

## Taking the First Step: Overcoming Stigma

by Stacy Hollingsworth

It's a feeling I've come to know well—the knot in my stomach, the palpitations, the racing thoughts that question the potential consequences of what I'm about to do. Should I tell them? Is it possible they'll understand what I'm going through? Will they think any less of me once they find out?

Questions such as these run through my mind every time an otherwise uneventful conversation suddenly turns into a highly personal one, often-times beginning with the phrase "I have a mental illness."

By the time I entered high school, I knew something was wrong. I noticed that I was depressed more often than not, was disinterested in activities I once enjoyed, and wanted to spend considerable time alone. After researching disorders on the Internet, I finally realized that I was facing a severe case of major depressive disorder. No matter how hard I tried, I could not identify a single cause or event that was responsible for the tremendous pain I was experiencing. It didn't make any sense to me. My life was just so picture-perfect, and yet there I was, so



miserable. I nearly convinced myself that things would get better without appropriate intervention, as my condition continued to deteriorate.

Because of the stigma surrounding mental illness, I felt compelled to hide my suffering from the outside world; even

those closest to me were unaware of my battle with depression. However, I could not hide from the fact that I was a walking time bomb. I was desperate for an end to the immense pain and therefore spent much

of my time pondering suicide.

Unlike many of my peers, for whom college represented independence, exciting new social opportunities, and an intellectually stimulating atmosphere, my personal transition into college was most notably a symbol of my entrance into the mental health care system—an opportunity to reclaim the life that had been stolen from me as a result of the depression.

I still recall the first day I set

foot into a counseling center on campus. I somewhat reluctantly got off the shuttle bus and quickly made sure no one who knew me saw where I was headed. At first, opening up about the illness was incredibly awkward. I was so nervous that I'm not even sure I was speaking in coherent sentences. Since then, though, I've had plenty of opportunities to discuss the illness with psychiatrists, therapists, and other people suffering from mental illness.

Because I was relatively treatment resistant, it took a lot of patience to get through the many failed treatment attempts, which included a variety of different medications, repetitive transcranial magnetic stimulation, acupuncture, and electroconvulsive therapy (ECT). Electrocon-

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# A Word from the ED

As I write for this issue of *Voice*, we at NAMI are in the final days of preparing for NAMI's annual Mind of America Foundation Gala in Washington D.C. At the Gala, we're giving a \$50,000 award to the scientist whose research has led to a greater understanding of mental illness. This year we are honoring Charles L. Bowden, M.D., for his seminal research on bipolar disorder.

Dr. Bowden is a world-renowned professor, researcher, and doctor, having authored and edited more than 300 publications and served as the principal investigator for over 70 studies, mostly focused on the symptoms and characteristics of bipolar disorder and the effectiveness of mood-stabilizing drugs.

NAMI recognizes that without the work of Dr. Bowden and other dedicated researchers, persons with mental illness would face even more severe challenges and disability. Every year, scientific advances bring more promise for better treat-



ments, but much more needs to be done.

The recently released CUtLASS 1 study, from Great Britain, and the CATIE, STAR D, STEP-BD, and TADS studies funded by the National Institute of Mental Health, all provide useful information to the field about the new generation of medications that treat serious mental illness. While these studies have their limitations, they do give us a clear message: There is a need to continue to make the existing array

of medications available, but we *urgently* need to develop better treatments for serious mental illness. These studies emphatically underscore the need for greater investment in scientific research, particularly in moving toward more effective, third-generation medications and, in time, a cure for serious mental illness.

NAMI will continue to press for more research. Research has always been at the core of our mission. We must ensure that a wide variety of effective treat-

ment services are made available to our communities. We must collectively challenge the scientific community, the private sector, and the federal government to development new approaches to treatment. The time is now. The need is urgent.

Your ongoing support is very important to us. Together we make a difference. Thank you for all that you do.

Michael Fitzpatrick,  
Executive Director

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2107 Wilson Boulevard, Suite 300  
Arlington, VA 22201-3042  
Phone: (800) 950-NAMI  
Fax: (703) 524-9094  
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## Calendar of Events

Dates	Events
November 3 - 5	Peer-to-Peer training, Austin, TX
November 16	Multicultural Action Center's press conference to release the National Action Plan to Eliminate Disparities in Mental Health for Racial/Ethnic Communities, Washington, D.C.
November 17 - 19	Peer-to-Peer training, Portland, OR
December 1 - 3	Family-to-Family Leadership Academy, St. Louis, MO
December 15 - 17	Peer-to-Peer training, Oklahoma City, OK

# Staff Profile:

## Marshall S. Epstein, Fulfillment Manager NAMI Education, Training and Peer Support Center

I am the Fulfillment Manager for NAMI's Education, Training and Peer Support Center. I ship Family-to-Family, Peer-to-Peer, In Our Own Voice, Provider Education, Hearts and Minds, family support group and NAMI C.A.R.E. materials to our customers. I also track shipments, provide access to all web-based Education, Training and Peer Support Center materials, and field questions about our department's programs. I am also the staff contact for NAMI-C.A.R.E.



In my spare time, I run a NAMI C.A.R.E. group in Falls Church, Virginia, and I also train NAMI C.A.R.E. facilitators. In addition, I serve on the board of directors for NAMI Northern Virginia. In that capacity, I chair two committees—those responsible for Education and for Support Groups. Lastly, I give about four or five In Our Own Voice presentations a year, and I'm a teacher in NAMI's wonderful, powerful Family-to-Family program.

To be frank, I am really glad to be doing these things; I have

felt moved toward this work for quite some time, in part because I am a person living with mental illness. I first started showing symptoms of mental illness in 1979, when I was eighteen.

Finally, after years of searching, and sometimes struggling, in 1995 I got a diagnosis that enabled me to start getting more of the help I really needed. I have bipolar disorder type I, with psychotic features. I have felt pretty stable the last five years, even as I know that I need to take my medication to avoid going into a tailspin.

But it is not my medications alone that keep me going, and keep me feeling well. It's also the dedication of so many of my fellow staff members to NAMI's goals. I have thrived on this. It's easy to feel inspired to do my best job here, because my supervisors, Lynne Saunders—Kathryn McNulty—and Joyce Burland—work so hard. I have also enjoyed working with so many NAMI people in the field. Many of them do all their volunteer work on top of holding down full-time jobs. I also really like

working at the NAMI conventions, where I have made a number of good friends.

Before coming to NAMI, I was a senior level economist working for the Internal Revenue Service. I worked there for fourteen and a half years. It was as a result of my illness that I retired from the IRS on disability. However, I still really enjoy keeping up with the economic news.

And I enjoy the hobbies I've had for years, watching football and basketball, studying history, and traveling. (Of the 25 countries I've traveled to so far, my favorite was Brazil. So exotic!) I also enjoy spending time with close friends, one of whom is Loren Booda, who works with the NAMI Helpline.

Some personal goals of mine: I would like to visit yet another new country each year. I want to continue to speak about my experiences living with a mental illness and, along with that, would like to help NAMI's Peer-to-Peer program be offered in Virginia. More generally, I would like to do all I can to one day see Family-to-Family, NAMI-C.A.R.E., and Peer-to-Peer offered in every state in the country.

## Overcoming Stigma continued from page 1

vulsive therapy, also referred to as "shock therapy," has quite a controversial history that extends into the present day. So, in addition to the fact that I was coping with a stigmatized illness, I was now undergoing a rather stigmatized treatment, as well. The use of medications in treating depression has gained accept-

ance in society, but shocking the brain? How barbaric, right?! Ironically, in our culture, it's perfectly acceptable to shock a heart in order to save someone's life, but it's not okay to shock a brain. Remember, the brain is an organ, too. Although ECT was personally ineffective, it did serve as a reminder that what I was

dealing with was a disabling medical disorder—not a character flaw.

Getting comfortable with the disorder to the point where you can speak about it openly does not happen overnight. It's a process, but one that does get easier over time. For me, it first took personal acceptance of the

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## Leadership Alliance Corner

I was reading an article the other day and came across some alarming statistics regarding mental illness.

Did you know that in the next 42 seconds, before you finish reading this letter, someone in the United States will try to commit suicide?

This is an alarming statistic by any measure. However what makes this even more alarming is the fact that the majority of those 2,000 Americans who will attempt suicide today are adolescents and young adults.

According to the Center for Disease Control, suicide is the third most common cause of death for persons 14 to 24, ahead of cancer, heart disease, AIDS, birth defects, stroke, pneumonia, flu and chronic lung disease combined!

This loss of life is just flat unacceptable and a tragedy that can be avoided. Many of these suicides can be prevented, because disorders that lead to

suicide can be treated. The reality is that the success rate of treatments for depression, bipolar and panic disorder, and schizophrenia surpasses those of other medical conditions such as heart disease.

Yet as many as eight million Americans who have serious mental illnesses do not receive adequate treatment each year.

NAMI is working to change that through our extensive public education and community outreach programs. NAMI assists individuals and communities in recognizing the signs of mental illnesses and is working side by side with NAMI community leaders to improve access to prevention, early intervention and treatment services.

We are continuing to promote mental health where people live, work and play. We support the emotional development of young people. We are empowering people to protect their rights and to direct their own mental health and well-being.

Since our founding more than 25 years ago, NAMI has educated millions about mental illnesses and reduced barriers to treatment and services. Because

of the Leadership Alliance efforts, many Americans with mental disorders have received care and now enjoy fulfilling, productive lives in their communities.

Yet we cannot escape the fact that there are still those 8 million Americans with serious mental illnesses who do not receive adequate treatment each year. And even more, we cannot escape the fact that there is another suicide attempt every 42 seconds.

Those of us who are already members of NAMI's Leadership Alliance need more of you to join our efforts with a gift of \$500 or more per year to NAMI. Your generous gift will fuel the work that NAMI does and it will allow us to save more lives. If you would like to join the Leadership Alliance or want to know more about it, please call Linda Radcliffe at 703-516-7970. If you are already a member of NAMI's Leadership Alliance, please continue to support NAMI at your current or an increased level of giving. There is much more to be done, and we desperately need your help to do it.

Darcy Taylor  
Director of Constituent Relations

**It is with great pleasure that we recognize our NAMI Leadership Alliance members who have given \$500 or more over the last year by listing their names below. Thanks to each of you for your continued support. We also want to thank our donors who wish to remain anonymous.**

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# NAMIWALKS Support Recovery Efforts in Wisconsin

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NAMI Waukesha in Wisconsin has had great success in their NAMIWALKS events in 2005 and 2006. One of the projects that the revenue generated by their WALK efforts is going to fund is a new program that will bring together NAMI Waukesha and the mental health service providers in their community to foster a system of care that embraces the concept of recovery for persons living with a mental illness. The program is called Consumer Advocacy Team, or CAT.

The focus of CAT is to ensure that persons receiving mental health services not only have a voice in their treatment services but also that they are satisfied with their treatment. To accomplish these goals, this customer centered program offer proactive ombudsman type services, thus assuring those providing services and those persons receiving the services are actually communicating with one another. It is grounded in the philosophy that recovery is not only achievable for persons living with a mental illness, but that it will be best and most quickly achieved when the recipient of the services is

intimately involved in the decisions surrounding his or her treatment, services and supports. As customers, they should be both helped and heard.

We know by experience that this approach will work since NAMI Racine (Wisconsin) has been using a similar program for several years with excellent results.

NAMI Waukesha plans to implement the CAT program in 2007. Their goal is to initially offer an outreach service and then add a cadre of extensively trained “peer mentors,” who are persons living with a mental illness but presently in recovery. These mentors will provide the unique and often critical support to fellow travelers living with a mental illness. Funds will be used to provide training and oversight for the mentoring process in Waukesha County.

Additionally, NAMI Waukesha will use WALK funds to expand their community education program that allows individuals living with mental illnesses to share their own poignant and personal mental health experiences and subsequent road to recovery stories with community groups. This

program is called In Our Own Voice and is offered across America where local groups have developed the resources to financially support it. To date, numerous community service organizations, clubs, churches, mental health organization’s staff, and others have been addressed in an attempt to help the public put a human face on persons with mental illnesses. The program expansion will allow for recruiting and training more presenters, as well as broader outreach into the community for more presentation venues, such as schools.

This program provides an opportunity for individuals experiencing recovery to share their experiences and dreams in an engaging way that not only builds their self-esteem, but also exposes members of the general public to persons with mental illnesses. For most of the public, their only exposure to mental illness is through the print and electronic media splashing “news” headlines which only increase stigma and ignorance.

These are two great programs made possible through the locally successful efforts of the NAMI-WALKS program.

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disorder, followed by the recognition that not everyone out there will understand or will want to understand the nature of the disorder. We cannot blame them—they haven’t been educated about mental illness. All we can do is be ourselves. We shouldn’t have to apologize for having to deal with a disorder that was uninvited in the first place.

Early intervention can improve your overall prognosis—not to mention spare you years of

suffering. You have to ask yourself what’s more important—that everyone thinks you’re doing well...or that you truly are doing well. This illness IS treatable. You CAN feel better. What are you waiting for?

*Editor’s Note:* Ms. Hollingsworth is a junior at Rutgers University in New Jersey, where she is starting a NAMI Campus-Based Affiliate. NAMI-Rutgers will open its doors to students and faculty in the fall and already

has generated quite a bit of interest on campus and an ambitious line-up of activities. NAMI-Rutgers will educate the campus community about mental illnesses, promote the early detection of mental illnesses and early intervention, provide support for students with mental illnesses, reach out to family members and friends of students living with mental illnesses and combat the unfortunate stigma that continues to exist with these illnesses.

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