



THE BELL

The newsletter of the National Mental Health Association ■ December 2001

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Sept. 11 Reinforces Need to Improve Mental Health Infrastructure

NMHA Identifies Key Concerns

The Sept. 11 attacks delivered a blow to all Americans. A Pew Research Center survey showed that about 40 percent of Americans felt depressed after the Sept. 11 attacks and that one in five Americans knows someone who was injured or killed in the attacks, or has a friend or relative who does. Statistics show that depressive and anxiety disorders are on the rise. Our mental health infrastructure is being tested like never before.

Yet, the federal government's response has been lacking. Although it provided some funding for substance abuse and mental health treatment to the District of Columbia and the eight states most affected by the tragedy, most federal funding has been limited to crisis counseling in the states in which the attacks occurred. Crisis counseling typically does not include many vital mental health services such as medication, office-based therapy, diagnostic services, and psychiatric and substance abuse treatment. And focusing on certain states ignores the widespread impact of the attacks on Americans across the country. Furthermore, a second \$20 billion emergency funding bill makes no mention of mental health or substance abuse needs.

continued on page 2-a in the winter 2001 State Advocacy Update

Also in this issue . . .

NMHA State Advocacy Update

See center insert for updates on key issues that affect state advocates, consumers and the mental health community-at-large, including:

- State Advocacy Efforts
- New Medicaid/SCHIP Policy
- New Advocacy Tools
- Healthcare Reform Advocacy Trainings

NMHA Vows to Continue Fight For Parity

Following a Dec. 18 congressional vote against mental health parity—which had widespread public support—NMHA President and CEO Michael Faenza vowed to continue the fight for parity next year.

“The battle for parity is a battle against stigma and discrimination,” Faenza said. “This legislative battle is not over.”

Visit <http://www.nmha.org> for ongoing information on the parity fight.



Hundreds of mental health insurance parity supporters took part in a bipartisan rally on Capitol Hill Nov. 29 urging Congress to pass parity. Speaking at the rally was Sen. Craig Thomas, R-Wyo. (pictured above at podium) along with author Kathy Cronkite; former first lady Rosalynn Carter; Sens. Ted Kennedy, D-Mass., Paul Wellstone, D-Minn., and Pete Domenici, R-N.M.

From the President

In the wake of September 11, mental health has taken on added importance in our country. Millions of Americans are experiencing overwhelming feelings of depression and anxiety, many for the first time. Employee assistance programs nationwide are receiving unprecedented requests for services.



In the hours, days and weeks after the New York City and nearby Pentagon attacks, I am proud to report that NMHA and its affiliates have worked tirelessly to ensure that Americans have the information and services they need to cope in these uncertain times.

Unfortunately, the federal response to the mental health impact of the terrorist attacks and ongoing war has been woefully insufficient. Despite the unprecedented demand, emergency funding for mental health services has been very limited. The recent rejection of full mental health parity legislation also does not bode well for Americans who are struggling with mental health problems, whether or not they are the result of the September 11 tragedy. We hope these setbacks are temporary.

What I can promise you is that NMHA will continue its fight in 2002 to improve our nation's response to all people with mental health needs and the systems that serve them.

Sincerely,

Michael M. Faenza
President and CEO

NMHA Speaks Out About Coping in Disaster's Wake

Americans across the country have responded to the Sept. 11 terrorist attacks, the war abroad and the ongoing anthrax scare with a variety of emotions that vary in intensity and duration. For most people, these feelings of anxiety, grief and anger are healthy and appropriate, and will lessen over time. For some people, however, the effects are more debilitating.

“Many people, particularly those who have experienced a mental illness or severe emotional trauma in the past, may be at an increased risk of experiencing symptoms of a mental illness,” said Michael Faenza, NMHA president and CEO. “These symptoms of depression, anxiety or other disorder may be so profound as to interfere in the ability of people to enjoy life.”

To help people deal with the range of emotions they may be experiencing in the wake of the tragedy, NMHA and its affiliates have been distributing to the media and general public a series of fact sheets targeting specific groups of people on how to cope. (The “Coping Series” is available at <http://www.nmha.org>.) NMHA also provided tips on how to decide whether to seek help.

“Knowing what a normal response is to an abnormal situation, and what signs might indicate you have a more serious problem, will help in determining if and when to seek help from a mental health professional,” said Faenza. “Paying attention to your mental health, and the mental health of those you love, has never been more critical.”

After September 11: Signs to Seek Help

If you have profound feelings of grief, depression or anxiety that do not go away in time or are so intense that they impair your ability to function in daily life, mental health care may be needed. Signs that indicate someone is not experiencing a normal reaction to the terrorist attacks include:

- Nightmares and recurring thoughts about the event
- Avoiding thoughts, feelings or conversations that remind you of the event
- Avoiding places or people that remind you of the event
- Having a sense of a foreshortened future
- Continued difficulty falling or staying asleep
- Feeling jumpy or easily startled
- Being overly concerned about safety
- Feeling guilty, worthless or hopeless
- Not taking pleasure in activities once enjoyed
- Having thoughts of death or suicide

For people experiencing these symptoms, talking with a mental health professional can help you understand how well you are coping with the recent events. For more information or referrals, call NMHA at 800-969-NMHA (6642).

MHA in New York City Took Quick Action When Crisis Struck

After looking on in shock at the collapse of the two World Trade Center towers from their Broadway Avenue office a mile away, the shaken staff of the MHA in New York City took swift action. Within minutes MHA staffers had initiated a crisis response that has played a critical role in keeping the city's mental health infrastructure afloat and effective.

“Our LifeNet hotline emerged as the city's 'front line' for deploying mental health workers to the disaster and relief sites. It was—and still is—the primary mental health information and referral clearinghouse for crisis services for the city and surrounding 10 counties,” says Giselle Stolper, the MHA's executive director.

The MHA's six-year-old LifeNet hotline is run in partnership with the New York City Department of Mental Health. City residents, groups and agencies depend on LifeNet for mental health information, referrals and crisis intervention 24 hours a day. Following the attacks, the MHA's LifeNet staff, along with the local mental health authority, moved quickly to deploy the city's mobile mental health crisis teams to emergency shelters and other locations.

“Our ‘800 lines’ went down but we used local back-up lines to take crisis calls, and communicate with state and city officials during the interim period,” Stolper says. “We served as the communication link between providers, hospitals, state offices of mental health and city agencies.” The MHA continues to coordinate trauma assistance with relief agencies, schools and offices, survivors and families affected by the tragedy.

Part of the MHA's success in responding to the disaster stems from its reputation for bringing together key stakeholders in the field, Stolper says. They were also able to leverage their expertise with LifeNet, which relies on a staff of mental health professionals to serve a large and culturally diverse community.

“Our LifeNet operators are already trained in crisis response and know how to interact with emergency personnel and debrief callers,” Stolper says. “Having that expertise allowed us to quickly assess how we could help the New York City community and direct our resources and partners in a very focused way.” This includes taking advantage of the city's resource

base of hospitals and public agencies to help increase their capacity to serve those in need.

To plan for an uncertain future, the MHA is joining a long-term project led by New York's top researchers to study the impact of the attacks and the ongoing bioterrorism threat on the mental health needs of the city's citizens. LifeNet workers—whose ranks have doubled to 50 referral specialists—are also using a new crisis resource database to help direct mental health professionals to training programs in trauma.

Chief among the lessons Stolper learned so far is the pressing need to create a new and flexible service model among providers that can expand to meet unusual stress when disaster hits and then contract when the need subsides. She points to the Army's structure as a possible prototype for this idea.

“Even in peace time, we have the Army reserves,” Stolper says. “We have to develop a mental health reserve that can be called up to temporary duty. We could learn a lot by studying the Army model.”

Stolper also says that mental health organizations need to go “beyond the field” to equip non-mental health professionals—such as teachers, religious leaders and even corporate executives—with skills that would empower them to help others during a crisis. Such professionals should know how to identify trauma and provide crisis support, Stolper suggests.

The MHA is also waging a powerful campaign to promote mental health in the wake of the tragedy. The multilingual effort encourages New Yorkers to “stay strong” and offers tips for doing so. In developing these messages, Stolper says, the association relied on information and coping tips provided by NMHA. “We worked collaboratively,” she says. “Any way in which NMHA could be helpful, they were there for us.”

But while we're doing all of this, Stolper says, we need to remember the people with persistent mental illness who needed our attention before the crisis. “There are new demands being placed on an already stressed out system,” she points out. “And we need to provide vigilant service to all people with mental illness.” 

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My Brother's Story

by Lori Cramer

On July 25 2000, my younger brother completed a court-approved treatment program for a DUI arrest that had occurred 13 months earlier. The following day, he sat alone in his apartment and drank himself to death. Authorities discovered his body two days later. The apartment was littered with seven empty half-gallon liquor bottles. His blood alcohol level was .402 and an autopsy revealed his liver weighted 9.9 pounds. He was just 33 years old.

For 15 years my family and I struggled to get my brother the help he so desperately needed. He was a functional alcoholic who was extremely adept at hiding his illness. For him, alcohol was an escape from underlying emotional issues and mental illness. Everywhere we turned, we got the same answers: "He needs to go to Alcoholics Anonymous" or "He needs to sign himself into rehab or break the law and be court mandated. Until then, there's nothing anyone can do."

All the while, he continued to take his life slowly over the course of 15 years. Mental health professionals argued that he needed to get sober before they could address his mental health issues. This very argument is why he fell through the complexities of the system. My brother suffered from co-occurring disorders and was caught in the debate: Does he belong in mental health or drug and alcohol treatment? Different laws and philosophies govern these two parts of the system, and, as a result, my brother continued to drink and was never treated effectively or appropriately.

After persistent health problems related to alcohol abuse and run-ins with police, doctors and law enforcement continued to suggest AA. In January 1998, my brother found our father's body after he had shot himself in the head. My brother now suffered from post-traumatic stress disorder. He had flashbacks, nightmares, agitation and insomnia. In April 1999, he was arrested on his first and only DUI charge, after totaling his car. Two days later he went on a drinking binge and threatened to kill himself and other family members. He was involuntarily committed to in-patient mental health where their focus was not PTSD but convincing him to enter a rehab clinic. He was released after five days and never returned for counseling. In September, he was accepted into a special program for first-time DUI offenders and evaluated for treatment at a treatment agency. None of his past medical or police records were permitted consideration by the courts or the agency. As a result, he was placed in one of the least invasive eight-week programs instead of a more appropriate in-patient setting.

In November he relapsed. Thirteen months after his arrest he finally began the treatment program of weekly group and individual therapy. In the last four weeks of the program he spent more than \$400 on liquor and was jaundiced from liver failure. His body was found three days after the program ended. He went into multi-system failure because he could not metabolize the alcohol he poisoned himself with one last time.

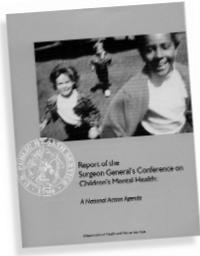
My brother's story is not uncommon. We can see that consistently attempting to put someone in a 12-step program without treating underlying mental health issues only perpetuates the vicious cycle of relapse. I have been working hard to bring positive change to the system. I want to create a collective effort among medical, mental health and law enforcement professionals as well as treatment agencies and policymakers to change the way people like my brother are treated. For 15 years, I felt helpless as I watched my brother, in pain and emotional torment, slowly take his life. Alcoholism is an epidemic and it is time we treated it effectively. 

Lori Cramer is a nurse's aide at Latrobe Area Hospital in Pennsylvania. Contact her at freebird@stargate.net or 724-694-2009, or through the MHA of Westmoreland County at 800-871-4445. Her article was reprinted with permission from "Mind Matters," the MHA's newsletter.

NMHA considers submissions to *The Bell* from consumers and other advocates who wish to share their stories on recovery or efforts in advocacy and public education. Stories should be 350-400 words. For more information or to submit a story for consideration, write to *The Bell*, National Mental Health Association, 1021 Prince Street, Alexandria, VA 22314-2971; thebell@nmha.org. Please include your name, full mailing address and telephone number.

NMHA and Affiliates Faced Down Disparities, Stigma in 2001

For mental health advocates, 2001 has been a year of triumph and tragedy. Through it all, NMHA and its affiliates have been on the forefront, influencing policy, offering public support, and leading the charge to end barriers to treatment and improve access to care for millions of Americans. Mental health also found its way onto the global stage as the focus of World Health Organization's yearlong campaign, which offered worldwide recognition that mental illness is indeed real, common and treatable (see page 6 for related story).



- The year took off with the U.S. Surgeon General's unprecedented focus on children's mental health in a report closely reflecting NMHA's positions and validating the work of advocates across the country. It highlighted comments from NMHA President and CEO, Michael Faenza, and was followed by other

landmark reports on youth violence and treatment disparities (visit <http://www.surgeongeneral.gov> for the full reports).

- As part of an ongoing campaign to challenge the stigma surrounding children's emotional disorders, NMHA launched its national *Children's Mental Health Matters* initiative to improve understanding and treatment of children's mental health. The initiative is part of NMHA's nationally recognized public awareness project, the *Campaign for America's Mental Health*. NMHA continued its advocacy

CHILDREN'S MENTAL HEALTH MATTERS

efforts on behalf of children and has expanded a range of programs, including the Children's Linkages Project, Childhood Depression Awareness Day and the Invisible Children's Project.

- This year, NMHA organized 18 state advocacy trainings to help produce positive policy changes in such areas as access to care, children's services, involuntary outpatient commitment, insurance parity and Medicaid.
- NMHA and its affiliates waged a high-profile crusade in the halls of Congress for mental health insurance parity, winning support from powerful legislators. The parity debate made its way from Senate chambers—where a committee passed the bill unanimously—to the pages of major newspapers, many times as a result of NMHA media campaigns (see cover story and visit <http://www.nmha.org> for more information). Other NMHA

advocacy focused on juvenile justice, appropriations, community-based services and federal entitlements among other issues.

- Mental health advocates, consumers and legislators from across the country gathered in Washington, D.C. last June at NMHA's largest annual meeting in a decade to confront widening disparities in access to care. Participants headed en force to Capitol Hill and visited with legislators to express support for parity legislation, mental health appropriations and other policy priorities.



MHA of Mississippi Executive Director Susan Richards with Sen. Trent Lott, R-Miss., during NMHA's annual meeting.



NMHA's Cecelia Vergaretti (right) with volunteers recruited by the MHA of Tarrant County (Texas) build a Habitat for Humanity house for a woman and her granddaughter, who has a mental illness.

- A series of groundbreaking NMHA surveys released throughout the year revealed improvement in the public perception of mental illness and uncovered alarming statistics about suicide. A recent NMHA study also charged that untreated and mistreated mental illness costs the nation \$110 billion annually in absenteeism, lost productivity, unemployment and welfare.

- NMHA teamed up with Habitat for Humanity and NAMI to break ground with the Partnership to Open Doors project, an initiative to build new housing for adults with mental health disorders. A Texas family moved into the first house this fall. The project is part of NMHA's continuing efforts to

meet the needs of adults with serious mental illness, including its nationwide *Partners in Care* program.

continued on page 6

A Moment in Mental Health History: Alex Sareyan Remembered

Alex Sareyan, one of the nation's foremost mental health advocates, died in April of heart failure in Yonkers, N.Y. Sareyan was 87.

Sareyan's advocacy for the humane treatment of people with mental illness was born out of his experience as a conscientious objector during World War II. As an alternative to military service, Sareyan served in the Civilian Public Service Program as an attendant in psychiatric hospitals, including the Connecticut State Hospital in Middletown, where he and a small group of objectors sought to stop the cruel and inhumane treatment of patients.

Sareyan continued his advocacy after the war by working for NMHA, where he created the first National Mental Health Week (later expanded to Mental Health Month) and recruited Eleanor Roosevelt, Lawrence Olivier and others to record radio public service announcements for NMHA. Sareyan later founded the Mental Health Materials Center, a nonprofit education organization, and in 1990 published *The Turning*

Point: How Men of Conscience Brought About Major Change in the Care of America's Mentally Ill.

Sareyan is survived by his wife, a daughter, a son, and four grandchildren.



Alex Sareyan (seated at center) discusses the first National Mental Health Week with representatives of other mental health organizations.

Mental Health Achievements in 2001

continued from page 5

- NMHA mobilized immediately following the Sept. 11 attacks to provide mental health information to the public and media, and to support MHAs in their local crisis response. A series of NMHA fact sheets providing tips on coping with disaster was sent to affiliates and widely reported in newspapers across the country (see story on page 2 and visit <http://www.nmha.org> to view the Coping Series).
- NMHA's National Consumer Supporter Technical Assistance Center and Safe Schools/Healthy Students Action Center continued serving the nation's consumer organizations and school districts, respectively, with needed mental health information and technical support.
- Capping a full year of advocacy, public education, research and service, NMHA was named the nation's top health charity for the second consecutive year by *SmartMoney*, a publication of *The Wall Street Journal*. NMHA also won high marks as one of the nation's top nonprofits from *Money*, *Worth*, *The Chronicle of Philanthropy* and *The Nonprofit Times*. 📖

Mental Disorders Are a Major Health Problem Worldwide, Says WHO

Mental disorders are among the leading cause of "ill health and disability," affecting 450 million people worldwide, according to the World Health Organization's (WHO) 2001 *World Health Report, Mental Health: New Understanding, New Hope*. Its findings show that mental and behavioral disorders-which affect one in four people-are caused by a complex and varied interaction of biology, psychology and environmental factors.

The report aims to raise awareness of this crucial public health priority and calls for mental health to be integrated into primary or general health care systems. "Treatments are available, but nearly two-thirds of people with a known mental disorder never seek help from a health professional," the WHO said, stressing that "stigma, discrimination and neglect" prevent people from getting care. Yet, some mental disorders can be prevented, most can be successfully treated, and prevention and treatment is affordable, the report holds.

The WHO advocates for increased world knowledge of the subject, stressing the enormous human and economic costs of not addressing mental health issues. "Where there is neglect, there is little or no understanding," the report said. "Where there is no understanding, there is neglect."

The report also closely examines different models of prevention, service and treatment worldwide, favoring community-based alternatives over less effective "mental institutions." It finds that the poor often "bear a greater burden of mental disorders," due to

increased risk factors for mental illness, such as stressful events, poor general health and lack of access to affordable treatment. Inadequate access leads to "a vicious circle of poverty and mental health disorders that is rarely broken," the WHO said.

The WHO's report is part of its first year-long campaign on mental health. For more information or a copy of the report, visit <http://www.who.int>. 📖

Advocates Make Headway in Fight Against Stigma

by Otto Wahl, Ph.D.

The stigma attached to mental illness is pervasive and powerful, and has been around for centuries. Advocacy organizations such as NMHA and its affiliate field have made substantial efforts to improve public understanding of mental illness and reduce stigma. But what kind of progress has been made toward the goal of diminishing what the U.S. Surgeon General called “the most formidable obstacle to future progress in the arena of mental illness and health.”

Our lack of progress in a few areas is discouraging. A recent study comparing current public attitudes toward mental illness with those of 50 years ago found that the tendency to associate mental illness with violence has actually increased. An assessment of an extensive, well-orchestrated public education campaign in Canada found that the yearlong effort produced little measurable change in attitudes. A study of newspaper coverage of mental illness found little fluctuation between 1989 and 1999; negative stories continued to outnumber positive stories, with crime and dangerousness the most common themes in both years.

But these same studies also produced some good news. They found that people now recognize more and different kinds of mental illness. And the ratio of negative to positive news stories has decreased from 4:1 to 2:1. Public opinion studies by NMHA also suggest a better understanding of mental illness. A recent NMHA survey shows that 55 percent of people now see depression as a disease rather than “a state of mind” compared to 38 percent in 1991.

A number of developments suggest more positive changes may be on the horizon. I have seen more activity around the issue of stigma in the past five years than in the entire 15 years before that. At numerous conferences and workshops across the country, sponsored by agencies large and small, fighting stigma is the major or exclusive topic. An array of innovative programs also combat stigma. These include Stigma Watch programs responding to media depictions of

mental illness, school programs designed to teach children about mental illness, speakers bureau-type programs that arrange for mental health consumers to speak to community and civic groups, and books, videos, and powerful public service announcements produced to educate the public about mental illnesses. We have also seen a dramatic increase in research on stigma and discrimination, and identifying effective practices in these areas.

Stigma has become a center of attention at national and international levels. The White House Conference on Mental Health in June 1999 and the first-ever U.S. Surgeon General's “Report on Mental Health” released the same year stressed the need to reduce stigma, and brought the topics of mental illness and stigma to the front pages of newspapers across the country. And the first National Mental Health Symposium to Address Stigma and Discrimination was held in Maryland in 2000.

Stigma reduction efforts are underway in all parts of the world, including Germany, Greece, Italy, Brazil, Egypt, Spain, India and Switzerland. Indeed, fighting stigma has moved to the forefront of mental health efforts. And this struggle against the prejudice and discrimination that prevent people with mental illnesses from fully participating in society has become a broad social movement, akin to the civil rights movement. Still in its early stages, our movement has impetus and momentum that cannot help but bring long overdue changes in public attitudes and behaviors toward those with mental illness. 

Dr. Otto Wahl is a professor of psychology at George Mason University in Fairfax, Va., a member of NMHA's Public Affairs Committee, and author of Media Madness: Public Images of Mental Illness and Telling is Risky Business: Mental Health Consumers Confront Stigma.

This column is a regular feature of NMHA's Stigma Watch program. For more information about the program or to report instances of stigma in the media, call 800-969-NMHA (6642).

NMHA Program Updates

Justice

NMHA, the Children's Defense Fund (CDF) and five NMHA affiliates are taking community leaders on tours of juvenile justice facilities to expose poor living conditions and the inferior services available to detained children. The tours, which are taking place in Vermont, North Carolina, Indiana, New York and Louisiana, are designed as a wake-up call to improve conditions in the facilities and increase access to mental health services. The Annie E. Casey Foundation

awarded NMHA a one-year grant to work with its affiliates and the CDF to develop local coalitions that advocate for improved mental health services for children and adolescents who are either in the juvenile justice system or at-risk for involvement in the system.

Healthcare Reform

NMHA won a \$150,000 grant from the W.K. Kellogg Foundation to develop a state “mental health report card” that will assess state investment in public mental health services and efforts to increase community-based care.



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The Bell is published by the National Mental Health Association, which works with more than 340 affiliates nationwide to promote mental health, prevent mental disorders and achieve victory over mental illnesses through advocacy, education, research and service.

To join NMHA and receive *The Bell*, visit NMHA's Web site at <http://www.nmha.org> or call 800-969-NMHA (6642).

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NMHA Named Top Health Charity In United States



Several publications have named NMHA as one of the top health charities in the United States: *SmartMoney* magazine, *Money* magazine, *Worth* magazine, *The Chronicle of Philanthropy* and *The Nonprofit Times*. NMHA earned high marks for its efficiency in fund raising, the high percentage of funds it devotes to program implementation and amount of funds it receives from public sources. In addition, the American Institute of Philanthropy

gave NMHA an "A+" rating for the high percentage of funds it commits to programming.

Your tax-deductible support can help NMHA remain on the forefront of mental health advocacy and services, and continue our mission on behalf of America's mental health.

**To make a tax-deductible donation to NMHA,
visit <http://www.nmha.org> or call 800-969-NMHA (6642).**

NMHA Annual Conference Set for June 2002

NMHA's 2002 Annual Conference, *Prevention, Resilience and Recovery: United for Mental Health*, will take place June 5-8 in Washington, D.C. Proposals are being accepted for presentations exploring strategies for promoting mental health and recovery from mental illness. NMHA is especially interested in presentations related to responses to the Sept. 11 tragedy, and prevention programs with a focus on post-traumatic stress disorder, depression, anxiety and substance abuse disorders. Deadline: Jan. 15, 2002.

For additional information on the annual conference, visit NMHA's Web site at <http://www.nmha.org> or call 800-969-NMHA (6642).