

THE CENTER FOR POLICY, ADVOCACY AND EDUCATION OF THE MENTAL HEALTH ASSOCIATION OF NEW YORK CITY

New York: 9/11 and After

Presented by Giselle Stolper, Executive Director of the Mental Health Association of New York City, to the National Institute of Mental Health Constituency Outreach and Education Program on April 26, 2003. This presentation was written by Giselle Stolper and Michael B. Friedman, Public Policy Consultant to the Mental Health Associations of New York City and Westchester.

I am honored by the invitation of The National Institute of Mental Health to be part of this year's Annual Meeting of the Constituency Outreach and Education Program. I understand, however, that I have been invited not because of what I have done personally but because my organization—The Mental Health Association of New York City—and especially LifeNet—our 24/7 hotline and information and referral service—have been part of the extraordinary response to terrorism mounted by New York City (NYC) and New York State (NYS).

For me it has been a remarkable experience to play a role in the heroic efforts of the people of New York. I constantly marvel at their courage, determination, inventiveness, and resilience.

Today I will speak briefly about the experience of 9/11 and its aftermath. I will try to give you a sense of the immediate experience, how we responded to it in New York City, of the services that we developed over time, some of the lessons we have learned, and a bit about our planning for future disasters.

The terrorist attack of 9/11, the subsequent anthrax attacks, and the frequent alerts of imminent danger of more terrorist attacks have created challenges to community mental health which are unparalleled in American history. These challenges have included not only developing services to help people recover from exposure to terrorism but also helping then to learn to live with the daily knowledge that future attacks are almost a certainty.

It seems to me that what it means to be psychologically normal in New York City—which may have always been a bit different from everyplace else—has changed because it is a time of constant anticipation of terror.

But I am getting ahead of myself. First let me tell you a bit about that day and the response to the immediate crisis.

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The Events of 9/11 as We Witnessed Them

It is still not easy to talk about the events of 9/11. When I do, harsh memories of that terrible day come back quickly and vividly.

Our office is just 20 blocks away from the World Trade Center. When the planes hit, we, like many, did not immediately know what happened. Was it an accident? Was it terrorism?

We could see the flames shooting from the tops of the towers, see the smoke which hung in the air for days, smell the fumes of fire that permeated the City for weeks.

We saw thousands of people running up Broadway, the main street in and out of lower Manhattan. They were covered with ashes and soot, tears ran down their faces.

The reality began to penetrate. "Oh my God. Oh my God" was all that we kept saying. We had no words for what we were seeing.

Or for what we were hearing--sirens loud enough to drown out all the sounds of the City--sirens coming from every direction--like an air raid of the kind I was constantly drilled to prepare for as a child.

On television we saw people leaping to their deaths; we saw the towers collapse; we saw huge balls of dust and debris chasing people who were running for their lives.

We heard speculation that perhaps 50,000 people had been in the Towers at the time of the attack, that perhaps 10,000 or more had died.

Out our windows, we saw lines of dust-covered people with shocked expressions begin to form at pay phones. Cell phones were down. People were desperate to reach their loved ones to tell them they had survived and to be sure that they had also survived.

Our LifeNet Telephone Hot Line Was Silent

Then we realized that our phones were dead silent. Even LifeNet--our 24 hour a day, 7 day a week information, referral, and telephone crisis center--which ordinarily is busy in the morning--was dead silent.

We knew that LifeNet would be a critical resource in a disaster of this magnitude, but we couldn't reach the New York City Department of Mental Health. The phone system for most of New York City's government was down and so were their cell phones.

Fortunately, we have local backup lines for our 1-800 numbers, so we were able to receive calls. But there were no calls during the first few hours.

Finally we heard from the New York City Department of Mental Health and the New York State Office of Mental Health--which could not communicate with each other directly. And for a while, MHA became the link between the city and the state.

MHA's offices are located in the "frozen zone"--an area of New York City that was virtually shut down after the terrorist attack. We were quite worried whether our workers

could come in around the clock to staff LifeNet. But they did, even if they had to walk to work.

Agencies Responded Heroically

Although New York City's disaster plan had not anticipated terrorism of this kind, the response by City and State Agencies, Federal Emergency Management Agency (FEMA), The American Red Cross, New York City's uniformed services, its hospitals, its voluntary mental health agencies, its social service organizations was heroic. They worked together to implement a vast emergency relief effort to get people who could help to the sites where they were needed.

It was a monumental job of coordination. I'm proud that, for mental health, LifeNet became the central point of communication and coordination for that relief effort.

Emergency sites set up by the City, the State, FEMA, and the Red Cross needed mental health professionals to be stationed there. New York's mental health system responded in new ways. Traditional treatment molds were broken. We knew that people would not be thinking about mental health needs at this time, but would have other things on their minds—dealing with death, taking care of their children, finding new sources of income, new jobs, for some, new places to live. So New York's mental health system became one without walls, deploying thousands to these emergency sites where most mental health interventions were carried out in corners of shelters, in armories across a table with a cup of coffee, a friendly word of support.

LifeNet took the calls requesting mental health professionals, contacted mental health providers throughout the City, and directed personnel to the sites where they were needed.

We also got calls from workplaces, schools, day care centers, community centers, houses of worship, senior citizen centers. Hundreds of organizations called LifeNet seeking help for their traumatized clients and for their own staffs, who were making heroic efforts to help even while they themselves were suffering and needed support.

Over and over again we heard helping organizations say, "We don't know what to do to help people with their grief and their emotional trauma. We need help to help them. And we need help ourselves."

We arranged for mental health professionals to be "stationed" in many of these settings. They conducted talks, did mental health screenings, and provided direct crisis counseling.

MHA of New York City's Crisis Resource Center Was Born to Fill Need

Thus MHA's Crisis Resource Center (CRC) was established. It arose to fill a void in a crisis, but continues to play a vital role in the process of recovery in the New York City area. Not only has it continued to facilitate group outreach services for hundreds of community organizations; it has also mailed hundreds of thousands of pieces of informational material to schools, businesses, and community agencies and created the Uniformed Services Committee, which brought together the counseling and support units for Emergency Medical Services (EMS), the New York Police Department (NYPD), and the New York Fire Department (NYFD). The CRC has also become the trauma training hub, facilitating trainings for over 2,000 professionals. I will say more about training in a

minute. Now CRC is preparing to shift from providing an infrastructure to support disaster response to promoting community resilience.

MHA, of course, was not alone in rising to the occasion. It was inspiring to see how people and organizations extended themselves. Hero after hero emerged ready to do whatever needed to be done.

Police, fire, and emergency medical personnel put their lives on the line; many sacrificed their lives. It is not possible to give them all the recognition and gratitude they deserve.

Crisis Was Being Managed

And somehow, out of the initial chaos, some order began to emerge. The crisis was being managed.

Over the next couple of months, there were more and more calls to LifeNet from individuals having terrible emotional experiences.

LifeNet Call One Month After 9/11

Here is one of their stories.

A 50-year-old man called LifeNet a month after the disaster to report that he had been in his office near the Twin Towers when he heard an explosion. He looked out his window, saw a gaping hole in one of the buildings, and thought a bomb caused it. He saw what he thought were "shadows coming down the building" and then realized that they were "people falling to their deaths." When he heard a second explosion and a rumble, he looked out to see the second tower crumbling. The lights went out in his building. He "saw a lot of smoke and smelled the dust," he said. He became "very nervous." Since the tragedy, he had been crying almost every day, was constantly waking up in the middle of the night, and felt so distraught and afraid that he wanted to get out of the Wall Street area. He was becoming increasingly angry and impatient — "snapping at people", even though he realized that he had to "take it easy and not take it out on others."

This call to LifeNet is, of course, just the tip of the iceberg. LifeNet has received thousands of calls like these since 9/11 and I will share some of the details of LifeNet's data in a few minutes.

I hope that I have managed to give you a feel of the immediate experience of 9/11. Now I want to comment briefly on some of the mental health services that developed over time and what we are still doing to help people recover and "bounce back" to their previous life as it was once known, or in most cases as we are learning – to "bounce forward" by adapting to meet the challenges that their new situation presents.

LifeNet Call One Year After 9/11

A call to LifeNet around the time of the 1st anniversary is a good illustration of the evolving needs of New Yorkers. A 35-year-old woman called to report that she had been standing a few blocks from the South Tower when the plane hit and she looked up and saw it crashing into the building. She first called LifeNet 2 weeks after 9/11, reporting some emotional distress but also saying that she felt she was coping fairly well. LifeNet referred her to a program sponsored by a community center in her neighborhood where

she would be able to receive several sessions of free crisis counseling. But months later, after her company had to lay her off, she began to experience nightmares in which she vividly relived the moment. After not working for a while, she had no savings left, couldn't find a job and couldn't bring herself to come back to Manhattan. The mental health provider she had been seeing for crisis counseling recommended outpatient therapy. In August she called LifeNet again after she heard about the new mental health benefit program that might cover the \$1,200 she had laid out in co-payments to her therapist. "I really need the money now", she said, "I am going to try to get to California and start all over. Everything is too sad here now."

Project Liberty, Funded by FEMA

The first service described in this scenario was provided by Project Liberty. Project Liberty is the largest mobilization of disaster-related mental health and crisis support services in the history of the United States. This FEMA funded program went into effect within weeks of the disaster and is still providing crisis counseling, outreach and education to people today throughout 15 counties of New York, 11 in New Jersey and several in Connecticut as well. Over 25,000 people have been helped by Project Liberty. Anyone in the greater New York Area can access Project Liberty services by calling 1-800-LifeNet.

Mental Health Benefit Program, Funded by Red Cross and September 11th Fund

Another groundbreaking service rolled out just before the 1st anniversary was the Mental Health Benefit Program established by the American Red Cross and the September 11th Fund. Knowing that many people would have treatment needs beyond short term crisis counseling, this "portable" benefit program allows many of the disaster's primary victims to receive treatment from a provider of their choice and have all of their out-of-pocket expenses treatment expenses (including medication) fully covered, up to the limits set by the charities (32 visits or \$3,000 per person). The program is available to those affected regardless of insurance, income or immigration status. I want to emphasize the "portability" of the benefit because it can be used anywhere the victim resides — nationally or internationally — as long as the person receives care from a mental health provider that is licensed in that region. Once again, LifeNet is the entry point for enrollment and MHA administers the benefit program.

The effectiveness of Project Liberty and of treatment for trauma depends, of course, on the skill of the people who provide services. Our post-9/11 experience made it clear that that there were many more people willing to help than there were people who were trained to help. In fact almost all of the mental health professionals who extended themselves heroically had no experience in evidence-based crisis interventions or in evidence-based treatment of post-traumatic stress disorder.

Before 9/11, training in trauma treatment was viewed as a specialty. Now it is a recognized necessity, and substantial public and private funds have been invested to train licensed clinicians in New York and the surrounding areas to respond appropriately to crisis, trauma, and bereavement. Curricula for these massive training efforts that seek to reach over 5,000 practitioners were developed from evidence-based procedures and formulated by some of the top experts in disaster, trauma and bereavement in the United States.

MHA Designated to Coordinate Training in Trauma Treatment

I am proud to say that MHA was designated as the engine to coordinate, promote, and register clinicians for these training opportunities.

We also learned from 9/11 that it is critical to address the fatigue and emotional distress faced by almost all mental health providers. And in New York City, the American Group Psychotherapy Association has organized support groups to relieve stress and prevent burnout among our helping professionals.

So far what I have talked about are services and supports which are consistent with the traditional practices of mental health professionals. Now I want to talk a bit about the importance of helping communities as well as the individuals and families who live within them.

Communities provide tremendous support for individuals and families. During disasters, communities face great challenges and, therefore, enhancing community resilience is critically important. In a city where a constant state of high alert has become the "new normal", efforts to support communities need to be ongoing.

For this reason, we have established a pilot project called "Freedom From Fear" in Staten Island. The project has divided the borough into 3 zones. Within each project staff identify hubs of social support, conduct community strengths surveys, develop a network of contacts, work with local media, and conduct many other activities that reduce stigma and build community identification.

So Many Lessons Learned

There are so many lessons learned that it has been a struggle for me to decide what I should focus on in the few minutes I have left in what feels like an ongoing odyssey.

I could comment about the complexity of psychological reactions as they unfold in the aftermath of terrorism. I could comment about the complex array of services that need to be put in place to respond to people's highly diverse mental health needs. I could comment on how little we know about the extent of adverse psychological reactions and about how to respond to them—about the need for better epidemiology and for evidence-based interventions. I could talk about the special psychological needs of children and those of diverse cultural groups when crisis hits and share with you how we handled them in New York City. I could comment on the complex systems issues that emerge because mental health services after terrorism are the responsibility of both the private and the public sector and because the public responsibility goes well beyond the traditional role of public mental health authorities.

I have decided that what will be most useful is:

- To share some data gleaned from calls to LifeNet
- To comment briefly on the importance and nature of public education
- To make some suggestions about readiness for the future

Our data show that LifeNet experienced great growth since 9/11. There was a rapid acceleration in calls. A huge number of people contacted us in September 2002. Over 12,000 calls, 4 times the level before 9/11.

LifeNet hotlines continue to receive more calls this year than they received last year at this time (only 4-7 months after the attacks). Now, not only are a significant proportion of callers reporting problems specifically related to 9/11, we are getting calls from people who were exposed to the catastrophe reporting that they were "managing OK until the war with Iraq started", and now they are "falling apart".

We saw a stunning increase in the percentage of callers who report some symptoms of PTSD (Post Traumatic Stress Disorder) as compared to pre-9/11. In March 2003, 18 months after the annihilation of the World Trade Center, 1 of 5 callers on the LifeNet lines report symptoms of post-traumatic stress, the same frequency that was reported at this time last year, amidst a blitz of 6- month anniversary media coverage. Clearly, many New Yorkers are having difficulty "struggling" to stay well in a post 9/11 New York City environment.

And finally we saw, and continue to see, a large group of callers who have had no prior mental health treatment. Before 9/11 it was roughly 1 in 3, now it's over half. This is encouraging in that we seem to be reaching those who have not sought treatment in the past and who are now acknowledging that they need help and seeking the help they need.

Vital Need to Educate the Public

Let me move now to public education, a topic that deserves much more attention than I have time to give it here.

Following a crisis, people tend to be comforted by knowing that their emotions and reactions are normal, by knowing what to expect in the recovery process, and by knowing what the warning signs are of potential problems. Public education fills this need.

Here are a few examples from some of our public education campaigns.

New York City continues to endure the challenges resulting from the aftermath of the 9/11 attacks. Recent studies underscore the potential for erosion of mental health over the course of accumulating stressful events following the disaster. This finding has chilling implications for a City faced with increasing economic hardships and living under the glare of a permanent "Orange Alert" status.

Of course, New York is not alone in its expectation of future terrorism. Almost every day public spokespeople tell the American people that terrorism will occur again in America and at a totally unpredictable time and place. It may be New York again or Washington. But it could be Chicago or Philadelphia, Atlanta or Dallas, Los Angeles or Butte, Montana. Some day one of you may be faced with the kind of catastrophe with which the greater NEW YORK CITY area is still coping.

We Must Be Ready

The clear implication is that we must be ready. And that is what I will focus on in these closing comments.

We know that communication and information about where to find help are critical to effective crisis response. It can reassure people that they are safe, validate their feelings, normalize their reactions, and get them the services they need.

New York City was ready to provide a communications hub for its crisis response because LifeNet already existed.

Of course, we had not anticipated a disaster on the scale of 9/11 and had to mobilize services we had never dreamed of, but we were only able to do this *because we had so much in place before 9/11*.

We already had a 24-hour a day/7 day a week telephonic crisis and information/referral system with a computerized database in place. It has bi-lingual, culturally competent *professional* staff prepared to interact with people from many cultures.

We were also able to respond because of our history of collegial, non-competitive ties with the community of mental health providers in New York City. MHA is not perceived as a competitor. As a result, we can be a trusted convener and organizer.

We believe that all communities should develop a service like LifeNet, both to help people with their everyday mental health needs and to provide the foundation for crisis response.

Of course, we have learned many additional lessons which can be used to be better prepared for future disasters.

Every Community in America Needs Its Own Plan

The first step, we believe, is that every community across the United States should establish a planning and review process to assure an adequate mental health response to future acts of terrorism or other disasters.

These plans need to be local—tailored to fit local circumstances.

We know that most localities have disaster plans, but we believe that all of these plans should be reviewed, and revised as needed, to provide more attention to the mental health needs of people in the aftermath of a disaster.

While local plans must vary, they all need to include a number of critical elements.

Tonight I only have time to list these elements. At MHA of New York City we have done a great deal of work to develop the details of what is needed. Please get in touch if you would like more information.

Key Elements for Disaster Plans

The elements are:

- A Local Mental Health Disaster Plan
- A Local Mental Health Disaster Response Entity
- Clarity Regarding Authority--Both in the Public and in the Private Sectors
- Established Linkages and Plans for Coordination
- Telephonic Communications Center
- Plan for Outreach
- Plan for Public Mental Health Education
- Readiness to Provide Public Communication to Mitigate Terror

- Shared, Evidence-Based, Models of Intervention and Treatment
- Cadres of Trained Personnel
- Support and Training for People Providing Help Including Uniformed Services Personnel
- Emergency Funding and Payment Mechanisms
- Review of Regulatory and Funding Structures
- Contingency Plans
- Routine Drills
- Plan for Evaluation

The work this requires is extensive and may seem like a lot to do to prepare for events we all hope will remain rare. The alternative, however, is to be unprepared and to rely on spontaneous heroism to muddle through.

We have great admiration for the heroic efforts that were made by FEMA, the City, the State, voluntary providers, hospitals, the American Red Cross, and thousands of individuals in response to the terrorist acts of September 11. It is almost unbelievable how effectively the response was mobilized under such terribly adverse conditions.

However, having been part of that heroic, but frantic effort, we at MHA of New York City believe it would be better to be better prepared for the next time; and we hope that the federal government will play a leading role in helping communities to be ready.

Thank you again for the invitation to speak tonight. It is a pleasure to be with you.