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Ask Dr. Ken
This fall marks NAMI’s 40th anniversary, a testament to our organization’s strength. Since 1979, NAMI has left its mark across this country. NAMI has grown from parents around a kitchen table to hundreds of thousands of advocates who are fighting to make life better for millions of people affected by mental illness.

While we are rightfully proud of how far we’ve come, I like to also think that this milestone is really a celebration of NAMI’s first 40 years. I saw many of you at this summer’s National Convention in Seattle and was energized by your excitement for what lies ahead. During our convention, we unveiled NAMI’s 2020-2025 Strategic Plan. This document will serve as a roadmap for the first five years of our next 40 years.

In crafting our strategic plan, we refined our vision statement — we envision a world where all people affected by mental illness live healthy, fulfilling lives supported by a community that cares — and reaffirmed our mission statement — we provide advocacy, education, support and public awareness so that all individuals and families affected by mental illness can lead better lives. We also determined the values that will guide us: hope, inclusion, empowerment, compassion and fairness.

We were intentional in our approach to the strategic plan, including thousands of stakeholders from all 50 states to help guide us toward what matters most to our movement. Your voices led us to three goals where we can make the most profound impact: 1) get people help early; 2) get people the best possible care; and 3) get people diverted from justice system involvement.

Finally, we identified “accelerators” that will bolster our impact: diversity and inclusion, technology, partnerships and financial strength.

NAMI’s strategic plan will serve as our North Star, showing us what to prioritize while providing us the flexibility to be agile and relevant in today’s changing world. It connects the strides we have made in the past to a clear path for the future. The plan is bold, but it is also attainable by harnessing the power of what has made NAMI so successful: our grassroots.

Thank you for being part of our movement and helping fuel our ambitious plan for the future.

Angela Kimball
NAMI Acting Chief Executive Officer

A Tribute to Our Founders

As each of us reflects on our personal desire to do good and leave the world a better place, it’s daunting to consider NAMI’s earliest advocates venturing down a path few had walked before. Or choosing a mission that hurled itself headlong against the thinking of the times and generations of ill-begotten myths. Or facing the harrowing realities of blame, guilt and long-term institutionalization — more often, warehousing — that had evolved over a century.

Think of how it must have torn at their hearts, as it does ours, to be jolted by the realities of deinstitutionalization: mental, physical and social needs left to chance and to dismayed families and disgruntled communities with barely a sense of what it meant to absorb, care for and care about those who largely had been abandoned to a dream without doors, a roof or windows — and too often, to the streets or to jails.

Yet, as we know, that’s what the founders of NAMI faced, not only in 1979 but decades earlier.

It’s easy to wax poetic about “founders” in our 21st-century thinking of mass communications and electrifying stories of rapid success in founding other social or medical movements in recent decades. To appreciate our founders’ efforts, we must remember that NAMI was not hatched in our digital age: there were no conference calls, no internet, no quick jaunts from one city airport to another.

The 1950s and 1960s are faraway times, yet that’s when NAMI’s story began: in the hearts and minds, in the grit and the courage of people who knew that nothing short of a medical revolution — a fundamental rethinking of mental illness — had to happen. That rigorous biomedical research had to replace conjecture, and that all lives touched by these mysterious illnesses deserved a revolution of compassion and hope, not simply a few adjustments.

NAMI officially dates itself back to 1979 — its first national convention in Madison, Wisconsin, Sept. 7-9, 1979, and its incorporation meeting on Sept. 9, 1979. That’s the much-celebrated date, and rightly so. However, reaching the point of incorporation or assembling of a national gathering, both daunting in their own right, had taken two decades and dozens of stalwart souls and their grassroots companions who stood by their commitment to change and put themselves squarely on the line with the ultimate questions: “If not us, who? If not now, when?”

For all the work ahead, we too — NAMI of today — must ask the same questions.

Adrienne Kennedy
President, NAMI National Board of Directors
with NAMI Georgia
Executive Director Kim H. Jones

You no longer have to imagine this because it has already happened to you, but place yourself in this moment: You are standing at the podium at a black-tie awards ceremony. What is going through your mind when you accept an award for your work?

I am humbled by and grateful for the many hardworking members I represent as the executive director of NAMI Georgia. I am honored to represent the dedication of my members to improve Georgia’s mental health system. I do my best to represent our organization with integrity and a commitment to collaborate. To me, helping those who are affected by mental illness is what my members do daily in their communities. I try to do the same, just at a macro level in NAMI Georgia’s community.

How would you describe yourself as a leader?

I demand and want the best for the people we serve, always thinking about the bigger picture of where we want Georgia to be.

You’ve been known to get in your car and hit the road when there is an issue that is not happening directly in the NAMI Georgia office. What impact do you think this has on resolving problems and the people involved?

I think that we bring the state voice into the field. When I travel to the source of the issue, I think people are surprised to see me, which is always a shock to me. My favorite part of my job is visiting and speaking with my affiliate leaders across the state to try to better understand their needs.

What has been the most satisfying moment of your leadership of NAMI Georgia?

I enjoy attending our annual meetings and meeting our members and the people we serve. I love to see their faces and hear stories about what their affiliate is doing to help people in their communities. I also love hearing what they need help with, so they can do even more. My members, especially my affiliate leaders, energize me.

What advice do you have for Affiliate and State Organization leaders?

Have gratitude for each level of our organization, and be nice. Each one of us plays an important role. Keep growing and focus on progress, not perfection. I often repeat a phrase I heard at my first NAMI Executive Directors Leadership Exchange: “Put down the pitchfork and paint a picture.” I am often in meetings with peers who get on their soapbox and angrily let our state leaders know all that is wrong with our system. By painting a picture of the problems and posing solutions rather than attacking, Georgia leaders have been more open to hearing our ideas. This approach has opened many doors and partnerships for us.

What are some of your ideas for building strong relationships in local communities?

To build strong relationships in my statewide community, I try to remember that God gave me two ears and one mouth. I need to listen twice as much as I talk. I also believe in purposely thanking people I work with for what they are doing to help our people. None of us can do this on our own, and it is hard work. We all need to lift each other up.

This year, NAMI is celebrating its 40th year of grassroots advocacy. What do you wish for NAMI in its next 40 years?

My wish for NAMI over the next 40 years is that we make mental health and wellness a priority for everyone, especially our leaders. We need to be intentional, thoughtful, and loud and proud about it.

I wish the same for NAMI Georgia. I, as a leader, must be intentional about our organization’s mental wellness. As a workaholic and mother of a child with mental health issues, this is not an easy task for me. I often tell my team, “Do as I say, not as I do, and don’t respond to emails over the weekend.” But as the NAMI Georgia leader, I have a responsibility to model mental wellness. My wish for NAMI in 2060 is to have our mission accomplished. I would love to see us become the “National Alliance on Mental Wellness.” Then we can all laugh at how people pronounce NAMW.
**New NAMI Headquarters in 2020**

In February 2020, NAMI will be moving its Arlington, Virginia, headquarters half a mile down the road from its current location. The new office space will be in Ballston, a vibrant and diverse neighborhood with both residential and commercial neighbors.

The pedestrian-friendly area offers restaurants, a shopping and entertainment center, and green spaces — an inviting mix of business and pleasure. Office construction began in late September and will result in a clean, modern workspace with enough room for national staff to be collocated on one floor, with ample collaboration space.

As of late February 2020, the new address will be 4301 Wilson Blvd., Suite 300, Arlington, VA 22203.

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**NAMI Creates Online Version of NAMI Basics**

NAMI Basics, an education program for parents, caregivers and other family members who provide care for youth experiencing mental health symptoms, is now available in a new online format: NAMI Basics OnDemand.

Just like the in-person format, NAMI Basics OnDemand is free to participants. The program is divided into six sessions, including:

- Basic elements of coping with mental health conditions
- Brain biology and getting a diagnosis
- Communication skills and crisis preparation
- Treatment and connecting with others by sharing your story
- Navigating the mental health and education systems
- Self-care and advocacy

Since 2009, NAMI Basics has been offered by NAMI Affiliates in an in-person group setting. The new format, which is available 24/7, is a direct response to increased demand for more convenient access to the program.

Learn more about NAMI Basics and NAMI Basics OnDemand at nami.org/basics.

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**NAMI Announces New Director of Inclusion and Diversity Officer**

NAMI is excited to welcome Monica Villalta, M.P.H., as its director of inclusion and diversity officer. In this newly created position, Villalta will provide strategic leadership for NAMI’s diversity, equity and inclusion (DEI) work. This new focus and investment reflect NAMI’s commitment to align our organizational values and advance the implementation of the 2020-2025 Strategic Plan. To NAMI, diversity and inclusion are core components of our aspirational values and key accelerators in expanding the reach of our work and NAMI programs.

Villalta brings more than 25 years of experience in public health and leadership in diversity, inclusion and cultural competency initiatives in the public and private sectors.

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**NAMICon 2020**

**Atlanta • July 15-18**

**Together Toward Tomorrow**

The NAMI National Convention is one of the largest community gatherings of mental health advocates in the United States. Join us in Atlanta as we celebrate 40 years of NAMI.

Register Today
nami.org/convention
The NAMI Homefront program produces significant benefits for both in-person and online participants, according to a study published this July in Psychiatric Services, a journal of the American Psychiatric Association.

NAMI Homefront is an adaptation of the evidence-based NAMI Family-to-Family program, designed to address the unique needs of family members, caregivers and friends of active-duty military service members and veterans experiencing post-traumatic stress disorder (PTSD), traumatic brain injury (TBI) and other mental health conditions. According to a RAND Corp. study, approximately 18.5% of service members returning from Iraq or Afghanistan have PTSD or depression, and 19% report experiencing a TBI during deployment. Another RAND study found that post-9/11 caregivers are more likely to care for an individual with a mental health or substance use condition than their pre-9/11 or civilian peers. Post-9/11 caregivers are also more likely to be lacking a network of support.

“We know that NAMI Homefront has helped countless military families across the country, and now there is science to prove it,” said Angela Kimball, NAMI’s Acting CEO. “This study reinforces the vital role family members, caregivers and friends can play in supporting service members and veterans with mental health conditions.”

The study saw improvements in empowerment, coping, psychological distress, family functioning, experience of caregiving, and knowledge of mental illness for both in-person and online participants.

NAMI Homefront is free to participants and consists of six 2.5-hour peer-taught sessions for the family members, caregivers and friends of military service members and veterans with mental health conditions. The program launched in 2014 and has since enrolled over 2,500 individuals — 1,100 in person, 1,470 online — to date.

NAMI Homefront is available in in-person settings, as well as online. To find the NAMI Homefront program nearest you or to sign up online, visit nami.org/Find-Support/NAMI-Programs/NAMI-Homefront.

Richele Keas is Senior Manager, Media Relations, at NAMI.
As a criminal justice professor, I follow crime and justice news on a regular basis. Crime and justice news can help explain why people commit crime and engage in deviant acts, inform crime prevention and response, and shine a light on emerging issues in the field.

Recently, I have noticed increased media coverage of incidents involving law enforcement and people with mental illness. As a former human services practitioner and current academician, I realize that short sound bites and brief news columns do not offer the full context. The media does not always clearly explain interactions where the police use deadly force, especially in situations involving people with developmental disabilities and mental illness.

However, one incident in particular had me questioning law enforcement’s response to situations involving people with developmental disorders and mental illness. While this incident involved someone with a developmental disorder rather than mental illness, I felt moved to advocate for improved law enforcement responses and the decriminalization of mental illness.

THE INCIDENT
On July 18, 2016, Arnaldo Rios Soto, a man with autism, ran away from his group home. He was later found sitting in the middle of the street, and someone called the police. His caretaker, Charles Kinsey, a behavioral therapist, sought his client and, once he found him, attempted to persuade him to return to the group home.

Sensing the danger of the situation, Kinsey laid on his back with his hands up and explained who he was to the responding officers. He stated that his client was not a threat, and that Arnaldo was holding a toy car in his hand, not a weapon. Video from a bystander showed Kinsey calmly cooperating. Then a North Miami police officer shot him while attempting to shoot Arnaldo (Kinsey survived).

While I can’t know what was going through the officer’s mind at the time, it is my opinion that the officer did not consider the context provided by Kinsey: that a man with a developmental disorder needed help and posed no harm. According to the National Institute of Mental Health, people with autism can have symptoms that impair their ability to function, including the ability to communicate.

What may be perceived by an officer as a person’s failure to
reply to orders might simply reflect symptoms. Unfortunately, Mr. Kinsey’s explanation and calm demeanor were not enough to de-escalate the tension surrounding the event.

THE CHALLENGE: LOSS OF TRUST
It’s unclear why some officers act more aggressively than their peers when confronted with a situation involving a person with mental illness.

Unfortunately, there is a cost associated with these controversial incidents. For instance, family members and friends may be reluctant to call the police for assistance in a crisis if they think their loved one may get hurt or killed as a result of their intervention.

Additionally, in cases of domestic violence and abuse, mental illness may manifest as a result of ongoing, targeted abuse by a partner. These victims may fear being viewed and treated as a criminal threat by law enforcement if they call for help.

People of color, particularly African Americans, have reported disparate treatment when calling the police to assist in a mental health crisis. Some researchers argue that implicit bias and preconceived notions of African Americans being more criminal in nature has led to quicker use of deadly force.

When people see stories like this in the news, they may lose trust in law enforcement and their ability to adequately address incidents that involve those with mental illness. These implications weaken the overall bond between community and law enforcement.

THE OPPORTUNITIES: EDUCATION AND IMPROVED AWARENESS
While these incidents are tragic, they have forced society to address this issue by considering ways to improve. Recognition that there is a problem is a vital step in supporting both individuals and their families, as well as law enforcement in their response.

It is vital that college educators such as myself, the police, mental health practitioners and community-based advocates work collectively to:

- **Work with the Media to Spread Awareness**
  Mental health providers and advocates can schedule sessions with local media to explain types of mental illness and the appropriate responses to them. They can encourage the media to include local and national resources in stories about police interactions with people who have mental illness.

- **Provide Training to Improve Officer Response**
  Central to improved responses are trainings, such as Crisis Intervention Team programs, that educate officers about mental illness so they can develop an understanding and equip themselves with the knowledge and tools to address such situations.

- **Collaborate and Create Beneficial Partnerships**
  Police departments and mental health providers can partner and collaborate to consider all approaches to responding to and supporting people with mental illness. Mental health specialists who can provide a continuum of care to people in need (persons in distress, victims and offenders experiencing mental illness) can offer rapid-response support to officers who are first responders on the scene. Police and mental health professionals also can point out to one another the biases that may set back progress.

- **Share Information and Resources to Strengthen Community Response**
  Educators in roles like mine can include special topics on mental illness and policing in curriculum content (e.g., best practices). This would help prepare criminal justice and public health students pursuing careers in law enforcement and mental health counseling for real-world incidents involving people having mental health crises. Also, criminal justice departments partnering with NAMI on the national, local and college levels can provide pathways for sharing relevant mental health information and resources on campus and in surrounding communities.

While we can’t turn back time and change the outcomes of controversial police interactions with those who have mental illness, we can learn from them. Learning and education can only lead to improved response, as long as the voices of the police, mental health providers and advocates are heard and respected.

If you follow these stories like me, you will agree that the time is now to improve responses to mental illness by learning from these incidents and working together to do better.

Johnny Rice II, DrPH, M.S., currently serves as assistant professor of criminal justice at Coppin State University in Baltimore and as a consultant for Ujima, a project of The National Center on Violence Against Women in the Black Community. For 21 years, he has provided leadership, technical assistance and support to organizations that serve low-income fathers and families. Specifically, he supports the areas of child welfare, youth development and criminal justice in efforts to create safe and stable communities. Follow Dr. Rice at drjohnyrice.com.

**COMING SOON: NAMI Sharing Your Story with Law Enforcement**

Your Story with Law Enforcement is a new online training that prepares peers and family members to share their personal experiences with mental illness during law enforcement trainings and will be released in 2020.
and supports. Direct your advocacy toward these decision-makers to ask them to prioritize mental health funding.

Nationally, members of Congress and the president are responsible for federal funding decisions. These include funding for community services through the Community Mental Health Block Grant, veterans’ mental health care through the Department of Veterans Affairs, innovative research at the National Institute of Mental Health (NIMH), housing assistance through the Department of Housing and Urban Development, and community policing and diversion initiatives through the Department of Justice. The federal government also funds mental health care through Medicare and Social Security Disability Insurance (SSDI).

At the state level, state legislators and governors decide on funding for community-based mental health services and supports, as well as funding for longer-term care and state-run psychiatric hospitals. If you’re looking to advocate for First Episode Psychosis programs or crisis services funding, direct your advocacy toward state legislators and governors.

Local officials like mayors, council members or county commissioners also make funding decisions for community-based mental health services and supports in their communities, especially if your local government provides care directly.

How Can You Advocate?
Being an advocate means speaking up for the change you wish to see. This can be accomplished by calling, emailing, tweeting, attending a town hall or sitting down and meeting with an elected official or their staff. If you want your policymaker to focus on mental health, you can:

• Connect with your local NAMI office at nami.org/local to see how you can get involved locally as an advocate;
• Text Advocate to 855-469-6629 to sign up to receive NAMI advocacy alerts; and
• Find a local NAMI Smarts for Advocacy class at nami.org/smarts to get trained on how to be an effective advocate.
**What Should You Say?**

Communicating with elected officials can seem a little scary. But with the right tools, you will be advocating in no time! Talking points are a great tool to help support your argument. You can use talking points with elected officials as a place to start your conversations in person, through email or on the phone. If you’re comfortable, add a brief personal story — no more than 90 seconds — about how mental health impacts you and how funding mental health services and supports will help you and your community.

Here’s some sample language to help you advocate for mental health funding:

- 1 in 5 Americans has a mental health condition, but tragically, more than half go without needed treatment.
- Mental health services and supports ensure that people with a mental illness receive treatment when they need it — helping them to stay in school, on the job and in recovery.
- Too often, mental illness is overlooked, marginalized and stigmatized.
- Please protect and strengthen [state/county/city’s] mental health programs and invest in proven community services and supports that promote and maintain recovery.
- Mental illness does not discriminate. It affects adults and children of every background, race and religion.
- Funding for mental health is a public health imperative. Please invest in mental health.

**What Else Can You Do?**

Fortunately, there are more ways to communicate with elected officials than email, phone and in-person. Now, elected officials are interacting with constituents on social media. You can find your elected officials’ social media accounts by going to nami.quorum.us/officials.

Want to engage your elected officials on social media? You can post the sample message below on their Facebook pages or @ them on Twitter or Instagram. Feel free to write your own posts and use #Act4MentalHealth so we can follow your advocacy!

1 in 5 Americans has a mental health condition. Funding for mental health is a public health imperative. Please invest in mental health. #Act4MentalHealth

NAMI is strong because of advocates like you: people who will raise their voices and speak out for all affected by mental health conditions. Thank you for helping make funding mental health services and supports a legislative priority!

Stay up to date on NAMI’s advocacy and public policy by following @NAMIAvocacy on Twitter (twitter.com/NAMIAvocacy).

Jessica W. Hart is Senior Manager, Field Advocacy, at NAMI and Brandon Graham is Manager, State Policy, at NAMI.

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**TIPS FOR INTERACTING WITH ELECTED OFFICIALS AND STAFF**

1. **Do your research.** Read the policymaker’s bio, find their picture and learn about their previous support or work on issues relevant to NAMI.
2. **Build a connection.** Encourage conversations by looking for common interests or connections between you and the elected official or staff member.
3. **Be prepared.** Talking points support your ask and stories move people — but keep your story to 90 seconds or less.
4. **Keep politics out of it.** NAMI is nonpartisan. Respect your elected official’s political views, even if they are different than your own.
5. **Follow-up.** Thank the elected official or their staff for their time and support (if applicable). Mention that NAMI is a resource that offers free local education and support programs. Thank-you notes are highly encouraged.
As we celebrate NAMI’s 40th anniversary, it is important to reflect on how we got here. From humble beginnings around kitchen tables to 48 NAMI State Organizations, over 600 NAMI Affiliates and a national headquarters, the evolution of NAMI is a story unlike most organizations.

At every step in this 40-year journey, the grassroots — the heart of NAMI — have guided the way. Like roots give strength to a towering tree, the fortitude of NAMI is anchored in our grassroots founding.

Stepping Out of the Darkness
Although NAMI was not officially established until 1979, the seeds were planted as early as the 1940s. Parents of people with severe mental health conditions grew restless, agitated by the lack of concern and treatment for their loved ones’ health. So, they began to advocate.

Pioneers in dozens of cities across the country claimed their stake in mental illness advocacy, sometimes without any knowledge of similar groups in neighboring communities.

In 1974, in San Mateo County, California, 15 people gathered in NAMI pioneer Eve Oliphant’s apartment home. Oliphant had placed an ad in a newspaper and sent invitations to families involved with the San Francisco Schizophrenia Association. United by concern for their adult children, Oliphant, along with Tony Hoffman and Fran Hoffman, transformed the small gathering of families into an organization called Parents of Adult Schizophrenics (PAS).

Only 10 people attended its inaugural meeting, but a year later, the organization had grown to 115 members. PAS evolved from a safe place to share woes to a politically-active organization.

In a speech before the World Congress on Psychiatry in 1977, Oliphant proclaimed, “We failed to understand why parents of a child with leukemia were treated with sympathy and understanding, while parents of a child with schizophrenia were treated with scorn and condemnation.”

PAS received coast-to-coast attention after a nationally syndicated column described the organization and its efforts. A flood of letters poured in from families affected by mental illness, as well as similar organizations, asking for guidance on how to advocate for the services their children lacked.

PAS eventually became a nonprofit association, changing its name to the Alliance for the Mentally Ill of San Mateo, one of several groups in California demanding better care for their family members. Today, this organization is known as NAMI San Mateo County. What started as a local organization in San Mateo spurred a national movement.

Forming a National Alliance
Noting the lack of a national presence, Harriet Shetler and Beverly Young pitched the idea of a national coalition to the board of directors of the Alliance for the Mentally Ill (AMI) of Dane County. With authorization from the board, Young and Shetler began exploring a plan to gather as many groups as they could find to come together for a national meeting.

The two women sought sponsorship from the University of Wisconsin – Extension Mental Health Department and secured a $5,000 grant, which covered most of the expenses and kept participant fees at a low cost. Together, the planning group organized a three-day national meeting with three objectives:

- To foster learning about federal legislation, current research and recent developments in the treatment of persons with chronic mental illness;
- To encourage sharing what citizens can do through mutual help/advocacy groups in improving the lives of people with mental illness and their families; and
- To create a national federation, coalition or network of local and state mutual help/advocacy groups.
On Sept. 7, 1979, 284 representatives from 59 groups in the U.S. and Canada arrived at the Wisconsin Center in Madison with a shared goal in mind: to create a national voice for those with mental illness. On the final day, a resolution was proposed and unanimously adopted to incorporate the National Alliance for the Mentally Ill.

**Planting Roots**

A steering committee was formed to navigate a path forward for NAMI, armed with just $4,000 in pledges and gifts collected from meeting attendees. The officers included George Hecker (president), Irving Berkowitz (first vice president), Beverly Young (second vice president), Eleanor Owen (secretary) and Shirley Starr (treasurer).

Within 10 days of the conference culmination, Hecker appeared before the Advisory Council for the National Institute of Mental Health (NIMH), and the following month, NAMI members traveled to Washington, D.C., to meet the NIMH director. In 1980, the steering committee officers:

- Laid the groundwork for the NAMI board of directors;
- Successfully incorporated NAMI as a not-for-profit organization;
- Secured a sizable grant from the MacArthur Foundation; and
- Joined the influential Mental Health Liaison Group, the main congressional lobbying coalition at that time.

Starr — who later became NAMI's president from 1980 to 1982 — made weekly treks from the Midwest to the nation’s capital to meet with leaders of other mental health organizations, as well as with members of Congress. When she’d reached her limit of hotel bills, she rented a fifth-floor apartment located on Massachusetts Avenue and desk space in the building’s basement. That studio apartment became the first NAMI national headquarters.

It also served as lodging for NAMI members visiting from their home states. Meetings were hosted in the living room, staff lunches consumed in the kitchen — and a steady rotation of volunteers and NAMI members circulated through the modest space.

By 1981, NAMI had moved to a two-room suite on 15th Street and hired its first executive director, H. Bernard Smith, as well as Lynne Saunders, who started as an administrative assistant, rose through the ranks and retired from NAMI as a senior advisor of field advancement in 2019.

Membership grew from the original 284 in 1979 to over 5,000 by 1981 and to 15,000 by 1985. With a national office firmly established in Arlington, Virginia, local grassroots affiliates continued to blossom. By the end of 1987, membership had reached 54,000 people, and 825 affiliates and 47 state organizations had been formed.

**Branching Out**

The next two decades brought exponential expansion. The organization developed education and support programs, including the NAMI HelpLine, NAMI Family-to-Family program, NAMI In Our Own Voice and NAMI Basics, among many other signature programs rooted in lived experience and peer education.

Advocacy efforts snowballed, and NAMI played an integral role in getting those with mental illness included in the Americans with Disabilities Act and, more recently, the achievement of mental health parity in the Affordable Care Act. NAMI hosted its first 12 NAMIWalks in 2003, and in 2019, more than 100 NAMIWalks took place across the country. The $27.4 million in revenue reported by NAMI in 2018 shows the level of growth achieved since the $4,000 raised in pledges from conference attendees at the 1979 meeting in Madison.

Over the course of 40 years, NAMI has become the leading grassroots mental health organization in the country, providing education, advocacy and support for millions of people affected by mental illness. What was born in living rooms and around kitchen tables has grown to a movement led by thousands of NAMI members across the nation. Today, NAMI is a beacon of help and hope, advocating for more research and better care, greater support and broader public awareness. NAMI State Organizations and NAMI Affiliates lead the grassroots presence — following in the footsteps of the small family groups that started this movement — to achieve a better world for people and families affected by mental illness.

Elise Kim is Director, Marketing Communications, at NAMI.
Betsy Greer remembers when NAMI was based in a one-bedroom apartment. Her husband, Richard Greer, who became NAMI’s third full-time employee, worked alongside the executive director and Lynne Saunders, retired senior advisor of field advancement, who was then the national office’s first administrative assistant.

Richard had discovered NAMI while attending a Pathways to Independence support group in 1980 to better understand the behavior of his son, who had returned from a residential boarding school.

“I’ll never forget the evening he came home and said, ‘I now understand what’s going on with our son. He has mental illness,’” Betsy said. “And it was like a great big boulder being taken off his shoulder.”

He retired as a staff member on Capitol Hill in 1981 and started volunteering at NAMI headquarters as a lobbyist. Eventually he became a part-time employee before accepting a job full-time as NAMI’s director of government relations.

Although Betsy did not join the NAMI movement officially until attending her first national convention in 1982, the workshops had a lasting impact. The convention, hosted by NAMI Maryland, D.C. and Northern Virginia Affiliates, was held at a hotel still under construction. In one session, the presenter talked about recruiting and training people with developmental disabilities to work for federal agencies and asked the audience for questions.

“And the first answer was a great example of how to help someone who has intellectual disabilities,” Betsy said. “But what do you do for people who have mental illness?” This was a defining moment for Betsy. It distinguished the experiences of those living with mental illness.

Growing Up
Early days at NAMI were filled with challenges, simply because NAMI was a very small operation. Betsy belonged to a NAMI support group but still worked a full-time job. Her conversations with her late husband about his work made NAMI an integral part of their family life. It also made her a litmus test for which ideas and policies might work — and which ones wouldn’t work.

“He would come home and say I was his skunk in the garden party because I had to tell them what they were considering wouldn’t help those who are struggling with a family member who had mental illness,” Betsy said.

Both Richard and Betsy became facilitators of the NAMI support group in Arlington and advocates at the local level. For 10 years, they published a newsletter of local activities for about 400 people. The newsletter, which continued until Betsy retired in 1987, offered a way for Betsy to learn as her readership was learning.

When Richard retired from NAMI and began working at the state level, they kept learning together. Betsy realized the power of the families supporting NAMI. The federal government was only one player in the mental health space, but NAMI families could impact state government, too.

“One of NAMI’s strengths is its grassroots, the support groups for families who are struggling with their loved ones, who would
be sent to a state hospital for care, and under the deinstitutionalization movement, which occurred during the ‘60s and the ‘70s, were treated in a hospital and then sent home,” said Betsy.

Many of these families believed there was nobody at the local level who understood their needs and cared for them, so they learned how to advocate and care for themselves.

“Everyone in the community needed help,” Betsy said. “It was the NAMI grassroots — people who finally found NAMI, finally found a home, finally found an outlet to advocate for the services that were needed at the local level.”

She remembers that NAMI started to flourish as a young organization when Laurie Flynn, executive director from 1984-2000, joined the movement. Among the reforms and accomplishments that happened under her leadership are the establishment of the NAMI HelpLine and Family-to-Family program, increased funding for severe mental illness through the National Institute of Mental Health, and passage of the Mental Health Parity Act of 1996, which required equity in mental illness health insurance benefits.

A Community That Cares
The era was a time of growth and advocacy in the Greer household, too. They were part of a growing network of families working for mental health awareness. Even the couple friends who socialized with them were involved.

Betsy is clear about the legacy both she and her late husband have built for NAMI and mental illness awareness: Richard Greer “understood the political processes of how to get legislation through,” she said. “He knew the right people.”

Betsy, who is still a member of two local committees that oversee health services, now plays a slightly different role in the local mental health movement.

“I’m still a troublemaker in this area. I like to describe the Arlington system like the girl with the curl in the middle of the forehead. When it’s good, it is very, very good, and when it’s bad, oh my God,” she said.

Her most rewarding work, though, happens in the support group she facilitates.

“How Eleanor Owen Helped Change Washington State Mental Health Law

Eleanor Owen’s journey as a mental health advocate started when her son was diagnosed with schizophrenia. At the time, it was difficult to get treatment because the law required a person to have done something dangerous or pose an immediate threat to hurt oneself or others to qualify for hospitalization.

In 1978, a local incident involving another Seattle family sparked Eleanor and others to unite to change the law. Despite volunteering to be committed to a Seattle psychiatric hospital, a 23-year-old with schizophrenia was unable to receive the care he needed.

“The police had picked him up, drove him to the local hospital, and he said he would go in and commit himself voluntarily,” Eleanor recalls. “Well, the hospital denied him admission because they didn’t feel he needed immediate help.”

Rather than remaining safe in a hospital, just hours later he was involved in a violent crime that resulted in the death of his neighbors. He was later convicted of murder.

The event was far-reaching. When media outlets began to talk about the story, they also started reaching out to families with similar circumstances. Eight of those families, including Eleanor, came together and formed Washington Advocates for the Mentally Ill, or WAMI.

The group knew they had to start their work by changing the law, and Eleanor led the way.

“I knew that if a person were gravely disabled, that was reason enough to get them into a protected environment,” Eleanor says.

At her kitchen table, she wrote an amendment to the state of Washington’s Involuntary Commitment Act that included a definition for “grave disability.” Several state senators signed the amendment, and after Eleanor
testified on behalf of WAMI, the amendment became law.

**Turning Point**
It was the Community Mental Health Act of 1963, signed into law by President John F. Kennedy, that inspired Eleanor to stay involved in this movement for life. The act spurred the opening of community mental health centers across the country, as well as the closure of state-run hospitals.

“And they had good reason, because the hospitals at that time were terrible places,” she says. “They didn’t have medication. They had no way of humanely treating people who were hallucinating. The hospitals strapped people down and put them in cells.”

In addition to the new law, doctors were starting to use antipsychotic medications to treat mental illness, but with state hospitals closing, Eleanor believes a different danger was born out of naivete.

“People thought that now that we can control the symptoms, we can release people from hospitals and refer them to community mental health programs. These individuals will return to the community. They’ll get jobs, they’ll get married, they’ll live happily ever after. This was a naive concept,” Eleanor says. “We know now that most serious mental illnesses require lifelong interventions.”

This systematic approach to mental illness created what Eleanor calls “victims without villains.” There are many people who need help and no one accountable for when they do not get what they need. “We have homeless people on the street who are really victims, not only of the illness, but of a system that is thriving. That’s how I got involved, and that’s how I remain involved,” she says.

**Lasting Legacy**
Eleanor is grateful that the work she has done has helped lead her son to recovery.

“I think he’s recovered primarily because he gained insight into his illness and began to recognize that he needed to be on medication and to stay on it. He went back to school, he got his own business license, now does carpentry. He works, he takes care of his own house,” she says.

Her son is one of many people in her family who have benefitted from NAMI. She had a sister and has a niece with schizophrenia. Another sister started a NAMI Affiliate in New York. And her father lived with bipolar disorder, a condition that she says her family didn’t understand when she was a girl.

“I consider mental illness an illness. I think it is a condition that responds to medical intervention, as well as talk therapy, as well as work therapy.”

Cherryl T. Cooley is Managing Editor, Content Marketing, at NAMI.
I have always been a birthday person, because I love remembering other people’s birthdays and the idea of reflecting on what your own special day means to you. I’ve spent my birthdays at some interesting places, but the two most interesting have to do with NAMI.

I learned about NAMI for the first time when I moved to Seattle in 2016. I was in the process of applying to grad schools to become a therapist and wanted to have volunteer experience at a place that works with mental health. After researching NAMI and learning how great the organization is, I signed up for their newsletter. Soon, I found myself signing up to go to NAMI Seattle’s volunteer orientation. I got the email and found out that the orientation was on June 20, which is my birthday. Since I didn’t have any plans for that day, I thought I’d go for it.

I was nervous going into the orientation because I didn’t know anyone who would be there. Being a very anxious person, I was worried about it. Once I got there, I met other young people like myself who were interested in the mental health field. We all learned about what the organization does and all the ways we could get involved. When we had to share about ourselves, I shared that it was my birthday, and everyone sang “Happy Birthday,” which was nice.

I left the orientation not just with a good sense of what NAMI does, but with a feeling that I had found my kind of people, those who were interested in some of the same things I was interested in and had gone through some of the struggles I had living with a mental health condition. On my drive home, I stopped for ice cream to celebrate my birthday.

I felt great and deeply wanted to be a part of NAMI. It was quite a way to spend my 24th birthday!

The next session I went to was about the NAMI In Our Own Voice and Ending the Silence programs. I was touched to see what great work NAMI Washington is doing with those programs. Also, knowing that I get the privilege to volunteer with the Ending the Silence program in Seattle makes my heart feel so full.

I spent the rest of the evening with one of my best friends, then came back the next day to the convention to help at the registration desk again. I will say again that it was quite a way to spend my 27th birthday!

People can celebrate birthdays in many ways, but I love to spend mine reflecting on the past year and being hopeful about what’s to come.

Flash forward to June 2019. I’ve been a volunteer with NAMI for three years. I decided not to pursue being a therapist, but have gone after my dream of becoming a writer. Many things have changed in those three years, but one thing has not, and that is how much I love what this organization does. I have become very active with the NAMI Ending the Silence program and have gone around to schools and churches to talk to teens about why mental health is so important. It’s been incredible to share my story and help the next generation end the stigma around mental health.

When NAMI announced its 2019 national convention would be in Seattle, I knew I wanted to go. I decided to volunteer at the convention, and it turned out that they needed me to volunteer on June 20. I volunteered to help at the registration desk in the morning and had a great time meeting people from all over the country who were in town for the convention. I got to meet folks from my home state of Ohio and learn about what NAMI Ohio is doing. After I was done at the registration desk, I went to some of the different convention sessions.

One of the sessions was about breaking barriers to mental health in black communities. I appreciated that session because as a black woman, I understand the importance of breaking those barriers in our community and sharing the importance of mental health awareness.

People can celebrate birthdays in many ways, but I love to spend mine reflecting on the past year and being hopeful about what’s to come. That feeling is the same feeling I get about NAMI. In the past three years, I have witnessed growth in the community around mental health, and I’m hopeful that with the work NAMI is doing every day to help the cause, things will get better. I look forward to many more birthdays spent with NAMI and to continuing to help spread awareness about mental health.

Monique Hebert is originally from Ohio but now resides in Seattle. She graduated with an English degree from Cleveland State University in 2014 and loves writing the three P’s: poems, personal essays and plays. She published her first book, Anxiety, Anxiety, Why Do You Have a Hold on Me?, about her experience with an anxiety disorder in May 2018. She’s most passionate about theatre and advocating for mental health.
As a kid, I vividly remember sitting around my grandmother’s house thinking, “I want to be an NFL player and have a big NFL contract one day.” Looking back, I never dreamed that I would be where I am now, in my second season with the Cleveland Browns.

However, it wasn’t an easy road. In addition to all of the physical demands of becoming a professional athlete, I have also battled with depression and anxiety.

The challenges started when I was a student: dealing with demanding transitions, bullying and balancing my schoolwork with athletics. I could see that others around me were going through similar issues, but I didn’t feel the need to speak to a school counselor. Along the way, I taught myself to brush off my symptoms, and I would try to shift my focus elsewhere.

During my time at the University of Alabama at Birmingham (UAB), balancing my schoolwork and football began to feel like a daily struggle. On top of that, the high expectations of the NFL draft started to take a toll on me. When you make the transition from college to pro-level sports, no one really talks about the pressure that comes with it.

That kind of pressure can wear on your body immensely and cause anxiety to really sink in. The anxiety felt like a constant voice in my head telling me, “I’m not good enough.” Thankfully, I had support from UAB counselors, who were able to help me with the stress and the transition. This is when I learned how important it is to seek out help, and not to be ashamed of it.

These lessons really helped me after I was undrafted in 2013 and went through a very tough time emotionally. I experienced a lot of self-doubt and
questioned whether this journey was right for me. And with support from my wife, I realized that it was. She was by my side throughout the whole process — from my lowest points to when I finally got the call from the Pittsburgh Steelers.

This was a time of joy in my life, but I still felt an immense amount of pressure: moving to an unfamiliar city, needing to perform well on the field, wanting to make my family and hometown proud. And then, four seasons later, when I was picked up by the Cleveland Browns, I went through that whole process and all of the anxiety again.

Even when you sign the contract of a lifetime, your anxiety doesn’t just fade away. You are still playing a high-intensity game that wears on you every day, beating you down physically and emotionally. But there’s always a way to get help. What worked for me was reaching out to someone close to me. It’s not always easy, but finding the courage to express yourself is better than bottling everything in.

More and more, we see professional athletes using their voice and platform for good, and that is exactly what I am hoping to accomplish. During Mental Health Awareness Month, I hosted the Cars & Coffee Rally for Mental Health Awareness in Columbus, Georgia.

Bringing attention to this event and my hometown means the world to me. It is not just one month of the year, but every day that I want to help spread mental health awareness. I want my community to know that their voices are being heard. I want them to know that it’s okay to ask for help.

Chris Hubbard is a NAMI Ambassador and an offensive lineman for the Cleveland Browns of the National Football League (NFL). In 2018, Hubbard started in all 16 games and played every offensive snap, as well as contributed on field goal protection. Hubbard was born in Columbus, Georgia, and enjoys spending time with his wife and son.

This article originally appeared on the NAMI Blog in May 2019.

**Bonus Video Content**

In the latest installment of NAMI’s “Strength Over Silence” docuseries, Chris Hubbard takes us on a journey back to his hometown, where he shares the unique challenges of playing competitive sports, encourages young athletes to take care of their mental health and relays the importance of asking for help. Watch at nami.org/strengthoversilence.

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**CARS & COFFEE RALLY — A Roaring Success**

Chris Hubbard, NAMI Ambassador and offensive lineman for the NFL’s Cleveland Browns, helped kick off May’s National Mental Health Awareness Month by hosting, alongside NAMI Columbus Georgia, a Cars & Coffee Rally on May 18 at PTAP (Perfect Touch Automotive Playground). Car enthusiasts viewed rare classic, exotic and muscle cars on display while enjoying their morning coffee. The event raised more than $12,000 and was one of the most successful one-day NAMI fundraisers ever held in Columbus.

A Columbus native with local roots, Hubbard led his former alma mater, George Washington Carver High School, to the Georgia Class AAA football state championship in 2007. He initiated the Cars & Coffee Rally and was on location at the event, along with NAMI Columbus board members Stephen Akinduro and Molly Jones.

This fun and engaging event allowed Hubbard and NAMI Columbus to engage with the local community, increase awareness of mental illness and welcome people who wanted to get involved with NAMI.

 CONTRIBUTED by Teri Owens, NAMI Columbus.
Fonda Bryant was 35 when she started experiencing suicidal ideation. At the time, she didn’t believe anything was wrong with her and was not open to help, most likely because she grew up in a family and culture that didn’t talk about mental health.

My anxiety was through the roof. If you grew up like me, you’re terrified from all the perceptions that are out there and from what you’ve seen on television about mental illness. As much as I tried to fight it, depression was a mental and physical thing. I could feel it, and it had started to overpower me.

One day, she called her Aunt Kellie and offered her all of her shoes — Fonda’s prize collection. It was one thing they had in common. Fonda had grown up with her aunt and saw her as a sister. This immediately tipped Aunt Kellie off that something was wrong.

Shortly after, a police officer came to Fonda’s door. Aunt Kellie arrived at the same time. When the officer told her that he needed to take her to Cedar Springs, a private psychiatric hospital, Fonda resisted. She scratched him, and the officer had to restrain her with handcuffs to take her away. Fonda’s son watched the entire scene unfold.

Aunt Kellie knew something wasn’t right and did not hesitate to have me involuntarily committed, which I didn’t even know you could do. I was really upset. I don’t curse, but I was cursing her out that day because I was steaming. As sad as that day was, I now know she did what was best for me. Aunt Kellie is a hero who doesn’t wear a cape. She saved my life.

Fonda has told this story many times to national audiences. Each time she does, someone asks how they, too, can have an Aunt Kellie. She tells them that they can’t have her Aunt Kellie, but they can certainly act in the same ways that her aunt did.

I think that’s the lesson. We were not educated on mental health, and that’s why what she did to help me was such an amazing thing.

Becoming an Advocate
It was Fonda’s son Wesley who helped her realize that mental health awareness was her life’s work. She was having negative thoughts one day while working out at a gym. When she got home, she walked past her son and isolated herself in her bedroom. Wesley followed her and chose that moment to tell her that she could help others living with mental illness.

He lovingly kicked me in my pants, and the light bulb went off. I knew what my purpose was. The next day I reached out to NAMI, and I’ve never looked back.

Since then, Fonda has launched a core of mental health initiatives in the metro Charlotte, North Carolina, area. Here are the main ones she’s been involved with since becoming an advocate.

Raising Her Voice for Minority Mental Health
Fonda regularly speaks out in her community about minority mental health and the inequities that minorities experience. According to the Office on Minority Health, part of the U.S. Department of Health and Human Services, disparities in minority mental health care include less access to mental health services and a lower quality of care. Additionally, minorities are less likely to receive diagnoses and treatment for their mental illness.
Her upbringing in an African American family was marked by suppression of mental illness, self-medicating, and denial that mental health was as important as physical health. Despite a known family history of depression, Fonda was taught that mental illness is a sign of weakness and that she just needed to be strong. She believes these social norms within her culture have developed over centuries of adversity experienced by African Americans. Though slavery was abolished more than 150 years ago, the legacy of social inequities, racism and systematic discrimination continues to pervade minority mental health outcomes.1

One of the challenges Fonda has seen through her advocacy is that members of her community have fewer role models and feel less comfortable turning to someone who has not experienced a similar cultural upbringing. As such, she serves as a mentor for African American youth, making herself available to those she interacts with at presentations, and she recently received peer support specialist certification. She also encourages athletic teams to hire mental health staff who are culturally competent and can relate to experiences unique to the African American community.

Therapy is therapy, but mental health is not one size fits all. When a young person can connect with a mental health care professional who can empathize with and understand their upbringing, walls come down more easily. We need to do better and work together, no matter our differing backgrounds, to make therapy more accessible for those who are scared to seek it.

Encouraging Exercise
She started Sanity Not Vanity, a partnership with the Fitness Connection gym chain that emphasizes the mental health benefits of working out. The program has been in place for five years and has featured appearances from professional sports mascots like the Charlotte Hornets’ Hugo the Hornet and Homer the Dragon of the Charlotte Knights, as well as local community leaders. In 2020, Sanity Not Vanity will expand to all Fitness Connection gyms in Charlotte. There are also plans to take the program to Raleigh, North Carolina, in 2021 and out of state in 2022.

Organizing Events
This year, she organized “Taking a Stand for Mental Health,” a concert featuring Living Colour, a rock band based in New York, to raise awareness for mental health and suicide. Nearly 400 people attended the inaugural event, which brought attention to the resources offered by NAMI and other mental health organizations. The same music group has already committed to perform again in April 2020, and Fonda has big plans for the next iteration of the event.

“I am passionate and determined. I don’t give up. If I don’t get in the first door, I find a side door. I think people hear my passion and know that I’m sincere.”

I like thinking outside of the box when it comes to planning awareness events for mental health. Panel discussions and lectures aren’t the only way to educate people about mental health. Plus, to me, music is therapy, and there’s nothing better than good music for a good cause.

Working with Athletes
Fonda makes it a priority to speak to athletes at nearby schools, including Wake Forest University and Johnson C. Smith University, to help reduce stigma and encourage athletes to seek mental health care if they need it. Fonda has facilitated a partnership between NAMI Charlotte and the city’s minor league hockey team, the Checkers, to support Mental Health Awareness Month. The event was so well-received that it was elevated to the Carolina Hurricanes professional hockey team, with the goal of increasing awareness of NAMI and its mission.

Inspired by the Big East Mental Health Summit, Fonda pitched the idea of a similar gathering to Atlantic Coast Conference (ACC) Commissioner John Swofford in 2017. On May 21-22, 2019, nearly 500 people, including ACC athletes, administrators and mental health professionals, came together for seminars and conversations at the inaugural Mental Health & Wellness Summit in Durham, North Carolina.

Making an Effort to Prevent Suicide
An awareness effort Fonda started that is getting national attention is her suicide-prevention signs on parking decks. The idea for the signs came after a conversation with journalist Courtney Francisco of Charlotte’s WCCB station, who mentioned that there had been several suicides in the 12-story parking deck where the station is located. After doing some research, Fonda discovered there had been six suicides there in the last four and a half years.

She secured the support of Kaiser Permanente and Maaco to help her pay for bright green wristbands, and parking lot owners and managers paid for signs in the parking deck that read, “You are not alone. Need Help?,” alongside the contact information for the National Suicide Prevention Lifeline.

Standing Up for Mental Health
Fonda may be perceived as “pushy” and “aggressive” by some, but she knows this kind of persistence gets things done. I am passionate and determined. I don’t give up. If I don’t get in the first door, I find a side door. I think people hear my passion and know that I’m sincere.

Fonda wants people to know that her passion for mental health awareness is what drives her. It’s hard work, but she’s happy to show up to do it every day.

It’s advocates like Fonda who show that you don’t have to be an expert or have a background or education in mental health to be a strong advocate. It’s advocates like Fonda who show that one person’s passion can make a difference — and that you can save lives by caring about others, just like her Aunt Kellie.

Cherryl T. Cooley is Managing Editor, Content Marketing, at NAMI.

You are strong and you are brave...."

The tears began spilling down my face before my therapist had even finished her sentence.

In all the time that I had been meeting with her, I had never expected anything less than compassion. Yet I had been searching so relentlessly for what I did wrong that I felt certain she'd agree with me on some level that, yes, I had failed my children. After all, I dated and married the wrong men. I was too attached — or maybe too detached, depending on which child you asked. I worked too much, or worked the wrong shift, or didn’t work enough (again, different answers from different kids). I was a poor role model who didn’t know how to communicate with my family. The list of my shortcomings seemed endless.

"When did things begin to go so wrong?" I found myself asking that the night I drove home from the hospital emergency room, after my youngest son was admitted for suicidal ideations.

No one could have been more shocked than me to find out that my son was struggling. Since that night, I’ve examined the story of his life with a fine-toothed comb, finding a thousand ways I had made mistakes with him, but virtually no examples of courage.

And that’s when the self-doubt began.

I fought it. Tenaciously.

But when it was reinforced by the voices of my grown children and ex-husband, fear and apprehension began to plague me.

It’s been many years since my youngest son first verbalized to me that he considered ending his life. During that first hospitalization, I was not prepared for the perceived apathy we received from the hospital staff. This was a life-shifting event for me as a parent, so you can imagine I was incredulous when he was discharged with no plan, few instructions and a handful of prescriptions.

After his second hospitalization, which came just weeks later, I had learned a few things. First, the purpose of the psychiatric inpatient unit was to stabilize my son, nothing more. Second, I realized that we had now entered a new and unfamiliar world, and in that world, my role was advocate and protector with my job now excruciatingly clear: keep my child alive.

As time went by, there were more visits to the adolescent psych unit than I could count. We worked with many therapists, psychiatrists and medications. My son entered a lengthy intensive outpatient program. He spent an even longer period at a locked psychiatric facility for adolescents.

I can recall only a few names of his care team members; there were only a handful who stuck around long enough to be memorable. However, not one of them made a difference in the trajectory of his illness.

According to my son, these well-intentioned interventions only made his illness worse. He became elusive in discussing his symptoms and suspicious of the next treatment plan. He trusted no one. Why should he? The only reward he received for sharing the thoughts that taunted and haunted him was another stint in isolation, locked away, medicated to the point where he would not be considered a threat to himself or others.

Frustrated as I was with the system of adolescent mental health care, I was also grateful. For even though I could see every day that my son desperately wanted to be alone, the stakes were far too high for us to grant him that wish. Even when he pushed me away and shut me out, as long as he was sitting on the couch bouncing his leg, looking at me like a caged animal, he was alive. And during those days, keeping him alive was all that mattered. When we attended meetings at school to figure out a plan for his education, I felt like I was sucking water from a sinking lifeboat through a narrow straw. I didn’t care if
he failed every class as long as he stayed alive. I didn’t care if he stayed home in his pajamas every day if that’s what he needed to live.

Please don’t misunderstand. It’s not that I didn’t care if he became an uneducated, unproductive member of society — far from it. But in this moment, I just wanted to keep this amazing, sensitive and funny son of mine alive until he believed in the hope of his future — a future in which I knew he could be and do great things.

And yet the visceral, heart-wrenching truth was always there. The most painful realization I’ve ever had to face is the acknowledgement that no matter what I did, I could not will my son to stay alive.

As my son’s suspicion of the mental health system grew, I found myself growing more and more suspicious of my son. I was in constant fear, never believing, knowing or trusting that he was OK. I circled the periphery of his life, watching like a hawk, waiting for any sign indicating I should swoop in to save him. I would describe his behavior by saying, “He seems fine ... until he isn’t.”

I wanted to hope for the best as I saw him doing well in school, enjoying his job and spending time with family, but I wasn’t going to be caught off-guard again. It wasn’t enough for me to see this tall, smiling young man act as if he didn’t need my help anymore. I was determined not to be the last to know if his depression grew overwhelming again, or if the voices in his head spoke in ways for him to believe suicide was a solution.

“Suicide” is such a loaded word. The dictionary tells me it comes from the Latin words “sui” (oneself) and “cide” (killing) to mean the killing or death of oneself. That describes the mechanics of the act, but there is no hint of the inner torture and torment that can drive one to that precipice.

Doctors prescribed medications to treat my son’s depression and hallucinations, but drugs only took the edge off. Clinicians expected us to be reassured when they told us that it was a sign of improvement if he only wanted to die once in a while and the voices weren’t commanding harm.

Meanwhile, my son had died a thousand times in my mind. I wondered whether it would always be that way, and whether I would ever be able to relax again. As vigilant as I tried to be, the truth is, I didn’t recognize his depression in the past — so how could I be sure I’d recognize it the next time? Together, we worked out a safety plan so we’d both know what to do if things got worse. We included responses for different levels of concern — from grounding techniques to calling 911. I was ready to speed-dial crisis hotlines or his therapist and I tried to be supportive and set healthy boundaries, but none of that fixed his depression, calmed his anxiety, silenced the voices, or changed the terrible truth that sometimes my son simply didn’t want to live anymore.

I resided in the ever-present shadow of uncertainty of the future. It sat on my chest, crushing me bit by bit, inch by inch, because I knew, even though my son may tell me he’s fine, if he wanted to die enough on any given day, he would die.

Back in my therapist’s office, I hear her reaffirm that I am a good mother even though I have made mistakes, as all mothers do. She looks me straight in the eye and tells me my son’s depression isn’t my fault. I agree, but I cannot let go of the guilt I feel for not protecting him from whatever trauma may have caused his mental illness.

I tell my therapist I wanted so much to stop fearing his death and help him start planning his life. I wanted him to hope and believe in his own future, knowing I would always be his safety net. I wanted so much for him — the world, the sun, the moon, the stars.

My therapist acknowledges that she knows all this. She knows I loved my son more than my own life. And she reassures me that my son knows this, too. But in the end, I could not save him. At the age of 19, my beloved child succumbed to his illness and died by suicide.

Depression is a thief and a liar, and because of it, my life and my family will never be the same. I am now an empty shell of a person, not brave or strong in the least. I am told the most courageous thing is to wake up every morning to the same nightmare of reality, yet keep going, keep breathing, keep living, even though my child is not.

This is a struggle for me. Each and every day. Maybe someday I will accept that I did the very best I could, and acknowledge that a lack of love was not part of the equation when my son took the final actions that ended his life. He was loved and he loved us — but the disease just won.

Cynthia Peschard is president of The Aslan Foundation and mother of five amazing children, including Andrew, who died by suicide on Christmas Eve 2017.
The open, loving and vulnerable essay, Loving Andrew, on the previous two pages is remarkable in so many ways. I'll try to add a few notes to this essay from my perspective as a psychiatrist.

“The disease just won.” This closing line is spot on. Even deeply loved people cannot survive the severity of some psychiatric illnesses. It is a very hard fact to integrate, but one that is simply true. We lose people all the time to various illnesses, and suicide is one way we lose people with mental illnesses. It’s also very hard to talk about, which makes Cynthia’s story so compelling.

The system failed. The mental health system is often a patchwork of services that are disconnected from each other. Our knowledge of the conditions leaves much to be desired, and our treatments are often modest in the face of the power of these illnesses. These are also very hard, true facts.

What Did I Do Wrong?
This must be the most common and painful question people ask. People have asked it in my office many times. It is so hard to get to a place of acceptance that, for all our flaws, we loved and did the best we could. I asked the same question when I lost a patient to suicide and questioned my fitness for the field. It still haunts me decades later.

I was once told by a wise veteran psychiatrist, “There are two kinds of psychiatrists — those who have lost a patient to suicide and those who will.” This was a small comfort in the face of my experience with feeling like a failure, but again, it is a hard truth.

Opening the windows into this painful topic is a very important step. NAMI members have had to deal with suicide attempts, and suicide itself, since the origin of our amazing organization. I deeply appreciate the openness Cynthia showed, and I hope it will lead to further discussion for those who have lost family members too soon to suicide. We are a community that embraces hard things to make them better, and we can be proud of that.

Thank you, Cynthia, for this honest and beautiful memorial to your beloved son Andrew. It will help many of us and has already helped me.

Ken Duckworth, M.D., is NAMI’s Medical Director.

RESOURCES

National Suicide Prevention Lifeline
800-273-TALK (8255)
suicidepreventionlifeline.org

NAMI HelpLine
1-800-950-NAMI (6264)

Crisis Textline
Text NAMI to 741-741

American Foundation for Suicide Prevention
afsp.org

Zero Suicide in Health and Behavioral Health Care
zerosuicide.sprc.org

The Jed Foundation
jedfoundation.org

Samaritans Helpline
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How Do You Know You’ve Found the “RIGHT” THERAPIST?

BY LUNA GREENSTEIN

I waited until anxiety crept into every aspect of my life before I finally decided to seek help. As someone who works at a mental health organization, this fact baffles me. I was always telling other people to seek help, but for a long time, I didn’t follow my own advice. Why? I was anxious about being able to find a therapist who actually could help me.

After extensive research of therapist credentials and reviews online, I finally met my current therapist, whom I’ve been seeing for two years. And through my sessions with her, I feel I now have a clear understanding of what it means to find the “right” therapist — which I was anxious I wouldn’t be able to find.

I learned that the only way to really know whether a therapist is the right fit for you is by trying them out. Finding the right therapist means finding someone you feel comfortable with, but you really can’t tell until you’ve interacted with them.

When deciding whether you’ve found the right therapist, here are a few questions to ask yourself.

Do They Show Acceptance and Compassion?
It’s one thing for your therapist to show concern or recommend against certain behaviors, but you shouldn’t feel judged or ashamed after a therapy session. The most effective therapists make you feel accepted and validated, showing understanding and sympathy/empathy for whatever you’re going through. They will approach you with compassion and kindness and build enough trust for you to share your darkest thoughts and memories with them.

Do They Guide You to Your Goals?
Be wary of any therapist who makes promises like: “I can get you to recovery in six months” or “I can help you get rid of your anxiety.” Therapists should guide you toward reaching your goals, not make guarantees about when and how you will reach them. How you improve should be at your own pace. Additionally, they are not there to set your goals for you. This is your treatment — you’re in the driver’s seat.

Do They Help You Grow?
You should feel that your therapist is helping you:
• Learn skills to manage difficult emotions, handle stressful situations or practice acceptance;
• Understand yourself better; and
• Develop healthy communication skills.

At the same time, this doesn’t mean telling you what to do. Rather, they should help you learn how to handle whatever life throws at you.

Do They Challenge You?
It’s important to recognize that therapy is not synonymous with friendship. An effective therapist will help you see things from a different perspective, even if it’s hard to hear. And they might give you homework you don’t like.

When I feel anxious, my reaction is to act compulsively to get rid of the anxiety. For example, if I’m coming home from a trip, I obsessively think about unpacking all day, then the second I walk through the door, I compulsively put away all my things. It offers relief from my anxiety. My therapist often tells me to wait before acting. She often says, “Sit with anxiety, accept that anxiety has visited you and observe how you feel.” She pushes me out of my comfort zone to help me overcome my fears and work toward my goal of not letting my obsessive thoughts dictate my actions.

Do They Check in with You?
It’s important for your therapist to check in with you about how you think therapy is going. Since each session is tailored to you, a good therapist should adjust treatment based on your feedback. For instance, if you feel like they pushed you to do something you weren’t ready to do and you say you want smaller, more achievable steps, your therapist should take this into consideration for future exercises.

Do They Treat You as an Equal?
An effective therapist works with you and supports you. They’re your partner in improving your mental health. They’re not the teacher instructing the “right ways” to behave or the parent asserting discipline over a child. There shouldn’t be any kind of power struggle or “doctor-knows-best” attitude in their demeanor. While it is important to respect their wealth of knowledge, you shouldn’t feel inferior to your therapist.

Therapy is one of the few parts of life that is all about you. Therapists are not there to express their own needs; they are there to help you reach your goals. Like any other worthwhile endeavor, the benefits of therapy don’t happen overnight, but over time, you should feel like your therapeutic relationship is nothing but beneficial to your well-being.

Over the past two years, I’ve experienced the benefit of having a strong, therapeutic relationship. I leave my therapist’s office feeling confident that I can manage my symptoms. That’s how I know I’ve found the “right” therapist.

Luna Greenstein is Associate Editor, Digital Content Marketing, at NAMI.
FEAR into ADVOCACY: My Journey with Schizoaffective Disorder

BY BRITTANY D.

In 2013, while I was a freshman in college — my second freshman year — my grades began to decline tremendously. I made any excuse to stay in bed to avoid my responsibilities: school, friends, family, even showering. Some started calling me lazy, but I knew in my heart something was wrong. I was terrified. What if it was a “scary” mental health concern that my family joked about and belittled? What if I needed medicine? If it was that, what would I tell my family? After all, the stigmatizing, “looney bin/crazy people,” old-fashioned and misinformed perception is how I was raised.

At the time, I wasn’t aware that the reality I was experiencing was different from others, I couldn’t tell the difference between reality and the symptoms I was experiencing. I would see men in suits that appeared to be following me. I also thought the cops were watching me. I was convinced my phone was tapped. I’d make people put away their phones so that no one could listen in on my conversations. I experienced a fear and mistrust that I can’t put into words. Whenever anyone was behind my car for more than a few seconds, I would instantly assume they were following me.

When I Realized I Needed Help

A year passed. By this point, I’d stopped caring about the stigma my family tried to embed in me; I knew I needed help. I made an appointment at the student health center on campus to see a psychiatrist. I had my own health insurance and was over 18, so I didn’t have to tell anyone anything if I chose not to. I met with a psychiatrist, and I was somewhat honest, but not entirely. The ingrained stigma and fear kept me from saying everything.

After a few months, I got much worse. I thought the men I saw following me were part of a secret society: the Illuminati. I also thought they were going to recruit me because I believed I was here for a purpose bigger than me — that I was special, and they needed me. One night, I was walking and there was a green Jeep Cherokee trying to run me over. I ran uphill as fast as I could. I got to an area where a car couldn’t drive, where it was safe to look back, and nothing was there. That was the moment when I promised myself I would be honest with my psychiatrist.

My doctor contacted the team leader of a local first episode psychosis (FEP) program so I could start FIRST team-based services. I received care from the local FIRST FEP team, including the psychiatrist I originally saw on campus, a case manager and a counselor. In counseling, I learned about psychosis and strategies, like reality-testing and stress management, to aid in my recovery. My FEP counselor told me that my diagnosis was a no-fault illness — that there was nothing I did or didn’t do to cause this illness. I also learned that psychosis is a non-discriminatory illness that can happen to anyone.
At my next appointment with my psychiatrist from the FEP program, I finally talked about how I felt like I was constantly being watched by unnamed sources, followed by both cops and men in suits. I mentioned how I thought I had a seizure, how time doesn’t feel real and that I thought I was almost run over by a Jeep. Then, with a simple word, I gave consent to be hospitalized.

When I Was Sent to the Hospital
My case manager sat with me in the emergency room. It was frightening. I had someone talking on my behalf, as if I couldn’t make my own choices. I felt like an animal, like what I had to say didn’t matter, or that I wasn’t even there. It took all day and most of the night to go from my psychiatrist’s office to the emergency room to the hospital. I knew I was being watched, but this time, I was right.

I finally got to the hospital in the middle of the night. I was exhausted. I didn’t speak at first, and I barely responded. They made me take off the clothes I was wearing and put on stiff, scratchy scrubs. I was numb at this point. I remember the nurse doing some sort of paperwork, then searching through my stuff. They took my phone away, which made me even more scared. I was constantly wondering who came up with these rules. I felt smaller than I did when I was a child.

Finally, I was escorted to the room where I’d be sleeping, which I was sharing with other women. The nurse told me to go to bed. I laid in bed, but sleep didn’t come. I could hear someone screaming. I cried, wishing I could take back my “sure” response (the consent I gave my doctor) and wondering what I did to end up there.

When Things Started to Improve
Despite the difficult start, the hospital stay helped me realize the value of the right medicine and support. I met with a team of doctors to determine what medicine I needed. The medicine they put me on drastically improved my symptoms.

I was grateful that the doctors could see I was able to participate in social events, like yoga and other activities. It was a way to get off the unit and get my mind on a new topic, even if it was temporary. I went to every activity individual counseling, group therapy session and social activity with an open mind. It was a life-changing moment, no matter how scary it was at the time.

It was during my hospital stay that I realized my recovery was up to me, that no one could force me to take medicine when I left. I realized I was worth this effort. I realized I still had choices — and that I still had my entire life ahead of me.

When I Started Cognitive Enhancement Therapy
I was in a counseling session in 2015 when my FEP counselor suggested a new form of therapy called cognitive enhancement therapy (CET). The counselor said there was a social group and some sort of computer training. Another requirement, besides the commitment to attend, was to be stable on medicine. I agreed to do it. I had no idea what I was getting myself into, least of all in an 18-month program, but I looked forward to the group sessions, where I could meet people and maybe even make friends.

Months into the program, I was not only creating goals for myself, I was also achieving them. I was feeling more confident and generally better. What I liked most about CET is that I finally had people who understood my struggle first-hand. That connection, combined with being able to see the others improve, gave me hope that we, the group, could all get better. For the first time, I was excited for my future rather than scared. I realized that even with a diagnosis of schizoaffective disorder, I still had my entire life to look forward to. I graduated CET with my class in November 2016. That same year, I went back to school for the second time, feeling more motivated than ever.

How I’m Doing Now
Currently, I have only one semester left of school, and I am proud of the grades I’ll graduate with! I also work as a peer-recovery support specialist. It’s the first job where I feel like I’m making a positive impact.

I now look at my diagnosis as a part of me. I know that I’m not my diagnosis, but it has helped shape my choices. Without this personal experience, I wouldn’t be who I am today.

Through this experience, I am stronger. I am able to help others realize their full potential. I provide hope for anyone with a “scary” diagnosis that things can get better. Please remember that even a diagnosis you might not understand isn’t the end of the world. People who have a schizophrenia spectrum disorder do get better. Never give up hope.

Brittany D. is a college student majoring in communication studies. She will graduate in May 2020. She also serves as a certified peer-recovery specialist to help others through their mental health journey.
Vice magazine recently had a remarkable piece titled, “The Psychiatric Wonder Drug That Almost No One Is Using.” I view their coverage of a major issue in the care of people with schizophrenia to be very positive for attitudes and for advancing public knowledge.

The feature emphasizes that clozapine is grossly underutilized for people with schizophrenia. Additionally, people often fail on many antipsychotic meds before they get a trial of this most effective antipsychotic, according to Deanna Kelly, a past president of the College of Psychiatric and Neurologic Pharmacists.

“The mean wait time for clozapine is 48 months because doctors are putting patients on a number of different drugs and combinations of drugs before they opt for it. That’s much longer than it should be,” said Kelly, who is also a psychiatric pharmacist and chief of the Treatment Research Program at the Maryland Psychiatric Research Center. A trial of any antipsychotic is around six weeks, and 12 weeks is all that’s needed to realize that one isn’t working. “There’s no reason you should be waiting for years and years [to try clozapine],” she said.

Despite the Vice article’s provocative title, clozapine is not actually a wonder drug; not everyone responds to it, and it has real side effects, some of which are quite serious. It is, however, sometimes an amazing treatment, and there are often long and unnecessary delays in getting it. The risk of white cell collapse, called agranulocytosis, is small but can be fatal. Clinicians use a Risk Evaluation and Mitigation Strategy, or REMS, to ensure that blood counts are in a healthy range before clozapine is administered. Weight gain, diabetes and seizures, among other risks, need proactive attention. As a prescriber, my experience with patients using clozapine has often, but not always, been very positive.

Clozapine is the only medicine cleared by the FDA for treatment of refractory schizophrenia (failure of two antipsychotic medications) and the only antipsychotic approved by the FDA to reduce the outcome of suicide in this population. There is also some evidence that it may reduce substance cravings and aggression, but these are not approved FDA indications.

I have been blessed to be NAMI’s medical director for over a decade. Among the joys of this role is the fact that every single year at our convention, someone comes up to me alone or with their family and tells me of their success on clozapine. I have come to call this annual convention moment the clozapine hug.

Getting accurate scientific information to our members is a core job, and I thank Vice for doing this important story. NAMI does not endorse any specific treatment, yet we do encourage people to know the FDA approvals on this and other important and often overlooked treatments.
Demand for mental health services has greatly outpaced the supply of providers. NAMI can claim some credit for improving attitudes toward seeking help and increasing demand. Our participation in getting mental health parity into law has increased demand as well.

Short supply can lead to difficult access to caregivers, even when a person has health insurance. However, the health plan, whether it is Medicaid or a private plan, has a legal obligation to find you someone or pay for you to go out of network. If you cannot find help on your own, I encourage you to call the number on your health insurance card and explain the situation. It is their job to help you problem-solve. If they do not respond, ask to speak to a supervisor. If that isn’t effective, contact your local NAMI and the attorney general’s office of your state. Enforcement of mental health parity is part of their role, and many states have active mental health parity teams.

If you do not have insurance, try the National Association of Free & Charitable Clinics at nafcclinics.org/find-clinic. The website lists 1,400 free and charitable clinics across America. They usually have protocols to help people get care and assess eligibility for insurance. Another resource is your local community health center or mental health center. Many of these clinics have ways to provide services, regardless of means, and can assess people for insurance eligibility.

FEP programs can be found on our website at nami.org/feplearningcommunity. These programs integrate services for individuals and their families as they contend with early-psychosis symptoms. The Recovery After an Initial Schizophrenia Episode (RAISE) studies conducted by NIMH have found that pulling together the services that we know work in one place makes a difference. These services include family engagement, helping the person learn to self-manage their experience, work and school support, and judicious use of (usually low dose) medications when necessary. The community of people in these programs can also make a difference in promoting recovery.

Our NAMI community was a key part of successfully advocating with SAMHSA for the expansion of these programs through state block grants. The programs were quite rare a decade ago (only Oregon had a comprehensive system) but now number over 250 strong nationwide. This success is another feather in our collective NAMI advocacy cap, but of course, there is much more to do in this and many other areas.

Ken Duckworth, M.D., is NAMI’s Medical Director.
Dr. Matcheri Keshavan
Receives 2019 NAMI Scientific Research Award

BY KEN DUCKWORTH, M.D.

 Matcheri Keshavan, M.D., is the 2019 recipient of the NAMI Scientific Research Award, in recognition of his prolific work in psychosis. He was honored at NAMI’s annual Inspiring Hope Through Research event, which took place in November at REACH, a 21st-century arts center with interactive contemporary spaces at the John F. Kennedy Center for the Performing Arts. The award ceremony was preceded by an academic lecture by the honoree titled, “Brain Plasticity, Cognitive Enhancement and Functional Recovery in Schizophrenia and Related Disorders.”

Dr. Keshavan, a leader in early intervention for psychosis, has devoted his career to research and teaching about the neurobiology of psychotic disorders. He also has worked to understand the best applications of Cognitive Enhancement Therapy, which works to promote cognitive functioning and confidence in one’s cognitive ability, to help people living with psychosis.

Dr. Keshavan is the Stanley Cobb Professor of Psychiatry at Harvard Medical School, Chair of Psychiatry at Beth Israel Deaconess Medical Center and Senior Psychiatric Advisor for the Massachusetts Mental Health Center (MMHC) in Boston. He is a distinguished fellow of the American Psychiatric Association and a fellow of the Royal College of Physicians, Canada, as well as the Royal College of Psychiatrists, United Kingdom. Dr. Keshavan is the editor-in-chief of Schizophrenia Research and serves on the editorial boards of major journals.

He received his medical training in Mysore, India, and his psychiatric training in Bangalore, Vienna, London and Detroit. He joined the faculty at Western Psychiatric Institute and Clinic in Pittsburgh, Pennsylvania, in 1986 and was appointed as full-tenured professor in 1998. Between 2004 and 2008, he served as tenured professor and associate chair of the Department of Psychiatry and Behavioral Neurosciences at Wayne State University in Detroit.

A well-known speaker at national and international conferences, he has received numerous awards for his teaching and research, which has resulted in over 550 publications, including more than 500 peer-reviewed papers and four books. Dr. Keshavan also spoke about Cognitive Enhancement Therapy at the 2012 NAMI National Convention in Seattle.

In addition to pursuing his own research endeavors, Dr. Keshavan is focused on mentoring the next generation of researchers in this field. His lab at MMHC gives trainees firsthand experience in several aspects of biological psychiatry research.

Research is an important component of NAMI’s mission to build better lives for people affected by mental illness and their families. The NAMI Scientific Research Award, now in its 15th year, is supported by the Peter Corbin Kohn Endowment and recognizes the work and research of individuals creating a difference and moving our scientific understanding and treatment of mental illnesses forward.

Learn more at nami.org/About-NAMI/Awards/Scientific-Research-Award.

Ken Duckworth, M.D., is NAMI’s Medical Director.
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