclusive members-only material on NAMI National's website

*Reminder:*

*If you are receiving this newsletter but are not a member, please consider joining NAMI.*

*If you are a member, please check to be sure your dues are up to date.*

*Please join or renew today.*

*There is strength in numbers!*

**The NAMI Syracuse Support & Sharing Meeting facilitated by Sheila Le Gacy is held on the 3rd Tuesday of each month at 7:00pm at ACCESS-CNY, 420 East Genesee Street, Syracuse. (Between South Townsend St. and South State St., next to the Onondaga County Sheriff's Department. Parking and entrance in the rear of the building.)**