



# THE BELL

The newsletter of the National Mental Health Association ■ July 2001

## NMHA Survey Finds Misconceptions About Disorders Impede Care

Common misconceptions about clinical depression and generalized anxiety disorder hinder millions of Americans from seeking diagnosis and treatment, or from getting the most from treatment if they are diagnosed, according to NMHA's second annual "America's Mental Health Survey."

The survey reveals that although 18 percent of Americans appear to meet the diagnostic criteria for clinical depression, generalized anxiety disorder or both at some point in their lives, more than 90 percent of those people do not associate their symptoms with a mental health disorder. In addition, nearly half of those with undiagnosed symptoms believe their symptoms are self-manageable.

The results of the survey, conducted by the research firm Roper Starch Worldwide Inc., have attracted widespread media attention, including a report on "ABC World News Tonight with Peter Jennings."

Released at NMHA's annual meeting last month, the survey also showed that receiving a diagnosis of clinical depression or generalized anxiety disorder does not appear to

*Continued on page 5*

### What's Inside

NMHA Caucus Weighs Risks and Benefits of Research Participation.....2

First Person: Riding the Roller Coaster.....3

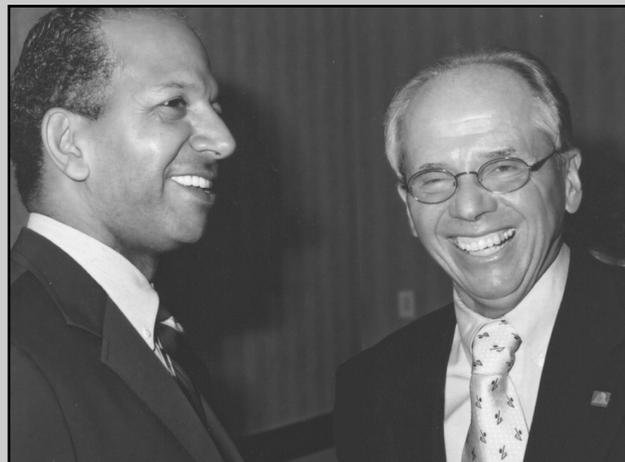
Lessons Learned: Dutchess County MHA Finds Hope in Homeless Program.....4

From the MHA Field.....5

NMHA Annual Meeting Photos.....6-7

A Moment in Mental Health History.....8

## NMHA Celebrates Largest Annual Meeting in Decade



*Washington, D.C., Mayor Anthony Williams and NMHA Board Chair Gary Tauscher share a laugh at the meeting's opening night reception.*

NMHA's annual conference last month in Washington, D.C. — its largest in a decade — brought together advocates from across the country for a whirlwind of advocacy, education and networking. Over the four-day event, attendees interacted with key lawmakers, national experts and colleagues. In the words of one attendee, "It was motivating, inspiring and informative."

*Continued on page 6*

## From the President

In all my years in the MHA movement, I have never been more proud and energized by an NMHA annual meeting than I was last month. It not only represented our largest gathering in a decade, but more important, the meeting reflected our commitment to addressing one of the most troubling issues in our work: disparities in care. No other major national mental health group has confronted this public health matter in such a meaningful way.



During the conference, our speakers challenged us to face some disturbing facts. Today in this country, people of color, sexual minorities and other Americans with mental illness face constant threats to their mental health from racism, discrimination, and stigma, and major hurdles when seeking care for mental health problems. For some in our movement, this fact was an eye-opener. For others, it was not a new message. For all, it was a clarion call for action.

In our position on the frontlines of mental health advocacy, we have a significant role to play in ensuring that all Americans can receive appropriate mental health services. That means fighting for more insurance coverage, more resources for services and systems, and a mental health community that better reflects our nation.

I believe we emerged from the meeting more prepared than ever before to act on this mission. And I promise we will not rest until every child and adult in this country, regardless of sexual orientation, race, ethnicity or mental health status, has the care they need.

Sincerely,

Michael M. Faenza  
President and CEO

## NMHA Caucus Weighs Risks and Benefits of Research Participation

by Susan Weiss, senior director, Research, NMHA

The importance of research in discovering new treatments for mental disorders cannot be overstated, but people face tough questions when deciding whether to participate in clinical studies. For example, what are the researchers' ethical standards? Are there any known long-term or irreversible risks? If I suffer adverse consequences, what are my legal rights?

A caucus at NMHA's annual meeting last month addressed such issues of concern to potential research participants and discussed steps consumers can take to protect their interests. At the session, "Risks and Benefits of Participation in Research," presenters Anne Riley, Ph.D., and Shannon Flynn of the National Institutes of Mental Health (NIMH), and Susan Weiss, Ph.D. of NMHA, discussed with attendees how the roles of research volunteers and leaders could and should be defined.

Attendees and presenters agreed that research volunteers need to become informed about the process, understand the differences between research and treatment, and agree to participate only after the risks and benefits of the research are clearly explained and considered. Most important, research participants need to know they have the right to withdraw from a study at any time without consequence. They should suffer no loss in whatever benefits or compensation they earned during the study, and should be able to resume the treatment and services they received before participating in the study.

To assist in the decision-making process, NMHA and NIMH developed and distributed to attendees a set of questions that potential study participants might want to consider before agreeing to be part of a research study. (The list will be posted on NMHA's Web site at [www.nmha.org](http://www.nmha.org).)

Attendees also expressed concern about clinical trials, particularly industry-sponsored trials, which are often conducted at major universities. Because researchers often receive financial benefits for conducting these types of studies, their research and methods may be compromised by financial conflicts of interest. Although the Food and Drug Administration maintains strict ethical guidelines for research involving products requiring their approval, issues concerning financial conflicts of interest are unresolved and remain a topic of heated debate among advisory groups.

MHAs can play various roles to help consumers who are considering participating in research studies:

- Disseminate current research information to ensure that consumers are knowledgeable about their treatment options.
- Become part of the research review process by serving on Institutional Review Boards that approve and monitor research protocols involving human participants.
- Help consumers find appropriate clinical trials upon request.
- Serve as watchdogs in the community to help ensure that research is conducted in an ethical manner, with respect for all who volunteer.

For more information, contact Susan Weiss at 703-797-2584 or [sweiss@nmha.org](mailto:sweiss@nmha.org).

## Riding the Roller Coaster

by Brandon Fletcher

Most of us at one time or another have ridden on a roller coaster. We have enjoyed the thrill of the ride. It may be the anticipation during the ascent or the excitement when the coaster soars downward. Living with bipolar disorder for me has been much like that experience. In the beginning, however, it was not an enjoyable feeling. My roller coaster was going much faster than normal. Sometimes I felt invincible; other times I lived in constant fear of it crashing as it sped downward. My life was out of control.

My ride began shortly after kindergarten when I was diagnosed with ADHD and was placed on Ritalin. By the time I was in third grade, I had been diagnosed with learning disabilities. I had to endure the constant teasing and bullying of my classmates. All the while the teachers discarded or ignored my feelings about the treatment I received from them. Teachers felt it was justified since “I CHOSE to act this way.”

When I entered the sixth grade, the roller coaster was speeding out of control. The teasing not only continued, it got worse. Kids were using me as their personal punching bag. Some days I was so angry that I would destroy things, hurt my little sister or myself. Some days I just cried. That was the first time that I tried to kill myself.

After changing schools, and finding the proper medications and support, I have been able to better get my life on track. I became a “roller coaster engineer.” I can control the roller coaster so it doesn't go so fast. I still have my good and bad days, but not as bad anymore because I'm better able to manage my illness. I don't want to kill myself anymore. Instead, I want to help others to become “roller coaster engineers.”

I am working to start a group for youth called Y.E.S. (Youth Encouraging Support) to help others learn to help themselves and support each other. We shouldn't be labeled as bad kids or told that we CHOOSE to act this way. People also need to see us as individuals and not as a group or disorder. We have the power to educate others and help reduce the stigma associated with mental illness. We can make people understand about our mental illness and our struggle to get better. Most importantly, we want them to understand that we want to be treated and accepted like everyone else. 📖



*“We shouldn't be labeled as bad kids or told that we CHOOSE to act this way.”*

*— Brandon Fletcher (far right) pictured at the 2001 NMHA Annual Meeting with NMHA staffers and other Medal of Excellence recipients: (left to right) staffer Jane Tobler, Katia Falcey, Clayton Luchsinger and Kaily Boyle, and staffer Lindy Garnette.*

*NMHA's Medals of Excellence were given to children and adolescents who have shown special courage in discussing their mental health disorders.*

Brandon Fletcher is 14 years old and lives in Kearny, Neb. Brandon received an NMHA Medal of Excellence at the association's recent annual meeting for his work raising awareness about mental illness among young people. He served as a youth representative at the U.S. Surgeon General's conference on mental health, and has contributed to articles and shared his story at conferences across the nation.

## At a Glance:

**MHA of  
Dutchess County (N.Y.)**

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### Other Programs

- **Support services** help families that include children who either have or are at risk for emotional disorders as well as parents with psychiatric disorders. Services include respite, support groups, school-based programming, and support for teens, and court-appointed special advocates for foster children.
- **Rehabilitation services** assist adults with a history of serious mental illness by providing clubhouses, and social, recreational and vocational rehabilitation services.
- **Community education** includes on-site supported educational services at the local community college, ongoing workshops and training programs such as mindfulness based stress reduction and managing defiant behavior in children, information and referral, a mental health library and a Kids on the Block puppet troupe.
- **Adult case management services**, in coordination with the local county department of mental hygiene, offer intensive and supported case management to adults with a history of serious mental illness.



*Participants of the MHA of Dutchess County's Living Room program enjoy the MHA's second annual "Peace Dinner," which is held on Martin Luther King Jr.'s birthday to promote understanding between people who are homeless and other members of the community.*

## Dutchess County MHA Finds Hope In Homeless Program

*by Melvin Garrett, director of the Living Room, MHA in Dutchess County, New York*

**N**o state across the nation is spared the scourge of homelessness, which disproportionately affects people with mental illness and substance abuse problems. And although lawmakers and citizens talk about helping the homeless, they generally fail to give homeless programs the dollars or respect they deserve. Doubt about the success of such

programs, and opposition from business owners and community members who fear being in proximity to centers and shelters often stall movement on this vital issue. But a day-program of the MHA of Dutchess County called the Living Room proves that hope is alive and progress is possible for the homeless.

The Living Room is not a shelter. It is a resource center for people who are homeless or at risk of being homeless, or who have a mental illness or addiction problems. About 60 people stop by each day for a secure daytime environment and a respite from the elements and dangers of the street. Our clients can take advantage of a wide range of on-site programs we offer — most in cooperation with other social service agencies — including recovery meetings for people with mental illness and co-occurring substance abuse disorders, Alcoholics Anonymous meetings in English and Spanish, men's and women's life skills group meetings, internships, counseling and support groups, an HIV/AIDS housing program and others.

The Living Room is also a place where visitors can make and receive phone calls, store belongings, receive mail (a legal address is a necessity for those receiving social services), read and write or use a computer, do laundry, take showers, snack on free baked goods and coffee, or watch videos on the weekends. It is not a place to sleep, but it is a home to 220 people each month.

Initial funding for the program came from New York State community reinvestment following the downsizing of state psychiatric centers. We fought to make our program a long-term success. In 1995, we started with two full-time staff members in a church basement. In 1997, after a two-year battle for acceptance from tenants and nearby merchants, we began renting space in a building that houses 20 other social service agencies — a sort of one-stop shopping for community services. We now have a staff of 13.

Our location in the community services building is one of the keys to our success. Not only does it give our visitors easy access to needed services, it gives us an opportunity to develop solid partnerships with agencies that benefit our clients. And that's another key to our success. By effectively networking with local service agencies, businesses,

## The Living Room

*Continued from previous page*

nonprofits and religious communities, we are able to provide special opportunities to our visitors. For example, through connections with large chain grocery stores, we offer donated snacks. Literacy Volunteers of America offers regularly scheduled educational assessments and literacy trainings onsite. A mediation center in the building donates mediation trainings to our staff. Now that we have the hard-won respect of the business community, professionals donate bus tickets to our clients, so they can visit family or get to job interviews. The list goes on.

Perhaps the most effective element of our program is that it's peer-based. We believe in leadership by example — people react best to what they see. Many of our staff members are in recovery themselves, like myself, and deal with other issues clients can relate to, such as mental illness or having been homeless or incarcerated. Our program is effective because our staff are living examples that it is possible to pull yourself out of any situation. The Living Room also places no demands on visitors other than requiring them to follow basic rules, such as not being disruptive or pitching in to clean, which helps build self-esteem. They know they can take advantage of our recovery services when they're ready, and most do, after time.

When we first set up the Living Room, people were skeptical. "They'll break everything. They'll steal stuff," we were told. But our clients don't do that. They love the place and treat it with respect. And now, so do our neighbors. 📖

## Misconceptions Impede Diagnosis and Treatment

*Continued from front page*

end misconceptions about the disorders. Nearly half of the respondents diagnosed with one or both of these disorders are embarrassed or ashamed by their symptoms, and only about 40 percent of those with a formal diagnosis believe their symptoms indicate a mental health disorder.

These misconceptions can affect a person's treatment as well. Only slightly more than half of the survey respondents who are diagnosed with one or both of these disorders and receive treatment expect to see any initial relief. In addition, nearly 60 percent of those diagnosed are unaware of basic terms associated with the recovery process, such as treatment response and remission, the optimal treatment goal.

For a copy of the survey, visit NMHA's Web site at <http://www.nmha.org>. 📖

## From the MHA Field

### Indiana

The **MHA of Elkhart County** created a unique fund-raiser with the help of CruiseOne, a unit of Travel Services International. Through CruiseOne, Carnival Cruise Line is offering large discounts on a seven-day Caribbean cruise in November with all proceeds going to the MHA. More info: call the MHA at 219-295-8935.

### Kansas/Missouri

The **MHA of the Heartland** purchased an eight-unit apartment complex in Kansas City, Mo., through its Heartland Housing Initiative, to provide life-skills training, treatment, employment and other services to people with mental illnesses who are homeless. The MHA purchased the complex with help from the Federal Home Loan Bank and the U.S. Department of Housing and Urban Development. More info: call the MHA at 913-281-2221.

### North Dakota

The North Dakota Psychiatric Society honored Rose Stoller, executive director of the **MHA of North Dakota**, with its 2001 Mental Health Service Award last month in Bismarck. Stoller was recognized as a leader in the state for raising public awareness of mental health issues. More info: call the MHA at 701-255-3692.

## 2001 Tipper Gore "Remember the Children" Award Winner



*NMHA honored Janet Marich, executive director of the MHA in Lake County (Ind.), with its 2001 Tipper Gore "Remember the Children" Award at the annual meeting. Marich was recognized for her leadership in providing quality mental health services to children and families.*

## NMHA Celebrates Largest Annual Meeting in Decade

*Continued from front page*

The 2001 conference centered on the theme “Justice for All: Addressing America's Mental Health Disparities.” Speaker after speaker, including MHA staff, challenged participants to respond to the complex and controversial issues related to healthcare inequities. Federal Center for Mental Health Services (CMHS) Deputy Director Camille Barry, Ph.D., opened the first plenary session with some troubling statistics showing that “racial and ethnic minorities have the least access to mental health services.” Referring to the growing minority population, she added. “That burden is likely to increase with shifts in demographics.”

At the opening dinner, keynote speaker Richard K. Nakamura, Ph.D., deputy director of the National Institute of Mental Health, pointed out that minority groups are also less likely to seek treatment than Caucasians for a variety of reasons, including stigma. “And when they do seek treatment, it is much inferior,” he said. Other speakers underscored the persistence of institutional racism and its effect on the healthcare system as a major barrier to care. “We live in a racist society, so our institutions are racist,” said plenary speaker Jerome Hanley, Ph.D., of the South Carolina Center for Innovation in Public Mental Health.

Presenters also focused on the many obstacles that discourage minorities from seeking care. In one workshop, Viviana Azar, M.S., L.C.M.F.T., of the Silver Spring (Md.) Multicultural Program, stressed that “Latinos and Vietnamese consumers ... face five general problems in accessing mental health services: language barriers,



*Jerome Hanley, Ph.D., director of the South Carolina Center for Innovation in Public Mental Health's Office of Children's Policy and Cultural Competence, discusses race and racism at the meeting's opening plenary.*



*Rep. Patrick Kennedy, D-R.I., addresses NMHA Annual Meeting participants about the need for Congress to pass the Mental Health Equitable Treatment Act of 2001. Kennedy, along with Sens. Pete Domenici, R-N.M., and Paul Wellstone, D-Minn., are NMHA's 2001 Legislators of the Year.*

immigration status, transportation, information on services and fear of deportation.”

Some speakers attributed sub-par care, in part, to the fact that minorities are often left out of clinical drug studies. “African Americans are more likely to get older drugs that they can't metabolize,” L. DiAnne Bradford, Ph.D., of the Morehouse School for Medicine charged in one session. Research shows these drugs could produce unknown harmful side effects or no benefit whatsoever in minorities, she said.

Mental health concerns for gays and lesbians were also raised at the event. “The 10 percent of the population that are gay and lesbian account for more than 30 percent of all adolescent suicides,” said Bob Decker, M.A., of the MHA of Central Florida. Decker attributes the high rate of suicide in large part to discrimination. Decker stressed that school officials can do many things to assist these youth, including identifying themselves as “gay friendly and approachable.”

Many speakers offered up possible solutions to pave the way to a fair mental health system. “When we view our work, we should look at the social, economic and family context to design an intervention,” said Henrie Treadwell of the W.K. Kellogg Foundation. “A pill is not enough if the neighborhood is the problem.”

Many MHA presenters provided case examples of effective programs that help bridge the gap in treatment disparities. They include the MHA of Dutchess County's (N.Y.) Living

*Continued on next page*



**Top photos from left:** Richard K. Nakamura, Ph.D., deputy director of the National Institute of Mental Health, delivers the keynote address; NMHA President and CEO Michael Faenza presents Alvin Poussaint, M.D., with NMHA's 2001 "Into the Light" award; former NMHA board member Dr. Betty Humphrey is honored at the opening night dinner.

**Left:** NMHA staffer Brian Cooper and others congratulate Bill Compton, NMHA's 2001 Clifford Beers Award winner.

*Continued from previous page*

Room homeless initiative (see page 4), the MHA of Middle Tennessee's "Encuentro Latino" focus groups, and this year's Innovation in Programming Award winner, MHA in Tulsa's SafeTeam violence prevention program.

Legislators also took a stand at the conference, and rallied attendees behind the Mental Health Equitable Treatment Act of 2001, insurance parity legislation that would give millions more Americans access to mental health care. "Because of blatant discrimination, opportunities are shut to millions," said Rep. Patrick Kennedy, D-R.I., Sen. Paul Wellstone, D-Minn., a cosponsor of the parity legislation, agreed. "It is time for the discrimination to stop, to stop warehousing people with mental illnesses," he insisted. "It is time to pass this legislation. It is time."



**Below:** Members of the American Indian Inter-Tribal Cultural Organization entertain meeting participants at the closing night dinner; staff and volunteers from the MHA of Indiana, NMHA Board Chair Gary Tauscher (second from right) and NMHA staffer Mark Helmke meet with Sen. Richard Lugar, R-Ind.



For more information and photos, visit <http://www.nmha.org>. 



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## A Moment in Mental Health History

Three key figures in the modern mental health movement led a workshop at NMHA's 2001 Annual Meeting in Washington, D.C., to discuss how they became involved in the movement and what today's generation of advocates can learn from their experiences during the last half-century.

The workshop, "Remembering Our Past to Guide Our Future," featured (from left to right) former NMHA board member and psychologist Patrick Okura, former NMHA staff member Doug Waterstreet, and the Deputy Secretary General of the World Federation for Mental Health Richard Hunter.

The workshop was held as part of NMHA's Heritage Preservation Task Force, which seeks to preserve the history of the mental health movement in the United States.

