



NAMI SYRACUSE

National Alliance on Mental Illness

Newsletter

MAY/JUNE 2014

Meeting Schedule

NAMI Syracuse - Support & Sharing Meeting
 Third Tuesday of each month, 7pm, Transitional Living Services,
 420 East Genesee Street, Syracuse

Madison County - Support & Sharing Meeting
 meetings have been cancelled until further notice

NAMI Syracuse - Information & Education Meeting
 as announced

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 EDUCATION *SHARING ADVOCACY*

Events Calendar

May 14, 2014	NAMI Syracuse Children’s Educational Conference: <i>Navigating Early Intervention Programs & Services for Children</i>
May 20, 2014	Support & Sharing Meeting Syracuse - 7:00pm
May 19-20, 2014	“SEE ME!” Art & Poetry Show Deadline for submissions <i>(see page 3 for details)</i>
May 31 thru August 15, 2014	“SEE ME!” Art & Poetry Show Community Folk Art Center 805 East Genesee Street, Syracuse <i>(see page 3 for details)</i>
June 17, 2014	Support & Sharing Meeting Syracuse - 7:00pm

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MESSAGE FROM THE PRESIDENT

Dear Members,

May is Mental Health Awareness Month. According to Wikipedia, Mental Health Awareness Month has been around since 1949 and was initially brought to our attention in the United States by Mental Health America. In 2013, President Obama officially proclaimed May as National Mental Health Awareness Month. NAMI National states that by highlighting the issue of mental health during May, it provides a time for people to come together and display the passion and strength of those working to improve the lives of the tens of millions of Americans affected by mental illness.

Besides our ongoing advocacy efforts, NAMI Syracuse is celebrating May is Mental Health Awareness Month by hosting our third annual Children's Conference: Navigating Early Intervention Programs and Services for Children on May 14 at the Rosamond Gifford Zoo. We will also be co-hosting SEE ME! ART and POETRY SHOW. Entries are due in May. See details for both these great events within this newsletter.

But what does mental health awareness really mean?

If you are receiving this newsletter, most likely your life has been touched by mental illness; you've felt the sting of stigma and the pain of isolation. You've known the feeling of helplessness and confusion and anger. But if you are receiving this newsletter, you've also known the relief that there are many others who understand. You know that there is a wealth of support and knowledge, and that there is hope and strength in our collective voice.

To me, mental health awareness means sharing our stories beyond NAMI, reaching out to the general community and letting our friends and our neighbors and our coworkers know that although our lives have been touched by mental illness, recovery is happening-that the faces of recovery are everywhere we look.

I hope that all of you will put fear of judgment aside and share your stories beyond our NAMI family. I think you'll be quite surprised how many people will in turn share their stories with you. During May is Mental Health Awareness Month take a chance and see how many lives you can touch in a positive way.

~~Karen

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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>

Still time to register!

***NAMI Syracuse 3rd Annual Children's Conference:
Navigating Early Intervention Programs and Services for Children***

***Wednesday, May 14, 2014, 9:00am-3:00pm
Welch Allyn Room at the Rosamond Gifford Zoo, Syracuse***

Registration Fee: \$35.00

Presenters:

****John H. Wohlers, Ph.D., Clinical Director, Centre Syracuse for the Treatment of Eating Disorders***

****Tanisha Wiggins/Katrina Castro, Message of Hope***

****Stephen J. Glatt, Ph.D., Breaking the Silence:***

Educating the Next Generation

****Updates on County and State Services for Children***

****Dr. Seetha Ramanathan & Julie Aspenleiter, Psy.D.,***

First Break, Early Intervention Program

call NAMI Syracuse, 315-487-2085 to register!

Attention NAMI Syracuse Members

2014 membership renewal is due. If you haven't already done so, please take the time to renew your membership in NAMI Syracuse right now!

\$35.00 Individual/Family Dues

\$ 3.00 Open Door Membership

(for those where dues present a hardship)

Thank you for your support of NAMI Syracuse. Your donation helps us to carry out our mission of providing support, education and advocacy to individuals and families affected by mental illness.

“SEE ME!” ART and POETRY SHOW

The heat is on, - maybe not in Syracuse but - for our first art show!

Consumers and family members 18 years old or older may submit one art piece or poem. Art work must be display ready.

Deadline for submission of art or poetry is Monday May 19 -Tuesday May 20.

Please see our entry form for details below.

Show will be held May 31st thru August 15th at **Community Folk Art Center**, 805 East Genesee Street, Syracuse.

Reception June 10th from 3-6pm

If you are interested in contributing to the reception on June 10th with desserts/soda/ munchies or to help, call the NAMI Syracuse office at 487-2085.

Please support our talented family members and families!

MANY THANKS to Community Folk Art Center for their support and donation of their beautiful space for this event!!!

“SEE ME!” NAMI Syracuse Art & Poetry Show

Name _____

Address _____

Phone _____ E-mail _____

Art Title _____ Media _____ Item for sale? _____ Price? _____

Poetry _____ May submit online to namisyracuse@namisyracuse.org

Do you want your name posted with your art work or first name only? _____

We are not liable for loss or damage to your property. We will take care with each piece but entry into this competition is at your own risk. We cannot guarantee privacy. This show is open to the public. Images may be displayed as part of promotion or an online gallery.

Your artwork must be display ready and wired. Must be 18 years old or older to enter.

One piece per person. If all work cannot be displayed, there will be an “online” gallery.

Please **drop off** your art piece **Monday, May 19th** or **Tuesday May 20th, 10am-5pm** at **Community Folk Art Center**, 805 East Genesee Street, Syracuse, NY, 13210, phone, 315-442-2230.

The show will run May 31st - August 15th.

NAMI Syracuse will host a reception Tuesday June 10th, 3pm-6pm.

GALLERY OPEN Tuesday-Friday, 10 am-5pm and Saturday, 11am-5pm

You may pick up your art work after August 15th.

HERE'S THE LINE ON SPECIAL-NEEDS TRUSTS, FROM AN EXPERT

(Article below is taken from Jane Bryant Quinn, personal finance expert writing in the AARP Bulletin July-August 2013, titled "Protecting a Relative with a Disability," much shortened and with slight editing.)

~~reprinted from NAMI Schenectady E-NEWS, May 1, 2014

A huge concern is how to pay for care if you die before your child does. Typically, the best plan is to create a special-needs trust. You might fund the trust with money you're leaving in your will, current savings or a life insurance policy. It's critical that the trust be drawn by a lawyer who knows the disability rules. To qualify for, and keep, their Medicaid and SSI, children and adults with disabilities have to have virtually no money in their own name.

Parents, relatives or friends can contribute to a third-party special-needs trust. Because the money never belonged to the child, it won't interfere with his or her government benefits. The trust can cover "extra" quality-of-life needs, such as personal care, gifts and travel. If the child personally comes into money, from an inheritance or an insurance settlement, that can go into a "self-funded" special-needs trust. The child continues on Medicaid or SSI, but when he or she dies, the government reaches into the self-funded trust to recover its money. That's why no one should leave money directly to the child. It should all go to the third-party trust.

As for insurance, caregivers need a "permanent" policy that covers them for life. Whole-life coverage is a good choice - its premiums and benefits are guaranteed. Universal-life policies permit a variety of payment schedules that might or might not be enough to fund the policy in later years. Please, don't let a special-needs planner or adviser at a financial services company talk you into buying more insurance than you need. (You might be shown a "financial plan" that is nothing more than a sales document.) Your policy should fund only the "extras" that you want the trust to pay.

If you're leaving a modest amount of money, consider trusts offered by non-profit organizations for people with disabilities, such as NYS-ARC (Delmar, NY) or the National Plan Alliance. The organizations manage the trust and work with the family on a general plan of care. For larger sums, check the Special Needs Alliance for a lawyer who has experience with these trusts.

For a spouse with a disabling disease, you also need a care plan, including insurance in case you die first. Check the National Academy of Elder Law Attorneys. Ask for a lawyer who can tell you if your spouse qualifies for Medicaid's nursing home coverage. Pay special attention to your spouse's health care proxy and living will. The care you want early in the disease might differ from what you want later. Your spouse should control personal medical and financial decisions as long as possible. Sign forms while your spouse still can.

ON WAKING: AN INSTALLATION PLAYFULLY EXPLORING DEPRESSION

by Liz Droge-Young

In my life, I am many things: a scientist, a graduate student, a wife, a friend, a daughter, and I also suffer from severe clinical depression. This last point - this last little fact about my life - inspired me to put on an art show. This past winter I was struck with an incredibly deep and impactful episode of depression that caused all of my normal life routines to crumble. Everything from parties with friends to holiday celebrations were slowly cancelled as I sunk into the emotional troughs of depression. This episode was so severe that I needed to take a leave of absence from my studies on insect mating systems and eventually seek hospitalization for my condition.

Depression made me reevaluate the importance of societal expectations and question traditional holiday celebrations, which frankly seemed absurd when struggling with survival. In processing these experiences I turned to writing, lots of writing, and the creation of funky little art objects. The artifacts I created often wove in unconventional takes on holiday decorations and my love of science - think short

essays about my experiences, mating insect Christmas ornaments, and stuffed animal reproductive organs. In creating these objects I was able to find brief moments of levity in a difficult time and maintain some connection to my research, which normally filled me with joy.

In honoring my process of healing from this episode of depression, I am putting on an art installation to both display my created objects and also to communicate my experience with depression. Think of it as one-half art installation and one-half natural history exhibit exploring life with mental illness.

Through the whole process I was also struck by how isolating of an experience suffering from depression is, despite it being so pervasive. Likewise, I frequently encountered misunderstandings of what depression is and what can be done to help. In addition to sharing my illogical, bizarre and sometimes humorous experiences, I also hope to inform about the severity of this disease and available resources to those who may have suffering loved ones.

On Waking: An Installation Playfully Exploring Depression

Friday May 30th, 5 - 9pm

Saturday May 31st, 2 - 9pm

Spark Art Space

1005 East Fayette St., Syracuse, NY 13210

For more information, please visit: onwaking2014.tumblr.com

Highly recommended new book! A memoir by a well known biographer. **The Splendid Things We Planned: A Family Portrait** by Blake Bailey, (Norton 2014). "This fine and haunting memoir touches the spot where family, responsibility and helplessness converge (David Sedaris). A memorable quote from this book: "When a child is young, you can catch him if he falls. Then he gets a little older and falls from a higher place. Maybe you can still catch him. But finally he's a full-grown adult and falls off the top of a building - then you have to decide: either get out of the way or be crushed."

~~from Sheila Le Gacy

Save the Date! Tuesday, October 7, 2014

NAMI Syracuse Educational Conference

“Crucial Conversations”

9am - 3pm, Rosamond Gifford Zoo, Syracuse

~~presenters~~

Professor Stephen Kuusisto, author, poet, disability advocate, and director of SU’s Renee Crown University Honors Program

Dr. Abdul Ahmed, Shared Decision Making

Dr. Rich O’Neill, Caring for the Caregiver

Sheila Le Gacy with Panel - Collaboration with Police Department, Crisis Intervention Team

STOMP out STIGMA

Dance for a great cause,
while havin’ a stompin’ good
time!

Saturday, May 31, 2014

American Foundry

246 West Seneca St., Oswego

Tickets: **\$30 advance, \$40 at the door.** Ticket includes BBQ Food

All proceeds to benefit:

**American Foundation for
Suicide Prevention**

6:00 - 7:00pm

Line Dancing Lessons

7:00 - 8:30pm

Live Music by Driftwater

8:30 - 9:15pm

**Open Dance - Joe Grosvent
spinning country favorites**

9:15-10:00pm

Live Auction

To purchase tickets:

**[http://afsp.donordrive.com/
event/StompOutStigma](http://afsp.donordrive.com/event/StompOutStigma)**

Family Tapestry’s Annual “Heroes of Hope” Walk

SATURDAY, MAY 10, 2014

Onondaga Lake Park's Willow Bay Saw Mill Creek Shelter Walk

10:00 am - 1:00 pm RAIN OR SHINE

Registration fee of \$25.00 includes T-Shirt

Family Tapestry, Inc., c/o Onondaga Case Management,

620 Erie Boulevard West, Syracuse, NY 13204

Family Tapestry is a grassroots not for profit organization that assists families who have children with mental health challenges. Our mission is to join families together to find strength and support from each other in their times of need. We work to empower them to become strong advocates for themselves and their families.

CONTACT Community Services offers Mental Health First Aid/ 8-hour workshop

Mental Health First Aid is a general class about mental health issues (including risk of suicide).

Sign up for this 8-hour workshop and learn to manage crises, reduce stigma and practice a 5-step plan for helping someone in a mental health crisis.

May 22 & 23 (Thursday and Friday), 9 am-1:15 pm each day

June 16 & 17 (Monday and Tuesday), 9 am-1:15 pm each day

Registration: Call 315-251-1400 x 132

Cost: \$75 (space is limited to first 20 paid registrants)

DOCTOR: ADHD DOES NOT EXIST

*Time Magazine: Dr. Richard Saul,
3/14/2014*

Recently, an article in the New York Times reported that between 2008 and 2012 the number of adults taking medications for ADHD has increased by 53%, and that in the case of young American adults, it has nearly doubled. While this is a staggering statistic, and points to younger generations becoming frequently reliant on stimulants, frankly, I'm not too surprised. Over the course of my 50-year-long career in behavioral neurology and treating patients with ADHD, it has been in the past decade that I have seen these diagnoses truly skyrocket. Every day my colleagues and I see more and more people coming in claiming they have trouble paying attention at school and at work, and diagnosing themselves with "ADHD."

If someone finds it difficult to pay attention or feels somewhat hyperactive, "Attention-deficit and Hyperactivity Disorder" has those symptoms right there in its name. It's an easy, catch-all phrase, which saves time for doctors to boot. But can we really lump all these people together? What if there are other things causing people to feel distracted? I don't deny that we, as a population, are more distracted today than we ever were before. And I don't deny that some of these patients who are distracted and impulsive need help. But what I do deny is the generally accepted definition of ADHD, which is long overdue for an update. In short, I've come to believe based on decades of treating patients that ADHD - as currently defined by the DSM and as it exists in the public imagination - does not exist.

Allow me to explain what I mean.

Ever since 1937, when Dr. Charles Bradley discovered that children who displayed symptoms of attention-deficit hyperactivity responded well to Benzedrine, a stimulant, we have been thinking about this "disorder" in almost the same way. Soon after Bradley's discovery the medical community began labeling children exhibiting these symptoms as having "minimal brain dysfunction,"

or MBD, and treating them with the stimulants Ritalin and Cylert. In the intervening years, the Diagnostic and Statistical Manual of Mental Disorders, or DSM, changed the label numerous times, from "hyperkinetic reaction of childhood" (it wasn't until 1980 that the DSM-III introduced a classification for adults with the condition), to the current label ADHD. But regardless of the label, we have been giving patients different variants of stimulant medication to cover up the symptoms. You'd think that after decades of advancements in neuroscience, we would shift our thinking.

Today, the fifth edition of the DSM only requires one to fulfill five of eighteen possible symptoms to qualify for an ADHD diagnosis. If you haven't seen the list yet, look it up. It will probably bother you. How many of us can claim we have difficulty with organization, or a tendency to lose things; that we are frequently forgetful, distracted, or fail to pay close attention to details? Under this subjective criteria, the entire U.S. population could potentially qualify. We've all had these moments, and in moderate amounts, it's a normal part of the human condition.

However, there are some instances in which attention symptoms are severe enough that patients truly need help. Over the course of my career, I have found more than 20 conditions that can lead to symptoms of ADHD, each of which requires its own approach to treatment. Among these are sleep disorders, undiagnosed vision and hearing problems, substance abuse (marijuana and alcohol in particular), iron deficiency, allergies (especially airborne and gluten intolerance), bipolar and major depressive disorder, obsessive compulsive disorder, and even learning disabilities like dyslexia, to name a few. Anyone with these issues will fit the ADHD criteria outlined by the DSM, but stimulants are not the way to treat them.

"What's so bad about stimulants?" you might be wondering. They seem to help a lot of people, don't they? The aforementioned article in the Times mentions that the "drugs can temper hallmark symptoms like severe inattention and hyperactivity but also carry risks like

sleep deprivation, appetite suppression and, more rarely, addiction and hallucinations." But this is only part of the picture.

Firstly, addiction to stimulant medication is not rare; it is common. The drugs' addictive qualities are obvious. We only need to observe the many patients who are forced to periodically increase their dosage if they want to concentrate. This is because the body stops producing the appropriate levels of neurotransmitters that ADHD meds replace - a trademark of addictive substances. I worry that a generation of Americans won't be able to concentrate without this medication; big pharma is understandably not as concerned.

Secondly, there are many side-effects to ADHD medication that most people are not aware of: increased anxiety, irritable or depressed mood, severe weight loss due to appetite suppression, and even potential for suicide. But there are consequences that are even less well-known. For example, many patients who are on stimulants report having erectile dysfunction when they are on the medication.

Thirdly, stimulants work for many people in the short-term, but in cases where there is an underlying condition causing them to feel distracted, the drugs serve as Band-Aids at best, masking and sometimes exacerbating the source of the problem.

In my view, there are two types of people who are diagnosed with ADHD: those who exhibit a normal level of distraction and impulsiveness, and those who have another condition or disorder that requires individual treatment.

For my patients who are the former, I recommend that they eat right, exercise more often, get eight hours of quality sleep a night, minimize caffeine intake in the afternoon, monitor their cellphone use while they're working, and most importantly, do something they're passionate about. As with many children who act out because they are not being challenged enough in the classroom, adults who have work or class subjects that are not personally fulfilling, or who don't engage in a meaningful hobby, will understandably become bored, depressed, and distracted. Similarly, today's standards are pressuring children and adults to perform better and longer at school and at work. I too often see patients who hope to excel on four hours of sleep a night with help from stimulants, but

this is a dangerous, unhealthy and unsustainable way of living long-term.

For my second group of patients, who have severe attention issues, I make them undergo a full evaluation to find the source of the problem. Usually, once the original condition is found and treated, the ADHD symptoms go away.

It's time to rethink our understanding of this condition, offer more thorough diagnostic work, and help people get the right treatment for attention deficit and hyperactivity.

*Dr. Richard Saul is a Behavioral Neurologist practicing in the Chicago area. His book, **ADHD Does Not Exist**, is published by HarperCollins.*

*The following articles have been edited from **Bipolar Network News Vol. 18, Issue 2, 2014** by Sheila Le Gacy, Director of the Family Support and Education Center, Enable/Transitional Living Services.*

FATTY ACIDS IN MOOD DISORDERS

Cultures in which people consume more omega-3 fatty acids (which have anti-inflammatory effects) and few omega-6 fatty acids (which have pro-inflammatory effects) have a lower incidence of depression and bipolar disorder. Levels of specific omega-6 fatty acids and their related enzymes were found to correlate with depression severity in a recent study. Since omega-6 fatty acids are pro-inflammatory, diets higher in omega-6 fatty acids are associated with more cardiovascular problems. Completed suicides in bipolar patients with cardiovascular disorders were significantly higher than in those with bipolar disorder without cardiovascular illness. *It seems a healthy diet can have multiple benefits, including potentially reducing depressive burden, cardiovascular risk, and suicide risk. Editors note: **More evidence for taking fish oil (omega 3s!)***

MEDICINAL HERB MAY HELP COGNITIVE DYSFUNCTION

In a double blind, placebo-controlled study in 2012, the herb **Ashwagandha** (sold under the name **Sensoril**) *Withania somnifera* (WSE) was significantly bet-

ter than placebo at improving patients' performance on three different cognitive tasks.

The herb, which has traditionally been used in Ayurvedic medicine in India as an aid to resisting stress and disease, improved performance on several cognitive tests (for more information see K. N. Roy Chengappa et al. published in the *Journal of Clinical Psychiatry* 2013).

MICRO-NUTRIENT PRODUCT EFFECTIVE IN ADULT ADHD

EMPowerPlus is a nutritional supplement marketed by the company Truehope as a way of correcting nutritional deficiencies that contribute to mood and anxiety disorders. In 2014 Rucklidge Et al. published the first controlled study of EMPowerPlus in the *British Journal of Psychiatry* showing that the supplement was more effective than placebo in adults with untreated ADHD.

EMPowerplus contains 36 ingredients, including 14 vitamins, 16 minerals, 3 amino acids, and 3 anti-oxidants.

Multiple uncontrolled studies have suggested the efficacy of EMPowerPlus in childhood mania and related conditions, but this is the first formal placebo-controlled study of the supplement in adults with ADHD. A study in children with ADHD is planned, but it would also be important to study this formulation in childhood bipolar disorder, where there is some anecdotal evidence of excellent responses in children with highly treatment-resistant bipolar illness.

LITHIUM LOWERS RISK OF SUICIDE AND MORTALITY

Suicide is a serious risk for people with mood disorders. Various studies of lithium show that the drug lowers suicide risk in people with mood disorders. A 2013 study confirms this finding. Lithium was more effective than placebo at reducing number of suicides and deaths from any cause, and more effective than carbamazepine and anticonvulsants in general at reducing deliberate self-harm. The authors wrote that lithium seems to reduce risk of suicide and death by more than 60% compared to placebo.

MARIJUANA ADDICTION ASSOCIATED WITH WHITE MATTER LOSS AND BRAIN CHANGES IN HEALTHY PEOPLE AND IN PEOPLE WITH SCHIZOPHRENIA

Future research is needed to determine whether marijuana causes these brain changes, or whether the brain changes are a biomarker that shows a vulnerability to marijuana addiction (although the latter is less likely than the former).

Other data show that marijuana is associated with an increase in psychosis (with heavy use), cognitive deficits, and an earlier onset of both bipolar disorder and schizophrenia in users compared to non-users. These findings make pot begin to look like a real health hazard. With legalization of marijuana occurring in many states, ease of access will increase, possibly accompanied by more heavy use. The most consistent pharmacological effect of marijuana is to produce an amotivational syndrome, characterized by apathy or lack of interest in one's usual activities. Particularly for those already struggling with depression, pot is not as benign a substance as it is often thought to be.

The Family Support & Education Center at TLS/Enable has been lending books out to families who have taken Supportive Family Training. This has been done on the honor system and has worked fairly well over a long period of time. However, it has come to our attention that a substantial number of books have not been returned. We are presently at the beginning of the Spring Course and find that some of the most helpful books have disappeared. So this is an appeal to those of you who have forgotten to return the books you have borrowed. Also, we are appealing to family members who might wish to donate books to our library. Our funds are limited and your books would be most appreciated. You could drop off books with the receptionists at TLS, 420 East Genesee St. between 8:30am and 4:30pm.

Thanks, Sheila Le Gacy Director of the Family Support & Education Center and Vanessa Watts, Assistant Director.

WE CAN DO BETTER. CHILDREN THAT NEED MENTAL HEALTH CARE AREN'T GETTING IT (COMMENTARY)

by *Thomas R. Welch, MD*

The situation for children needing psychiatric hospitalization is arguably worse than it was 10 years ago.

On February 6th, there were five children with acute mental health emergencies staying in rooms at the Upstate Golisano Children's Hospital. They were not receiving psychiatric care; the hospital is not licensed by New York state to provide inpatient child psychiatry. They were not receiving other medical care either; none had complicating medical problems requiring hospitalization.

They were in the hospital because it was unsafe for them to be at home and there were no available child psychiatry beds in New York state.

While February 6th was a record-setting day for the hospital, it was hardly atypical. In 2013 alone, there were 160 admissions to our children's hospital for no reason other than the lack of an available mental health bed in the state.

One might reasonably assume that consideration was being given to expanding psychiatric inpatient services for children in light of this experience. While there has been activity related to child psychiatry beds in New York, that "activity" has been closing facilities, not expanding them. The child and adolescent unit at Hutchings Psychiatric Center is slated to close with some of their activity being moved to the Utica Psychiatric Center.

Part of the rationale for this counter-intuitive decision is that it will be accompanied by enhanced outpatient services, allowing children to be treated early and avoiding hospitalization. Does this argument sound familiar? It was the mantra a few decades ago when the country embarked on a massive effort at closing psychiatric hospitals, promising to compensate with increased availability of outpatient services. How has this worked? Just check out the homeless on the streets of our great cities. Many of these folks represent the collateral damage of missing psychiatric services.

Can one imagine the public outcry if we were unable to care for children with diabetes in Syracuse? Picture parents being told that their child has diabetes and needs to go to a hospital in Utica (or New York City) for treatment. Then, visualize the emergency physician telling the family that there were no beds in the "diabetes hospital" at this time, so their child would have to wait in the children's hospital until a "diabetes bed" in the state was located. Of course, while they were waiting for placement, the disease would not be treated because the children's hospital was not licensed to treat diabetes.

Of course this seems farfetched. Yet, we seem to accept this scenario if the disease was not diabetes but was depression or schizophrenia. How can we possibly permit this situation to continue? Mental illnesses in children are real, disabling, and have just as much of a biologic basis as diabetes or heart failure. Untreated childhood mental illness not uncommonly leads to jail, suicide, or well-publicized tragedies. Suicide is the third leading cause of death in older children, and it has been estimated that up to 70 percent of incarcerated juveniles have some sort of psychiatric disorder.

Over a decade ago, I spearheaded the campaign to bring a children's hospital to Syracuse. The public support was massive, the community became engaged, and we now have a world-class facility. Despite this, the situation for children needing psychiatric hospitalization is arguably worse than it was 10 years ago.

Now, we need to complete the job we began with the Upstate Golisano Children's Hospital. The children of this county need to be assured that their depression and anxiety will be treated as comprehensively as their leukemia and pneumonia. Like the original children's hospital campaign, this will require a huge community effort on many levels. The Golisano Children's Hospital Advisory Council has recently committed to take on the project, but cannot do so in a vacuum.

I would like to challenge everyone to get informed about this issue, and start discussing it with friends and neighbors. The problem is multifaceted, and will require action on multiple levels. We owe it to our children. Let's get our entire county behind this now!

~Dr. Thomas R. Welch is a professor and chair of the Department of Pediatrics at Upstate Golisano Children's Hospital.

~from syracuse.com

NAMI CALLS ON CONGRESS TO PROMOTE NATIONWIDE EXPANSION OF POLICE CRISIS INTERVENTION TEAMS (CIT)

The National Alliance on Mental Illness (NAMI) is calling for nationwide expansion of Crisis Intervention Teams (CIT) to reduce fatal events involving police and people living with mental illness.

"CIT saves lives," wrote NAMI Policy Director Ron Honberg and NAMI CIT Program Manager Laura Usher in testimony submitted to a U.S. Senate Judiciary subcommittee hearing on April 29 on "Law Enforcement Responses to Disabled Americans."

"Police are often the first responders when a person is in psychiatric distress" said the NAMI testimony. "Every community owes it to them to provide the knowledge and training to handle mental health crisis situations safely and compassionately."

"At the same time, people living with mental illness-through no fault of their own-deserve to be helped through appropriate understanding and de-escalation tactics. Ultimately, we should be promoting treatment rather than warehousing them in jails and prisons."

CIT includes 40 hours of intensive training for police as well as coordination with mental health providers in a community to transfer individuals in crisis directly to treatment facilities.

The CIT model was established 25 years ago in Memphis. Following establishment of the Memphis program, injuries to police officers responding to mental health calls dropped 80 percent.

CIT helps to reduce arrests and save money, yet only 15 percent of law enforcement jurisdictions have adopted the program. One in five jail and prison inmates lives with mental illness. Many might have been diverted into treatment rather than incarcerated.

In calling for CIT expansion, NAMI emphasized that federal and state policies should focus on providing incentives rather than mandates. "CIT won't work if it is imposed from above," the testimony noted. "The commitment has to be rooted in the community, involving local leaders, police and mental health professionals."

THE FUTURE OF MENTAL HEALTH CARE

Huffington Post, Lloyd Sederer, MD, 4/21/14

On April 1, 1944, Mary began keeping a personal diary of her experience as a patient in a tuberculosis hospital, a sanatorium. She was a professional woman in her early 30s, married with a toddler of 15 months. She had been admitted to the hospital, according to the medical standards for care at that time, which called for months to years of rest, relaxation and fresh air -- the best therapeutic regimen known then for her illness. She had to leave Bill, her husband, as well as her work, community and baby son, Mark, for an extended period of institutional care -- with no guarantee of success. She did recover, over many months, yet wrote, "I feel bitter and miserable... anyone with some intelligence must surely learn how to treat oneself..." remarking on how the care she received was one to avoid, if at all possible.

It was also in 1944, after 100 years of service, that TB sanatoriums began to close, giving way to care that could be done, effectively and more agreeably, as patients lived in their homes, walked in their own neighborhoods and were surrounded by people who knew them and wanted to help. Mary experienced the end of a once necessary but, by then, dated era. Prophetic?

The origins of mental hospitals, with their mission of delivering humane medical care, date back well before the TB sanatoriums: Asylums, as they were first called, began in the late 1700s abroad and the early 1800s here in the U.S. At first, they were true to their mission. Over time, they were not -- not because of their intent or the dedicated people who worked in them. Instead, patients, families and doctors came to realize that dependent, institutional living typically undid a person's abilities to function as did their extraction from family and everyday life.

"Mental patients" in asylums also became (not for the first time) a target of social discrimination and stigma. To make matters worse, lengthy inpatient

treatments have not delivered demonstrable rates of clinical improvement, nor ensured that people who were mentally ill would no longer be a danger to themselves or others once out of hospital confinement. Also, the great financial and social investments in hospital-based treatment have not produced desired improvements in functioning for many people with chronic mental illnesses that would enable them to build a life with relationships, school or work, purpose, and dignity -- the same aspirations that we all harbor.

Massive reductions in hospital treatment for people with serious mental illnesses began in the 1960s, with the passage of the Federal Community Mental Health Act, the introduction of Medicare and Medicaid to pay for general hospital and some community services, and the widespread use of anti-psychotic and anti-manic medications that brought some of the most disturbing and disruptive symptoms under control. The aims of these massive social, clinical and economic changes, at that time, were to provide better care more humanely, sustain safety for patients and their communities, and more responsibly spend public dollars.

But while inpatient psychiatric beds decreased substantially over the ensuing decades, a commensurate increase in accessible and quality community mental health services and housing did not. Some attribute the growth of shelters and street homelessness and the high prevalence of mental illness in jails and prisons with the failure to deliver on the promises of the 1960s; this has been called "trans-institutionalization," where vulnerable people continue to be housed in institutions (like correctional settings or shelters) or tough it out on the streets.

What makes today, right now, opportune for realizing the hopes of 50 years ago is that states and counties no longer can afford to sustain the dysfunctional and costly medical, social and correctional services that have evolved. It is not only legally mandated but it costs less to have people live in supportive housing with mental and social services in the community than it does to pay for jails, prisons, shelters and acute care hospitals

(that often "house" people with mental illness admitted with infections, trauma, heart failure and the like because their medical needs have gone neglected). Now is the time for today's psychiatric patients to write, in journals or elsewhere, and record the transition from history's lengthy era of institutional treatment to lives of dignity, with family and friends, in their communities.

Three principal social and economic forces make achieving safe, humane and affordable mental health (and substance use) treatment in the community now seem inescapable are: 1) requirements that people be treated in what is called the "least restrictive environment"; 2) that costs be controlled by managing care to ensure that cost-effective treatments prevail over financially wasteful and ineffective services; and 3) that "patient/family first" care is provided, with vocal patient and family advocacy groups insisting that this works far better than services organized for the convenience of payers, practitioners and health care organizations.

While achieving these ends has to date defied real success, we now have the opportunity to try again, leveraging current, macro forces to escape centuries of institutional care in hospitals, other medical settings (like nursing homes), correctional facilities, and shelters.

1) Least Restrictive Environment

The US Department of Justice (DOJ), acting on decisions driven by the Americans with Disabilities Act (ADA) and a Federal legal decision (*Olmstead vs. LC*, 1999) has taken up the cause of people who are confined to settings that restrict their freedoms.

New York State is among many states where the DOJ has determined that entire groups of people are being denied their rights: Some of these people are in nursing homes, some in adult homes (congregate settings with disproportionate numbers of adults with mental illnesses), and some in psychiatric hospitals. But no matter where they are, the DOJ has demanded of New York and other states that they reengineer their services to ensure that these individuals live in less restrictive settings designed for them to succeed, even thrive, in community settings where they are more the masters of their own lives.

Olmstead has already resulted in plans, in New York and other states, to move people

out of nursing facilities, adult homes and state psychiatric hospitals. Not only will those already institutionalized need to be given opportunities outside of where they now reside but it also will impact those about to enter institutional care who will be entitled to receive clinical services in community settings, including housing, fit to meet the needs of people with significant disabilities.

2) Cost Control

Many states have engaged managed care companies to try to stem the runaway costs of Medicaid. Some began over 20 years ago. But the early years of managed medical care, especially for mental and substance use disorders, often were characterized by profit seeking that drained money from patient care and generated corporate windfall profits. Those excesses appear to be over, at least in this country, as clinical performance goals drive contracting and consumer advocacy organizations and governments have learned to better protect their interests.

The Affordable Care Act (Obama-care) will result in tens of millions of people nationally becoming insured, especially under Medicaid. New York State, with over 5 million people on Medicaid (with the state responsible for 50 percent of their costs), spends more per person and overall to provide medical services to these recipients than almost any other state or territory in the U.S. More people entering the insurance pool, in Medicaid and commercial carriers, will further raise the demand for prudent and effective management of services and dollars -- an essential alternative to sustaining financially unbearable and less than ineffective care. The vast expenditures of money on health and social services have not produced better outcomes for patients, families and communities

Medicaid is a "budget buster" in most states. And money spent on Medicaid is not available for education, transportation, safety, public health or other valued goals for a state's citizens. In 2015 (2016 for children and adolescents), all NYS mental health and addiction services will be managed by health plans, not under The Office of Mental Health and The

Office of Alcohol and Substance Abuse Services (OASAS), respectively, that heretofore have had responsibility for people with the most serious and persistent mental and substance use disorders.

What this means is that the Medicaid health plans will be the purchasers of mental health and addiction services. They will be at risk, financially and contractually, to improve access and health, using measurable, evidence based, quality services, and for doing so less expensively. This is a profound change in the landscape of care for mental health (and substance use) patients. This has happened in other states. Generally, it has not been pretty to observe as many states have had to learn the hard way to do it right. Providers of services, as well, have had to transform their work to be in compliance with Federal mandates for ADA and Olmstead.

This second force, cost control through managed care, is upon NYS, and continues to spread throughout the nation. There is still time to get it right, but not much. Time spent pretending it will not happen or imagining that hospitals or state and municipal governments will continue to ineffectively spend disproportionate state (and federal) dollars for high need individuals only delays the inevitable and will likely make it harder to effectively transform today's care into better, more affordable community based services.

3) Patients and Families First

A remarkable change in the culture of health care is underway and rapidly unfolding. Instead of "the doctor knows best" or delivering services for the convenience of providers we are witnessing an inversion: Services must now meet the clinical and personal need of recipients, not of those delivering or paying for them.

Recipients of services, patients and families, wisely want to be informed partners in their health care. "Nothing about us without us" is one way this has been articulated. For this to happen, medical information must be transparent and comprehensible. Data on the performance of providers (and governments) also must be publicly available, comprehensible and meaningful.

Advocates for mental health (and addictions) service recipients and families know that what works best are comprehensive,

continuous, evidence-based services delivered at times and in places that allow recipients to not have their work or family responsibilities disrupted. The use of hospitals, which by their nature abridge liberty, is the least desirable alternative for someone with an acute mental illness. Everyone has something to gain from preventing involuntary treatments delivered late in the course of an illness in settings removed from family and community.

The Future of Mental Health Care

The end of tuberculosis hospitals 70 years ago heralds the future of mental health care today, with its own unique movement away from institutions and into the community.

We owe people with mental illness, including substance use disorders, "patient-centered" care -- not as a slogan but as a standard of practice. People in crisis or leaving acute care need immediate access to services, same day appointments or home visits, instead of waiting for days or weeks for an appointment. Clinicians will need to meet with patients (and families) outside the four walls of a clinic, in settings more natural and less stigmatizing (this is particularly necessary for younger people). Care managers and patient "navigators" will need to help vulnerable people understand how to engage and remain in care that will give them a chance at recovery.

Patients and families must be active participants in treatment, and living a healthy life, especially for the vast majority of illnesses which do not abate in days, weeks or months (the global burden of disease has now tipped to chronic disorders, mental and general medical). "Shared decision-making" is but one way to make patients partners in their care and helps them take responsibility for managing their conditions.

We have learned a great deal about what treatments work (evidence-based treatments) for mental and substance use disorders. But the gap between what medical professionals know and what they do remains vast -- and represents an immediate opportunity to improve the public mental health.

Special attention needs to be paid to what is needed to keep youth in school and adults in work, or on a path to work. Medi-

cations must be prescribed in a highly judicious manner with particular attention to limiting or managing the side effects that frequently deter patients from taking them. Over-reliance on medications for children and adults, without using -- instead of or in addition to -- an effective psychotherapy or rehabilitation service, is unfortunate and shortsighted. Alternative and complementary medicine, including meditation, yoga, exercise, diet, and nutraceuticals, is employed by patients far more than doctors know; it needs to be welcomed into medical care as an ally, not as something alien to be eschewed.

We must enlist the help of families who can serve as an early warning system for problems in their loved ones. Most often (though not always) families also are the most reliable and enduring source of support for a person with a medical illness, including mental disorders.

All these ideas are not new. Many have been around for some time. But achieving on them will take an overhaul, not just more tinkering. We can provide better care with dignity and find ways to restore and save lives -- and money. Success will depend on undaunting leadership and relentless efforts because change of this magnitude is really hard, even when indisputably needed and conditions seemingly opportune.

Humane, patient centered services in least restrictive environments with prudently managed resources are the paths out of suffering, disability, coercion and unbridled costs. Staying the course, achieving these goals, would be something to be proud of.

A PARENT'S LEARNING CURVE

by Karen Winters Schwartz

"You have no idea what goes on in my head!"

It was true. I didn't. But at the time, I let those words and others of their kind pass over me. "I hate you!" "Everybody else is going." "Everybody hates me!"

It wasn't that I was complacent or cavalier. I was simply the mother of two teenage daughters, trying to do the best I

could when I had no idea what I was doing. All I could draw from was my own recollection of adolescence. I knew they didn't hate me, everybody else wasn't going, and everyone didn't hate them, because I had once felt the same way.

But the words "You have no idea what goes on in my head" have come back to me like tiny drops of guilt.

When I held each of my girls as newborns, I just knew this was the most beautiful baby ever. I just knew this child would grow to become the most amazing human being ever. This was not grandiose thinking - this was a new mother's reality.

Then in a blink of a baby's eye, my children - only 20 months apart - were both teenagers and all bets were clearly off. I found myself precariously treading the line of what was normal teenage angst and what pushed into foggy abnormality. When street drugs entered the picture, it only upped the ante.

Close encounters with the justice system, hysterical private and public scenes, suicidal despair, shouting matches, traumatic family dinners - these all became part of our "norm". My adolescence had not been like this. I had no reference point, no knowledge, and, it seemed, no place to turn.

When my older daughter, then 18, desperately asked for help, I tried--really I did--to get her an appointment with a psychiatrist. It turned into an impossible task. So I took her to a family doctor, the only place I could get her in. She was given an inaccurate diagnosis of depression and put on an antidepressant. Within a very short time, she was as sick as she ever would be.

Really, none of us knew what we were doing. We were all--even the doctors--just fumbling along.

If I had known then what I know now, I would have pulled my head up, brushed the sand from my face and *listened*. When my older daughter started school and began to tell me, "I have ADHD," I would have dug deeper into why she felt that way instead of just dismissing it.

When she became a defiant teenager, I would have resisted matching her anger with my own. When she was verbally abusive, I would have responded, "I love you, but I can't talk to you when you're like this." I would have given her the support to heal, without smothering her with my ineffective attempts at "fixing" her.

As it is, her struggles led me to the National Alliance on Mental Illness (NAMI). The knowledge and empathy I acquired from NAMI helped get us through the sudden decompensation of my younger daughter, making her road to wellness that much smoother - although I wish I'd known to pay more mind to her horrible night terrors and social struggles early on.

The truth is, I could not "fix" either of my children. They did not improve until I stepped back and let them do what was necessary to become the wonderful women they are - who they were so clearly and rightly destined to be.

What I know now is that no one is truly alone or helpless. Like so many, we share a story of survival and family and love. And though I will never truly know what goes on in my daughters' heads, I do have a better idea.

*Karen Winters Schwartz is a writer, speaker, and president of NAMI Syracuse. Her novels include **Where Are the Cocoa Puffs: A Family's Journey Through Bipolar Disorder** and the forthcoming **The Chocolate Debacle**.*

-- from bp magazine, Spring 2014



May is Mental Health Month!

What are you doing to raise awareness and educate the public about mental illness?

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____ Individual/Family 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

The NAMI Syracuse Support & Sharing Meeting facilitated by Sheila Le Gacy and Vanessa Watts is held on the 3rd Tuesday of each month at 7:00pm at Transitional Living Services, 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.)