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## From Relief to Recovery: Peer Support by Consumers Relieves the Traumas of Disasters and Facilitates Recovery from Mental Illness


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# FROM RELIEF TO RECOVERY:

## *Peer Support by Consumers Relieves the Traumas of Disasters and Facilitates Recovery from Mental Illness*

by Daniel Fisher, National Empowerment Center (NEC),  
with assistance from  
Kay Rote, Oklahoma; LaVerne Miller, New York;  
David Romprey, Oregon; and Beth Filson, Georgia



Paper done in collaboration with GAINS Center, 2006.



*Louisiana Peer Support Leaders*

# “From Relief to Recovery: Peer Support by Consumers Relieves the Traumas of Disasters and Facilitates Recovery from Mental Illness”

by Daniel Fisher, National Empowerment Center (NEC), with assistance from  
Kay Rote, Oklahoma; LaVerne Miller, New York;  
David Romprey, Oregon; and Beth Filson, Georgia

*Recently, concluding a very lengthy Friday evening teleconference with peers from Meaningful Minds of Louisiana, I asked the group why we were so committed. Quietly, we heard the gentle voice of Nelda from Alexandria, “Because we love each other.”*

## I. Introduction

We, who have experienced the trauma of mental illness, know first hand about the love and solidarity that grows from the shared experience of suffering. We, who have experienced and triumphed over the personal disasters in our own lives, understand and feel impelled to respond to victims of national disasters. This paper is about the expertise those with a lived experience of recovery from personal trauma can bring to disaster relief efforts in the form of peer support.

At times of disaster, peer support has served as a vital complement to professional services. Following the bombing of the Alfred P. Murrah Building in Oklahoma City and the destruction of the twin towers in New York on 9/11, mental health consumers provided valuable peer support services to traumatized individuals. Peers have also been mobilized to assist in relief efforts in Louisiana following hurricanes Katrina and Rita. This paper will describe how the recovery approach to mental illness is consistent with crisis counseling following disasters. Peer support not only provides relief from trauma but in so doing assists in peoples’ recovery from mental illness.

Mental health consumers’ experiences with recovery from a variety of traumas have well equipped us to assist people at times of disaster. Indeed, the shift in role from passive victim of a disaster to active agent providing assistance itself plays a valuable role in

relief from trauma as well as recovery from mental illness. Louisiana serves as a case example of the challenges and advantages of peer support. Clearly, it is important to prepare for disasters proactively by developing a network of peer supporters across each state. This network ideally would be coordinated by statewide consumer organizations. In addition, we recommend an ongoing national consumer advisory group on disaster recovery be established to ensure that the statewide consumer groups have the supports needed for meeting their disaster needs.

## II. History of Consumer Involvement Following Disasters

### A. Peer support following the 1995 Oklahoma City bombing and 1999 tornado disaster

[Kay Rote, Director of the Oklahoma Mental Health Consumer Council, shared the following]:

*Oklahoma City experienced the bombing of the Alfred P. Murrah Federal Building in 1995. This was the first time that the heartland of the United States experienced an internal attack of terror. The effects of the bombing resulted in a scene similar to terrorist attacks and acts of war in other countries. Not only did we experience the loss of a major hub of work, 168 lives, and over 1,000 injured, we also experienced the destruction of many businesses, homeless shelters, and condos that were within the six-block radius of the bomb site. The shock of this event would have an impact on mental health services for years to come.*

*Personal involvement and pressure from national consumer leaders allowed the Oklahoma Mental Health Consumer Council to be included in the resulting FEMA operation known as Project Heartland. A mere \$70,000 was allocated to OMHCC for the ex-*

*pressed purpose “to aid individuals in returning to pre-crisis functioning levels, to alleviate acute mental distress related to the bombing, and to assist in the re-establishment of social bonds and support networks fractures by the bombing.”*

*Immediately, a training course for peer counselor/ support was developed to train and certify the first groups of consumer leaders to complete the following:*

- *Provide peer-level crisis counseling*
- *Set up community support groups*
- *Offer extensive community outreach*
- *Provide referrals to more long-term care*
- *Make home visits*
- *Arrange transportation.*

*On May 9, 1999, Project Heartland was reactivated after the world’s largest tornado disaster ripped apart sixteen counties in Oklahoma, devastating everyone and everything in its path. OMHCC requested to be a part of the newest FEMA project, and was granted another \$70,000 for consumer peer support and outreach.*

*This type of program is powerful and economically valuable in providing assistance in necessary referrals and preventing unnecessary hospitalizations at state psychiatric hospitals and emergency rooms. Consumer peer support stationed at hospitals proved to be invaluable in their ability to reduce anxiety, expediting the initial intake and discharge process as well as referral to other services and support groups when hospitalization was not necessary. Consumer peer support was commended for their ability to “triage” those most directly affected by the disaster, especially when pre-existing mental health issues were present.*

#### **What We Learned**

- *Initial assistance after disaster is provided to the local citizenry with strongest need for outreach.*
- *One-year anniversaries of both events brought*

*the largest initiation of service to first responders and rescue workers—even though continuous debriefings were held.*

- *Two years from each event brought participants who were long-term care providers, mental health professionals, and reconstruction teams, as well as persons who had never before experienced issues such as PTSD, depression, and bipolar symptoms.*
- *As much as five years from each event there was an increase in the number of persons who were experiencing trauma-induced behaviors without any understanding of mental health issues. These referrals came particularly from family*

*members and business partners seeking help for another person. We saw many who were in extreme denial, despite behaviors reaching a point of needing crisis intervention. Family members could pinpoint the initiation of “odd” behavior that gradually worsened due to lack of understanding and early diagnosis.*

- *Remain in contact with initial citizenry participants, first responders, rescue teams, and reconstruction workers.*
- *Watch our children carefully. The continuous onslaught of media coverage as well as the repetitive scenes and inane heartbreaking interviews will have a profound effect on younger children.*
- *Elderly populations with childhood trauma will probably experience severe flash back and PTSD. This is true as well for those in the military who have experienced combat.*

#### **B. Project Liberty following 9/11**

[The following is an abstract of an evaluation of the Project Liberty Peer Initiative (PLPI) prepared by Hardiman et al., 2005.]

The PLPI program represents an innovative and successful effort to provide a range of mental health supports to individuals with psychiatric disabilities, a

*Mental health consumers’ experiences with recovery from a variety of traumas have well equipped us to assist people at times of disaster.*

population thought to be particularly vulnerable to the impacts of trauma and the potential recurrence of post-traumatic stress-related symptoms.

*One senior staff member observed that “we spend virtually all of our lives coping with one crisis after another. Who is better prepared to help those who are experiencing the darkness and despair that we see than those of us who bear witness to triumphs over darkness every day of our lives?”*

Those individuals who participated in PLPI services, either through provision or receipt of services, collectively shared a fascinating and compelling story of compassion, dedication, mutual aid, connection, and community following the devastating effects of a horrible disaster with far-reaching potential for traumatic impact. Individuals with psychiatric disabilities (mental illnesses) living in New York City were able to organize together, apply for federal relief monies, and successfully reach out to more than 10,000 people throughout the New York metropolitan area. Recipient interviewees described PLPI services as absolutely critical in the restoration of meaningful post-disaster lives. Our data, taken in combination with the quantitative utilization data captured by Project Liberty, indicate that the program was incredibly successful in meeting its goals and that it dramatically impacted the lives of thousands of individuals.

Recipients of PLPI services gained access to valuable supports, including individual counseling, group sessions, and after-hours telephone support. Perhaps more importantly, they were exposed to other individuals like themselves, who had experienced psychiatric disability and were struggling with how to cope with post-9/11 life.

There were a number of activities of peer support found to be of value to both the participants and the peer workers, such as:

#### **Shared Identification.**

The significance of identifying with a peer who is in a service provision role was a recurrent theme for almost all PLPI recipients. One PLPI staff member described this identification process as, “peer support, you understand... people have gone through the same things. It’s like, difficult for me to talk to somebody about crack who had never smoked it... So I like to be around people who know this... and I can talk to them about it and they can identify with me and I can identify with them.” Another participant described the PLPI group experience as “very supportive to me because I was able to identify with a lot of things concerning my mental history.”

#### **The Importance of Listening.**

The majority of participants placed tremendous emphasis on the role of listening within the peer support services offered by the PLPI program. Listening was defined by one recipient as the ability “...just to hear other people’s problems, what they had to talk about... and to compare those to what I had gone through in the past.” Listening was perceived as a rare quality among service providers, and the afore-mentioned credibility of peer providers combined with an ability to actively listen to recipients proved an effective combination for many group members. As described by a recipient, “I felt that I could open up to this person and tell him my true feelings about what I’m doing with my life. And he listened. I didn’t have that in my life before... someone to just listen.”

#### **Promoting Choice and New Alternatives.**

Many participants indicated that the experience of receiving formalized peer support services through the PLPI program allowed them access to new resources, increased choices in their lives, and new alternative ways to live in the community. PLPI groups were described by recipients as “opening new doors” and “shining a light on new things.” Through participating in the exchange of peer support, being treated as equals, and perhaps most importantly, helping other

peers, individuals were able to construct new possibilities for their lives. One recipient indicated that “the peer movement will motivate you. You will get supports, you will get resources, something that you might not get in other areas in other agencies.”

### **Credibility and Authenticity.**

Many of the other elements of peer support fed into the credibility of PLPI peer providers. For instance, shared identification made peer providers’ encouraging narratives more feasible to consumers. One recipient said, “When you’re dealing with someone and they identify with what you’ve gone through... you feel like this person’s not lying to you... And his diagnosis, he was schizophrenic, and he has depression... he didn’t let that stop him from leading a normal life.” Perceived credibility and authenticity also went hand in hand with role modeling for most participants. If a peer provider was perceived as credible, “real,” and knowledgeable, there was a greater likelihood that group members would also view him or her as an inspirational role model.

### **Collective Sharing.**

The mutual reciprocity of the sharing process had a powerful impact on many PLPI group members. Several indicated that they had never attended a group in which a true mutual exchange of support occurred. One person said, “The same way we came to them, with... things we felt that were bothering us, they would confide in us. That’s where I got my information from. They would confide in us, in the group and in me at the same time.” Another said, “I mean it’s a two-way thing... it’s no good unless you’re giving it away, because it’s coming back. It’s coming back, believe it or not.”

This story should be heard by administrators and planners of disaster relief services, and should be considered in planning for future disaster relief efforts. The core principles of peer support that provided the framework for the PLPI program offer a natural, respectful, flexible, and community-based way to provide mental health support services based on shared life experience. Rather than being devalued, stigmatized, or ignored, peer-delivered mental health support services should be incorporated into all stages of plan-

ning and implementation for relief efforts following a large-scale public disaster.

[LaVerne Miller, Director of the Howie the Harp Peer Advocacy Center, shared the following]:

*Peers are often overlooked as an invaluable resource in assisting state, local, and federal governments in creating disaster plans that meet the often unique needs of mental health consumers. Similarly, they have been overlooked as potential first- and second-responders capable of providing crisis counseling, support, and public education to other consumers and others impacted by a disaster. This frequently results in the development of disaster-related services that have little or no impact in relieving the suffering of mental health consumers.*

*The Howie the Harp Peer Advocacy Center, in collaboration with NYAPRS, the Mental Health Empowerment Project, and several other consumer leaders, developed the Project Liberty Peer Support Initiative in response to our concern that many consumers were re-traumatized by the 9/11 tragedy, and that traditional mental health care providers were unable or unwilling to meet the increased needs of this community. The services provided were individual crisis counseling, group counseling, and public education. The initiative also created a warmline providing support services to consumers from 5:00 PM to 12:00 AM and on weekends.*

*Five of the initial thirty outreach workers and two senior staff members employed by the Project Liberty Peer Support Initiative were mental health consumers with a history of incarceration in jail and or prison. All five of the outreach workers and one of the senior staff members were employed for the duration of the project (February 2002 to August 2003) and all transitioned to competitive employment positions following the end of their tenure with the Project. Peers worked in a wide range of settings ranging from the subways and streets, to traditional mental health programs such as clinics and day treatment programs, to emergency rooms and city hospitals.*

*Interviews with these staff regarding their experiences and the experiences of mental health consumers*

*with histories of incarceration who received one or more of the services offered by the initiative strongly suggest that most were re-traumatized by the disaster and that peer-provided services assisted them in connecting with the larger consumer community, introduced them to concepts of self-help and recovery, and most importantly helped them identify and gain access to traditional and peer-driven mental health services.*

*One of the most significant lessons learned was that peers are capable of providing crisis services without “decompensating” or becoming ill due to the stressful nature of the work. Like all workers, staff benefited from training designed to mitigate the stressful nature of the work and ongoing support, but all agreed that employment and the “act” of helping assisted their own personal recovery. One senior staff member observed that “we spend virtually all of our lives coping with one crisis after another. Who is better prepared to help those who are experiencing the darkness and despair that we see than those of us who bear witness to triumphs over darkness every day of our lives?”*

### **III. The Empowerment Model of Recovery from Mental Illness Is a Useful Basis for Recovery from Trauma**

The recent emphasis on recovery through empowerment and peer support among consumer groups gives consumers a unique capacity to assist each other in times of disaster. The principles of recovery from mental illness are consistent with recovery from trauma. In fact, the theme for recovery from trauma at times of disasters, that people are having normal reactions to abnormal situations, fits with the philosophy of trauma-informed peer support emerging from the lived experiences of consumers.

The recovery approach in mental health has emphasized that consumers need the relationships and skills to enable them to (re)gain control of their lives. The Empowerment Model of Recovery (Ahern and Fisher, 2001; Fisher, 2006), developed at the NEC, fits nicely with the trauma model of recovery as they are both rooted in people’s lived experiences. Peer supporters often understand this strengths-based ap-

proach better than professionals whose training has emphasized the model of the expert removing pathological symptoms.

Perhaps the greatest contribution of peers in assisting persons in disasters, personal and community-wide, is our special way of being with ourselves and others, born from painful experiences. Having gone through our own suffering, we as peers can offer a way of being in the world which can promote the inner healing essential to recovery from trauma. We are not trying to control the other. We just try to be with them deeply in such a manner that they can regain control of their lives. This may be the essence of mutual support. At a deep level we share the conviction that we are fellow travelers, that the other person’s suffering is our suffering. In Louisiana, we called this “solidarity through suffering.” We also bring an urgent emphasis on the present moment, which is where growth begins (Stern, 2004). There are so many distractions from the present moment in times of crisis, yet we need to be able to return to it.

Many of the principles of peer support (Solomon and Draine, 2001; Solomon, 2004; Salzer, 2002; Holter et al, 2004), such as the peer principle, the helper principle, empowerment, and advocacy, apply equally at times of community crisis:

- Peer principle: affiliation with someone with a similar form of life experience and having an equal relationship;
- Helper principle: being helpful to another person helps one’s own recovery;
- Empowerment: gaining confidence in one’s own capacity to make decisions and have control over one’s life;
- Advocacy: positive risk taking, support, sense of community (Campbell, 2004).

In addition, Shery Mead has emphasized the need to maintain a mutual relationship, despite one person being designated the helper. She thinks a great deal of this shift is achieved through a new use of language in describing the problems, and through uses or narratives in the person’s own voice instead of professionally authored versions (Mead, 2005).



#### IV. From Relief to Recovery after Katrina and Rita in Louisiana

Louisiana is a living example of the promise and challenges of peer support following disaster. In many ways, the involvement of national and local consumer leaders in Louisiana helps us understand the variety of opportunities and challenges of peer support at times

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of disaster. Peer support has become an instinctive reaction to suffering among those of us who have suffered severe emotional distress. We felt compelled not only to act but also to get involved in a personal manner with the consumers in Louisiana.

This is likely because there is a strong bond formed among consumers, dubbed by one peer the “solidarity of suffering.”

Therefore, there was a positive response from consumers across the country to NEC’s request to assist the consumers in Louisiana. Through teleconferences, in two weeks, NEC helped establish a national consumer disaster advisory group which named itself Consumers Organizing for Recovery after Katrina, or CORK. With the addition of consumers from Louisiana, this group became LaCORK.

After the devastation of Katrina and Rita, mental health consumers across the country, like everyone else, wanted to assist the people affected. Joseph Rogers and members of the Self Help Clearinghouse assisted in Texas. Patrick Hendry and another consumer drove an RV from southwest Florida to assist persons in Mississippi. The following is a very moving account by LaCORK member David Romprey, an advocate from Oregon who accompanied me on both my trips to Louisiana. We formed a very good team, with his

doing much of the connecting and my doing more of the organizing.

#### Hurricane of Hope

*People who go through natural or other disasters have different reactions to the stress and trauma of such events. Persons who are diagnosed with mental illness also vary in how they respond to emergency or life-threatening calamity. It adds to stigma and stereotypes to assume that public mental health consumers will react less strongly, or more fearfully, during regional chaos and tragedy.*

*As our nation turned to hear and feel the rage and bragging rights of hurricane personalities Katrina and Rita, I was left in another kind of mind-bending wake. What stunned me more than the two Super-Sized Storm Sisters was what a broken life (by virtue of years of isolating and dignity-stripping mental health treatment) could do for others during such an hour. I was privileged to advise a team of peer trainers in Baton Rouge, Louisiana, on their goal of outreach to other mental health consumers in their surrounding area within two weeks of the main storms hitting the Gulf Coast.*

*In Louisiana, while government officials and their staffs from the parish to federal level were scurrying between press conferences and performing acts of heroism and outright common sense to meet the needs of the people, the state’s public mental health recipients were not forgotten. Louisiana’s Department of Mental Health and its director, Dr. Cheryl Bowe-Stephens, were working fast and effectively to identify any disaster-related needs of psychiatric patients, predicting and preparing for “relapse,” and setting up mobile response teams to ensure that medications and diagnostic services reached all of their charges no matter what shelter or where they may have relocated to. What wasn’t known to the Department was that a self-styled yet deceitfully deep band of “mental patients” was busy organizing their own recovery—and redemption.*

*Meaningful Minds of Louisiana* blew my mind—turned over the very streets that were meant to deliver their help by instead stirring and unfurling a **hurricane of hope**. As a people stigmatized to be in need of perpetual help and trained guidance, they instead

*transformed themselves. Yet another government burden became instead a powerful partner in the solutions to Louisiana's post-disaster planning.*

*By refusing to be further victimized and marginalized during the storms that captured our worst fears as a nation, Meaningful Minds trained and encouraged their peers and communities. Refusing to be considered helpless, they instead hoped themselves and others to new life. The lesson of Baton Rouge was an example and show of force in my life to believe the best of all people, and not fear their fears for them. I only fear, to be honest, that what Meaningful Minds did for each other will not somehow serve as way of teaching hope to us all.*

Another member of CORK, Beth Filson, who heads the Georgia Peer Specialist Program, gave the following description of her training and organizing in New Orleans following Katrina:

*In the past decade, due to the increasing frequency of disasters, peer support has had to encompass more than the commonality of our lived experience with mental illness. We who are consumers/survivors/ex-patients have shared with our non-peer neighbors, colleagues, friends, and still others the event of communal catastrophe—the collapse of our known external systems of supports. Tragically, disaster has now become an equalizing force in our society.*

*In community, every person's acts have the potential to be heroic. Alone, assumptions about people with mental illness place us at terrible risk for ongoing trauma and further alienation from others. It is a matter of survival to come to some reckoning about what it is we bring as human being to these scenes of so much despair—allowing us to actively connect and keep on connecting to each other; to seek out each other, to keep on demanding from each other that for every blow, there must be another peer-led response.*

*Peer support will keep on evolving as we all become more deliberate about our presence in each others' lives—from crisis and disaster preparation and planning, to surviving its impact, to incorporating the new world view catastrophe will always frame. We are already refuting the notion that there can ever be a return*

*to a “pre-crisis levels of functioning”—for anyone, consumer and non-consumer alike. We are always, irrevocably, changed. The litmus test of our survival is what we think about those changes, and how we incorporate those changes in our peer support communities and in the larger context of our world. This is the genesis of making meaning out of our lives. In the dawn of*

*Through participating in the exchange of peer support, being treated as equals, and perhaps most importantly, helping other peers, individuals were able to construct new possibilities for their lives.*

*incorporating trauma-informed mental health systems, we understand the absolute necessity of hearing all our stories within the scope of our whole lives.*

*Despite the fact that I spent a short period of time with a group of train-the-trainers in Jefferson Parish, three things were reaffirmed for me about what peer support in my own life has meant: that bearing witness to another's grief is a profound act, that people live in multiple contexts and we never really know them all, and, finally, that there is an insatiable need in all of us to be heard.*

*Disaster lays bare the whole continuum of human experience—not just the experience of mental illness—along which we are able to take part with each other in the entire, complex, mysterious, sometimes terrible condition of being human. Disaster leaves us with no alternative but to survive or assist others in their survival. This breadth of cultural, physical, personal, spiritual, and experiential diversity has become a measure of our communities' resilience. In the consumer/survivor/ex-patient community, this is our shared wisdom. We've known this. Maybe the only change is that today I feel its greater urgency.*

*Prior to conducting a train-the-trainer on peer support for a group of c/s/x in Jefferson Parish, my first contact with the tragedy in Louisiana took place in my*

home state—as a volunteer at different Crisis Relief Centers in Georgia. One of these centers was located at Dobbins Air Force Base. Volunteers from various state agencies hoisted people on stretchers out of airplanes, or assisted others with the support of medics and other personnel. For the most part, these were the most vulnerable—mothers with newborns, nursing home patients, hospital patients, the sick, the infirm; the ones who could not have evacuated on their own and had been impacted by the ordeal of surviving the floods.

A colleague of mine described this scene: A woman arrived in four-point restraints. The most prominent indication of her condition was a large tag on her chest that read “SCHIZOPHRENIA.” Her boyfriend hovered anxiously around her, pleading for someone to take her out of the cuffs. There was no indication of psychosis. She was conspicuously calm despite her circumstances. However, the fact of a history of a mental illness, and her ongoing medication regimen, had been enough to warrant disregard for further assessment of her state of mind. She had been indiscriminately restrained for transport. Assumptions about how people with mental illness will respond to catastrophe had robbed her of her self-efficacy. My colleague stayed with the couple until she was able to wrangle a physician to the gurney where, after seeing her condition and knowing the circumstances from which she had been airlifted, he destroyed the orders for her transport to a state facility, stating that there was no indication for commitment.

In Jefferson Parish, two participants in the training, also consumer/survivor/ex-patients, recounted their

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experience with Katrina: Harry did not sleep for five days. His partner, Sue (not their real names) confirms this with a huge, somber nod. Instead, he sat on the carport at night with a gun in his lap. He had no choice. He makes me understand this. He had NO choice. There’s looting—fires on other streets. Snipers are firing at helicopters overhead. Sue explains the terror she felt. She uses her eyes and mouth and posture to explain this because it seems that the word “terror” itself is not enough to convey the largeness of her experience. There is a kind of panic in Sue’s body that mere memory provokes and makes palpable around her.

She describes how Harry crawled on all fours down to the storm drain in the midst of the hurricane to clear away rubbish and timber that threatened to flood their street. They go back and forth like that, telling their story. Harry watches Sue talk. Sue wants me to understand what Harry did. I learn how Harry foraged out during the day for MREs, water, whatever he could find. Sue confirms that he kept them alive. Somehow he’d gotten his hands on an all-terrain vehicle. He kept it gassed by siphoning fuel from abandoned cars. He’d leave his name and address under the windshield wipers, he said. He traded information with other stranded neighbors along his route. He found out what they had, what he could barter, what they needed so he could keep his eyes open for them....

Since my trip, I have come to believe that the indiscriminate determination of people’s needs based on the premises of a mental illness must be the luxury of those who do not need to rely on each other for survival.

It will take a while, I believe, to shape into a meaningful body of knowledge all our experiences—to be able to talk dispassionately about how we respond to disaster, and how to strengthen our own communities of intentional healing and support. We have turned our focus more and more to this task—to create meaning out of events like 9/11, the Oklahoma City bombing, and now Hurricanes Katrina and Rita. In the end, I know that I had nothing to teach my peers in that dusty training room in Jefferson Parish. Maybe the only reason I was there was to be present. While present, I saw Martha across the room quietly crying. I stammered, “What’s wrong? What is it?” as if there needed to be more to all that devastation. She said quietly, and with

*finality, “All my dreams are dead.” I knew in the ensuing silence that our work began then.... This work will take a lot of us.*

In late September, David Romprey and I spent two days in Louisiana strengthening the local consumer-run organization, *Meaningful Minds*. We carried out community organizing to assess the supports present and supports needed. We established a working relationship with the Louisiana Office of Mental Health. The consumers urgently requested training in peer support and crisis counseling. They wanted a written curriculum on these topics. During the next three weeks, LaCORK assembled such a curriculum (*Beyond Relief to Recovery*, 2005). The major topics in the curriculum are recovery from mental illness and its relationship to crisis support, peer support, cultural competency, warmlines, and psychological first aid.

Between October 17 and 21, 2005, four national consumer trainers and I provided training in peer support to forty-six Louisiana consumers. NEC identified experienced trainers: David Romprey from Oregon, Beth Filson from Georgia, Ike Powell from Georgia, and LaVerne Miller from New York. David has ten years of experience in organizing consumer groups; Beth and Ike have developed and carried out the peer specialist trainings in Georgia and many other states; Laverne had experience running Project Liberty Peer Initiative following 9/11.

It is hard to find words for this life-changing experience. Trainers and trainees alike have been profoundly moved by the experience (as evidenced by their testimony in this paper). The people of Louisiana captured our hearts. The creoles, the Cajuns, and the rednecks embraced us. We found solidarity in our suffering. They all had a story to tell and we listened. The training itself was the embodiment of the spirit of peer support. In that spirit, we the trainers were helped as well. As a peer from Michigan had recently shared, “The trainings transformed the poison of mental illness into a medicine we could share with our peers.” Several Louisiana peers have explained that the tight bonds formed through our work and social gatherings over gumbo are based on love. I would agree. Peer support was as much a factor in the process of our work as in its outcome.

Meaningful Minds of Louisiana and the OMH Office of Consumer Relations played an enormous role in coordinating the trainings. They selected the participants and secured the sites and housing for trainees and trainers. Of particular note were the efforts of Denver Noble. He went to his church and appeared on television appealing for housing. Through these efforts, he secured housing for twelve trainees and a trainer in the Lafayette area. Sylvia Pearson, of Extra Mile, was able to find hotel space in the New Orleans area for two trainers and a trainee. These were all remarkable feats considering the devastation around them and the stress they were all going through.

There were a number of other benefits resulting from our presence there. The trainings gave the trainees an opportunity to share their feelings about the disasters. At the New Orleans site one trainee said he experienced flashbacks related to his traumas in Vietnam. Another trainee said the disasters reminded her of the Holocaust, which her parents had survived. Another trainee, a taxi driver, took two of the trainers on an emotional trip around the devastated parts of New Orleans.

*The trainees also wanted to know how they would put their training to use. In addition to applying the lessons learned in assisting their peers informally, the leaders of MML wanted to ensure that peer support was a part of the FEMA grant the state needs to submit. The trainers assisted MML and the OMH Office of Consumer Relations in outlining ways that mental health consumers could participate in setting up several warm*

*The thing that made the difference [about recovery] to me was to see a person who was diagnosed and a person not diagnosed on the same page about recovery.... That commonality was just unreal—it really was.*

lines and peer support centers. The trainers also facilitated a meeting between the officers of MML and the Assistant Secretary of State of DHH for Louisiana, Dr. Cheryl Bower-Stephens. Dr. Bower-Stephens understood the importance of an independent consumer voice and peer support.

*A nurse shared this observation with me in Japan. She said, “I envy you all who have been struggling with mental illness. You know firsthand the feelings of the experience and that enables you to share a bond we who have not been there can never understand.”*

Debra LaVergne of Lake Charles, Executive Director of MML, showed great courage. Despite her house having lost its roof and being covered in mold, she organized a van of eight trainees to come up from the Lake Charles area for the training. Daily Dupré, a long-time consumer leader and member of MML, and Carole Glover, president of the board of MML, also deserve special recognition. Through their advocacy with OMH they were able to ensure that the trainings took place. Our first contact in Louisiana, Margaret Mitchell, Director of the Office of Consumer Relations, has been a consistent supporter, recruiter of trainees, and organizer.

In early 2006, Linda Donovan, a doctoral student from Arkansas, spent several days interviewing the peers in Louisiana who received the training in October. She shared the following moving feedback concerning the impact of the trainings:

- *I’m saying more. I used to not talk as much. [The thing that made the difference to me was] having a psychiatrist, especially a recovering one, telling you this is something you can do and will make a difference to you and to other people. All [of the group was] excited about [hearing that] there was something they could do that they could benefit other people based on their experiences. Mentally*

*ill people were capable of having responsible jobs [- t]hat they had something they could offer.*

- *The thing that made the difference to me was the representation of the level of the humanity of the people doing the training for us.... I could notice a difference in me relating to them—I’d never related to anyone at that level. It was a group but felt like one-on-one. It was really something else!*
- *The thing that made the difference [about recovery] to me was to see a person who was diagnosed and a person not diagnosed on the same page about recovery.... That commonality was just unreal—it really was.*
- *What the training [meant] to me was it made me aware that we could make a difference to other consumers’ lives with the proper training.*
- *The biggest benefit I got from the training was to help set up the training. Being involved in the preparation was a high for me; the anticipation of what would be taught and how well it would be received. Looking around the room and viewing the faces soaking up the information like a sponge so this information can be used to aid another one of our peers when a circumstance or situation would arise.*
- *For me to know recovery is possible was to just look around the room of the training because it was obvious the information we were getting was changing lives right in front of me. Excitement grew, statements of self-esteem [were] made, and action was being taken during the training through participation in the training. Each day of the training everyone was more and more energized to make positive changes in their lives to provide for a deeper recovery.*
- *[The thing that made a difference to me] was hearing about Peer Specialists and how one person can make such a difference in other people’s lives, like Dr. Dan Fisher.*
- *I have always been told, “You don’t get recovered from mental illness.” Well, I have found out that that’s a lie and I can recover and live a full life without mental illness.*
- *After training I felt I was on the right track with*

*the person-to-person approach—and in a word—empowered.*

- *One of the things that I have noticed about some of my “peers” is they have gone to work! Not just volunteer work... real work! Amazing. I believe they have the moral support of people on the net to help... there are more resources, too!*

Meaningful Minds participated in several trainings nationally. They presented their experiences, as members of a panel, to 900 participants of the Alternatives Conference in October, 2006, and in a webcast sponsored by SAMHSA on peer support and disaster relief, December 15, 2005 (SAMHSA webcast, 2005).

*In a deep sense, I have learned important lessons about what it means to be a peer helping others. First of all, I realize how fundamentally different it is to help on a peer-to-peer basis. We lead with our heart, not our head. We enter into relationships first and foremost, then, we see how we can assist the others. This is opposite from the way professionals are trained, to enter at the thinking level with theories about what they will see, and set themselves apart, in an elevated position of ‘professional’. Then they try to draw out the person’s feelings, but by then the person is further defended. The formality of the traditional system combined with the power differential between professionals and those in need of assistance make opening up more difficult.*

*A nurse shared this observation with me in Japan. She said, “I envy you all who have been struggling with mental illness. You know firsthand the feelings of the experience and that enables you to share a bond we who have not been there can never understand.” Peers can take the lead in times of crisis, and in so doing build the bridges of trust between people suffering and professionals who want to help them. We are willing and capable of bridging these worlds as well as providing support. We are a resource the system cannot afford to overlook.*

## **V. Conclusion**

Each state should develop a disaster plan that includes peer support services. These peer support services are best coordinated by a statewide consumer

organization. Louisiana and Oklahoma have illustrated the importance of having a statewide consumer-run organization in order to sustain disaster relief after the acute aspect has passed. The applications for funding, the coordination with other agencies, the cooperation among different parts of the state, all require the sustained involvement of peers. New York illustrated how a strong local consumer-run organization can be a useful adjunct to professional services in time of disaster. Mississippi lacked even the beginnings of a peer network, and there was nothing to draw on in time of crisis.

There is a pressing need to ensure that consumers are involved in all levels of disaster planning. It is of concern that SAMHSA has not involved consumers in two of its recent disaster-oriented activities. The April, 2006, summit in New Orleans on disaster relief involved only two invited consumers from across the country out of over 600 attendees, and a manual on disaster relief being prepared by SAMHSA has no mention of peer support.

### **PRIMARY RECOMMENDATION:**

**In keeping with the New Freedom Commission report, which calls for a consumer-driven system that includes peer support, we recommend that SAMHSA, FEMA, and state agencies involved in disaster relief, ensure there is significant participation of consumers in future planning, training, and delivery of disaster relief services.**

### Specific Recommendations:

1. Proposal for a National Consumer Recovery from Disaster Network with representatives from each state. SAMHSA could fund such a network, with coordination by the three consumer-run TA Centers. This network could build on the work of CORK. It could help ongoing training of consumers in each state in disaster readiness. This training could include Peer Crisis Support as well as personal disaster planning. This network could assist local groups to cope more effectively at times of crisis. It also could help in coordination of peer support with SAMHSA, FEMA, and state Departments of Mental Health.

2. Training must include disaster response training; contact options or “calling trees” when telephone lines are unavailable; warmlines; trauma aftercare; outreach programs; an emergency medication program; and finally, long-term approaches to mental health services.
3. Proactive preparation in each state through development of a strong consumer-run, statewide organization capable of drawing on the national consumer network to establish an accessible site for centralizing resource materials, and coordinating peer trauma training program.

Additional recommendations [developed by the Peer Support Work Group of the Conference on “After the Disaster,” held by the GAINS Center, April, 2006]:

1. Consumer TA Centers—provide funding for Centers to support development – bringing these TA Centers into the discussion w/ GAINS/CWVT/CMHS, as well as survivor organizations.
2. Overreaching support and TA from CMHS and Centers to provide guidance and support (mentorship) around what strategies to use—Develop national disaster plan based on these principles—National Disaster Recovery Network based on these principles, based upon LACORK model, National VOAC, National Case Management Consortium (VOA, SA, Catholic Charities, others)—reach out to existing consortiums/organizations that are already preparing/providing disaster response to incorporate these key principles in their response efforts.
3. Involve Homeland Security—conversation at the federal level, continuing discussion at state level (state disaster plans are under auspices of

federal and/or state Departments of Homeland Security).

4. Proceed with a public education campaign—you’ve been through a lot, it’s okay to talk about it—focus on connecting with others—normal reactions to abnormal events—everybody has a story to tell (builds on “it’s not what’s wrong with you, what happened to you”).
5. Develop online database to serve as repository for information (programmatic or otherwise) and resources and continue the discussion—related repository of programs (promising, EBPs)/peer support models—providing information and linkages—develop program descriptions of promising programs (NYC, LA, OK, AL, etc.) as exemplars of what models exist.
6. Go beyond a database to continue connections and foster relationships—facilitates collaboration and working together—series of meetings to complement the database activities—stories need to be told.
7. Build evaluation capacity into development efforts and seek to build evaluation data on existing programs—Making efforts as of NATIONAL SIGNIFICANCE, have a Coordinating Center to manage this process, collect and analyze data, document promising programs/practices and EBPs—greatly support/influence Congress/Policymakers.
8. Rethink how agencies relate to the field—it’s not bringing people to the table, it’s going to their tables, working locally/keeping locus of control at local level—integration happens at the local and individual level, which is at the heart of peer support—use community organizing as a tool to stimulate.



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