the Clearinghouse

The Key ASSISTANCE REPORT

Focus on **DISASTER AND RECOVERY**

National Mental Health Consumers' Self-Help Clearinghouse

IN THIS ISSUE

PEER SUPPORT FROM THE GROUND UP

Wednesday, September 21, 2005: President of the Mental Health Association of Southeastern Pennsylvania Joseph Rogers reports from Texas that mental health consumers who evacuated to the state from the Gulf Coast because of Hurricane Katrina are in distress. He's there with a handful of his staff to assist with a peer support initiative, and he's growing very concerned. Shelters are closing, he writes, and many people with mental illnesses still don't have places to stay.

"Here in Austin, (officials) need their convention center back Friday and they have told the remaining folks they must be out," he says. "Most of these folk are our folk and need more specialized housing, of which there is just not enough available."

Rogers, who also founded and heads the National Mental Health Consumers' Self-Help Clearinghouse, which produces this report, expresses his fears that many consumers will end up homeless, as he once was, and suffer as he did. "Once this kind of disruption takes place, it can take years to find us and get us back to 'normal,' if ever," he states.

Photo by Andrea Booher provided by the Federal Emergency Management Agency

Counselors and volunteers helped evacuees to the Astrodome in Houston, TX., deal with trauma after Hurricane Katrina hit the Gulf Coast in 2005. Some volunteers provided child care to give mothers a break during the day.

"In my case, I was lost for three years."

Rogers' ability to empathize with the evacuees illustrates the central concept behind programs that call on consumers to provide peer support for disaster victims: that people with mental illnesses are well-positioned to help trauma victims because many mental health consumers have experienced catastrophic upheavals in their own lives.

Such efforts were welcomed by the national Center for Mental Health Services, a division of the Substance Abuse and Mental Health Services Administration, or SAMHSA, according to Associate Director for Consumer Affairs Paolo Delvecchio.

"We were looking at ways of encouraging peer support in the impacted areas," he said, adding that peer support "has a proven and valuable role in post-disaster recovery."

RECOVERY ON A STRING

Unfortunately, peer support initiatives often receive less encouragement at the state level. A group of national leaders who mobilized a recovery effort for consumers affected by the disaster in Louisiana learned this first-hand.

The leaders, several of whom had cut their teeth on some of the worst catastrophes ever to occur on American soil, worked intensely for three weeks to help shore up the state's consumer group, Meaningful Minds of Louisiana. The national leaders guided the group, which had a budget of $22,500, through the process of becoming a non-profit and helped draft a proposal for almost $2 million in disaster relief funds from the Federal Emergency Management Agency, or FEMA. The leaders also developed a curriculum and trained forty-six people to provide peer advocacy, and their FEMA proposal stated that Meaningful Minds would use disaster relief funds to train and employ sixty to seventy more peer supporters within two years. Those people would staff new warmlines and resource centers, the proposal stated.

Throughout the process, the out-of-towners also helped Meaningful Minds navigate the politics involved in getting convincing state officials to include the proposal in the state's application for FEMA aid. Still, Meaningful Minds President Carole Glover said in April that the group could not even get confirmation that the proposal had been included. She said attributed this to department's attitude toward consumers.

"We feel that the Office of Mental Health is not standing behind us to become a viable consumer-run organization," she said. "They're still (acting on) the model that consumers are not ready or capable to do anything but take their medications and go home."

With little hope of gaining support at the state level before the next hurricane season, the group is now looking to national sources—an effort that has begun to pay off. As of April, Meaningful Minds had received at least one three-year grant to establish regional chapters.

Advocates from the Mental Health Association of Southeastern Pennsylvania held peer support trainings in Texas using a curriculum developed with researchers from the University of Pennsylvania to promote recovery after community disasters. The manual is available for download at www.mhselfhelp.org/resources.

GEOGRAPHY MATTERS

The idea of bolstering a consumer-led recovery effort might have been more readily embraced in Louisiana if officials had accepted before the disaster that people with mental illnesses could help peers recover. Still, even the hospital-centered system in the state was weak before the storms, and this may have led to the founding of Meaningful Minds in the first place.

In fact, the man who spearheaded the national effort said he focused on Louisiana partly because it was hardest hit; partly because he had a cousin who lived there at whose place he could stay when he arrived; partly because he was able to locate leaders of a fledgling statewide consumer group there who welcomed the mentors with open arms; and partly because he could not find such a group in neighboring Mississippi, which had also been affected but had a mental health system squarely centered on institutions.

"I could get nowhere in Mississippi," said Director of the National Empowerment Center Daniel Fisher, a practicing psychiatrist who has been diagnosed with schizophrenia. The Boston organization is one of five national centers funded by SAMHSA to provide technical assistance on topics including recovery and advocacy. "The problem was there wasn't even a beginning there," he said of Mississippi. "There were no consumer leaders even to call. At least in Louisiana, they had a history. They had an idea and a concept of what peer support means."

A COMPLICATED ISSUE

The difference between these two states highlights a key issue in disaster preparedness and response: You have to work with what you have, and what you have depends on where you are. Even with help from a network of national mentors, any recovery effort can only begin where affected areas' mental health systems leave off.

"In New Jersey, Pennsylvania, you would just call the various consumer-run organizations and say, 'Let's have a meeting,'" Fisher explained. "But in some of these other states, you're trying to bolster up a non-existent or just-budding group."

Several of the leaders Fisher assembled said they hoped the 2005 Gulf Coast disaster would spur advocates to network more and help develop community-centered recovery cultures in states that lag behind. Without such changes, Fisher said consumers may find themselves in crisis and asking mental health authorities to make a "double jump."

"They have to jump into the idea of community services more readily and they have to jump into the idea that these services can be provided by peers." he explained.

Oklahoma Mental Health Consumer Council President Kaye Rote, who gained support from her state for recovery initiatives after bombs destroyed the Alfred P. Murrah Federal Building in Oklahoma City in 1995, and again in 1999, when tornados devastated sixteen counties in her state, said consumer groups should work together to prepare for disaster long before it's on the radar.

"You have to develop a statewide disaster plan, and groups have to be doing that right now," she stated. "It's too hard

Disaster relief veteran and consumer leader Kaye Rote of Oklahoma recommends assigning one person to contact the following when disaster threatens:

1. The state department of mental health.
2. The U.S. Department of Homeland Security.
3. Pharmacies and pharmaceutical companies for information on how people can access medications quickly.
4. Private practice therapists to compile a list of those who will volunteer time.
5. Mental health advocacy leaders, starting in state and branching out nationally.

Director of the National Alliance on Mental Illness in Louisiana Jennifer Jantz said she received many calls following the 2005 hurricanes from family members searching for consumers who had been evacuated from group homes, hospitals and other mental health facilities. Some of the consumers eventually contacted their families, and Jantz tracked their locations so she could tell other families where consumers from the same programs were likely to be. When possible, she recommends that consumer groups contact inpatient and residential programs before disaster strikes to learn about evacuation plans.

and you make too many mistakes when you throw something together on an immediate basis."

Though some may be in a position to heed Fisher's and Rote's advice, an informal telephone poll of statewide consumer organizations early in 2006 revealed that many weren't. The majority of leaders contacted said they lacked the resources to advocate for changes in policy and adequately support their peers when not faced with disaster, and they didn't know when or if they'd be able to draft a disaster plan.

SIMPLE PLANS

Some aspects of disaster preparation—like advocating for community-based services and training consumers to provide peer support—make for good practices even when disaster is not on the horizon. However, finding funds to support those efforts can be near impossible for some.

Fisher, who served on the President's New Freedom Commission on Mental Health, said he learned through his work with the commission that this is the case more often than not.

"I just see it as we're always in a crisis in a way," he said. "In almost every state, the department of mental health is in crisis; there are never enough resources to go around."

Still, almost all consumer groups can make room for at least a little disaster preparation, especially things like networking that cost little and can lead to big returns down the line.

Many of the consumers involved with the Louisiana effort said maintaining a strong relationship with the state mental health authority is crucial. Also, they recommended making sure that peer support is included in any funding proposals to provide mental health services—both before and after disasters. Rote stressed that this will come into play when applying for FEMA funds.

Rote also stressed the importance of having a communication plan to be put in place when land lines are down. Such a plan might involve using cell phones and computers and having phone-tree-type methods of spreading information quickly.

Other ways to prepare include helping consumers create emergency health information cards and emergency 'go-bags' that they can grab quickly if they have to evacuate. However, peer supporters should take care in introducing such activities because some consumers may become fearful that disaster is immediately imminent and that information is being withheld from them.

Creating an Emergency Health Information Card

First responders who find a person unconscious or incoherent are trained to look for this information in places like purses, wallets and pockets. The American Red Cross recommends also keeping copies of the card in emergency kits, in the car, in the workplace, and in emergency 'go-bags.' The card should be customized for each person to include all pertinent information.

The American Red Cross Recommends These Basics:

ON THE FRONT:

- Name
- Street address
- City, state, zip
- Home and work phone
- Birth date
- Blood type
- Social Security number
- Health insurance carrier and individual group number
- Physician information

ON THE BACK:

- Emergency contacts
- Health conditions, disability
- Medication information, including names dosages, times taken and any special instructions
- Name, address, phone and fax numbers for the pharmacy that fills the prescriptions
- Allergies
- Immunization dates
- Languages understood / barriers to communication

CREATING AN EVACUATION BAG

When disaster threatens, consumers will likely see and hear a lot of information about creating emergency kits to keep at home and evacuation bags they can grab quickly on the way out. Here are some items that could be included in a compact, low-cost 'go-bag:'

- copies of important documents, including birth and marriage certificates, passports, immunization records, bank account and insurance information, and Social Security cards.
- bar or bottle of soap
- map of city or town and state, which may be photocopied from a library book
- contact information for emergency response and mental health agencies
- bottle of rubbing alcohol
- handful of cotton balls
- adhesive bandages
- bottled water—even a little is better than none
- sealed pouches of food, often sold at dollar stores; or cans with easy-open tabs
- toothbrush and travel-size tube of toothpaste
- At least three days' supply of medication.
- inspirational reading material

Place the items—or at least the paperwork—in a waterproof container or airtight plastic bag.

Still have questions about disaster and recovery? Contact the National Mental Health Consumers' Self-Help Clearinghouse at 1-800-553-4KEY or info@mhselfhelp.org.

INTERNET RESOURCES

A Web search for "disaster mental health" will bring up many sites where agencies and organizations have posted information about disaster relief and preparedness for people with mental health issues. Here are some highlights:

U.S. Substance Abuse and Mental Health Services Administration (SAMHSA):
www.mentalhealth.samhsa.gov

December 2005 Web cast on "Peer Support: Disaster Preparation for People with Psychiatric Disabilities:"
www.connectlive.com/events/samhsa

Knowledge Hound Disaster Preparedness Page lists many useful links:
www.knowledgehound.com/topics/survival.htm

The National Center for PTSD site features information about typical responses to trauma, symptoms of post-traumatic stress disorder and other disaster-related topics:
www.ncptsd.va.gov

The National Mental Health Association provides disaster-related material under "Mental Health Information:"
www.nmha.org

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