Executive Director’s Message  By Wendy Burch

Those who are actively involved with NAMI in New York will see over the upcoming year an increased emphasis on “Telling Your Story.” Many of us have recognized firsthand how powerful and impactful relating one’s own experiences can be when told to members of the public and decision makers. We have several newly trained NAMI Smarts trainers strategically located around the state available to offer training to NAMI affiliates on how to effectively advocate with legislators.

The NAMI-NYS 2019 Education Conference, set for October 25-27 in Albany, will also focus on various ways to tell our stories. In addition to workshops and lectures, this will involve theatrical, artistic and musical modes of expression for relating our own experiences on a more personal level.

We have the unique opportunity this year to be able to offer another event that promotes creativity to raise awareness and much needed funding for NAMI-NYS initiatives. The “Off the Mask” fashion show and juried art exhibit will showcase people using their stories to bring attention to mental health. “Off the Mask” refers to our commitment to being more open about mental health conditions and the need to stop hiding behind the masks and instead be our true selves. The more we talk about it, the more we dispel the stigma of mental illness and encourage the community to advocate for access to services for all who need them. The event is taking place the evening of May 10th at the Hearst Media Center in Albany.

NAMI-NYS is also proud to announce the completion of the re-affiliation process in 2018. Congratulations to all the affiliates who either remained a NAMI or joined its members with another affiliate. This has been a work in progress for several years, and now that it is complete, the affiliates can better concentrate on providing the support, education and advocacy so vital to the wellbeing of their communities.

Best wishes on a successful year of telling our stories and making a difference for the lives of those impacted by mental health conditions.

New Board Members

NAMI-NYS welcomes back five Board members for another term, including Lynda Regan, Cecelie Green, Rob Laitman, Evelyne Tropper and Judy Watt. Ariel Coffman was appointed to fill the vacant position left by former BOD member Erin Clancy, who resigned in 2018. All have contributed so much to NAMI-NYS in the past, and we are happy to have them serve another term with the NAMI-NYS Board of Directors.

Social Media

Website: www.naminy.org  NAMINewYorkState  @NAMINEWYORK
President’s Message  By Ariel Coffman

First and foremost, I must say thank you. If you are reading this message you are undoubtedly someone who cares deeply about advancing the cause of dignity, health access, treatment and opportunity for people affected by mental illness and neurobiological disorders. NAMI-NYS only exists because of you, and I hope during 2019 I will be able to meet as many of you as possible.

I must preface the rest of this message by telling you that I am bone tired as I write this. While I hold the work of NAMI as one of my top priorities this year, my life hasn’t stopped to accommodate my new responsibilities. Every day is still a balancing act that includes working full-time at a behavioral health center, managing our family’s household, showing up for my Dad as his primary support, and when needed, as his advocate and caretaker.

I have been at the hospital with my father twice this week and over the past ten years, I would venture to say I have sat by his side through nearly 20 hospitalizations, both medical and psychiatric. While I don’t know every NAMI member, advocate, and individual in recovery who is reading this story personally, I am confident that my story rings true to each of you. Each person I have met through NAMI-NYS has their own unique individualized story that has defined their life. These stories have the power to impact the world profoundly. Our stories, filled with empathy, pain, gratitude, grit and perseverance of body and spirit are what makes NAMI so special. We do not do this work for accolades, we do it out of love and the sheer human desire to see our own lives and the lives of our friends and family members get better. Each one of us has come to NAMI as part of a difficult journey, and through our connections we have found knowledge, support, and the hug or kind word we needed to keep going while seeking and sometimes demanding answers within a healthcare system that has never kept its promises to meet the needs of people who want nothing more than to get better, feel like part of a community and move forward.

This year is a time of unprecedented opportunity to use our stories to push forward an agenda that protects the dignity and worth of ourselves, our families, and our communities. We are ready for a vigorous charge forward to advance legislation that protects and evolves the rights of individuals living with mental illness in NYS. Please take some time to review our advocacy priorities for 2019 outlined in this newsletter and join us to make your voice heard. In a state where suicide is the #2 cause of death for young people between ages 15-24, the suicide rate among NYS prison populations is 56% higher than the national average for all US prisons, and attempts to dismantle Medicaid nationwide have been relentless, we cannot afford to be silent. Silence kills, and each one of us has too much to lose.

We can no longer tolerate a health care system with holes that gape so wide that our loved ones fall into them and never return. We must demand mental health insurance parity, housing access, expanded and innovative treatment options, decriminalization of mental illness, and full integration of mental health treatment into the healthcare system with an assertiveness and passion that is driven by our sense of what is right for ourselves and our families. We must confront discrimination and demand a health system that treats mental health as an essential component of health. There is no health without mental health and when the brain is not working properly, whether it is biologically based, trauma based, or environmentally based, it must be treated as urgently and holistically as physical illnesses. Without fully integrated care and true accountability for enforcing mental health parity the death rate will not stop climbing and I don’t think any of us can live with that knowledge.

I am looking forward to standing by your side while we fortify NAMI-NYS, take on new challenges and evolve to become an even stronger voice for those whose voice has been pushed to the margin. Happy New Year to all of the advocates, family members, educators, and people in recovery who are a part of NAMI-NYS’s movement. This year is going to be about change, evolution, and speaking truth to power even if our voices shake while we do it.

Wishing you all peace, love, and strength,
Ariel Coffman, NAMI-NYS Board President
NAMIWalks
Legislative Advocacy Update: Act for Mental Health and Tell Your Story to Help Enact NAMI-NYS’s Advocacy Agenda

The New York State Legislative session is underway and NAMI-NYS and our members are magnifying our collective activism voice and building upon the legislative advancements we and our advocacy colleagues made in 2018. NAMI-NYS has introduced new resources designed to enhance our ability to tell our stories and communicate directly with elected officials during what has the makings for a landmark 2019.

First, NAMI-NYS has entered an agreement with NAMI to use Quorum Advocacy Software. This new tool will allow NAMI-NYS and our members to more effectively communicate our advocacy concerns to elected officials both in Albany and Washington D.C., as we will now be able to send direct messages to our leaders on key issues via emails.

Second is the publication of the second NAMI-NYS Advocacy Guide. This online resource provides information on: the 2019 NAMI-NYS Action Agenda, details on the many newly elected legislators and how our members can begin developing relationships with our new leaders and familiarize them with issues impacting mental health in our state, how to tell your story as an advocacy tool, how to have effective meetings with your legislators, how to advocate through social media and how to advocate through traditional media. The guide can be found on the advocacy section of our website.

Lastly, NAMI-NYS now has several freshly trained teachers for the NAMI Smarts for Advocacy Program. On November 17-18, NAMI held a regional training for new facilitators of the program in New York City. NAMI-NYS President Ariel Coffman, along with Government Affairs Committee members Ann Canastra and Lynda Regan and Associate Director, Public Affairs Matthew Shapiro took the training. NAMI NYC Metro also had a team of four trained. The training also featured participants from New Jersey, Connecticut and Rhode Island.

NAMI-NYS and NAMI NYC Metro are both excited to begin offering the training and developing the most effective advocates possible. We now have trainers available in New York City, Long Island (Ariel), Central New York (Ann) and Western New York (Lynda) as well as Matthew who can give presentations throughout the state and has recorded web-based video trainings highlighting elements of the Smarts training. The three training videos can also be found on the advocacy portion of our website. If you are interested in hosting an advocacy training, please email Matthew@naminys.org.

The pieces are in place to make 2019 an historic year where several of the reforms NAMI-NYS has worked towards for many years now have a good chance of being enacted, and NAMI-NYS plans to be a driving force to bring about the changes necessary to create a more mentally healthy New York State.

The political landscape in New York State has drastically changed this year after the Senate flipped and now both houses of the legislature along with the Executive Branch are under control of the Democrats. While NAMI-NYS is a non-political and non-partisan organization, it is important for us to mention this shift in power for two reasons. The first is that a new party in charge means new committee chairs. NAMI-NYS was enthusiastic to learn that NYS Senator David Carlucci was named as the Chair of the Mental Health and Developmental Disability Committee. NAMI-NYS has enjoyed a great working relationship with Senator Carlucci as he previously chaired the committee and has continued to distinguish himself as a champion for mental health, and we look forward to his leadership of the committee.

The second reason it’s important to note the leadership change is that many of the bills we have worked to advance for the last few years have passed through the Assembly just to die in the Senate. We are optimistic that we will finally see the passage of several key initiatives. Early in the session saw the first of these issues, the Extreme Risk Protection Orders (ERPO) law get passed by the Legislature and signed by the Governor. Under the ERPO Law, families can petition to remove guns from the homes of loved ones believed to be a danger to themselves or others. NAMI has long advocated for the passage of this bill as not only will it play a major role in reducing suicide, but it is also one of the few laws that encourages and values family insights. On January 29th, the bill passed both houses and NAMI-NYS was invited to stand alongside legislative leaders at a press conference announcing the bill. Senate Leader Andrea Stewart-Cousins praised NAMI-NYS’s advocacy efforts during the press conference.

With the passage of the ERPO bill NAMI-NYS is now focusing on two other key pieces of legislation that have historically passed the Assembly but failed in the Senate. These initiatives are the HALT bill (reforming the use of solitary confinement) and Non-Medical Switching (regulating the practice of private insurance plans changing the drug formulary during a contract year).

NAMI-NYS got a head start on our advocacy for the 2019 session on Thursday December 6th, when Assemblywoman Aileen Gunther, Chair of the Mental Health Committee, held a special hearing on the 2019/20 Mental Hygiene budget. NAMI-NYS’s Associate Director, Public Affairs Matthew Shapiro detailed our budget priorities and the need to broaden access to services, while our Government Affairs Chair Evelyne Tropper explained the difficulties her family has had trying to find appropriate services for her adult daughter living with schizophrenia.
In describing the feelings of families struggling to guide their loved ones towards recovery, Evelyne said, “We feel stymied and let down that psychiatric patients are the last frontier of discrimination. There are now more people with psychiatric disorders in jails, prisons and on the streets than in treatment. We as a society should be ashamed by this, and no family should have to struggle and watch their loved ones suffer the way we have. It is heartbreaking and it is wrong and I know we can do better, we must do better; my daughter and the thousands like her deserve the care needed to live happy and healthy lives.”

Evelyne concluded by adding, “Despite my family’s experience, I remain optimistic; New York has shown that it can be a leader in introducing mental health reforms such as enacting mental health education, Kendra’s Law and Timothy’s Law. Please help lead people with neurobiological disorders and their families out of this wilderness and ensure that we no longer have to name laws after people failed by the mental health system.”

Later on December 6th, Matthew Shapiro was also invited to be a guest on Spectrum’s News Capital Tonight program to discuss NAMI-NYS’s 2019 Action Agenda and budget priorities. Specifically Matthew detailed the need to invest in mental health housing with wraparound support services, ensuring there is a fully funded mental health workforce and how there needs to be a full range of community-based services to meet the needs of people on all points of the spectrum of psychiatric disorders. A copy of NAMI-NYS’s testimony and the Capital Tonight segment can be found at www.naminys.org.

As the year began, NAMI-NYS unveiled our 2019 Legislative Action Agenda designed to increase access to mental health services and create a more mentally healthy New York State. The issues comprising the Action Agenda are:

- Access to Appropriate Services and Medication
- Continued Investments in Community Services and the Mental Health Workforce
- Mental Health Housing With Wraparound Support Services
- Improve the Criminal Justice-Mental Illness Interface
- Expand Joseph P. Dwyer Veteran’s Mental Health Program

NAMI-NYS expressed our concerns about the budget on February 7th, when Board president Ariel Coffman and Executive Director Wendy Burch had the opportunity to testify before the joint legislative budget hearing, outlining NAMI-NYS’s priorities for the state’s budget.

As Ariel stated in her testimony: “NAMI NYS is advocating so strongly for increased access to hospital beds, more mobile treatment options especially in rural areas, investment in the mental health work force, housing, and community mental health treatment, because New Yorkers who fall through the gaping holes in this system are dying. The 30% rise in the suicide rate in NYS speaks clearly to this danger as does the high rate of re-hospitalization for those with co-occurring chronic medical and mental health conditions.”

The centerpiece of our advocacy activities was our 2019 Legislative Action Day, which took place on February 12th. For the second year in a row the weather did not cooperate with us as a major snow storm throughout the state hindered many people’s ability to participate. However, the NAMI-NYS spirit could not be deterred. Though the numbers were smaller than planned, the dedicated advocates who braved the weather ensured that our presence was felt and our voices were heard. NAMI-NYS still managed to make more than 50 meetings that day and packets were distributed to offices where meetings could not take place. We want to express our deepest gratitude to all of those who worked so hard to make the day a success. If you were unable to attend our Legislative Action Day, but would like to meet with your legislators in their district office, you can email Matthew@Naminys.org to have packets mailed to you.

Finally, along with our work in Albany, NAMI-NYS has also been active in projecting our voice on federal issues. On November 28-29th, NAMI-
The 2018 NAMI-NYS Education Conference, *Moving Forward: Identifying and Advocating for the Latest Breakthroughs in Research and Treatment of Mental Health Issues and Neurobiological Disorders*, took place on October 26-28th and was a tremendous success as many attendees remarked how this was the most inspiring conference ever produced by NAMI-NYS.

Two major themes running through the conference were how every fight needs a voice and that sharing your story can be a powerful advocacy tool in providing that voice in the fight for reforms. These ideals were showcased at Friday night’s Leaders of Mental Health Awareness celebration where NAMI-NYS honored those on the forefront of telling their stories and fighting to bring about awareness in order to improve the lives of individuals and families affected by mental illness. Friday evening began with a rousing presentation by NAMI CEO Mary Giliberti, who discussed how the grassroots determination and spirit that NAMI was founded on is still very much needed today. “Stigma is real. Discrimination is everywhere. And all too often, our health care system treats mental health as separate and unequal.” Mary noted while adding, “Our founders had a deep understanding of what we are affirming here tonight. That every fight needs a voice. And whether the setting is a suburban living room or the floor of the U.S. Congress, we are determined to be heard.”

The awards demonstrated the impact telling one’s story can have in addressing critical issues. 2018 marks the ten-year anniversary of the Mental Health Parity and Addiction Equity Act and NAMI-NYS used the occasion to present Parity@10 awards to leaders in the fight for parity. The first two awards were presented to Tom O’Clair, whose family’s story inspired Timothy’s Law, New York State’s parity law and Congressman Paul Tonko (NY-20) who sponsored and championed the law during his service in the NYS Assembly. Congressman Tonko became emotional recalling learning of Timothy’s story and the lengths Tom and his family had to go to in order to try and get Timothy the help he needed and how their efforts still failed to prevent the tragic loss of Timothy’s life by suicide. It was the story of the O’Claire’s struggle that deeply resonated with Congressman Tonko and led him to be a crusader for parity. Parity@10 awards were also presented to Andrew Malekoff, Executive Director of the North Shore Child & Family Guidance Center and Karla Lopez of the Community Service Society.

Toni Lasicki, of the Association for Community Living, received the first Leaders of Mental Health Awareness Award for her role as the leading voice in the fight for mental health housing. The other two Leaders of Mental Health Awards were given in recognition of prominent figures who in the past year have told their stories of fighting mental illness with the hope of letting others know that they are not alone in battling psychiatric disorders. Renowned ADHD specialist and New York Times best-selling author Dr. Edward Hallowell was awarded for the publication of his memoir, *Because I Come From A Crazy Family: The Makings of a Psychiatrist*, in which he recounts how mental illness has impacted him and many members...
of his family. The evening’s final honoree, Mauro Ranallo, ended the celebration of storytelling on a high note. Ranallo, the lead commentator for Showtime Championship Boxing and WWE NXT was the subject of the documentary *Bipolar Rock’N’Roller*, which chronicled his experiences living with bipolar disorder (including several hospitalizations) and how, despite being faced with the challenges of the illness, he has been able to rise to the top of his field. Mauro made his presence felt throughout the conference as he watched as the film was screened earlier in the day, visited with all the conference exhibitors, talked to many conference attendees to learn about their stories and was featured on Spectrum News.

The power of telling your story was also demonstrated during Saturday’s two featured sessions. In the afternoon, Dr. Xavier Amador, founder of the LEAP Institute and author of *I Am Not Sick, I Don’t Need Help*, explained how he used his own experience of trying to communicate with his brother who lived with schizophrenia to develop LEAP (“Listen-Empathize-Agree-Partner”). The LEAP method is designed to allow someone to quickly gain the trust of a person you are at odds with by no longer trying to convince the other person they are wrong or simply misguided and instead listen to them in a new way that conveys respect for the other person’s point of view and complete lack of judgment.

The evening’s keynote address was an emotionally charged presentation by marathon legend Dick Beardsley. Dick detailed his historic showdown with Alberto Salazar at the 1982 Boston Marathon, dubbed the “Dual in the Sun.” While the account of the famous race was riveting, it was Dick’s detailing his mental health struggles and how he persevered through substance abuse and the loss of his son by suicide that really made an impact on the audience.

Although the conference added the new addition on the power of storytelling, it did not stray from its mission of presenting the latest educational information on the research and treatment of psychiatric disorders and examining other major issues surrounding mental health. The traditional Saturday morning NIMH presentation was made by Dr. Bruce Luber, who detailed NIMH’s new study comparing the effectiveness of ECT versus Transmagnetic Stimulation in addressing treatment resistant depression. The exceptional psychiatric work being conducted at the New York State Psychiatric Institute was detailed in concurrent plenary sessions where Dr. Ragy Girgis, recipient of the 2018 NAMI-NYS Excellence in Research Award, detailed his work and Dr. Sapena...

Continued on next page 10
Patel detailed the groundbreaking treatment advancements being offered at the Center for Practice Innovations. Saturday afternoon also offered workshops on schizophrenia, depression, borderline personality and anxiety disorders.

The conference also continued its mission of exploring ways to curtail suicide as this year's ZERO SUICIDE focus featured two sessions, one on the role families can play in prevention and the other on how NAMI can help drive prevention. Other major issues discussed throughout the conference were improving the mental illness-criminal justice interface, children's mental health, addressing veterans' mental health, expanding the Faithnet program, employment, housing and introducing mental health resources to traditionally underserved populations.

Sunday morning featured a tribute to Dr. Lew Opler, followed by a presentation on the importance of family engagement in the recovery led by NAMI-NYS board member, Dr. Robert Laitman and featuring members Christine Robinson Cooley and Curtis Robinson. This was followed by Town Hall led by Dr. Lloyd Sederer. This year, Dr. Sederer explored the timely topic of the overlap between mental illness and addiction. Following the presentation, Dr. Sederer engaged in a lively conversation with the audience on a great many topics surrounding the New York State Office of Mental Health and the delivery of mental health
services. The conference concluded with an Ask the Doctor session led by Dr. Donna Anthony, Chief Medical Officer of Gracie Square Hospital.

NAMI-NYS wants to once again thank the 2018 Conference Committee and all the presenters, exhibitors and attendees who made the event such an outstanding success. NAMI-NYS hopes that the conference’s emphasis on the importance of telling your story will inspire all our members and plant a seed that will grow into a more vibrant and impactful advocacy voice. Telling our stories will be a focus for NAMI-NYS throughout 2019 and we hope you join us in telling your story and that collectively our stories will help create a more mentally healthy New York State.

Along with providing the latest information in research, treatment and issues impacting the delivery of mental health care, the conference also emphasized the power of telling your story as a means to generate both awareness and advocacy. The impact of story telling will be a major focus of NAMI-NYS in 2019, as we want to give our members the tools to most effectively tell their story in order to advocate for themselves, their family and their community.

Save the date! Next year’s NAMI-NYS Education Conference is set for October 25-27, 2019 in Albany.
First of all, we applaud the NoC clubs that are doing important and collaborative work at their schools and with many of our local affiliates. We found many instances of stellar connections and amazing efforts demonstrated during this research phase of discovery. We also found challenging situations that will need to be addressed going forward.

Based on the research findings we have outlined the following plan to move forward:

- NAMI has designated a staff person – Jennifer Rothman – as the Senior Manager of Youth & Young Adult Initiatives to coordinate future efforts with this demographic, including NAMI on Campus work.
- To achieve the greatest level of success, going forward NoC clubs must be aligned with NAMI local affiliates or NAMI state offices.
- Existing NoC clubs that are still ACTIVE are encouraged to continue working closely with the NAMI Affiliate (NA) or NAMI State Organization (NSO) in their community. Those that are not currently involved with the NA/NSO will be connected for ongoing support.
- Existing NoC clubs that are still INACTIVE and not involved with an NA or NSO will be placed in a temporary closed status until further support and collaboration can be established with the NA/NSO.
- Groups of students who have secured club designation from their college or university and wish to pursue forming a mental health club on their campus have two options:
  a. To become a club through their NA or NSO, which makes them an activity area aligned with the NA or NSO. The details for these processes are yet to be determined. Jennifer will be working closely with the Field Advancement team and those of you in the field with experience with the campus clubs.
  b. If the club wishes to operate independently of the NAMI NSO/NA, they should be referred to Active Minds for credentialing and offered the opportunity to stay connected to the NAMI Affiliate in their community for the complimentary programs and services available through NAMI.

**BACKGROUND**

Here is a brief summary of some of the findings that led to these decisions to provide you a better understanding of what needs to happen going forward.

- The NoC club model shifted in 2012 from being closely connected to local affiliate groups to having limited or no structured connection to NAMI organizations in the field. This was done in an attempt to help NoC clubs flourish in numbers by limiting barriers for organizing. When that shift occurred, the number of registered NoC clubs increased but, because the credentialing of the clubs was through NAMI’s national office, without any required involvement with the NSO or NA, the relationship with those clubs diminished over time due to student turnover and lack of reporting standards. Other challenges have also occurred due to this model shift:
  - Once credentialed, the clubs were able to develop independent of a structured model. Therefore, what happens in each club varies widely, with some reports of activities and business practices outside of NAMI’s accepted practices. This creates a risk to the NAMI brand at all levels.
  - NoC clubs existed independent of NAMI which left students unconnected at graduation or when they otherwise leave school.
  - As students graduate or relocate, the continuous transition in leadership on campuses compromises the sustainability of a national club model.
  - A lack of reporting standards created a difficult information gap which severely reduces the opportunity to know where clubs existed, which were active, or what activities they initiated or participated in.

- Of the 168 certified NoC clubs, the research conducted was only able to collect data on 59 of them. Of those 59, only 37 were still active. 109 currently credentialed clubs have a status that is unknown to NAMI at this time.

- We heard loud and clear that it is important for youth and young adults to have access to information about mental health and the resources available for those facing the challenges of mental health conditions.

- What we don’t yet know is what type of youth/young adult programs is best supported and sustained on college campuses and what broader youth initiatives should also be considered to meet the needs of youth and young adults in a variety of geographic and economic settings. Jennifer will be working closely with other staff at NAMI as well as NA/NSO leaders and other stakeholders – including young adults – to thoughtfully move forward in our efforts to reach this demographic. We are confident that our current strategic planning process will clarify what efforts and investments need to take place, so we can have the most significant impact in early identification and intervention of mental health conditions with youth and young adults.

Ongoing efforts need specific leadership and appropriate resources to support next steps and we’re excited that Jennifer Rothman has accepted the position to lead these efforts. Jennifer will be following up with each of the existing Active and Inactive clubs to confirm status and ensure that there is a working relationship in place with the NA/NSO to move forward.

She will also be convening groups of stakeholders to help inform the specifics of what the clubs will look like going forward as part of the NA or NSO – including logo use and other branding/operational details. Please contact her at jrothman@nami.org as we continue conversations about next steps.

We look forward to further exploring the mental health needs of youth/young adults and working with leaders in the field as well as other organizations serving this demographic to further define the best ways for NAMI to help meet those needs with a constant focus on early identification and intervention.
Save the Date!

On Friday, May 10, 2019 from 6:00 pm – 9:00 pm at the Hearst Media Center, Albany, NY, NAMI-NYS will be celebrating recovery and mental wellness with our “Off The Mask” event. This community focused event will host a fashion show, a juried art exhibit with pieces created by peers, and a silent auction to inspire, motivate, spread awareness, and end the stigma. We are grateful for Maya McNulty, the CEO of Up In Your Business and Melissa O’Reilly, Business Consultant for We Think Advertising, for spearheading the project with the American Psychiatric Association, Capital District Psychiatric Center, St. Peter’s Hospital, Albany Medical Center, Four Winds of Saratoga, and the Troy Art Center as collaborative partners. There is limited seating available. To purchase tickets, please visit: www.offthemask.org. For more information, please contact: tina@naminys.org.

Proceeds from “Off the Mask” go to supporting the work in the community that NAMI-NYS and the NAMI affiliates do to assist people with mental illness and their families. Even if you cannot attend this exciting event, there are opportunities to sponsor one or more of our models, each of whom is raising money in support of NAMI-NYS and the affiliates. Please visit the “Off the Mask” website to support their efforts!

Top Five Tips to Help Build Partnerships

At our October 2018 NAMI-NYS Education Conference, Brenda Episcopo, President and CEO of United Way New York State, shared the Top Five Tips for our NAMI affiliates to help build partnerships and secure funding with United Way and other community organizations.

A. Make sure your NAMI Affiliate listing is correct with 2-1-1
   - Conduct a Test Call/Speak with Resource Specialist
   - Offer to share 211 literature with your clients

B. Recognize and Quantify Your VALUE
   - Can you provide training for staff, volunteers or others at United Way?
   - Do you/your volunteers facilitate large community conversations around mental health? Offer to do a presentation at your local United Way.

C. Clearly Identify and List what you bring to your community
   - Focus on your NAMI Affiliate’s Expertise and strengths: Is it advocacy?
     NAMI Signature program delivery? Support groups?
   - Collaboration Building (link to collective impact, coalition building)
   - Volunteer on a local committee, campaign or event in your community

D. Align with one of United Way key issues/initiatives
   - Focus on women and children eg: NAMI Basics
   - Focus on youth: eg: Ending the Silence

E. Use United Way’s ALICE data in your grant applications
   https://www.unitedwayalice.org/overview

Re-Affiliation

By Tammie Paradis

NAMI-NYS would like to congratulate the following 3 affiliates that have recently completed the re-affiliation process: NAMI Columbia County, NAMI Huntington and NAMI Schenectady. This brings the total to 23 out of 24 affiliates that have completed the re-affiliation process.

Congratulations again to the following New York State affiliates:

NAMI Buffalo & Erie County, NAMI Capital Region, NAMI Cattaraugus County, NAMI Cayuga County, NAMI Champlain Valley, NAMI Columbia County, NAMI Delaware & Otsego Counties, NAMI Finger Lakes, NAMI Huntington, NAMI Mid-Hudson, NAMI Montgomery, Fulton & Hamilton Counties, NAMI New York City Metro, NAMI NYC Staten Island, NAMI Orange County, NAMI Putnam County, NAMI Queens/Nassau, NAMI Rochester, NAMI Rockland, NAMI Saratoga, NAMI Schenectady, NAMI Sullivan County, NAMI Syracuse, and NAMI Westchester County.

Thank you for all of your hard work and all that you do!
**NAMI Syracuse Veterans Parade** by Maggie Bristol

On Saturday, November 10th, Kryssy Ridgway and I had the pleasure of attending the 2018 CNY Veterans Parade and Expo, representing NAMI Syracuse. Located at the Center of Progress Building at the New York State Fairgrounds, the event’s purpose is to thank veterans for their military service and to recognize their importance in our communities. This year, the expo featured a special screening of “The Lost Tapes: Tet Offensive,” Connected Warriors Yoga, a large exhibit celebrating 100 years of the American Legion, and numerous vendors. There was even a kids’ area featuring activities, games, displays and face painting. The focal point of the day was the one and one-half hour long parade that began at noon, and featured more than 90 veteran and military organizations, and even high school bands from throughout Central New York. This was quite an impressive selection of displays and activities, considering parking and admission are free!

Kryssy and I thoroughly enjoyed speaking to several veterans and family members, who expressed interest in our organization, asked many questions, and inquired about programs and support groups for themselves or loved ones. We were thrilled to meet so many individuals, who noted “I didn’t realize NAMI supported veterans too,” and “I am a vet/my spouse is a vet, but [our child/cousin/friend] has mental illness and I didn’t realize what your organization was!” It sincerely warmed our hearts to pass on pamphlets, our newsletter, contact information, and resources to the many that shared their personal stories, and were genuinely grateful for this opportunity and newfound information. We also connected with a few other CNY organizations, such as Two Brothers’ Light, an association that supports those affected by suicide and mental health issues. We hope that the mutual friendships and partnerships we made will benefit those individuals, NAMI Syracuse, and all organizations in spreading the word about resources, raising awareness, and erasing the stigmas surrounding mental illness. We are greatly looking forward to returning to the CNY Veterans Parade and Expo next November, and hope to see some familiar and new faces stop by our booth!

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**NAMI Syracuse Holiday Party** by Marla Byrnes

The annual general meeting and holiday party were held at local venue Francesca’s December 4th and was attended by 44 members. Voted in new board members include Maggie Bristol, Beth Camosino, Scotty MacQueen, Carol Notar, Brad Webster and Tanisha Wiggins. The affiliate honored Frank and Esther Mazzotti for their many years of devotion to NAMI Syracuse and PROMISE residential. Letters of appreciation to our outgoing board members Sherie Ramsgard, August Cornell, Steve Comer, Sandra Carter, Deb Mahaney, and George VanLatham were presented in recognition of their many contributions to the affiliate and the community. NAMI Syracuse also cited the great work of Dr. Paula Zebrowski, Pamela Fortino and Marie Mahar as “Friends of NAMI.” We also honored guests Judge Ross Andrews and his wife Ann Atkins for their efforts to start a mental health court in Syracuse. The Syracuse Recovery Court officially starts January 2019. We also announced we will be holding a regional Family-to-Family training at our offices January 11-13, 2019 and is fully supported by NAMI NYS.

We have much to be grateful for this year —three successful fundraisers “Music for Mental Health” and “Harvest Hopela” and a well-attended fall conference fighting stigma. Coming in 2019 our continued relationship with SUNY ESF on an anti-stigma campaign, more signature programs and trainings, and upgrading our residences. We are looking forward to utilizing the talents and energy of our new board members as the work is never done!

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**NAMI Syracuse Conference**

NAMI Syracuse held their annual conference at the Rosamond Gifford Zoo on October 10. The Topic was “Stand Against Stigma: Changing Minds about Mental Illness.” Dr. Malika Carter presented on the NAMI Syracuse and SUNY ESF college partnership fighting stigma on campus. Sherie Ramsgard, chairperson of the conference, presented on DNA and pharmacogenetics testing. Dr. Julio Licinio, from Upstate, discussed new genetic findings that show common genes for many disorders. Dr. Christopher Brown, superintendent of West Genesee school district, talked about integrating mental health education and awareness in school districts. Steven DiMarzo and Jennifer Crider, therapists at HELIOS, presented information on LGBTQ and concepts in cultural diversity. The day was well received and 140 attendees benefited from our lively discussions. This was our first year of CEU’s available to professionals thanks to the support of Steve Comer and HELIOS.
**Buffalo and Erie**

**DJ Jaffe Event on November 1 with NAMI Buffalo & Erie County a Great Success**

On November 1st, NAMI Buffalo & Erie County welcomed author and activist DJ Jaffe to Western New York at Daemen College in Amherst. Jaffe presented to an audience of over 150 people, despite very inclement weather—it’s Buffalo, we’re brave! His presentation addressed many important issues and policy perspectives that affect treatment and support for those who live with serious mental illness, and their caregivers and families.

At the event, Jaffe signed copies of his book, “*Insane Consequences: How the Mental Health Industry Fails the Mentally Ill.*” It was a thought-provoking, highly successful evening. The following morning he also presented to psychiatric professionals at Grand Rounds at the Buffalo Psychiatric Center.

NAMI Buffalo & Erie County is grateful to the Patrick P. Lee Foundation, which is committed to improving the lives of individuals who have mental illness, for supporting this event.

**NAMI Buffalo & Erie County Wraps Up Three Family-to-Family Classes**

This fall, three Family-to-Family classes spanned from Hamburg to Niagara Falls, NY for the first time. Hosted at the Niagara Falls Memorial Medical Center, the newest class was very well received. Families are so thankful to have the class information and to be with others—teachers and class participants—who understand the challenges and needs of caregivers of those who live with mental illness. We are looking forward to the Spring classes that are being planned soon and discussing the possibility of again offering a Summer session, which we introduced last Summer. Our volunteers are the best, always going above and beyond.

**NAMI Buffalo & Erie County Installs New Officers and Board Members, Extends Thanks to Those Stepping Down, and Continues Looking Toward the Future**

Liz Carone was named the new President of NAMI Buffalo & Erie County with Jackie Thompson as Vice President. Johnathan Miles will continue this year as the affiliate Treasurer and Cambria Daniels is continuing as Recording Secretary. New members of the Board of Directors include Linda Mallia, Gail Michaels, and Christopher Syracuse. Liz acknowledged our affiliate appreciation for the service of “retiring” Directors Mary Lou Bond, Colleen Frey, President Emerita Marcy Rose, and Barbara Utter. We are grateful that they all will remain active with various committees and projects.

The new officers and board will embark in the new year on a strategic planning process made possible through a grant from the Peter & Elizabeth Tower Foundation, which supports organizations located in Erie and Niagara counties, help young people from birth through age 26, including those challenged by mental illness – one of its four focus areas.

**NAMI Sullivan**

NAMI Sullivan County, NY in conjunction with the Sullivan County Dramatic Workshop was invited to present “*Every Brilliant Thing*” at the Theatre Association of New York State (TANYS) Festival the weekend of November 16th in Auburn, NY. The performance held at the NAMI-NYS Educational Conference was adjudicated by TANYS Roving Adjudicator, Paul Nelson and earned Lori Schneider a TANYS award for Excellence in Performance. “*Every Brilliant Thing*” was one of only nine shows chosen from around the State to be presented at the TANYS Festival. The performance was well received by Festival audience members and critically acclaimed by the Festival adjudicators. Some representatives from NAMI Cayuga were in attendance, and there are tentative plans in the works for a joint NAMI Sullivan/Cayuga fundraiser/awareness raiser in the Spring. Schneider’s performance at Festival earned her a People’s Choice Award (one of only four given out for performances over the Festival weekend) for Best Actor.

**Sullivan County - Every Brilliant Thing**

**Lori Schneider - People’s Choice award**

Winter 2019 • NAMI | NYS News
**Rochester**

**FAMILY Program Updates** by Caneia Titus–Family Program Coordinator

While getting ready for the approaching cold weather, we ramped up our signature programs here at NAMI Rochester. Our Fall 2018 NAMI Family-to-Family education program kicked off in THREE counties! Hooray!

We had our Family-to-Family signature program going in Monroe, Wayne and Genesee County. The 12-week course ran from Wednesday, September 5th to Wednesday, November 21st with wonderful facilitators including Claire Perlman & Rosemarie Jaouen for the Monroe County class, Judy Watt & Christine Michel for the Wayne County class and Cheryl Netter & Vicki Spurr for the Genesee County class.

We also kicked off our Peer-to-Peer education program that ran from Tuesday, September 18th to Tuesday, November 27th. Lynne Fisher and Jack Goldstein are the facilitators for this recovery education course open to anyone experiencing a mental health challenge. The course is designed to encourage growth, healing and recovery among participants.

Dialectical Behavior Therapy—DBT Based Skills and Support For Families classes has begun this Fall taught by Amy Baker and Deborah Aylward. DBT skills can help family members change interpersonal patterns that cause distress. The goal is to help families respond more effectively to their loved ones, including Mindfulness skills: our ability to be in touch with others and ourselves, emotion regulations skills: our ability to manage difficult or extreme emotions (Emotional resilience), Interpersonal Communication skills: our ability to maintain and improve our relationships and Distress Tolerance skills: our ability to survive crisis situations without making things worse.

The class is not meant to be therapy.

If you are interested in learning more about any of our programs, please contact NAMI Rochester’s Family Program Coordinator, Caneia Titus at (585) 423-1593 x 206 or email at Caneia.titus@namirochester.org.

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**Mid-Hudson**

**Mid-Hudson Update** by Jo Ann Brown

NAMI Mid-Hudson had a productive fall quarter of providing education, support and resources to those living in our community with mental health conditions through the Family-to-Family, Peer-to-Peer and Ending the Silence programs.

NAMI Mid-Hudson finished another successful Family-to-Family fall course, led by Judy and Kevin Walker. This husband and wife are an awesome dedicated teaching team. The outstanding positive comments of the graduates really show their commitment and relatability to the participants. The number of class participants stays strong throughout the course due to the resources, information and workshop skills taught. Participants no longer feel alone, learn where to get information and help and will stay connected through the support groups available throughout Dutchess and Ulster Counties now that class has ended. Congratulations to the graduates!

Also going strong is the NAMI Peer-to-Peer 8 week class. Leaders are enjoying teaching the new material to participants. The revised material and exercises are a pleasure to teach!

Ending the Silence for Students has been presented to over 700 students this fall alone. NAMI Mid-Hudson has also provided their first presentation of Ending the Silence for Families and Staff.

**Table Events**

Eastern Dutchess benefited from NAMI Mid-Hudson providing information at the Community Day event with a table and activity to reinforce the importance of educating our community on mental health.

Thank you to all the dedicated volunteers for their hard work. A special thank you to NAMI Mid-Hudson Office Clerk, Barbara Desilets for her hard work and dedication.
NAMI Westchester’s Third Annual Educational Event

NAMI Westchester held its Third Annual Educational Event, What Matters to You, on October 23, 2018 at Mercy College with an attendance of approximately 100 people.

The objective of the program was to promote an understanding of community services for people with Co-Occurring Disorders – mental health, trauma, physical health, and substance abuse. Dr. Damara Gutnick, Medical Director of Montefiore Hudson Valley Collaborative, spoke on the national campaign. For more information on this initiative, see https://vimeo.com/269067278.

Neil Boyle, Director of Pupil Personnel Services at North Salem Schools, moderated a panel discussion with Dr. Gutnick, Kathy Pandekakes (CEO of Human Development Services of Westchester-HDSW), Stephanie Marquesano (Founder of the Harris Project) and Jacqueline Burgess (Peer Case Manager at HDSW). There were 15 exhibitors present representing agencies and hospitals in our county. Michael Orth opened the evening and stated, “I would like to thank and congratulate NAMI Westchester in their progressive thinking by hosting the What Matters to You program and for working collaboratively in our county, as evidenced by them bringing in so many community organizations that are here tonight to share their programs and resources.”

We wish to thank our sponsors: Westchester County Department of Community Mental Health, MHA of Westchester, the Harris Project, Putnam-Northern Westchester BOCES, Westchester Jewish Community Services, HDSW, St. Vincent’s Hospital and Mercy College.

NAMI Westchester Film Event, SUICIDE: THE RIPPLE EFFECT

We had a wonderful film event on September 26. We showed the documentary screening of “Suicide: The Ripple Effect” by Kevin Hines. Following the movie there was a panel discussion and a meet-and-greet with Kevin. Incredible stores of both pain and recovery were shared, with the resounding message of hope. Kevin led the audience of 175 in a powerful message of “Be here tomorrow!”

Thank you to our sponsors, Westchester County Department of Community Mental Health, Jed Foundation, Human Development Services of Westchester, Mental Health Association of Westchester, American Foundation for Suicide Prevention and the Westchester County Suicide Prevention & Awareness Task Force. Thank you also to the clinicians who volunteered their time and to all that came.

NYC Metro

NAMI NYC Metro Panel Discussion

On October 23, NAMI New York City Metro hosted a panel discussion about an essential and often-overlooked topic: the intersection of mental illness and substance use.

Our panelists were Dr. Lloyd Sederer, Chief Medical Officer of the New York State Office of Mental Health and author of The Addiction Solution: Treating Our Dependence on Opioids and Other Drugs, Dr. Richard Friedman, New York Times contributor and psychopharmacology clinic director at Weill Cornell Medical College, and Karen Varano, NAMI NYC Metro Program Director and parent of a recovering addict. They shared insights, personal experiences, and answered questions moderated by Alexandra Botti, of WNYC’s The Takeaway. The room was packed, and the group asked excellent, thoughtful questions. It’s clear there is a need for more discussion around this topic.

If you’re interested, you can watch video of the entire discussion on our Facebook at facebook.com/NAMINYC.
**AFFILIATE NEWS**

**Cayuga**

**NAMI Cayuga Article** by Bart Wasilenko

On Dec 1st and 2nd, Cayuga Community College in Auburn, NY hosted its annual Christmas Craft Fair. All nonprofit organizations obtained a space for free. NAMI Cayuga County sold warm hats, mittens, scarves, and vest neck warmers. The affiliate raised more than $600.00.

WAZU Ceramics and more, owned by the affiliate’s co-president Bart Wasilenko, sold his ceramic designs and 100% of all sales were donated to NAMI Cayuga County. All of the knitted donations that did not sell were donated to the Auburn Community Hospital Behavioral Health Unit. Upon discharge, our mission is to provide consumers with something warm to wear during the winter months to come. Two generous NAMI Cayuga County board members donated a basket and a child’s battery operated (ride on) Paw Patrol Car for raffles.

Many conversations revolved around mental illness during the holiday times. Several individuals indicated the need for family support and hopefully will follow through with attending our next family support group meeting. Sign-up sheets were there to register the public for Mental Health First Aid classes. Bart and Terri Wasilenko are certified state trainers.

Our next event to look forward to will be the 2nd Annual Tea Party when the Frank and Eliza Tryon House and gardens open for the pleasure of all who attend this NAMI Cayuga County fundraiser. The 1882 house and grounds are included in the U. S. National Register of Historic Sites. We hope to include many more from the public in our mission to educate and provide advocacy regarding mental illness and attached stigma.

**Schenectady**

**NAMI Schenectady’s Annual Holiday Dinner**

On Friday, December 7th, NAMI Schenectady honored two individuals during its annual holiday dinner. Honored for life-time achievement as one of the co-founders of the Schenectady group of caregivers who eventually became NAMI Schenectady was Roy Neville, who also was the recipient of the Muriel Shepherd Award at the NAMI NYS Education Conference this past October. Also honored by NAMI Schenectady was Kevin Moran, psychiatric social worker from Ellis Hospital who recently retired after several decades of service. Mr. Moran has facilitated the Wednesday night family support group at Ellis Hospital for many years to which many NAMI Schenectady members and friends from the greater Schenectady community regularly attended.

Speaking to those in attendance is Kevin Moran, flanked to his right by affiliate secretary Roy Neville, long-time member Patty Costa and President Cindy Seacord.

**NAMI at SUNY Schenectady**

During Mental Health Awareness Month this past May, NAMI Schenectady participated in a program at SUNY Schenectady sponsored by the college’s Office of ADA Transition Services for prospective college students from Capital District high schools. The program’s focus was on providing information to future students who might require academic accommodations under the American with Disabilities Act when entering college. Cindy Seacord was on hand with a laptop to administer NAMI’s on-line Cure Stigma Quiz to interested attendees, as well as to answer questions and disseminate NAMI information, including advertisements for NAMIWalks and the May NAMI Ribbon Campaign.
We are Most Grateful to Those Who Made Financial Donations To NAMI-NYS During The 3rd and 4th Quarter 2018

**Up to $100**  

**$100 to $200**  

**$200-$300**  
John B. Allen, Jr., Christine Robinson Cooley, Alice Howard, Ernest Michel & Heidi Kruse, Abraham Ofer, Lawrence O’Heron, Sheila Rabinowitz, Sydney & Jonathan Stern, Gilbert Yablon

**$500 to $1,000**  

**Over $1,000**  
Myron & Janet Susin

Where Does Your Donation Go?

NAMI-NYS financially supports the NAMI signature programs delivered by NAMI affiliates throughout the state. For example, $50 funds 2 Ending the Silence presentations to students and educators, $100 funds 3 In Our Own Voice presentations to the public, $500 funds 2 NAMI Basics classes for parents of children with mental health issues, $1000 funds 2 Family to Family classes for family members with a loved one living with mental illness, and $2,000 funds a state training of new teachers for NAMI programs like Family to Family, Peer to Peer, Basics, Homefront, Family Support Group and Connection.

Your contribution also supports NAMI-NYS’s advocacy efforts. Legislative Advocacy Day is an opportunity to bring NAMI members and supporters together in Albany to spread our advocacy voice on legislative issues that affect ourselves and our families, like housing, criminal justice issues, research and access to services. Selected NAMI-NYS Board and staff members recently trained to become leaders in NAMI Smarts, a course designed to teach advocacy techniques, and they will be providing training around the state to ensure that we all have the tools we need for the most effective advocacy. In addition to legislative outreach, NAMI-NYS works with the local affiliates to promote community awareness through activities like the Ribbon Awareness Campaign and by developing community partnerships to bring a better understanding of mental health conditions, support for community resources and the elimination of the stigma surrounding mental illness.

Every year, NAMI-NYS presents an outstanding Education Conference that offers information and research on mental health for individuals living with a mental illness, caregivers and family members, educators, court and law enforcement officers and providers. The conference offers sessions focused on criminal justice issues, veterans’ issues, children and adolescents, young adults, housing, employment, research, treatment and wellness. Your generous contribution supports the conference and allows NAMI-NYS to offer scholarships to NAMI members, educators, veterans, young adults and those in the criminal justice field.

NAMI-NYS operates a helpline that provides information on local resources for callers throughout the state. Donations support the helpline activities, including the distribution of many thousands of pieces of literature annually with information about mental health and resources. These brochures, pamphlets and other information are placed by both NAMI-NYS and the local NAMI affiliates throughout the community and serve as an educational tool and a valuable resource for those seeking help and services.
Highlighting Services and Effectiveness Research at NIMH

By Joshua Gordon on June 26, 2018

NIMH envisions a world in which mental illnesses are prevented and cured. Our vision statement says it all. We won’t stop our efforts to transform the understanding and treatment of mental illnesses until that vision is realized. To that end, we invest in basic research to understand the mechanisms and origins of mental illnesses, as well as translational research to develop novel treatments and prevention measures based on this understanding. But research doesn’t stop with the discovery of a new treatment. In order to prevent and cure illnesses, these treatments need to actually be tested and put to use in the clinic. Once the effectiveness of an intervention is established, figuring out how best to deliver effective therapies is the domain of services research, a key component of our research portfolio at NIMH that focuses on impacting patients in the near term.

Services research includes figuring out who needs treatment, where they are, and how to keep people engaged in treatment long enough to receive benefit. Services researchers also examine how best to ensure quality—making sure evidence-based treatments are accurately and appropriately delivered; effectiveness—making sure treatments have a positive impact on individuals with mental illnesses seen in community practice settings (a.k.a., the real world); equity—making sure treatments are accessible and efficacious for all groups of people; and value—making sure the outcomes are worth the investment because in all settings, resources are limited and tradeoffs often need to be made.

Ideally, care can be delivered by a diverse group of practitioners distributed across a diverse range of clinical settings. In all of this work, NIMH research focuses squarely on acute and long-term symptom reduction, remission, and improved community functioning—endpoints that are truly meaningful for individuals and families dealing with mental illness. To accomplish these goals, researchers work directly with individuals and families who are struggling, but also work with providers, decision makers, and healthcare system leaders to effect changes at multiple levels. In this Director’s Message, I thought I would highlight a few notable examples of services and effectiveness research being pursued by NIMH-supported investigators.

Identifying those in need
A key aspect of services research is determining who needs services. I have written in the past about an outstanding example of NIMH-funded research into the identification of suicide risk, the ED-SAFE (Emergency Department Safety Assessment and Follow-up Evaluation) study. The ED-SAFE study showed that universal screening for suicide risk in emergency rooms is an effective way to identify individuals at risk, and that cost-effective interventions in this group can reduce suicide attempts. We have also funded research on big-data approaches to identifying those at risk, with follow-up studies, to determine the effectiveness of interventions, in support of the Zero Suicide campaign.

Big data approaches are helping further define the service needs of individuals with serious mental illness (SMI). For example, a recent study by the NIMH-supported Mental Health Research Network (MHRN) examined health outcomes of individuals under their care as a function of psychiatric diagnosis. The researchers uncovered a startling truth—in the first three years after their diagnosis, individuals experiencing a first episode of psychosis were 7 ½ times more likely to die than someone without psychosis. These data underscore the need for comprehensive, coordinated care for teenagers and young adults with psychosis. Accordingly, NIMH has put forward a series of initiatives to encourage research on strategies for improving the health and longevity of individuals with SMI (see RFA-MH-13-140, RFA-MH-14-060, and RFA-MH-16-600). Another area in which early identification is crucial is autism. We know that children with autism do better when they get into treatment sooner. NIMH’s ServeASD (Service Research Across the Lifespan for Autism Spectrum Disorder) program supports efforts to develop and study the effectiveness of screening programs aimed at identifying children with autism in the first two years of life. Children enrolled will then be followed into treatment to show definitively that screening improves outcomes by facilitating earlier entry into treatment programs. Other components of the ServeASD program are aimed at the development and testing of interventions and service strategies focused on teenagers and young adults with autism, to determine how...
best to help them navigate the challenging transition from childhood to adulthood.

Recognizing the importance of early detection and services in general, a current NIMH initiative encourages research focused on developing and testing the effectiveness and implementation of family navigator models designed to promote early access, engagement, and coordination of mental health treatment and services for children and adolescents who are experiencing early symptoms of mental health problems (see PAR-18-428 and PAR-18-429).

Delivering the highest level of care

Effectiveness and services research at NIMH has been deeply informed by the Recovery After Initial Schizophrenia Episode (RAISE) program. The RAISE study demonstrated that coordinated specialty care, involving a team-based approach to medication management, psychotherapy, supports for work and education, and case management improves outcomes for those experiencing a first episode of psychosis. Based on this evidence, Congress provided additional resources to the Substance Abuse and Mental Health Services Administration (SAMHSA) to help start up coordinated specialty care clinics around the country. Working closely together, NIMH and SAMHSA accomplished rapid translation of science to service in first episode psychosis. There are now over 200 clinics offering coordinated specialty care to those with first episode psychosis, and studies have shown the intervention to be cost-effective in addition to being helpful.

Assessing the quality of mental health care is crucial to informing how to effectively implement treatments and improve quality in community settings. Through a recent initiative, several NIMH-supported investigator teams are evaluating a complementary range of innovative approaches to assess the quality of psychotherapy across a variety of target populations. Such efforts include assessing the quality of cognitive behavioral therapy by creating a series of web-based virtual client sessions paired with automated scoring algorithms, or by using mobile technology along with traditional records of treatment sessions to record and rate fidelity to evidence-based practices. Other projects are focused on developing toolkits to make it easier to measure the quality of treatment delivery in child mental health settings: for example, one project seeks to develop a measurement tool for therapist-guided exposure treatment for anxiety disorders among youth.

We remain acutely aware of the fact that even well-delivered therapies only work if they are accessible. NIMH services research includes a number of efforts aimed at understanding when, why, and how mental health services can be challenging to access, with a particular focus on identifying strategies for improving access to effective interventions and services in underserved communities to address health disparities. NIMH-supported research, for example, has shown that one strategy for improving access to effective mental health care is by delivery in integrated care settings, where the individual with a mental health condition can more readily access the treatment she needs. Such access may be especially important for some groups. For example, results of a recent NIMH-funded study showed that brief treatment in pediatric primary care was effective, and Hispanic children and adolescents in particular were much more likely to complete and respond to a mental health treatment delivered in a general pediatric clinic as opposed to when referred to a mental health clinic.

We recognize the tremendous burden imposed by SMI in general and schizophrenia in particular. In order to build on RAISE and other recent successes, NIMH wants to encourage similarly creative and comprehensive studies of the effectiveness of interventions, to achieve rapid implementation of promising interventions, and to enhance the delivery and quality of effective services. To this end, we have begun funding a series of centers focused on research with potential for near-term impact for reducing the burden of SMI. Accelerating the Reach and Impact of Treatments for Youth and Adults with Mental Illness (ALACRITY) Research Centers incorporate new discoveries in basic and clinical research, transformative health care technologies, advances in information science, behavioral economic strategies for influencing health behaviors, and input from stakeholders (e.g., service users, family members, clinicians, payers). The goal is to foster innovative research aimed at increasing the effectiveness of existing interventions, improving delivery and quality of evidence-based services, and accelerating the diffusion, implementation, and continuous improvement of new practices in diverse settings.

These examples underscore the crucial importance of NIMH investments in services and effectiveness research. We remain committed to a robust services and effectiveness portfolio aimed squarely at having a near-term public health impact, recognizing the key role such research plays in achieving our ambitious vision.
As we gear up for the Off the Mask fundraising and awareness event on May 10th, we’ve held a couple of activities as a foretaste to the main event. The first was a mask making event, where NAMI supporters and artists created masks for the models to wear in May. It was tons of fun and we appreciate the help of Dina Ziskin-Fortune for organizing the event. On February 15th, Glennpeter Diamond Centre in Albany hosted a “Meet & Greet” for the models participating in Off the Mask. The evening featured a silent auction and raffle, and attendees were introduced to many of the models who are set to walk the catwalk.
NYS was in Washington D.C. to voice our concerns about proposed changes to Medicare Part D. Specifically we focused on issues around the insurers’ liability in the coverage gap, or the Donut-Hole portion of the program, and our concern that more of a burden will be pushed onto the consumer, as well as the soon to expire controls over expanding the rates of the catastrophic threshold, which is the point at which a patient has incurred enough costs to enter catastrophic coverage.

NAMI-NYS met with the offices of Senator Chuck Schumer and House Representatives Grace Meng, Elise Stefanik, Yvette Clark, Hakeem Jefferies and Tom Reed.

While 2019 has the potential to be a year of monumental change, these improvements can only be achieved if we work together to project our collective voice and vocalize why these reforms are needed. Please be on the look-out for our Action Alerts throughout the session and please take part in these necessary actions. It is our stories that separate us as advocates from those lobbying for special interests and it is our stories that resonate with leaders. We need your and your stories to be a part of these efforts as we come together to create a more mentally healthy New York State. The Advocacy guide has resources on how to tell your story as an advocacy tool, and if you would like to submit a written copy of your story and how it is an example of one of the issues on our Action Agenda, you can email it to Matthew@naminys.org.

We look forward to updating you and working together as we progress towards a more mentally healthy New York State.
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