End Stigma

**Bring NAMI Programs and Services to Your Community**

Today, NAMI is our nation’s largest grassroots mental health organization with more than 1,100 affiliates across the country engaging in advocacy, research, education and support. Here in Missouri, we have 12 active affiliates and nearly 3000 members. Even so, there are areas in which NAMI support, education and advocacy services are not available. We want to change that.

As members and volunteers, we know NAMI programs and services change lives for the better. We know the need is huge because mental illness is so pervasive. One in four adults will experience a mental health disorder in any given year and one in five teens live with a mental health condition.

Supported by a few paid staff, NAMI programs and services are delivered by NAMI member volunteers who receive specialized training. Training qualifications vary, but NAMI membership and your PH. D. in lived experiences as a family member, friend or person pursuing recovery is the first priority. (continued on pg. 3)

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Office: (573) 634-7727 or (800) 374-2138
Cindi Keele, executive director of NAMI Missouri, the state organization of the National Alliance on Mental Illness, issued the following statement today, clarifying news reports earlier this week about the closing of its NAMI Greater Kansas City affiliate’s office.

“NAMI Missouri wants to reassure the Greater Kansas City community that only its local office has closed. Education and support programs will continue to be offered to individuals and families in the local community who are affected by mental illness.

NAMI Greater Kansas City’s core programs of education and support will continue to be offered thanks to the efforts of Kansas City’s trained NAMI member volunteers. Current support schedules, locations, teachers and facilitators will not change. Volunteers will receive staff support from NAMI Missouri.

NAMI Missouri is the statewide umbrella for 12 affiliates providing support, education, and advocacy to individuals and families affected by mental illness in the state. We will continue to offer NAMI’s signature programs in Greater Kansas City: NAMI Family to-Family Education; NAMI Basics for parents and caregivers of children and teens with mental health conditions; NAMI Connection recovery support groups; NAMI family support groups and In Our Own Voice speaker presentations and very soon, NAMI Homefront for families of active service members and veterans.

The affiliate’s decision to close its office represents a transition, but not a retreat from NAMI’s commitment to help improve the lives of individuals and families affected by mental illness.

NAMI grassroots volunteers provide the energy and dedication that enable our programs to make a difference in the lives of others. Their role and importance remains unchanged. We are grateful to them and all our friends and supporters in the Greater Kansas City community, new and old, for their continued support.

Anyone in the Greater Kansas City area needing information or assistance can call NAMI Missouri’s toll-free help line at (800) 374-2138 or go to www.namimissouri.org.
Bring NAMI Programs and Services to Your Community

(continued from page 1)

NAMI affiliate and other volunteers from all walks of life work to educate their communities, teach family courses, mental health workshops, conduct stigma reduction and advocacy activities. They work to eliminate feelings of isolation by extending the warm hand of friendship and support. And together, they raise a strong collective voice to fight for positive change.

Did you know that NAMI was credited in 1982 with singlehandedly shifting the National Institutes of Health’s research focus from primarily sociological and parenting related causes to brain biology and genetic studies? This is why our current approach to treating mental illness is vastly different in the 21st Century.

All NAMI signature programs have a basis in best practices and some have even been deemed “exemplary” as community mental health interventions. All work to chip away at stigma.

NAMI MO is one of just a handful of state NAMI organizations to pay 100% of volunteer’s training costs including hotel, food and travel expenses. Post training, NAMI MO provides the materials needed to teach courses, facilitate groups or make community presentations free of charge. We also assist with outreach and, in some instances, pay for newspaper ads to help you fill classes.

We want to invite you to become a beacon of hope and an agent for change in your community. Volunteer training opportunities are listed in this newsletter. As a NAMI volunteer you can help create more acceptance and understanding in your community.

End “Criminalization” of Mental Illness

NAMI tells U.S. Senate hearing

In February NAMI told the U.S. Senate Judiciary Committee that the criminalization of people living with mental illness has reached “crisis proportions.”

In written testimony, NAMI argued in support of a reform bill known as the Mental Health and Safe Communities Act. Provisions include training first responders in crisis intervention, supporting specialized mental health and drug courts, improving mental health treatment in correctional facilities, and collecting data on interactions between people with mental illness and the criminal justice system.

According to NAMI, about two million people with serious mental illness are admitted to jails each year, and incarceration usually leads to a worsening of psychiatric symptoms. Furthermore, NAMI said, “it costs less to put non-violent individuals with mental illness into treatment than to put them in jail,” making diversion cost-effective as well as humane.
Memorial Donations & Tributes

A memorial donation in memory of Gene and JoAnn Ruhr by Kay Callison of NAMI Columbia

A memorial donation in the memory of Craig Siebels, son of former NAMI MO President Bettye Siebels by Cindi Keele

A donation in memory of Adam Custin, son of NAMI Greater KC Area President Joe Custin and his wife Heidi

A memorial donation in the memory of Leslie Silvey by Cindi Keele

NAMI Missouri’s implementation of the new six-session course for family members of veterans/active military/guard/reserve and the many VA facilities in MO is moving ahead. In March, NAMI Homefront teacher trainer Michael Jones, Ph.D. made a formal presentation to the Family and Warrior Support Division of the Missouri National Guard. A memorandum of understanding (MOU) between the Missouri National Guard and NAMI MO is in the works. Once the MOU is signed it will be up to our affiliates and NAMI members to begin contacting the military organizations in their communities. Working with our 22 NAMI Homefront instructors we can make a Major difference for the family members who support our warriors who keep us free.

Dr. Jones also made a presentation to the Missouri Healthcare Alliance, an organization comprised of a variety of health care organizations across the state who serve veterans. Dr. Jones will be making a NAMI Homefront presentation to the Missouri Veterans Commission this summer and if you have a Veterans Service Organization in your community, please let them know that Dr. Jones is available to tell them about NAMI Homefront and how it can serve military family members who deserve the best.
Training Opportunities for NAMI Volunteers

Contact Alice Kliethermes about these trainings at Alice@namimissouri.org

In Our Own Voice: Living With Mental Illness Training
June 3-4, 2016
Training for teams of 2 consumers to make interactive presentations about their own lived experience and recovery journey with video and group discussion. IOOV is a very effective stigma reducing intervention. Limited to 16.

NAMI Connection Recovery and Support Groups Facilitator Training
August 5-6-7, 2016
Training in teams of two consumers to make a difference by acquiring the skills necessary to facilitate a peer support group. Limited to 18.

Contact Kim Hoffman about this training at kim@namimissouri.org

NAMI Basics Teacher Training
June 10 - 12, 2016
Find a teaching partner and make a difference in the lives of parents, foster parents, and custodial relatives of children and adolescents with mental health needs by teaching this effective 6-session course.

Contact Sonya Baumgartner about these trainings at Sonya@namimissouri.org

Family-to-Family Teacher Training
July 15 - 17, 2016
Find a teaching partner and become a beacon of hope to family members of adults with serious mental illness by teaching the famous Family-to-Family course. Taught over 12 sessions, this course is on the National Registry of evidence based mental health interventions.

NAMI MO Mental Health and Allied Provider Workshop with CEUs
August 13 - 14, 2016
A six-hour workshop; medication update, latest mental health info, children’s issues, family panel, recovery panel and more.

Family Support Group Facilitator Training
August 13 - 14, 2016
Tap into shared wisdom and provide no blame, no shame environment in which family members of children and adults with mental illness can feel support for their feelings.

All above trainings will take place in Jefferson City, unless otherwise indicated.

Maxine Frankenberg and Tamara Oberbeck at a Provider Workshop. Never underestimate the power of NAMI mommies.
In the Know

Missouri 2016 Legislative Session

How Did NAMI Priorities Fare?

The 2016 legislative session ended at 6:00 p.m. on Friday, May 13 with some of the best results we have seen in recent years. Big thanks go out to NAMI advocates and colleagues for a fulfilling legislative session!

Missouri lawmakers approved an increase for the Department of Mental Health’s Strengthening Mental Health Program. This will pay for a boost to the emergency room enhancement (ERE) initiative and more Community Mental Health Liaisons (CMHLs). Monies were also approved for a 3% provider increase for mental health, substance abuse and developmental disabilities providers.

The Mental Health Crisis Project, a proposal NAMI MO has been watching very closely, won approval. A request to waive Medicaid rules has been submitted. If approved, some uninsured 21-35 year olds with mental illness or substance addiction disorders will get Medicaid coverage and recovery-oriented community services. The project will serve approximately 2000 uninsured individuals with low incomes. Participants must be referred by a CMHL or through an emergency room participating in the state’s ERE program. It is hoped this project will be up and running by the end of August, 2016. Monies were also approved to keep the waiting list for in-home services for people with developmental disabilities at zero.

Late in the session a group of mental health advocates (including NAMI MO’s Scott Perkins and NAMI St. Louis’ Jackie Hudson) fought back a proposal that would have imposed restrictions on atypical antipsychotic medications in Medicaid. Medicaid recipients with mental illness will continue to be able to get the antipsychotic medication they and their doctors find most effective. This provision in MO law may be challenged again next year. Stay tuned.

HB 1565, the bill to increase the asset limit in Medicaid from $999 to $2000 for an individual, passed! The $999 limit amount was set in 1967, based on 1967 dollars.

Thanks to passage of SB 646 public school teachers will be able to count two hours of suicide prevention training toward their annual continuing education requirement and school districts will now be required to develop suicide prevention plans.

An amended version of HB 2029 passed! This bill will allow physicians to override managed care step therapy (or fail first) medication coverage policies in certain instances. Step therapy requires individuals to “fail” on cheaper medications before a more expensive medication will be covered by an individual’s managed care plan.

Lack of action toward closing Missouri’s insurance coverage gap was our biggest disappointment this session. It is estimated that 300,000 uninsured Missourians could receive coverage if Medicaid eligibility were extended to 138% of the poverty level (approx $15,800 annually). According to a March 2013 MO DMH report, nearly 50,000 of these uninsured are people with mental health needs. Many are young adults between the ages of 18-30 with developing mental illness such as schizophrenia or bipolar disorder. Our public health system does not serve young adults well because they are often uninsured and have no means to pay for their treatment. For now, Missouri’s Medicaid program will remain one of the stingiest in the nation. A mother with two children and just $4000 in annual income will continue to be considered too wealthy for Medicaid health coverage.
Finding Our Way Through Psychosis
by Brendan McLean, NAMI Communications Coordinator

“It’s the most soul-wrenching experience anyone can go through.” “I felt like everything my child had worked so hard for was going to come crashing to an end.” This was how two respondents described the harrowing journey of what it feels like when a loved one experiences psychosis in NAMI’s survey on first episodes of psychosis. Many others voiced some of the same thoughts: tales of confusion, feelings of isolation and anxiety about what the future would hold.

Questions about what would happen to their or their loved one’s well-being abounded. Can I maintain my current life? Can I still have a job? Will my friends abandon me?

More than 1,200 individuals who experienced psychosis and more than 2,800 family members and loved ones shared their perspectives on their experiences with psychosis in a hope to improve the difficult road many others will face behind them. The results of the study were published in the October 2011 NAMI report First Episode: Psychosis.

Psychosis is not a diagnosis but a frightening symptom experienced in some cases of mental illness. It is most commonly seen in cases of schizophrenia, but can be observed in others. Psychosis can also be a consequence of medical causes such as a brain tumor or the use of substances such as cocaine or marijuana.

However, because of its prevalence in schizophrenia, bipolar disorder and other mental illnesses, it is not often discussed as a separate topic. “While mental health service users and families will be able to find plenty of resources and literature on schizophrenia, less is available on the first episode of psychosis, which may or may not evolve into schizophrenia,” said Michael T. Compton, M.D., M.P.H., professor and director of research initiatives for the department of psychiatry and behavioral sciences at the George Washington University. Dr. Compton is the co-author of the book The First Episode of Psychosis: A Guide for Patients and Their Families.

Because there is a lack of readily available information, individuals are often unsure where to turn. The single greatest response to the survey question of who had been “most helpful” during the experience of the first episode of psychosis was “no one.” “This is simply unacceptable,” said NAMI Medical Director Ken Duckworth, M.D. “With this new project, however, I am delighted to say that NAMI has begun to address these important and compelling needs.”

With the release of the website section, NAMI now offers an arena devoted to dispersing knowledge-based support geared toward first episodes of psychosis. Having a wealth of information gathered together in an easily accessible place will prove invaluable; nearly 50 percent of survey participants state the Internet was an important source of information.

This website is an appreciated addition to the emotional support already offered through many of NAMI’s classes such as NAMI Basics and Family-to-Family and NAMI Peer-to-Peer.

Including information on topics such as diagnosis, symptomology and treatments, the new site will attempt to fill a hole that has been left open for far too long. Psychosis is a condition that has historically been associated with shame, humiliation and prejudice, making the need for better information very important. NAMI believes that having access to information helps individuals and families make better choices and helps reduce the isolation so common to these experiences.
What Is Psychosis?

Like mental illness, psychosis does not have one specific cause. Rather, it is caused by a combination of risk factors. These risk factors can be categorized into two areas: external risk factors (the environment) and internal risk factors (genes).

However, one specific gene is not believed to be the sole cause for the appearance of a mental illness or the occurrence of psychosis. Instead, it is believed that a multitude of genes interact to produce the illness. For example, 80 to 85 percent of the time, the occurrence of schizophrenia is believed to be controlled by genetics.

Individuals experiencing psychosis often begin to lose contact with reality because of hallucinations or delusions. These symptoms may be intermittent, transient or part of a longer-lasting psychiatric condition.

Hallucinations involve sensing or perceiving things that no one else notices. They are most commonly auditory in nature (e.g., hearing voices), but can also include visual experiences and, more rarely, olfactory sensations.

Delusions are false beliefs held regardless of legitimate evidence to the contrary. Examples may involve paranoia (e.g., a man who believes the FBI is chasing him) or mistaken identity (e.g., a woman who believes her mother is an imposter).

Psychosis, however, does not usually manifest itself in fully developed hallucinations overnight. There are usually small signs that begin to exhibit themselves first, such as a decline in academic performance, a decline in self-care or personal hygiene, a suspiciousness or uneasiness with others, an increasing sensitivity to sights or sounds or hearing voices. Addressing these symptoms at their earliest moments and beginning treatment early is paramount in providing the most successful interventions and methods of support. As there is an increase in symptoms, behavior worsens and treatment is often less effective.

“Don’t delay,” said Dr. Compton. “Find a psychiatrist experienced in psychosis and work closely with him or her through the initial evaluation and treatment planning. Work together as a family.”

The last part is often the most difficult. Those affected by a first episode of psychosis may tend to isolate themselves. However, staying connected to family, friends and mental health professionals is very important.

Additionally, although the survey found that 40 percent of individuals who experienced psychosis said they spotted their symptoms on their own, over half of family and friends who responded to the survey opined that they witnessed them first. This discrepancy points to the need of having a good supportive community to not only help identify trouble but ensure that treatment is followed.

“We have many effective treatments now, including both medications and psychosocial interventions, which are usually combined for maximal effectiveness,” Dr. Compton said. “But these treatments can only be effective if those affected embrace them and work closely with mental health professionals who have expertise in psychosis.”
Children

Poorer Eating Habits in Youths with Bipolar Disorder

Youths with bipolar disorder have significantly poorer eating habits than peers without the disorder, a new study has found, and stress-induced eating is the likely culprit.

Canadian researchers measured unhealthy eating behaviors such as binge eating and excessive intake of fat and sugar. They found that emotional dysregulation and impulsivity were associated with unhealthful nutritional habits. The researchers said it’s important to screen for stress-induced eating and to intervene when needed to improve the nutritional intake of youths and young adults with bipolar disorder.

The study, which appeared in the Journal of Affective Disorders online ahead of print, was entitled “Binge eating and emotional eating behaviors among adolescents and young adults with bipolar disorder.”

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Ozark Center Launches Super Me! App

Aids in Healthy Child Development

The Ozark Center in Joplin just launched Super Me!, an app for Apple devices. Super Me! helps children develop resilience and positive coping skills through a series of in-game and out-of-game activities. Aimed at elementary and middle school aged children, this app is designed to open the door to parents and children to foster resilience and positive coping skills.

“Many children experience tough situations,” said Mary Parrigon, Ozark Center Executive Director. “Unfortunately, not every child has access to resources to help them recover, heal, grow and succeed. This app gives them the tools to overcome those challenges, move forward and grow into a healthy adult.”

Stage one of Super Me! focuses on belonging to a community. Children select a character, a house and family members. Values of resilience are promoted by encouraging players to get to know their neighbors and other community members such as teachers, firefighters and police officers.

“Developing a true SuperMe! gives children the encouragement and skills to handle difficult situations and teaches them to interact and draw comfort and support from the community,” said Vicky Mieseler, Ozark Center Vice President of Clinical Services. “If a child has a good connection to the community that he or she can utilize during stressful times, it can make a difference.”

Other levels include support, safety, health, education, creativity, values, and creating change. Each stage includes home discussion points, which encourage children to share thoughts and feelings about resilience and promote the development of community and social support. Guides are available for parents and teachers to help reinforce the SuperMe! concepts.
According to Dr. Laura Prager, director of Child Psychiatry Emergency Service at Massachusetts General Hospital, “Anxiety is one of those diagnoses that is a great Macquerader. It can look like a lot of things. Particularly with kids who may not have the words to express their feelings, or because no one is listening to them, they might manifest their anxiety with behavioral dysregulation.”

For a child with an anxiety disorder, the commonly recognized symptoms are things like trouble sleeping in his own room, trouble separating from parents, avoidance of certain activities and behaviorally inhibited temperament/extreme shyness. In young children we see freezing and clinging behaviors. When a child has temper tantrums, disrupts his classroom, or throws himself on the floor at the shopping mall, its harder to know what that means.

To demonstrate the surprising range of ways young children express anxiety, Dr. Prager shares a case of a young child she saw in the emergency room with hallucinations. She predicts this child will end up being somewhere on the anxiety spectrum. “Little kids who say they’re hearing things or seeing things, for example, may or may not be doing that. These may not be the frank hallucinations we see in older patients who are schizophrenic, for example. They might be a manifestation of anxiety and this is the way the child expresses it.”

Disruptive behavior at school is common for children with undiagnosed anxiety. School may present demands and expectations that put pressure on them they can’t handle. Kids who become disruptive push away the very adults they need to help them feel secure and less anxious. They spend half the day in the principal’s office instead of learning, and this only make the problem worse.

Anxiety also drives a lot of symptoms in a school setting that are easily misconstrued as ADHD or defiant behavior. Symptoms common in ADHD such as getting up out of his seat all the time, going to the bathroom a lot, getting in other kids’ spaces is frustrating to the teacher. She wonders why he is so wrapped up in what other kids are doing and whether they are following the rules. Kids with OCD can be mislabeled as inattentive when they actually not asking questions because they’re not listening, but rather feeling ill at ease and needing reassurance.

What it all boils down to is that kids are complicated and symptoms can overlap diagnostic categories. Comprehensive diagnostic assessment is needed.

What are the goals of the NAMI Basics program?

- To give the parent/caregiver the basic information necessary to take the best care possible of their child, their family, and themselves.

- To help the parent/caregiver cope with the impact that mental illness has on the child living with the illness and the entire family.

- To provide tools for the parent/caregiver to use even after completing the program that will assist in making the best decisions possible for the care of the child.

Would you like to help families who care for children with mental illness?

Who would make a good teacher?

- Parents/primary caregivers of children or adolescents who developed symptoms of mental health issues prior to the age 13.

- Those who feel comfortable with the emotional issues families face and can self-disclose about their own feelings of guilt, anger, shame, etc.

- Those willing to make a commitment of teaching 2.5 hours a week for 6 consecutive weeks with a co-teacher. No teaching experience necessary.

Sign up now!
June 10-12, 2016
Call (800) 374-2138
JOIN US!

Every membership strengthens our effort. If you belong to a NAMI chapter, you are already a member of NAMI Missouri. All members receive the quarterly NAMI Missouri Newsletter and the Advocate, the quarterly magazine published by NAMI. Members also receive reduced fees to attend NAMI Missouri’s Annual Conference.

All Donations are Tax Deductible

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