NAMI Buffalo & Erie County
National Alliance on Mental Illness

the challenger

vol. 11 - No.3, Winter 2018

Mark Your Calendar - Meeting Location Info Below

Family Education Meetings *are held 2nd Thursdays of the month at St. Paul's Lutheran Church, 4007 Main St., Amherst (near Eggert Rd.) 14226 on the 2nd floor (main entrance at back of the church).* ***Family Support Group Meetings: NORTH*** *on 3rd Wednesdays, at St. Paul's Lutheran Church, 1st floor (church entrance at ground level at left rear of the building); and* ***SOUTH*** *on 3rd Thursdays, at the Watermark Wesleyan Church of Hamburg, 4999 McKinley Pkwy., Door 3, Rm. 124, Hamburg, NY 14075.* ***Board meetings*** *are usually at St. Paul's Lutheran Church (location listed above); members welcome. You may wish to call ahead to confirm meeting dates and locations.*

(Box above shows meeting locations.)

Dec - No Family Education Meeting
Happy holidays to you and yours
from NAMI Buffalo & Erie County!

4 Tues Board Meeting, *7 p.m.*

19 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

20 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

NOTE: New Door and Rm. # in box above.

Jan 2019 - Happy New Year!

8 Board Meeting, 7 p.m.

10 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Presenter: Christopher Syracuse, Executive Director/Vice President, Residential Services at Living Opportunities of DePaul. Topic: How DePaul helps individuals achieve their optimum level of independence and success in the environment of their choice*

16 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

17 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*
NOTE: New Door and Rm. # in box above.

Feb

5 Tues Board Meeting, *7 p.m.*

14 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Topic: ECMC's Comprehensive Psychiatric Emergency Program (CPEP); On-site Emergency Care and Other Services. Speakers: Susan Fallis, VP Behavioral Health Nursing, ECMC & Donna Gatti, CPEP Director*

20 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

21 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

Mar

5 Tues Board Meeting, *7 p.m.*

14 Thurs Education Meeting, *7 p.m. Library/coffee hour 7:30 p.m. Speaker: Best Self Behavioral Health, Topic TBA*

20 Wed Family Support Group, *NORTH, 7–8:30 p.m.*

21 Thurs Family Support Group, *SOUTH, 7–8:30 p.m.*

President's Corner

I am honored to have been elected in October and beginning to serve a one year term as the new Board President of NAMI Buffalo & Erie County. I'd like to take a minute here to introduce myself to you. I joined NAMI early in 2013 so I could learn about serious mental illness, as a loved one had recently been diagnosed with such an illness. Taking the Family-to-Family class touched me in such a way that I became a teacher. I enjoy volunteering and helping in any way, and joined the Board—and took on the role of Chair of the Outreach Committee as well. As I met more and more of our volunteers and class participants, I continued learning about the challenges to families coping with a loved one's serious illness. I was inspired by their courage and strength to step up. My experience with HelpLine volunteers, learning about issues and advocacy at NAMI state and national conferences, and commitment to making NAMI an even better known organization moved me to step forward into this new leadership role.

- Special thanks to our out-going Board President, Ann Venuto, who guided NAMI through some new adventures with such grace and dedication.

- Thank you, also, to Jackie Thompson who was elected as Vice President—I look forward to all we will accomplish together; and thanks to Cambria Daniels, staying on as Recording Secretary, and Johnathan Miles, our continuing Treasurer.

- Thank you to retiring Board members Mary Lou Bond, Colleen Frey, Marcy Rose, and Barbara Utter who will form the core of the newest Advisory Board and stay on, active as ever, and volunteering where needed: HelpLine calls, Crisis Intervention Team (CIT) trainings, membership renewal work, our annual

President's Corner *cont.'s on pg. 2*

President's Corner *from pg. 1*

holiday project—and the many other things we count on your presence with us for.

- A warm welcome to new Board Members Linda Mallia, Gail Michaels, and Christopher Syracuse. We are excited to have you join us and look forward to your enthusiasm and participation.

- Our outreach in October, with National Mental Illness Awareness Week, included many wellness fairs and community events, including several new ones: "Pink for Life" with Alpha Kappa Alpha Xi Epsilon Omega Chapter; Ingram Micro; U.S. Customs and Border Protection agents; True Bethel Baptist Church, and Hilbert College among others.

- Our three fall Family-to-Family classes are coming to a close, including our first class at the Niagara Falls Memorial Medical Center. We are looking forward to the spring classes—our list of people interested in the class grows constantly.

- NAMI Buffalo & Erie County was selected to be the Affiliate of the Year at the NAMI NYS Education Conference in October.

- DJ Jaffe, author of "Insane Consequences: How the Mental Health Industry Fails the Mentally Ill", speaker, Executive Director of the Mental Illness Policy Org. and ardent activist for people with a serious mental illness spoke on November 1st at Daemen College with sponsorship by NAMI Buffalo & Erie County and the Patrick P. Lee Foundation. There were 150 people there, despite awful weather. He also addressed area psychiatric professionals at Grand Rounds the following day.

- We continue to advocate for more funding for research and needed services; for safe, affordable housing; and putting a stop to the incarceration of people with a serious mental illness.

- The Board has begun a process of creating a new strategic plan, thanks to a generous grant from the Peter & Elizabeth Tower Foundation. The grant enabled us to engage a consultant to lead us through this process. A well-articulated plan is critical as we position ourselves to expand our programs and services, and meet the needs of our member families and the community. Please contact us with issues or needs you'd like considered as we craft the plan.

It has been a strong start and smooth transition into this presidency for me because of the shared experience and support of all my fellow board members and our staff. I look forward to continuing progress on many fronts to improve the quality of life for those who live with serious mental illness.

Thank you!

Liz Carone

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Our Fall Fundraiser is underway! Please give as generously as you are able to our once-a-year drive to ensure our work is supported throughout the coming New Year.

Special thanks to:

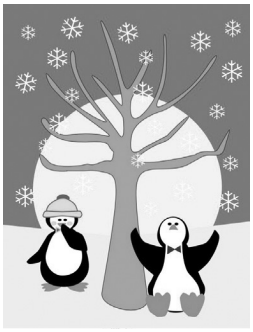
Patsy Foster and **Ann Venuto** for covering presentations to dozens of school districts' counseling and nursing staff groups this fall. Mental health and illness awareness, and the need to fight stigma are "hot" issues as we head into cooler temps. Also, **to Sherry Byrnes, Liz Carone, Bryan Taylor,** and **Jackie Thompson** who represented us at many community outreach and awareness events.

Judy Capodicasa, Colleen Frey, Carol Ann Gleason, Jill Mead, and **Sue Stievater** for their help with membership renewals and bulk mailings—you are gems!

Support group facilitators (Amherst) **Virginia Eberle, Pat Seifert, Ann Venuto** and (Hamburg) **Terry Fleig** and **Karen Gordon** who bring consistent comfort and relief to so many families.

Congratulations to **Lynda Regan** for re-election to the NAMI-NYS board. We appreciate your time and dedication in representing our WNY voice in Albany.

Our deepest condolences to the Regan and Hoekstra families who recently lost loved ones and honored NAMI Buffalo & Erie County with requests for donations in their loved ones' memory.



As the Holidays Approach, Some Changes for Our *Christmas is for Kids!* Project

Christmas is for Kids! has been a beloved project of NAMI Buffalo for nearly 30 years. It has provided gifts, and joy, to countless children and adolescents throughout WNY during the holiday season. We look forward to continuing our tradition of bringing joy and holiday cheer to children who are in the hospital or residential treatment facilities for psychiatric care. Our commitment to these children remains as strong as it has been for the nearly three decades of the project.

Due to a number of factors, we are returning to the *Christmas is for Kids!* project's original focus, intent, and scale: providing gifts primarily to children who are in residential treatment and hospital settings. Over the past few years, changes in volunteer availability, especially with some key retirements, and limited staff hours have outpaced our ability to continue coordinating this project with the numerous non-residential programs and organizations we had "grown into", especially during the short holiday season. It simply became overwhelming to handle the volume of toy donations and requests for not only in-patient and residential children but for other agencies whose needs--while certainly worthy--are beyond our scope.

This season we will continue to provide gifts for children and youth at WNY Children's Psychiatric Center, BryLin, ECMC, Transitional Services, Inc., Baker Victory Services, and others who fall within our project's focus.

We want first and foremost to thank all of you who have donated and volunteered generously for *Christmas is for Kids!* over the years.

In going forward with a more manageable *Christmas is for Kids!* project, one that reflects our volunteer and staff capacity, we are not making a separate request this year for donations to *Christmas is for Kids!* We hope, however, you will consider donating to NAMI Buffalo & Erie County so we will be able to effectively serve families in advocating for and meeting the mental health needs of their children-of all ages--with our programs and services all year long.

Christmas is for Kids! **Changes** *cont.'s on pg. 5*

New York State Health Care Open Enrollment Period is Now

Did you know it's time to sign up for health coverage for 2019? If you need health insurance in NewYork state, you must enroll during the period from **November 1, 2018** through **January 31, 2019.** In order for coverage to begin on January 1, 2019, though, you must enroll by **December 15, 2018.** The NYS open enrollment period closes on **January 31st, 2019.**

You can enroll in, or renew, a health plan by:

- Calling the Customer Service Center at 1-855-355-5777.
- Logging onto **www.nystateofhealth.ny.gov**
- Meeting with an In-Person Assistor (IPA) Navigator.

For a list of assistors near you, call the number above or go to "Get Help" on the website and click on "IPA/ Navigator Site Locations" where you can open a printable downloadable directory of all NYS county sites for in-person help. If you can't access the internet, contact the Customer Service Center number above.
Note: If you are eligible for the Essential Plan, Medicaid and Child Health Plus (very low income limits) enrollment is open all year.

Here are the top things you need to know:

The Affordable Care Act (ACA) is still the law and ensures that health coverage is available for those who need it.

Comprehensive coverage is available. New York State or HealthCare.Gov plans cannot discriminate against you due to your mental health condition. Additionally, they must include key benefits like mental health care, prescription drug coverage and hospitalization services.

Coverage is affordable. Most people will qualify for a discount based on their income. Last year, more than 8 in 10 enrollees could get a plan for less than $100/ month. Additionally, premium price increases for 2019 are expected to be much lower than previous years, and some states will even see price decreases.

Nationally, enrollment runs from Nov. 1- Dec. 15.
Some states (like New York) offer extended deadlines, but in order to have coverage that begins Jan. 1, you must enroll by Dec. 15.

Need to Know *cont.'s on pg. 5*

News from the Substance Abuse and Mental Health Services Administration (SAMHSA)

Following is a synopsis of an online article, "The Substance Abuse and Mental Health Services Administration (SAMHSA): New Directions" by Elinore McCance-Katz, M.D., Ph.D. published in *Psychiatric Services* 2018;69:1046-1048 doi: 10.1176/appi.ps.201800281 1048; Aug. 13, 2018 and additional comments by NAMI Buffalo & Erie County President Emerita Ann Venuto, RN

N.B. - Previously the Chief Medical Officer of the Substance Abuse and Mental Health Services Administration (SAMHSA), Elinore McCance-Katz, M.D., Ph.D. resigned because of concerns that SAMHSA was not addressing the needs of the seriously mentally ill (as our recent speaker DJ Jaffe of Mental Illness Policy Org. documented and affirmed). Since her return as the first Assistant Secretary for Mental Health and Substance Use overseeing SAMHSA, partially motivated by the 21st Century Cures Act, she is promoting a clear vision of the new directions the organization must pursue.

The foundation of McCance-Katz's plan is to prioritize, "…the training of health care practitioners to provide evidence-based treatment and technical assistance to provider organizations that will help to ensure the modernization of the care and delivery of mental and substance use disorder services." Of all of the criticisms of SAMHSA, the lack of rigorous standards for evidence-based programs was their greatest weakness. This commitment to scientific standards is the best hope for recovery for those who live with serious mental illness and/or substance use disorders.

In addition McCance-Katz has championed a national system of technical assistance and training that will be available at low-cost or no cost to any individual or program. A national Evidence-Based Practices Resource Center will catalog evidenced–based programs and practices such as Treatment Improvement Protocols, clinical practice guidelines, toolkits and other resources to clinicians and communities who are in need of more supports. (www.samhsa.gov/ebp-resource-center).

The American Psychiatric Association (APA) has been named as the grantee for the Clinical Support System for Serious Mental Illness, offering webinars, online trainings with an emphasis on pharmacotherapy including the use of clozapine, long-acting injectables and guidelines to address metabolic syndrome which is often a side effect of atypical antipsychotics. A course on Assisted Outpatient Treatment (AOT) will be featured as well.

SAMHSA's new vision includes launching new technology transfer centers across the country, including hubs that will focus on serving Native Americans and Latinas These centers will guarantee that all health care providers and agencies are eligible for education that will enhance their proficiencies to meet the mental health and substance use disorder needs of all Americans.

McCance-Katz has emphasized that the agency will shift more of its focus onto serious mental illness, providing evidence-based psychiatric treatment which previously had suffered from neglect. SAMHSA will support, "… a collaborative care model with community resource providers, including peers and recovery supports". Other priorities are the promotion of Zero Suicide, mental health courts, diversion from incarceration, Assisted Outpatient Treatment (AOT) and Assertive Community Treatment (ACT). Additional funding was recently approved for Certified Community Behavioral Health Clinics which model integrated care for substance use disorders, mental illness and medical care. The need for peer and family supports has been addressed as well.

> *These are important times for addressing behavioral health issues --specifically, the mental and substance use disorders that affect over 64 million Americans every year. The enactment of the 21st Century Cures Act brought into sharp focus the importance of these issues in the lives of individuals, families, communities, and the nation. Never in the history of this country has there been a time of greater need for attention to these issues. ~ Elinore McCance-Katz*

N.B. - It's no surprise that Dr. Elinore McCance-Katz in her new title at SAMHSA has been named as one of the 50 most influential physician executives and leaders by Modern Health Care Media. The new directions offered by SAMHSA provide hope to those who live with mental illness and the people who advocate for them.

Original article: https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201800281

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Need to Know *from pg. 3*

How should you choose your health plan?

Whether choosing insurance for the first time or reevaluating your current plan, here are some things to keep in mind:

Affordability. Compare monthly premiums, deductibles, co-pays and/or co-insurance to make sure you have selected the best option for your health insurance needs. Consider not only about how much you will pay each month in premiums but also how much you will need to pay to cover co-pays and co-insurance.

Availability of mental health professionals. If you use mental health care, check to see if your mental health professional(s) and other health care providers are in a health plan's network. If they are not, find out if the insurance plan will pay for out-of-network providers—and how much they will cover.

Coverage of prescription medications. If you currently take any medications, find a plan that covers the medication(s) you need to maintain your wellness.

Limits on mental health office visits. Check to see if a plan will cover the number of therapy visits you may need. Depending on your needs, you may also need to consider differences in inpatient and outpatient coverage.

Don't wait to get health insurance.

Although there is no longer a penalty for being uninsured for 2019, don't risk not having health and mental health coverage in the new year. The enrollment period is just a few weeks long. Take action by Dec. 15. Help is available.

Signing up for new coverage or renewing your plan takes as little as 10 minutes. Get started now by going to www.nystateofhealth.ny.gov.

NYStateofHealth.ny.gov is the place to start. HealthCare.Gov or your state-based marketplace can only sell ACA plans, so you can rest easy knowing you're getting a comprehensive plan that will be there for you when you need it.

All health plans offered through Healthcare.gov, including New York State's healthcare plans, must cover mental health and substance use services at the same level as other health conditions. However, some plans offer better benefits than others, so review your options carefully. ***For health coverage in states other than New York, call the national marketplace call center at 1-800-318-2596 to find in-person local help.***

Having health insurance can provide peace of mind, financial security and access to comprehensive health care. Join the millions who have gained health insurance thanks to the ACA.

An important note is that 8 out of 10 people who sign up on Healthcare.gov qualify for financial help, which can lower your monthly premiums by about $50 to $100.
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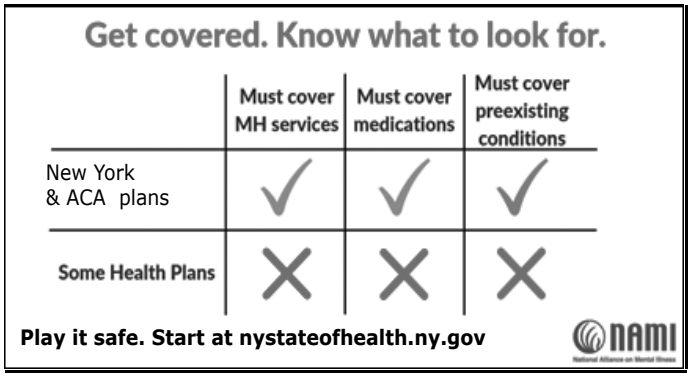

Christmas is for Kids! Changes *from pg. 3*

We are especially grateful to Mary Kirkland and the founders of *Christmas is for Kids!,* and all our previous chairpersons and volunteers for building an amazing, kind, thoughtful holiday-giving project for children in psychiatric care in our community. Under the continuing direction of Mary Lou Bond, we hope to continue to bring joy to patients at the holidays and throughout the year. For those who have volunteered on Wrap Day in the past, we invite you to help us with gift donation pick-up, sorting and delivery from Monday, December 10th - Friday, December 14th. To schedule a time to help, contact project chair Mary Lou Bond at 716-649-7581. We wish you happy holidays and a bright new year.
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Proposed Corrections Specialist Advisory Board for County Jail Oversight Needs More Representation on Behalf of Those with Mental Illness

Please contact your county legislators!

A proposed Erie County law, if enacted, will establish an advisory board to the sheriff's jail management division. Creating such a board may help to end years of abuse and neglect prisoners have suffered in our county jails, especially those with serious, untreated mental illness. **We encourage you to please send a letter to your county legislator in support of the bill's passage.**

The complete proposed bill, sponsored by Leg. April N.M. Baskin (Chair of the Public Safety Committee), LL Intro. 8-1, dated 9/6/18 can be found on line at: https://bit.ly/2zr3Rih

Here is a sample letter to send if you are rushed for time. You may write you own letter if you wish.

Dear Legislator _____,

I write to ask that you vote in favor of the proposed local law to establish a Corrections Specialist Advisory Board, with representation for those affected by mental illness and substance abuse. The long history of mismanagement of our county jails, and history of prisoner abuse and neglect convince me that we need such a board. As I understand it, its members will volunteer their time, so the cost to the county is nil, and its potential to improve conditions is great.

Respectfully,

Your name
Your address
Date

You can send your letter to your representative by e-mail, or by the US Postal Service. Here are the legislators' e-mail addresses:

§ **District No. 1: Hon. Barbara Miller-Williams**
District Office: 427 William St., Buffalo 14204 - Phone: 842-0490; Fax: 854-5722; E-Mail: Barbara.Miller-Williams@erie.gov

§ **District No. 2: Hon. April N.M. Baskin (Majority Leader)**
District Office: 792 E. Delevan Ave., Buffalo 14215 - Phone: 895-1849;Fax: 895-1910; E-Mail: April.McCants-Baskin@erie.gov

§ **District No. 3: Hon. Peter J. Savage, III (Chair of the Legislature)**
District Office: 1701 Hertel Ave., Buffalo 14216 - Phone: 832-0493; Fax: 832-0494; E-Mail: Peter.Savage@erie.gov

§ **District No. 4: Hon. Kevin R. Hardwick**
Legislative Office: 92 Franklin St., 4th Floor, Buffalo 14202 - Phone: 858-8672; Fax: 858-8818; E-Mail: Kevin.Hardwick@erie.gov

§ **District No. 5: Hon. Thomas A. Loughran**
District Office: 4549 Main St., Ste. 203, Amherst 14226 - Phone: 836-0198; Fax: 836-0199; E-Mail: Thomas.Loughran@erie.gov

§ **District No. 6: Hon. Edward A. Rath, III**
Legislative Office: 92 Franklin St., 4th Floor, Buffalo 14202 - Phone: 858-8676; Fax: 858-8818; E-Mail: Edward.Rath@erie.gov

§ **District No. 7: Hon. Patrick B. Burke**
District Office: 2189 Seneca Street, Buffalo 14220 - Phone: 823-0752; Fax: 826-2870; E-Mail: Patrick.Burke@erie.gov

§ **District No. 8: Hon. John Bruso**
District Office: 5135 Transit Road, Depew 14043 - Phone: 858-8856; Fax: 858-8895; E-Mail: John.Bruso@erie.gov

§ **District No. 9: Hon. Lynne M. Dixon**
Legislative Office: 92 Franklin St.,4th Floor, Buffalo 14202 - Phone: 858-8671; Fax: 858-8818; E-Mail: Lynne.Dixon@erie.gov

§ **District No. 10: Hon. Joseph C. Lorigo (Minority Leader)**
Legislative Office: 92 Franklin St.,4th Floor, Buffalo 14202 - Phone: 858-8922; Fax: 858-8818; E-Mail: Joseph.Lorigo@erie.gov

§ **District No. 11: Hon. John J. Mills**
Legislative Office: 92 Franklin St., 4th Floor, Buffalo 14202 - Phone: 858-8850; Fax: 858-8818; E-Mail: John.Mills@erie.gov

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The Crazy Talk About Bringing Back Asylums

by the New York Times Editorial Board

The editorial board represents the opinions of the board, its editor and the publisher. It is separate from the newsroom and the Op-Ed section.

June 2, 2018

When President Trump mused that the mass shooting at a high school in Parkland, Fla., in February might have been prevented if the United States had more mental institutions, he revived a not-quite-dormant debate: Should the country bring back asylums?

Psychiatric facilities are unlikely to prevent crimes similar to the Parkland shooting because people are typically not committed until after a serious incident. Still, a string of news articles, editorials and policy forums have noted that plenty of mental health experts agree with the president's broader point.

The question of whether to open mental institutions tends to divide the people who provide, use and support mental health services — let's call them the mental health community — into two camps. There are just 14 or so psychiatric beds per every 100,000 people in the United States, a 95 percent decline from the 1950s. One camp says this profound shortage is a chief reason that so many people suffering from mental health conditions have ended up in jail, on the streets or worse. The other argues that large psychiatric institutions are morally repugnant, and that the problem is not the lack of such facilities but how little has been done to fill the void since they were shut down.

Neither side wants to return to the era of "insane asylums," the warehouse-like hospitals that closed en masse between the 1960s and 1980s. Nor does anyone disagree that the "system" that replaced them is a colossal failure. Nearly 10 times as many people suffering from serious mental illnesses are being kept in jails and prisons as are receiving treatment in psychiatric hospitals.

What's more, both sides broadly agree that mental institutions alone would not be the solution. "Bring back the asylums" sounds catchy, but here are some more useful slogans to help steer the conversation:

1. DEMAND SENSIBLE COMMITMENT STANDARDS Exact wording varies by state, but commitment standards in general dictate that people cannot be hospitalized against their will unless they pose a clear and significant danger to themselves or others. That sounds reasonable, but with so few inpatient facilities, mental health workers have a strong incentive to determine that even someone who needs to be committed — perhaps someone dangerously delusional — does not meet that standard.

2. CREATE A CONTINUUM OF CARE Deinstitutionalization was predicated on the 1963 Community Mental Health Act, which was supposed to create well-staffed, well-funded community mental health centers in about 1,500 catchment areas across the country. These centers were supposed to provide clinical care, housing and employment support, and community outreach. When President John F. Kennedy announced the legislation, he estimated that it would ultimately return about half of the 500,000 or so people then living in state psychiatric hospitals to be "treated in their own communities and returned to a useful place in society."

If only the law had been given a chance to work. States failed to devote their savings from the closure of large institutions to community-based care, and few communities were willing to host the centers in their backyards. In the end, only about 750 centers were ever built, and zero were ever fully funded. Today, less than half of all adults suffering from mental health conditions receive help, and mental illness is the leading cause of lost workdays in the United States, costing about $193 billion in lost earnings a year.

People who suffer from behavioral and psychiatric disorders need and deserve a wide range of care options: community mental health centers, short-term care facilities, and — yes — longer-term arrangements for the small portion of people who can't live safely in the community. The pro-asylum camp is right that the number of people needing those longer-term placements is greater than zero. But the figure is also small enough to avoid the need for the thousand-plus-bed facilities that were once the sites of so much abuse.

3. STAND UP FOR INSURANCE PARITY This October marks 10 years since Congress passed the Mental Health Parity and Addiction Equity Act, which requires health insurers to provide the same level of benefits for mental health treatments and services as they provide for medical and surgical care. On paper at least, both the Affordable Care Act and the 21st Century Cures Act bolstered that 2008 statute by requiring plans on the health insurance exchange to cover a list of essential behavioral health benefits and by enacting greater enforcement of the parity rules.

In practice, though, the three laws have yet to create true equity. "In some situations, you still can't get into a psychiatric facility unless you are suicidal or otherwise near death," says Ellen Weber, vice president for health initiatives at the Legal Action Center, a nonprofit that is fighting parity violations in several states. "That's an abhorrent double standard. We don't do that for medical or surgical need."

Asylums ***cont.'s on pg.8***

NAMI Excited With New Opportunities To Improve Medicaid Mental Health Care

11/13/2018
Source: www.nami.org; https://bit.ly/2SgjD6m

Secretary Alex Azar, U.S. Health & Human Services, announced that the Administration will allow states to apply for Medicaid waivers to pay for mental health treatment in inpatient settings known as IMDs, or institutions of mental disease. Historically, Medicaid has not paid for treatment in these settings for most adults. While this policy was intended to reduce inhumane institutionalization, it also resulted in unequal coverage of mental health and, tragically, a lack of appropriate options for people with severe mental health conditions. If we treated other chronic conditions this way, far more people would die from diabetes, epilepsy, hypertension and heart disease.

On September 12th, NAMI and 11 of our colleagues on the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) sent a letter to Administrator Seema Verma of the Centers for Medicare & Medicaid Services, calling for Medicaid to cover care provided in inpatient settings, or IMDs and strengthen quality and continuity of care to community services. The ISMICC letter also asked for greater flexibility to pay for evidence-based outpatient services to reduce reliance on hospitalization, such as Coordinated Specialty Care in early psychosis programs and Assertive Community Treatment (ACT) teams. We are so pleased that our recommendations were well received and are being implemented. These changes will make a positive impact on people living with severe mental illness.

"This is a landmark day for people living with severe mental illness and their families," according to Mary Giliberti, NAMI's CEO. "ISMICC played a key role in changing the paradigm from neglect to one of care and compassion for the millions of children, youth and adults of all ages who live with severe mental illness in America. We're grateful that the Administration listened and provided the flexibility and direction for states to improve access to continuity of care for millions of Americans and their families."

NAMI applauds CMS for issuing a detailed letter to State Medicaid Directors that not only allows greater flexibility for inpatient treatment in IMDs, it also takes heartening steps to encourage states to improve outpatient services, including crisis stabilization programs. Today's guidance could provide a shot in the arm to mental health care. NAMI strongly urges states to step up to the plate and use this flexibility from CMS to improve care for people with mental health conditions.
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Asylums *from pg. 7*

And because regulators at the federal Departments of Labor and Health and Human Services are required to investigate complaints, not prevent them from happening, the burden of proving a parity violation falls on the consumer. "This is a law that's almost impossible to enforce as it stands," Ms. Weber says. "It requires a tremendous amount of information gathering and sophisticated analysis that most consumers are not equipped to take on, especially in the middle of a medical crisis."

Why not have regulators certify that plans meet parity rules before they go to market? Officials at H.H.S. and the Department of Justice could then step in to police insurers for violations — before problems become clear. While we're at it, Medicaid ought to lift its longstanding exclusion of inpatient psychiatric care.

Because "asylum" is a loaded term, it can draw attention to crucial issues facing vulnerable Americans, but it also tends to foreclose discussion of real solutions. Most of those solutions aren't even controversial. There just needs to be the collective will, and basic decency, to act.

A version of this article appears in print on June 3, 2018, on Page SR8 of the New York edition with the headline: The Crazy Talk About Asylums.
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In Research News...

Medicinal Herb May Relieve Worsening Symptoms of Schizophrenia

From *Brain & Behavior Research Foundation eNews*, Sept. 5, 2018

A small clinical trial reported July 10 in the *Journal of Clinical Psychiatry* suggests that patients with schizophrenia whose symptoms have recently worsened may benefit from taking a medicinal herb called ashwagandha in addition to their regular medications.

Ashwagandha, or Withania somnifera, has been used as a traditional medicine in India for thousands of years. In a randomized study involving 66 patients, it was more effective than a placebo at reducing the "negative" and other general symptoms of schizophrenia as well as patients' stress over a 12-week treatment period.

The negative symptoms of schizophrenia include social withdrawal, poverty of speech and difficulty showing emotions. These tend to be the symptoms that patients and families say are most disruptive to their lives, and they are harder to treat than the disorder's "positive" symptoms—hallucinations, delusions, and other disturbances in thinking. The latter are successfully managed in many patients with currently available antipsychotic medicines.

K.N. Roy Chengappa, M.D., FRCPC, a 2007 and 2004 Brain & Behavior Research Foundation (BBRF) Independent Investigator at the University of Pittsburgh Medical Center, led the study investigating ashwagandha's effects. He and his team, including 2004 BBRF Young Investigator Jaspreet S. Brar, MBBS, Ph.D., also at the University of Pittsburgh Medical Center, were hopeful that it might help patients with schizophrenia because the herb is thought to have anti-inflammatory and immune system-modulating effects. Some scientists suspect excessive inflammation contributes to the symptoms of schizophrenia.

Participants in the study were in their mid-to-late 40s and had been living with schizophrenia for more than 20 years. All were taking antipsychotic medications, and all had experienced recent exacerbations in their symptoms. During the clinical trial, they continued their regular medications and also took either an ashwagandha extract or a placebo each day for 3 months.

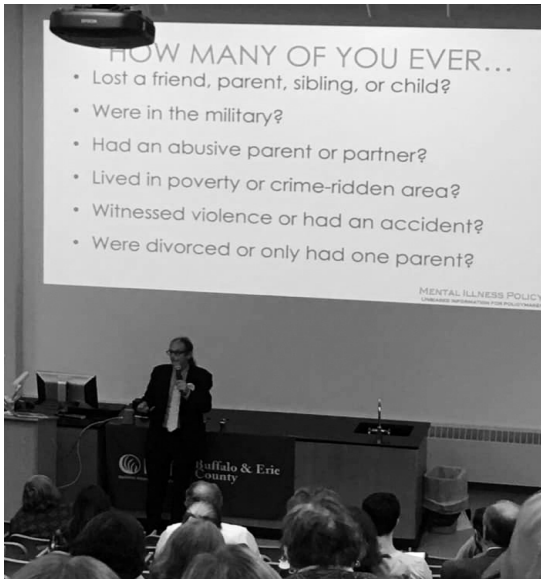
Dr. Chengappa and his colleagues began evaluating the effects of the treatment after two weeks. Beginning at 4 weeks and through the end of the 12-week study, patients receiving ashwagandha exhibited significantly greater reductions in negative symptoms than those taking the placebo. They also experienced a greater reduction in general psychiatric symptoms, such as depression and anxiety. Ashwagandha had no significant effect on patients' positive schizophrenia symptoms. Side-effects were transient and mild, sedation being more common in those taking ashwagandha than placebo, Dr. Chengappa says.

■

NAMI-NYS Education Conference 2018 Recap

NAMI Buffalo & Erie County was named NYS affiliate of the year and was represented by (L to R) Michele Brooks, Executive Director; Jackie Thompson, Vice President; Liz Carone, President; with Dr. Xavier Amador, author of "I'm Not Sick, I Don't Need Help"; and Lynda Regan, NAMI Buffalo & Erie County Board Member and NAMI NYS Board Member.

NAMI Buffalo & Erie County was also represented with workshops presentations that included former president Marcy Rose, on Crisis Intervention Teams (CIT), Rev. Daryl Bennett, on NAMI Faithnet; and new NAMI Buffalo & Erie;County Board Member Christopher Syracuse, on Housing Options.



Above, L to R:
NAMI volunteers greet event guests; DJ Jaffe presenting at Daemen College; Erie County Commissioner of Mental Health, Michael Ranney with NAMI Buffalo Executive Director Michele Brooks.

DJ Jaffe Event on Nov. 1 a Great Success

On November 1st, NAMI Buffalo & Erie County welcomed author and activist DJ Jaffe to western New York at Daemen College. Jaffe presented to an audience of over 150 people many important issues and policy perspectives that affect treatment and support for those who live with serious mental illness, and their caregivers and families.

For those interested, DJ also signed copies of his book, "Insane Consequences: How the Mental Health Industry Fails the Mentally Ill". It was a thought provoking, highly successful evening.

We are grateful to the Patrick P. Lee Foundation for supporting this event.

■

The Brain Continues to Develop in Young People With Schizophrenia, Research Reveals

A research team has discovered something important—and encouraging—about what happens to the brain in the period immediately following the onset of schizophrenia. Based on analysis of functional MRI brain imaging, they conclude that during the first one to two years following diagnosis, the brain continues to follow its normal developmental path in most young patients.

Such patients do not show deterioration or disruption of the developmental process, the researchers say. This is important since the illness typically manifests during adolescence or young adulthood, a period crucial in the maturation of the brain. "Patients show ongoing brain development comparable to that of healthy controls [of the same age], highlighting the possibility for plasticity and developmental capacity" that might be boosted by therapy.

In arriving at their conclusion, the team, led by Foundation Scientific Council member Cameron S. Carter, M.D., of the University of California, Davis, focused on cognitive control. This refers to brain functions that allow information processing and behavior to vary adaptively from moment to moment depending on a person's current goals, rather than remaining rigid and inflexible.

Impairments in cognitive control are associated with deficits in attention, memory, language comprehension and emotional processing, and have long been observed in people with schizophrenia.

The essential point in the newly published research, which appeared October 3, 2018 in JAMA Psychiatry, is that the brain continues to develop after schizophrenia is recognized. In a group of 180 young participants aged 12 to 25, 87 of whom had been diagnosed with schizophrenia, patients performed less well than healthy controls of the same age in performing tasks reflecting cognitive control. Yet both groups showed improvements when followed up over the next two years, reflecting the fact that their brains continued to develop.

"Patients continue to benefit from

(Cont's on pg 11, col. 1)

ongoing brain maturation," say the researchers, who included 2012 BBRF Young Investigator Tara A. Niendam, Ph.D., the paper's first author, also of UC Davis. The team also included Daniel Ragland, Ph.D., a 2004 BBRF Independent Investigator; and Marjorie Solomon, Ph.D., a 2009 BBRF Young Investigator. Dr. Carter, the senior team member, is a 2001 Klerman prizewinner, 2007 Distinguished Investigator and 1994 Young Investigator.

The team suggests that future research should examine the effects of various interventions, such as cognitive training, psychotherapy, medication and supported education and employment on the trajectory of cognitive control deficits in schizophrenia and other illnesses that involve psychosis.

Related Article:
Computer-Delivered Cognitive Training Significantly Helped Schizophrenia Patients in Rehab Setting

■

Please consider naming NAMI Buffalo & Erie County in your will. Your gift ensures that your support for our mission will continue into the future.

Thank you.

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A copy of our latest annual report may be obtained upon request from our office and the Charities Bureau, 28 Libertry St., 15th flr., NY, NY 10005

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Gratitude unlocks the fullness of life. It turns what we have into enough, and more. It turns denial into acceptance, chaos to order, confusion to clarity. It can turn a meal into a feast, a house into a home, a stranger into a friend.
~ Melody Beattie

Season's Greetings

and best wishes for a Happy New Year!