

# **THE NEEDS OF PEOPLE WITH PSYCHIATRIC DISABILITIES DURING AND AFTER HURRICANES KATRINA AND RITA: POSITION PAPER AND RECOMMENDATIONS**

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## **EXECUTIVE SUMMARY**

In Fall of 2005, the destructive forces of Hurricanes Katrina and Rita wreaked an emotional as well as a physical toll on residents of the Gulf Coast region. Millions of Americans from across the country reached out to hurricane survivors, opening their homes and their hearts.

Government employees at local, state and federal levels worked long and hard to help evacuate and rescue people in the Gulf Coast. Many of these people are still in the Gulf Coast helping to rebuild communities. In the months since the hurricanes devastated the Gulf Coast, media coverage of the hurricane survivors has waned. However, for hurricane survivors with psychiatric disabilities, the hurricanes' destruction resulted in "trauma that didn't last 24 hours, then go away. ... It goes on and on." Some of these challenges were unavoidable. As one government official said, "No one ever planned for 'what happens when your social service infrastructure is completely wiped out.'" Nonetheless, many of the problems could have been avoided with proper planning. As NCD predicted in its April 2005 report, *Saving Lives: Including People with Disabilities in Disaster Planning*, "[i]f planning does not embrace the value that everyone should survive, they will not." As a result of its research, NCD found that much pre-Katrina disaster planning did not contemplate the needs of people with psychiatric disabilities, and as a result, many people died or unnecessarily suffered severely traumatic experiences. This paper includes the following major findings and recommendations, as well as various specific recommendations for emergency management officials and policymakers at the local, state and federal levels.

### **Major Findings**

- **In Violation of Federal Policy and Law, People with Psychiatric Disabilities were Discriminated Against During Evacuation, Rescue, and Relief Phases**

First responders and emergency managers such as shelter operators often violated the civil rights requirements of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. As a result, people with disabilities did not have access to critical services and relief. Some of the most common forms of discrimination included: People with disabilities were segregated from the general population in some shelters while other shelter simply refused to let them enter. People with psychiatric disabilities were denied access to housing and other services because of erroneous fears and stereotypes of people with psychiatric disabilities.

- **Mismanaged Evacuations Resulted in the Loss, Mistreatment, and Inappropriate Institutionalization of People with Psychiatric Disabilities**

Disaster response plans often did not include protocols to evacuate people with psychiatric disabilities. During evacuations, emergency officials physically lost residents of group homes and psychiatric facilities many of who are still missing. Others have not or cannot return home because essential supports have not been restored or because the cost of living has increased too much. When people with psychiatric disabilities arrived at evacuation locations – ranging from state parks to churches – those locations often were not prepared to meet the medical and mental health needs of the evacuees with psychiatric disabilities. Many people with psychiatric disabilities never made it to evacuation shelters because they were inappropriately and involuntarily institutionalized. Some of these people still have not been discharged, despite evaluations that indicate they should be.

- **People with Psychiatric Disabilities Were Not Included in Disaster Planning or Relief and Recovery Efforts**

Most emergency plans were not developed with the inclusion of people with disabilities, psychiatric or otherwise. As a result, emergency planners could not anticipate the many special needs required by evacuees with disabilities. Houston was an exception to that general rule, where people with disabilities were significantly involved with a local emergency response coalition.

People with psychiatric disabilities were not included in relief and recovery efforts. For example, there have been many calls for greater screening, diagnostic and professional treatment capacity after natural disasters. However, professional treatment after a disaster should be augmented by peer support from clients of the mental health system. The Substance Abuse and Mental Health Services Administration (SAMHSA) provided some funding for peer support training.

People with psychiatric disabilities were not included in the development of plans to evacuate citizens using police assistance. Uniformed police officers often were not trained to work with people with psychiatric disabilities, and as a result, many evacuees with psychiatric disabilities had negative evacuation experiences with the police.

- **Disaster Management Efforts Often Failed Because No Individual or Office Had Responsibility, Accountability, and Authority for Disability Related Issues**

As in previous disasters, there was a lack of coordination and communication, not only between levels of government, or between different agencies at the same level of government, but between people at different levels in the same agency. One disability advocate recalled, “When I asked [who had ownership of disability issues] in the state I was assessing, no one raised their hand. I asked five different logistical places, and no one claimed ownership of disability-related issues for the state... anything coordinated out to the state levels was fragmented, not standardized, not coordinated across the board.”

- **Disaster Plans Were Shortsighted and Relief Services Were Terminated Prematurely**

Accumulated experience from other highly traumatic events – such as September 11<sup>th</sup> and the Oklahoma City bombing – indicates that suffering and symptoms related to traumatic events often emerge years later. Just as policymakers should make long-term plans for disaster survivors' physical needs, such as housing and employment, policymakers also should plan for long-term psychiatric needs. However, many relief services have been prematurely terminated. For example, the Federal Emergency Management Agency's (FEMA) "long-term" crisis counseling programs expire after nine months; however, mental health experts predict major eruptions of post-traumatic stress disorder on the one-year anniversary of the disaster.

### **Major Recommendations**

- **Nondiscrimination in the Administration of Emergency Services**

The federal National Response Plan and state and local emergency plans should require that services and shelters be accessible to people with disabilities, including people with psychiatric disabilities (who live independently or in congregate living situations such as hospitals, group homes, or assisted living), in compliance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. State plans should be reviewed by independent disability experts familiar with that state.

- **Plans for the Evacuation of People with Psychiatric Disabilities**

Evacuation planners should have a plan that (a) tracks the transfer of residents of group homes and psychiatric facilities; (b) maintains contact between people with psychiatric disabilities and their family members and caretakers; (c) helps facilitate the return of evacuees to their homes; (d) ensures that sites that receive evacuees are equipped to meet the needs of people with psychiatric disabilities; and (e) prevents the inappropriate institutionalization of evacuees with psychiatric disabilities.

- **Inclusion of People with Psychiatric Disabilities in Emergency Planning**

People with psychiatric disabilities must be involved at every stage of disaster and evacuation planning and with the administration of relief and recovery efforts. Communities should develop interagency, multi-level disaster planning coalitions that include people with disabilities, similar to the coalition developed in Houston.

- **Person or Office Responsible for Disability Issues During Disasters**

A single person or office must be responsible, accountable and able to make decisions related to disability issues. This person or office would be responsible for training first responders and organizing disability-specific evacuation, relief and recovery efforts. This person or office would also serve as a communication link between people with disabilities and the respective local, state or federal government.

- **Disaster Relief Should Continue for at least Two Years After the Disaster**

Relief and recovery efforts should continue for at least two years from the date of the disaster, including Medicaid waivers, HUD housing waivers, and FEMA housing for people with disabilities. Disasters often result in long-term psychiatric consequences for people, and in some cases, the traumatic impact of the disaster does not manifest itself until many months or years later. Additionally, the social service infrastructure in some locations was utterly wiped out. Emergency planners should ensure treatment continuity by planning for relief services to be available for at least two years after the disaster.

Many of these findings and recommendations align with NCD's 2005 report, *Saving Lives:*

*Including People with Disabilities in Disaster Planning*, available on the web at

[http://www.ncd.gov/newsroom/publications/2005/saving\\_lives.htm](http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm). NCD encourages

policymakers, emergency planners and people with disabilities to carefully review that report.

NCD stands ready to provide guidance to those who are ready to make their emergency plans

and services more accessible to people with disabilities. As emergency managers and

policymakers create plans that seek to ensure that all people, regardless of disability, survive

catastrophes such as Hurricanes Katrina and Rita, we will incorporate the principles of inclusion

and nondiscrimination into our national consciousness.

## **I. INTRODUCTION**

Hurricanes Katrina and Rita devastated the lives of many people who lived on the Gulf Coast. Graphic video footage and news reporting have produced a vivid image of the physical toll of the devastation on homes, businesses and human lives. The media also showed how millions of Americans from across the country reached out to hurricane survivors, opening their homes and their hearts. Government employees at local, state and federal levels worked long and hard to help evacuate and rescue people in the Gulf Coast. Many of these people are still in the Gulf Coast helping to rebuild communities. In the months since the hurricanes devastated the Gulf Coast, media coverage of the hurricane survivors has waned. Yet the hurricanes' destructive forces wreaked an unrelenting emotional toll on residents of the Gulf Coast region. For hurricane survivors, the hurricanes' destruction resulted in "trauma that didn't last 24 hours, then go away... It goes on and on," according to Dr. Crapanzano, the Louisiana medical director for the Office of Mental Health.<sup>1</sup> As the new hurricane season approaches, it is likely that similar mental health issues will surface and existing mental health problems may be exacerbated. In preparation for future hurricane seasons and other disasters, policymakers and consumers of mental health services must learn from the successes and failures of the emergency management during Hurricanes Katrina and Rita. The National Council on Disability (NCD) is the federal agency charged with providing advice to Congress and the President on improving the lives of people with disabilities. In this paper, NCD addresses the impact of Hurricanes Katrina and Rita on people who were already struggling emotionally before the hurricanes hit and on people who developed psychiatric disabilities as a result of the hurricanes' devastation. This paper also provides recommendations to improve the provision of mental health services during and after a disaster.

People with psychiatric disabilities were discriminated against in their access to disaster relief during and after the hurricanes. For example, according to some Katrina survivors with psychiatric disabilities, the Federal Emergency Management Agency (FEMA) excluded them from its trailers because of concerns that the individuals' psychiatric disabilities made them dangerous, despite assurances from mental health professionals that the individuals were not dangerous.<sup>2</sup> FEMA gave rental assistance to individual families, but turned down requests to

reimburse church groups that provided housing to former residents and staff of group homes for people with psychiatric disabilities.<sup>3</sup> The American Red Cross barred sign language interpreters for people who are deaf, and shelter officials also turned away disability protection and advocacy groups in some shelters in Louisiana, Mississippi and Texas.<sup>4</sup> According to one Texas mental health official, “[w]e were presented with many barriers by the American Red Cross, who would not let our outreach and peer support folks into the shelters.”<sup>5</sup> Some American Red Cross shelters excluded or evicted people with psychiatric disabilities, and other shelters refused to allow people with psychiatric disabilities to reenter the shelters after leaving for medical appointments. Some people with psychiatric disabilities were transferred to other states, where they lacked support systems and were separated from family members; these same people were inappropriately institutionalized, and some were discharged but lacked transportation to return home and became homeless in a strange city. Disaster relief services were inaccessible to people with disabilities, because emergency managers failed to include people with disabilities in the planning process. For people with psychiatric disabilities, the consequences were devastating, and sometimes deadly.

Although national media attention on the Gulf Coast reconstruction efforts has waned, the problems for people with disabilities persist. For example, many mental health clients still do not have access to critical medication.<sup>6</sup> Since Katrina, all of the mental health facilities in New Orleans have closed down and only two hospitals remain but they only accept insured patients.<sup>7</sup> In Alabama, FEMA evicted a New Orleans woman with severe emotional and medical disabilities from her temporary housing; she died a few days later.<sup>8</sup> Due to the lack of mental health facilities and personnel (only eleven percent of New Orleans psychiatrists remain in the city), untrained and ill-equipped police officers have become the city’s first responders to residents with emotional needs.<sup>9</sup> A New Orleans police official called the situation “a lose-lose for everybody.”<sup>10</sup>

Many current Gulf Coast mental health clients developed psychiatric disabilities as a consequence of the devastation and mismanaged relief efforts. Many Gulf Coast residents have developed post-traumatic stress disorder and depression.<sup>11</sup> Officials believe that the problem is likely to worsen, because post-traumatic stress disorder often takes months or years to emerge.<sup>12</sup> The New Orleans police department reported that in the months following Katrina, the city’s



suicide rate was nine times the national average. As the first anniversary of Hurricanes Katrina and Rita approaches, it is likely that hurricane survivors and first responders will experience increased anxiety levels, trauma, grief, and post-traumatic stress disorder.

Scattered amidst the devastation are shining stories of heroism, resilience, and care which provide valuable lessons for future disaster relief and recovery efforts. There were individual heroes, such as first responders and caregivers who stayed with their clients, and groups of heroes, including neighbors and churches in local communities who organized spontaneously to help the displaced people who poured into their towns. Additionally, people with psychiatric disabilities banded together to support each other and provide help to others. From these inspiring stories, NCD has learned that ongoing, permanent, local plans and programs are essential to effective disaster relief and recovery. These stories also underscore the need to involve people with psychiatric disabilities in developing plans and programs for disaster relief and recovery.

## **II. THE PRE-HURRICANE PSYCHIATRIC DISABILITY POPULATION IN THE GULF COAST REGION**

People who had psychiatric disabilities prior to Hurricanes Katrina and Rita were not a niche population in the hurricane-hit regions. Less than three months before hurricane Katrina, the Report on the State of the Mental Health Delivery System in Louisiana identified one in five individuals in Louisiana as experiencing a “diagnosable mental disorder” in any given year—650,000 adults and 245,000 children.<sup>13</sup> In 2004, Louisiana admitted 4,550 people to state-operated acute psychiatric units.<sup>14</sup> According to the 2000 Census, 23.2 percent of New Orleans residents had some type of physical or mental disability.<sup>15</sup> Almost 65,000 people in the greater New Orleans metropolitan area were identified as having a “mental disability.”<sup>16</sup> Most people served by the Louisiana mental health system who were affected by the hurricanes were poor people from diverse cultural groups, predominantly African-American. In Alabama, the Department of Mental Health and Mental Retardation served 102,000 people prior to the hurricane, including residents of a small psychiatric institution and a large community mental health center in Mobile who were evacuated. Census data for one hard-hit Mississippi county identified 27.2 percent of the population as “disabled.”<sup>17</sup> Hurricanes Katrina and Rita significantly added to the population of people with psychiatric disabilities in the Gulf Coast

region, including first responders. There will be an increased demand for mental health services in the upcoming hurricane season.

People who are dependent on public mental health system services, many of which have been certified as having disabilities by the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs, often have been ignored in articles, reports and surveys that might be expected to include them. Articles about mental health issues as a result of the hurricanes tend to focus on people with no prior psychiatric history whose reaction to the disasters has been manifested by withdrawal, nightmares, and suicide. Reports about evacuation and disaster planning for people with special needs have focused on the elderly, nursing home populations, general hospital patients, and people with physical disabilities.<sup>18</sup> Additionally, researchers have not yet thoroughly examined the effects of the hurricane on children previously diagnosed with mental illnesses and emotional or psychiatric disabilities; rather, most reports have focused on the psychiatric toll of the hurricanes on children who did not previously have psychiatric disabilities. As we prepare and set policy for future disasters, it is important to remember and plan for the population of people who developed psychiatric disabilities during and after Katrina, but we must not overlook challenges faced by hurricane survivors with pre-existing psychiatric disabilities.

Some people with psychiatric disabilities reacted with resilience and were a support to other evacuees even when their own homes were lost; others endured major psychiatric crises when faced with the loss of everything that had anchored them to a precarious existence, including (most importantly) the people they knew and trusted. The relief and rescue systems that were set up by federal and state governments and the American Red Cross were not designed to adequately serve people with pre-existing psychiatric disabilities. Fortunately, in at least some instances, neighbors, strangers, churches and small community groups stepped in to fill the rescue and relief vacuum left by government agencies.

### **III. MAJOR FINDINGS AND RECOMMENDATIONS**

In the chaos and urgency caused by the hurricanes, it was difficult to keep track of people with psychiatric disabilities. Many clients of the mental health system and people who lived in group

homes still have not been found. Government entities (such as the National Council on Disability and the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities) as well as private non-governmental organizations confirmed first-hand accounts of communication breakdowns, loss of housing and possessions, crowded shelters, forced resettling from one evacuation center to another, and discrimination. Hurricane evacuees and advocacy groups on the ground in New Orleans raised important issues with broad social policy implications regarding planning, evacuation, housing and medication. This section provides principles and policy guidance for emergency planners and decision makers. Also included are concrete examples of the application of these policy recommendations in specific circumstances. The law requires many of these policy recommendations – the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

**A. In Violation of Federal Policy and Law, People with Psychiatric Disabilities were Discriminated Against During Evacuation, Rescue and Relief Phases.**

***Recommendation:*** The federal National Response Plan and state and local emergency plans should require that services and shelters are accessible to people with disabilities, including people with psychiatric disabilities (who live independently or in congregate living situations such as hospitals, group homes or assisted living), in compliance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. Independent disability experts familiar with the state should review state plans.

The principles of nondiscrimination codified in law and federal policy should provide the framework for emergency planning and response for people with disabilities. Discriminatory planning and implementation can have deadly consequences for people with disabilities. When it came to planning for and providing services in a nondiscriminatory fashion to evacuees, “people with disabilities were footnotes.”<sup>19</sup> For example, evacuees in American Red Cross shelters reported that essential medical services were positioned on upper floors of shelters and there was no elevator access. Following the principles embodied in these laws and other federal policies when planning for disaster relief and implementation is not only required, but it is also good policy.

**1. Discrimination During Evacuation**

People with disabilities were discriminated against during evacuation efforts. Some people with psychiatric disabilities had difficulty comprehending the evacuation messages and other essential communications and some were treated roughly because they could not follow the instructions. Marcie Roth of the National Spinal Cord Injury Association provided Congress with other examples of discrimination when she testified on the loss of human life due to the failure of paratransit services during the crisis.<sup>20</sup>

## **2. Discrimination in Emergency Shelters**

People with psychiatric disabilities were often discriminated against within the emergency shelters. There is broad consensus among people with disabilities, advocates, professionals, first responders, and service providers that people with psychiatric disabilities encountered enormous problems with general shelters, especially those run by the American Red Cross. As one advocate reported: “calls to our [Alabama] State Governor’s Office on Disability reported about how people with psychiatric disabilities were not well served in shelters.”<sup>21</sup> Shelters were crowded, noisy, chaotic, confusing, and sometimes violent, all inadequate circumstances for a person with psychosis, anxiety, or depression. Many smoking-dependent people with psychiatric disabilities were not allowed to reenter shelters when they left to smoke. Many ended up living right outside the shelters, and services were not provided to people living outside the shelters. Some shelters “dumped” difficult evacuees by sending them to jails, emergency rooms, nursing homes, or mental institutions.<sup>22</sup> In other shelters, people with psychiatric disabilities huddled in corners behind physical barriers segregating them from the general population.<sup>23</sup>

Some areas established segregated “special needs” shelters to accommodate people with disabilities. At their peak, special needs shelters served about 9,600 people.<sup>24</sup> Some of these special needs shelters served a useful function: they provided a central location for people with disabilities to have access to vital emergency services for people with disabilities. The special needs shelters received some evacuees with psychiatric disabilities who likely would have been shunted into institutions had the special needs shelters not existed. However, most special needs shelters were established specifically for people with medical and physical disabilities, not for people with psychiatric disabilities. As a result, when general shelters referred people with psychiatric disabilities to special needs shelters, those shelters did not have the necessary

services to support them. In Texas, special needs shelter operators tried to get evacuees with psychiatric disabilities admitted to inpatient psychiatric beds because they felt the people with psychiatric disabilities “did not blend in well.”<sup>25</sup>

Sometimes, the mere existence of special needs shelters served as an excuse to discriminate against people with disabilities who sought access to general shelters. The American Red Cross adopted a policy of rejecting people with obvious disabilities. Because of this policy, American Red Cross personnel sometimes referred people with disabilities to special needs shelters but other times, rejecting access to a shelter resulted in evacuees with disabilities living in the streets. People with disabilities who are able to live independently in their communities should not be segregated during an emergency. Rather, general shelters should adhere to federal policies and laws that prohibit discrimination based on disability, and require accommodations for people with disabilities to enjoy equal access to the life-saving services provided in general shelters.

### **3. Discrimination in the Administration of Relief Services**

The federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) recommended that Homeland Security funding be used to ensure that all aspects of emergency preparedness, response, and recovery promote the full integration of people with disabilities.<sup>26</sup> Despite this nondiscrimination policy recommendation, Homeland Security funds still paid for inaccessible emergency services. For example, many people with psychiatric disabilities could not navigate FEMA relief and housing applications without assistance. Advocates who could have assisted with the applications were denied access to some shelters in Louisiana and Texas (in Mississippi, local American Red Cross volunteers contacted advocates to help fill out the applications). According to “Jenny,” a hurricane survivor and mental health consumer, she was wrongfully denied FEMA housing because FEMA was concerned with her psychiatric disabilities. As a result, Jenny spent months in an institution, despite evaluations by mental health professionals who concluded that she was perfectly able to live in FEMA housing.<sup>27</sup> FEMA’s decision also conflicted with the nondiscrimination policy articulated in the President’s New Freedom Initiative, which promises to “break down barriers to equality” facing people with disabilities.<sup>28</sup>

Another example of discrimination was FEMA's refusal to reimburse crisis counseling costs for many people with pre-existing psychiatric disabilities because FEMA officials said that they consider the treatment to be "continuing" mental health treatment.<sup>29</sup> FEMA representatives also reportedly told people from group homes that they were ineligible for reimbursement for shelter, temporary housing, or other kinds of services. "Group homes and other entities had problems at first getting the feds to understand their issues and eligibility."<sup>30</sup> Individuals with psychiatric disabilities who had lived independently before the hurricanes hit were deemed ineligible for housing assistance (such as trailers) because untrained FEMA employees made uninformed assessments of their disabilities. FEMA reportedly deemed one woman ineligible for housing because, after living through the terror of post-Katrina chaos, she slept with a knife under her pillow for protection. In New Orleans, emergency departments were turning away people with psychiatric disabilities as late as May 2006 and there were no services to which they could be referred.<sup>31</sup>

Policymakers and emergency planners must incorporate the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act into their planning in order to provide nondiscriminatory relief services. Disparate treatment of people with psychiatric disabilities is discriminatory, unlawful, and hurtful. The ADA and Section 504 provide that when a public entity or an entity receiving federal funds provides services, including disaster services, people with disabilities should not be excluded from those services on the basis of their disabilities, as happened to some people with psychiatric disabilities. These laws require that providers of public services make reasonable accommodations to their facilities or services when necessary, unless those modifications would "fundamentally alter" the disaster relief program at issue. Finally, these laws permit the provision of different or separate aids, benefits, and services, if that is what is necessary to provide individuals with disabilities with services that are as effective as those received by people without disabilities. However, an individual with a disability cannot be forced to accept those separate services.

The ADA and Section 504 apply to every vital aspect of disaster relief, including evacuation plans, emergency communication, transportation, medical care, shelters, temporary housing and recovery efforts. Daniel Sutherland, head of the Office of Civil Rights and Civil Liberties for the Department of Homeland Security, stated that "[i]t is a violation of basic principles of human

freedom for people who want to live on their own, independently, to be forced to live in institutional settings.”<sup>32</sup> Disaster relief is not an exception to this rule. Policymakers should remedy the lack of adequate funding streams, fiscal incentives, and rigorous enforcement of federal legal requirements that are necessary to provide nondiscriminatory disaster services.

## **B. Mismanaged Evacuations Resulted in the Loss, Mistreatment, and Inappropriate Institutionalization of People with Psychiatric Disabilities**

***Recommendation:*** Evacuation planners should have a plan that (a) tracks the transfer of residents of group homes and psychiatric facilities, (b) maintains contact between people with psychiatric disabilities and their family members and caretakers, (c) helps facilitate the return of evacuees to their homes, (d) ensures that sites that receive evacuees are equipped to meet the needs of people with psychiatric disabilities, and (e) prevents the inappropriate institutionalization of evacuees with psychiatric disabilities.

People with psychiatric disabilities were evacuated to a variety of settings, including state emergency departments, general shelters, nursing homes, “special needs” shelters, churches, homes of compassionate strangers, jails, and psychiatric institutions. In many cases, the choice of setting depended on decisions by first responders who had no training in disability issues and who did not have access to information that would have helped them work with people with disabilities.

### **1. Residents of Group Homes and Psychiatric Facilities Were Lost During Evacuations, and Many Still Have Not or Cannot Return Home**

While some state psychiatric facilities and group homes successfully evacuated in an orderly and timely manner, officials did not have prearranged destinations for the evacuees. As a result, family members were unable to find loved ones who had been evacuated from state facilities. “People were just sent all over the place,” said Jennifer Jantz, executive director of the Louisiana chapter of the National Alliance for the Mentally Ill. “Nobody is sure where everybody is. We got calls, people looking for loved ones. People didn’t know where group homes were evacuated to. We’re still getting those calls.”<sup>33</sup> To exacerbate problems, Medicaid will be sending thousands of notices that eligibility to receive Medicaid services in a state other than the state of origin is about to expire. Most of these notices will never be received, and therefore the time period to appeal will expire.

There are many examples of the displacement of people with psychiatric disabilities. One bus with group home members and staff went to Tuscaloosa, Alabama, because one of the directors had a brother in Tuscaloosa. That is how Tuscaloosa ended up providing services to sixty-five people for over three months. Because destinations were not determined in advance, it has been difficult to track down evacuees. According to one mental health advocate, nine out of ten residents at a group home in Mississippi still cannot be found.<sup>34</sup> Many people are still unaccounted for because no system existed to coordinate and track people as they were moved from shelters to state parks to churches. When asked “what happened to people with psychiatric disabilities who lost their homes,” the answer from many mental health professionals is “we don’t know.”<sup>35</sup> For example, one government official encountered an encampment of twenty people with psychiatric disabilities in Purlington, Mississippi. They had banded together and lived in small tents. The Salvation Army provided them with food. The official found the band of people on the day that Hurricane Rita was expected to hit, and sent help to transport them out.<sup>36</sup> Whether they survived Rita, and where they are today, remains unknown.

Residents of psychiatric facilities and clients of the state mental health system in Mississippi as well as several other surrounding areas were evacuated to places throughout the United States, sometimes thousands of miles from their homes. Many people with pre-existing psychiatric disabilities were surviving on meager assisted-incomes prior to the hurricanes and cannot return to cities where rental prices have tripled.<sup>37</sup> Others are concerned that essential services and supports have not been reestablished. After months of unnecessary hospitalization, some evacuees are just now returning to their home states. Others who were “temporarily” institutionalized have not yet been discharged.

Some people who evacuated from Louisiana have not yet returned home because necessary support services and structures have not yet been re-established. Advocates in Louisiana observed that the Louisiana state mental health system was disorganized and uncoordinated before Hurricane Katrina. One advocate said, “I don’t really have a handle yet on the extent to which the hurricane harmed the system and the extent to which the system was broken and in turmoil anyway before the hurricane.”<sup>38</sup> In fact, less than three months before Hurricane Katrina, a report by the Secretary of the Louisiana Department of Health and Hospitals noted that Louisiana’s mental health system was inadequate, fragmented, and suffered from a lack of



appropriately trained professionals.<sup>39</sup> Today, only a fraction of that inadequate system in New Orleans remains, and the rest of the Louisiana mental health system is strained beyond capacity. To facilitate the return to their homes, evacuees with psychiatric disabilities should be advised on the level of supports and services that have been re-established in their home communities so that they can make informed decisions. Governments should strive to re-establish those services quickly, so people with psychiatric disabilities can finally return home.

## **2. Evacuation Locations Were Not Prepared To Meet the Medical and Mental Health Needs of People With Psychiatric Disabilities**

Many destination facilities were ill prepared to receive evacuees. One state psychiatric facility in Louisiana was not notified that evacuees were coming to them until buses arrived and thirty people got out. Currently under-equipped facilities continue to service evacuees, nearly a year later. “Between two and three hundred” people from Louisiana are now part of the mental health system in Alabama, according to Anne Evans, Executive Assistant to the Commissioner of the Alabama Department of Mental Health and Mental Retardation.<sup>40</sup> According to Cindy Hopkins of the Texas Department of State Health Services, 250,000 evacuees remain of the 600,000 who arrived in Texas almost a year ago.<sup>41</sup>

Evacuees with psychiatric disabilities experienced different treatment based on the location to which they were evacuated. “Evacuation” can mean self-evacuating from a home or apartment to a shelter in New Orleans, or it can mean being sent from a New Orleans shelter across the country to places such as Massachusetts or South Dakota. People who were evacuated to rural Mississippi and Alabama often had very few medical and mental health services because the systems were strained before the evacuees arrived. One Mississippi advocate reported that American Red Cross shelters were only opened in urban areas, not rural areas, in Mississippi.<sup>42</sup> Wind Creek State Park in Alabama initially served four to five hundred evacuees; most were impoverished people from the Ninth Ward in New Orleans.<sup>43</sup> At least thirty of the evacuees had urgent mental health needs, including people with autism, bipolar disorders and schizophrenia. Some of the evacuees were rape victims who required trauma treatment. The county mental health region in which Wind Creek Park is located had one psychiatrist prior to Hurricane Katrina. When the evacuees started streaming into the park, there was one nurse for four hundred people.<sup>44</sup>

Evacuation locations often lacked psychiatric support, treatment services and medications. Many people who arrived at shelters did not have medications. Some people did not know what medications they were taking nor did they remember the dosage level. People who brought medications with them consumed far less than the prescribed dosage in an attempt to make them last as long as possible. When medical assistance was provided, people sometimes had to choose. One woman recounted that the host state's Medicaid program would only cover three of her usual eight prescriptions. It is critical for people's health and safety that they be allowed to remain on medications they were taking prior to the hurricane. Nearly all interviewees for this paper expressed that they had difficulties obtaining medication during the disaster. For some people with psychiatric disabilities, this remains one of their chief concerns for the next hurricane season. There have been recent discussions at the federal level as to whether psychotropic medications should be added to the CDC's Medication Stockpile.<sup>45</sup> People with psychiatric disabilities should be involved in those discussions.

Some doctors and health professionals reportedly declined to serve people with psychiatric disabilities because they were unfamiliar with the evacuees' mental health and medical histories and were therefore concerned that they might be held liable for erroneous treatments or prescriptions. The American Psychiatric Association's Disaster Psychiatry Handbook contains an entire chapter on 'Medicolegal and Ethical Issues in Disaster Psychiatry,' which warns prospective volunteers not to underestimate the chances of litigation, or rely on "Good Samaritan" statutes to protect them.<sup>46</sup> These issues need to be discussed by emergency planners at the federal, state and local levels with the inclusion of people with psychiatric disabilities.

### **3. Many People with Psychiatric Disabilities Were Inappropriately Institutionalized**

Some people with psychiatric disabilities were sent to state psychiatric institutions or jails when all they needed was a medication refill. People were moved for a variety of reasons from one setting to another, with little or no notice or explanation. A recurring theme was that people with psychiatric disabilities were placed in nursing homes and institutions, not because they required that level of care, but because there was nowhere else for them to go,<sup>47</sup> or because they needed medications that the shelters did not have. At least one person in Alabama was unnecessarily

hospitalized because FEMA would not permit her to remain in FEMA housing due to concerns about her psychiatric disability – concerns that were unfounded, according to the mental health professionals who evaluated her.<sup>48</sup> In Mississippi, some evacuees with psychiatric disabilities were sent to the state hospital, which served as an evacuation site. One individual was able to get out of the state hospital because his sister came to get him.<sup>49</sup> Some people who had previously lived in the community were “evacuated” to Texas state psychiatric hospitals, where they remained for many months after Hurricane Katrina.<sup>50</sup> Advocacy Inc, the Texas Protection and Advocacy agency, made a concerted effort to identify, locate and advocate for the discharge of Texas evacuees.<sup>51</sup> Other evacuees with psychiatric disabilities were arrested and jailed in the wake of the hurricane, sometimes dragged out of shelters and other times removed from the streets. However, both Alabama and Texas were able to serve most evacuees with psychiatric disabilities in shelters and transition them to community settings (although a few were sent to state hospitals), demonstrating that it is possible to evacuate people with psychiatric disabilities without institutionalizing them.

Some of the unnecessary transfers to institutions were the results of reception center triage by individuals with no training, experience, or assistance in identifying or treating people with psychiatric disabilities. Substance Abuse and Mental Health Services Administration (SAMHSA) is preparing a toolkit for first responders, which includes an assessment tool to appropriately identify the level of care and needs of people with various disabilities. The assessment tool comes in two parts: a brief set of questions for reception center triage, and a longer set of questions for shelter providers, to ensure that people are not inappropriately hospitalized, and that shelter services provided or contracted for by states are, as required by law, provided in the “most integrated setting appropriate to the needs” of individuals with disabilities.<sup>52</sup> The toolkit is said to be available soon,<sup>53</sup> and NCD urges its release and widespread distribution to first responders and shelter managers as soon as possible.

When evacuation plans do call for psychiatric hospitalization, emergency planners should follow a process such as the inpatient referral system established by the Texas Department of State Health Services. Evacuees with psychiatric disabilities who were referred for inpatient psychiatric hospitalization were evaluated by the Office of the Medical Director for Behavioral Health of the Department of State Health Services on a 24-hour a day basis. The office also

monitored utilization daily and kept an active census board that tracked admissions of hurricane evacuees. Every involuntary admission was screened in person by the local mental health authority prior to commitment. As a result of this rigorous program, fewer than seventy people were admitted out of more than 600 who were presented for admission.<sup>54</sup>

### **C. People with Psychiatric Disabilities Were Not Included in Disaster Planning or Relief and Recovery Efforts**

***Recommendation:*** People with psychiatric disabilities must be involved at every stage of disaster and evacuation planning and with the administration of relief and recovery efforts.

Evacuations of people with psychiatric disabilities often failed because emergency planners did not include people with psychiatric disabilities in the planning process. Inclusion of consumers of mental health services in disaster planning and in providing peer services during disasters makes sense and saves lives. Despite the creation of an Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) few people with disabilities – and even fewer with psychiatric disabilities– sit on planning committees at the federal, state or local levels. Although the Federal Government has provided some funds to organizations for people with physical and sensory disabilities – to prepare model emergency preparedness community education programs<sup>55</sup> – the government has not included people with psychiatric disabilities to the same degree in planning for future emergencies or in relief and recovery efforts.

However, some cities and counties fared well in their efforts to evacuate people with disabilities. In Houston, for example, a local coalition included people from local, state, and federal government entities, non-governmental organizations, and faith-based initiatives. The coalition had a corps of trained volunteers ready to respond to disasters. The coalition reached out to the disability community, received input from disability-related agencies and planned to provide a wide range of services needed for people with disabilities, including people with psychiatric disabilities. “Developing and working a [disaster] plan requires complete communication, coordination, cooperation, and even friendships between emergency managers and professionals in all levels of government.”<sup>56</sup> Another trait of the Houston plan was its flexibility to accommodate changing needs; Houston successfully modified its initial plan for 2,000 evacuees to include more than 23,750.<sup>57</sup> While there is no direct evidence that the Harris County/Houston

coalition specifically included people with psychiatric disabilities, the coalition's inclusion of people with disabilities is a step in the right direction. Other communities would do well to emulate the efforts of the Houston coalition to incorporate people with disabilities at the highest levels of emergency response planning.

People with psychiatric disabilities were not included in most relief and recovery efforts. For example, people with psychiatric disabilities could work as peer advocates in the aftermath of a disaster such as Hurricanes Katrina and Rita. While there have been many calls for greater screening, diagnostic and professional treatment capacity after natural disasters, peer support also can play a crucial role. Peer advocates are generally local people, who are more familiar with the culture of individuals with psychiatric disabilities than are professionals who have volunteered from other states. Dr. Daniel Fisher, a member of the New Freedom Mental Health Commission and a psychiatrist, worked with Meaningful Minds, a Louisiana-based group of mental health consumers, to assist in peer advocacy efforts. A consumer-led recovery effort also began in Texas when mental health consumers from the Mental Health Association in Southeastern Pennsylvania held peer support trainings for consumers of mental health services, using a curriculum developed in collaboration with the University of Pennsylvania to promote recovery after community disasters.<sup>58</sup> Participants of these kinds of consumer efforts report extremely positive results, despite under-funding. The federal Substance Abuse and Mental Health Services Administration (SAMHSA) provided some funding for peer advocacy training initiatives. Government agencies should investigate the possible expansion of programs to train and deploy peer advocates after disasters.

People with psychiatric disabilities need to be involved in evacuation planning, including the development of protocols for police assistance in evacuating people with psychiatric disabilities. Uniformed police officers often were not trained to work with people with psychiatric disabilities, and as a result, many evacuees with psychiatric disabilities had negative evacuation experiences with the police. Additionally, many people with psychiatric disabilities previously had negative experiences where uniformed officers arrived at their doorsteps to forcibly remove them from their homes to institutions. The experience of police officers arriving at their homes during Katrina and Rita carried a particular resonance for people involved with the mental health system. Evacuees with disabilities had a difficult time conveying the trauma caused by the

unexpected arrival of uniformed officers who ordered them out of their homes and sometimes forcibly removed them. Even after people were evacuated, people with psychiatric disabilities continued to misunderstand the meaning of police uniforms. Because of the negative connotations associated with police uniforms, a number of people with psychiatric disabilities in Austin shelters avoided the police department victim services staff assigned to provide counseling and assistance to people with disabilities.<sup>59</sup> Police assigned to these duties should be trained to work with people with psychiatric disabilities, such as the training provided by the Crisis Intervention Team (CIT) program pioneered in Memphis, Tennessee to teach police officers how to interact with people with psychiatric disabilities.<sup>60</sup>

#### **D. Disaster Management Efforts Often Failed Because No Individual or Office Had Responsibility, Accountability, and Authority for Disability Related Issues**

***Recommendation:*** A single person or office must be responsible, accountable and able to make decisions related to disability issues.

As in previous disasters, there was a lack of coordination and communication, not only between levels of government, or between different agencies at the same level of government, but between people at different levels in the same agency. Hurricane evacuees and first responders reported that they received contradictory and conflicting messages from upper management in FEMA and the American Red Cross regarding disability issues. Many local, state and federal government officials did not have a clear organizational hierarchy that included a designated official for disability issues. One disability advocate recalled, “When I asked [who had ownership of disability issues] in the state I was assessing, no one raised their hand. I asked five different logistical places, and no one claimed ownership of disability-related issues for the state... anything coordinated out to the state levels was fragmented, not standardized, not coordinated across the board.”<sup>61</sup>

With the 2006 hurricane season now underway, it is unclear whether state and local governments have designated an emergency management official with stewardship over disability issues. For example, although the city of New Orleans now provides an Emergency Guide for Citizens with Disabilities, the plan only provides information on personal disaster preparation but does not include information on how the city will provide for the emergency needs of people with disabilities.<sup>62</sup> The guide instructs people with disabilities to contact the mayor’s office with any

questions. However, the “mayor’s office” is the official contact point for all emergency-related questions and it is unlikely that the office has the resources to successfully respond to disability issues during an emergency. The New Orleans web site contains no further information for the special needs of the disability population, including people with psychiatric disabilities.<sup>63</sup> Public entities should designate a single official for disability-related emergency issues, and provide contact information to the public for that individual on government websites and at government facilities.

#### **E. Disaster Plans Were Shortsighted and Relief and Recovery Services Were Terminated Prematurely**

***Recommendation:*** Relief and recovery efforts should continue for at least two years from the date of the disaster, including Medicaid and HUD housing waivers and FEMA housing for people with disabilities.

Accumulated experience from other highly traumatic events – such as September 11 and the Oklahoma City bombing – indicates that suffering and symptoms related to traumatic events often emerge years later.<sup>64</sup> Patrick Libbey, executive director of the National Association of County and City Health Officials observed, “We may need to rethink what we mean by the terms ‘temporary’ and ‘interim.’” Just as policymakers should make long-term plans for disaster survivors’ physical needs, such as housing and employment, so should policymakers plan for long-term psychiatric needs. This is particularly true for people with psychiatric disabilities, for whom mental health services were stretched thin in the Gulf States prior to Katrina and have not yet been restored in many areas of New Orleans. The collapse of mental health services in New Orleans has impacted the entire state as other hospitals in Louisiana have tried to absorb some of the overflow. At least half of the psychiatric patients that Louisiana hospitals treat are uninsured. Alabama and Mississippi state mental health systems are still serving Katrina evacuees, and while they have been coping with the influx, serving yet another wave of evacuees will put strained systems at risk of collapse.

Social service systems were not prepared to manage mental health care demands of evacuees. “No one ever planned for ‘what happens when your social service infrastructure is completely wiped out.’”<sup>65</sup> The Federal Government and other states sent volunteer mental health clinicians to hurricane-affected areas where they served for two to three week stints. Additionally, it was

not uncommon for those volunteers to develop psychiatric disabilities of their own, such as depression or post-traumatic stress disorder.<sup>66</sup> Although residents are deeply grateful for any assistance, the lack of continuity in the provision of mental health services impairs long-term recovery.

Government disaster relief timetables were shortsighted and these timetables compounded the difficulty of long-term recovery for people with disabilities. For example, FEMA began to evict people from temporary housing in March of 2006 but many hurricane survivors cannot return to their homes because mental health services have not yet been restored. Another example of shortsightedness is that Alabama's Katrina-related Medicaid waiver is set to expire in June 2006, during the next hurricane season. FEMA's "long-term" crisis counseling programs expire after nine months, but mental health experts predict major eruptions of post-traumatic stress disorder on the one-year anniversary of the disaster.

#### **IV. RECOMMENDATIONS FOR SPECIFIC BRANCHES OF GOVERNMENT AND FOR THE AMERICAN RED CROSS**

This section provides individualized recommendations for different entities. These recommendations are derived from the findings and broad recommendations articulated in the previous section.

##### **A. The United States Congress**

Congress can help ensure that federal services are delivered in a non-discriminatory fashion to people with psychiatric disabilities. Some of the changes that Congress should make include:

##### **1. Medicaid Amendments**

Amend the Medicaid program to require all states to provide specified Medicaid services to Katrina survivors with disabilities, with a presumption of income eligibility, through the start of fiscal year 2008. Covered services should include psychotherapy, rehabilitative services and other effective treatments, administered by psychiatrists, psychologists, and social workers, for conditions exacerbated by or resulting from the hurricane.



## **2. FEMA Amendments**

Congress should amend the Robert T. Stafford Disaster Relief and Emergency Assistance Act of 1974 to permit crisis counseling and other FEMA services to people with pre-existing psychiatric disabilities, until state service systems have been restored. Congress should also clarify that crisis counseling can be provided through trained peer services, similar to the peer services provided after the Oklahoma City bombing.

## **3. New Legislation**

Congress should pass uniform “Good Samaritan” legislation applicable for a limited and specified period of time in areas where the President has declared a state of emergency. Some doctors, especially those from out of state, were hesitant to volunteer or provide treatment in shelters because of fears of liability associated with treating strangers without having access to medical records. Although many states have “Good Samaritan” laws, which permit doctors to provide treatment to unknown individuals in certain medical emergencies (e.g. roadside emergency treatment of a car wreck victim, or treating a person who has a heart attack on an airplane), it is not clear that those statutes apply to the treatment of large numbers of people who are conscious and capable of informed consent. In addition, Good Samaritan laws vary widely from state to state and it is impractical in the immediate aftermath of a disaster to predict which state law will apply and to what extent.<sup>67</sup> Congress should act to clarify the scope of existing Good Samaritan laws during mass disasters.

## **4. Federal funding and reimbursement for disaster related assistance contingent on compliance with the ADA and Section 504**

Congress should instruct the Department of Homeland Security to withhold federal reimbursement to agencies and the American Red Cross if evacuation plans and shelter are not accessible for people with disabilities, including psychiatric disabilities. Congress should make clear that evacuation plans and shelters must meet the needs of all citizens, and that plans or shelters that do not provide for the needs of people with visual, auditory, mobility, cognitive and psychiatric disabilities, or are inaccessible to them, will not be funded.

## **5. Research, Report and Data Collections**

Congress should ensure that research projects, reports, and data collection activities related to emergency preparedness and implementation of relief plans include information about people with psychiatric disabilities, especially clients of state mental health systems. Five months before Hurricane Katrina, the National Council on Disability issued a prescient report *Saving Lives: Including People with Disabilities in Emergency Planning*. In that paper, NCD pointed to the “scarce research on experiences of people with disabilities and activity limitations in disaster activities that include planning, mitigation, preparedness, response and recovery.” The Executive Branch, Congress and several independent groups have issued reports about Hurricane Katrina, but there are very few references to people who had psychiatric disabilities before the hurricane.<sup>68</sup>

### **B. The Executive Branch of the United States**

#### **1. The Department of Homeland Security – FEMA**

FEMA regulations and policies should ensure that:

- applications for housing and assistance can be completed by people with disabilities, as required by federal law.
- applications and intake procedures for housing and assistance include questions that help identify the needs of people with disabilities.
- people from group homes or supported housing are eligible for FEMA services.
- people with psychiatric disabilities are not excluded from FEMA housing or trailers without an appropriate evaluation by a licensed mental health professional.
- a system exists for people to seek accommodations or waivers of FEMA regulation on the basis of disability; the system should be communicated to recipients of FEMA assistance.
- partnerships are established with protection and advocacy agencies and other disability advocacy groups.
- the National Disaster Medical System is more attuned to issues related to the large percentage of evacuees with disabilities, including psychiatric disabilities.

- trained, certified peer advocates are included among the groups of people permitted to provide crisis counseling under the Crisis Counseling Assistance and Training Program.

## **2. The Department of Homeland Security - Office of Civil Rights and Civil Liberties**

The Office of Civil Rights and Civil Liberties of the Department of Homeland Security should work closely with the Department of Justice to ensure that state disaster relief plans meet the requirements of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, and should provide technical assistance to states, their disaster relief agencies, and non-profit organizations to ensure that disaster relief efforts are successful.

## **3. The Department of Health and Human Services – The Centers for Disease Control and Prevention (CDC)**

The CDC should include people with psychiatric disabilities in discussions about whether to include psychotropic medications in the national medical stockpile, and in discussions about agreements with pharmaceutical companies to develop a rapid purchase and distribution plan in federal emergencies.

## **4. The Department of Health and Human Services – Substance Abuse and Mental Health Services Administration (SAMHSA)**

- SAMHSA should sponsor research and data collection to bolster empirical knowledge about the effects of disasters on clients of state mental health systems.
- SAMHSA should ensure that disaster reports include information and statistics about clients of state mental health systems.
- SAMHSA should finish developing its mental health toolkit for first responders, and rapidly disseminate the toolkit.
- SAMHSA should familiarize clinicians with concepts of recovery and trauma and how these concepts apply in different cultures.
- SAMHSA should encourage states to include representatives of peer groups in disaster planning, relief and recovery efforts.

- SAMHSA should work closely with local mental health agencies and local consumer organizations in disaster planning.

### **C. The Legislative Branch of State Governments**

- State Legislatures should examine creative means to encourage health professionals to provide voluntary treatment during emergencies; this could include plans to decrease potential legal liability during disasters, such as Good Samaritan laws.
- Ensure that existing Good Samaritan laws indemnify volunteer medical providers during a period of natural disaster or terrorist attack.
- Ensure that there is one “point of contact” person or office responsible for disaster relief planning and disbursement of funds who is responsible and accountable for disability issues, and one information number that is accessible to people with disabilities.
- Ensure that the state has a Crisis Counseling Assistance and Training Program grant filled out to the extent possible, that it applies for federal crisis counseling funds in a timely fashion, and that trained, certified peer advocates are included among those who can provide crisis counseling under the program.

### **D. The Executive Branch of State Governments**

- The State Attorney General’s Office should issue an opinion on the applicability of the state’s Good Samaritan law to volunteer medical services in an emergency.
- The Executive Branch should assign an individual or an office with the primary responsibility for disability issues in emergency planning and relief.
- The Executive Branch should ensure that people with psychiatric disabilities are included in mock disaster drills and trainings.
- The Executive Branch should establish pick-up points for evacuees to be taken to shelters; the location of those pick-up points should be communicated to the public in advance.
- The Executive Branch should establish and publicize a voluntary state-wide registry for people with special needs. The self-registry could include: contact information, name of an emergency contact for the individual and information on medical needs.

- The Executive Branch should develop and implement programs to ensure that first responders can meet the needs of people with psychiatric disabilities. For example, the Executive Branch could investigate the possibility of providing wristbands with medication names and dosages for people with psychiatric disabilities who cannot administer their own medications; first responders could use the information to provide medical support. Another possible resource to train first responders is the toolkit currently being created by SAMHSA.

#### **E. The American Red Cross**

The American Red Cross should train employees and volunteers to work with people with psychiatric disabilities and emotional disabilities. The training should include proper shelter intake procedures to help identify evacuees' needs.

### **V. CONCLUSION**

As NCD predicted in its April 2005 report, *Saving Lives: Including People with Disabilities in Disaster Planning*, “[i]f planning does not embrace the value that everyone should survive, they will not.”<sup>69</sup> As a result of its research, NCD found that much pre-Katrina disaster planning did not contemplate the needs of people with psychiatric disabilities, and as a result, many people died or unnecessarily suffered severely traumatic experiences. However, NCD was pleased to discover some examples of successful evacuation and relief for people with disabilities, such as Houston’s local coalition that included people with disabilities in emergency planning. Hurricane survivors with psychiatric disabilities expressed their sincere gratitude to compassionate Americans who labored diligently to help them in their hour of need. Policymakers and emergency planners should learn from the failures and successes articulated in this report. Because the Federal Government has yet to fully examine the needs of people with psychiatric disabilities during natural or man-made disasters, much of the information and recommendations of this report are new and broad in scope. However, the themes are familiar. Many of these findings and recommendations align with NCD’s 2005 *Saving Lives* report, available on the web at [http://www.ncd.gov/newsroom/publications/2005/saving\\_lives.htm](http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm). NCD encourages policymakers, emergency planners and people with disabilities to carefully review that report.

NCD stands ready to provide guidance to those who are ready to make their emergency plans and services more accessible to people with disabilities.

In conclusion, NCD wishes to highlight two key recommendations from this report and from the 2005 *Saving Lives* report. First, people with disabilities, including psychiatric disabilities, must be included in emergency planning and in relief efforts. Emergency management planners should not merely plan *about* people with disabilities; rather they must plan *with* people with disabilities. Second, emergency management planners at the local, state and federal levels must remember that federal laws and policies require that emergency services be administered in a nondiscriminatory fashion. The ADA and Section 504 require evacuation services and emergency shelters to be accessible to people with disabilities. Congress and the President should ensure that federal funds are used only for nondiscriminatory emergency services and relief and recovery efforts. As we plan to ensure that all people, regardless of disability, survive catastrophes such as Hurricanes Katrina and Rita, we will incorporate the principles of inclusion and nondiscrimination into our national consciousness.

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*The National Council on Disability (NCD) wishes to express its appreciation to Susan Stefan and Ann Marshall for drafting this report.*

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<sup>1</sup> Susan Saulny, *A Legacy of the Storm: Depression and Suicide*, The New York Times (June 21, 2006) <http://www.nytimes.com/2006/06/21/us/21depress.html>.

<sup>2</sup> Based on interviews with mental health consumers and advocates.

<sup>3</sup> Angela Browne, *Mentally Disabled Hurricane Victims Find a Refuge in East Texas*, Associated Press, Oct. 6, 2005, [www.semissouian.com/story/1121017.html](http://www.semissouian.com/story/1121017.html). Church camps and retreat centers were not eligible for FEMA reimbursement and were told to “work through local governments for reimbursement.” See *FEMA reports paying \$669 Million to Katrina victims*, USA Today (September 11, 2005) [http://www.usatoday.com/news/nation/2005-09-11-femaaid\\_x.htm](http://www.usatoday.com/news/nation/2005-09-11-femaaid_x.htm).

<sup>4</sup> Interview with Cindy Hopkins, Texas Department of State Health Services.

<sup>5</sup> *Id.*

<sup>6</sup> Ben Lemoine, *Emotional Needs of Katrina Victims Not Being Met*, WWLTV, May 19, 2006. <http://www.wwltv.com/medical/stories/WWL051906tpemotional.4d59f5.html>.

<sup>7</sup> See Saulny, note 1.

<sup>8</sup> Interview with Ann Marshall, a 30-year advocate for people with disabilities in Alabama and the nation.

<sup>9</sup> See Lemoine, note 6.

<sup>10</sup> *Id.*

<sup>11</sup> See Saulny, note 7.

<sup>12</sup> Brian DeBose, *Katrina Trauma Besets the Big Easy*, The Washington Times (May 1, 2006). <http://www.washtimes.com/national/20060501-123001-9306r.htm>.

<sup>13</sup> Governor’s Health Care Reform Panel Meeting, Report on the State of the Mental Health Delivery System in Louisiana (June 30, 2005) Louisiana Department of Health and Hospitals.

<sup>14</sup> *Id.*

<sup>15</sup> See *National Council on Disability on Hurricane Affected Areas*, NCD (September 2, 2005). <http://www.ncd.gov/newsroom/publications/2005/katrina2.htm>.

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- <sup>16</sup> Daniel W. Sutherland, Office of Civil Rights and Civil Liberties, Department of Homeland Security, and Chairman, Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, Remarks at National Hurricane Conference (April 14, 2006). [http://www.disabilitypreparedness.gov/ds04\\_14\\_06.htm](http://www.disabilitypreparedness.gov/ds04_14_06.htm).
- <sup>17</sup> See *EPI Press Conference regarding report on SNAKE teams' assessment of Katrina response and Rescue efforts*, National Organization on Disability (October 5, 2005).
- <sup>18</sup> GAO, Disaster Preparedness: Preliminary Observations on the Evacuation of Hospitals and Nursing Homes Due to Hurricanes, GAO-06-443R (Feb. 16, 2006). A notable exception was the letter from the Campaign for Mental Health Reform to members of Congress, sent September 14, 2005, which focused on both trauma reactions of displaced persons and "the hundreds of thousands of Gulf Coast Americans with serious mental illnesses pre-dating the hurricane."
- <sup>19</sup> Interview with Jim Downing, Employment and Training Administration.
- <sup>20</sup> Marcie Roth, Testimony in Congressional Briefing *Emergency Management and People with Disabilities: Before, During and After* (November 10, 2005). [http://www.ncd.gov/newsroom/publications/2005/transcript\\_emergencymgt.htm](http://www.ncd.gov/newsroom/publications/2005/transcript_emergencymgt.htm).
- <sup>21</sup> Marshall interview, note 8.
- <sup>22</sup> Based on interviews with Nell Hahn of Louisiana Protection and Advocacy; Beth Mitchell of Advocacy Inc., in Texas; and Ann Marshall, note 8.
- <sup>23</sup> Downing interview, note 19.
- <sup>24</sup> See *EPI Press Conference regarding report on SNAKE teams' assessment of Katrina response and Rescue efforts*, National Organization on Disability (October 5, 2005). [http://www.nod.org/Resources/PDFs/katrina\\_snake\\_briefing.doc](http://www.nod.org/Resources/PDFs/katrina_snake_briefing.doc).
- <sup>25</sup> Hopkins interview, note 4.
- <sup>26</sup> See *Individuals with Disabilities in Emergency Preparedness: Executive Order 13347*, Department of Homeland Security (July 2005) [http://www.dhs.gov/interweb/assetlibrary/CRCL\\_IWDEP\\_AnnualReport\\_2005.pdf](http://www.dhs.gov/interweb/assetlibrary/CRCL_IWDEP_AnnualReport_2005.pdf).
- <sup>27</sup> Interview with "Jenny", consumer and hurricane survivor who lived in a FEMA trailer. Her name has been changed to protect her privacy.
- <sup>28</sup> George W. Bush, *State of the Union* (February 27, 2001). <http://www.whitehouse.gov/news/releases/2001/02/20010228.html>.
- <sup>29</sup> Based on interviews with Katrina-affected psychiatric survivors.
- <sup>30</sup> Marshall interview, note 8.
- <sup>31</sup> See LeMoine, note 6; see also Saulny, note 7.
- <sup>32</sup> Daniel W. Sutherland, Remarks at National Hurricane Conference, Department of Homeland Security (April 14, 2006) [http://www.disabilitypreparedness.gov/ds04\\_14\\_06.htm](http://www.disabilitypreparedness.gov/ds04_14_06.htm).
- <sup>33</sup> Bruce Taylor Seeman, *Hurricane Victims with Mental Problems Parted from Health Care*, Newhouse News Service (September 16, 2005) [www.newhousenews.com/archive/seeman091605.html](http://www.newhousenews.com/archive/seeman091605.html).
- <sup>34</sup> Interview with Talatha Denison, Mental Health Advocate, Mississippi Protection and Advocacy.
- <sup>35</sup> Interviews with Anne Evans, Executive Assistant to the Commissioner of the Alabama Department of Mental Health and Mental Retardation; and Jim Downing, note 19.
- <sup>36</sup> Downing interview, note 19.
- <sup>37</sup> Denison interview, note 34.
- <sup>38</sup> Hahn interview.
- <sup>39</sup> Governor's Health Care Reform Panel Meeting, Report on the State of the Mental Health Delivery System in Louisiana (June 30, 2005) Louisiana Department of Health and Hospitals.
- <sup>40</sup> Evans interview, note 35.
- <sup>41</sup> Hopkins interview, note 4.
- <sup>42</sup> Denison interview, note 34.
- <sup>43</sup> Interview with "Sue," an evacuee with psychiatric disabilities who came from New Orleans' Ninth Ward. To protect her privacy, Sue's name has been changed.
- <sup>44</sup> *Id.*
- <sup>45</sup> This is a sensitive issue for people with psychiatric disabilities, who have not been invited to participate in the discussion whether to include psychotropic medications in the national stockpile. Mental health consumers agree that it was disastrous for people who were already taking these medications to not have access to them during the emergency. Emergency planners should plan for people who are on these medications to continue to have access to them during and after an emergency. However, mental health consumers also recognize that many of these

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medications require careful monitoring (e.g., blood levels for lithium and clozapine) or have known side effects that might be of concern in the aftermath of a disaster (potentially increased suicide rates for some SSRIs). In addition, in the confusion, chaos, and inevitable shortages of resources and expertise, many people with psychiatric disabilities, including those who rely on psychotropic medications themselves, worry that these drugs would be misused to maintain calm and order, muffle grief, and numb suffering; in other words, to assist *responders* rather than *evacuees*.

<sup>46</sup> Anand Pandya, "Medicolegal and Ethical Issues in Disaster Psychiatry," American Psychiatric Association, Committee on Psychiatric Dimensions of Disaster, Disaster Psychiatry Handbook (last updated Nov. 2004).

<sup>47</sup> Denison interview, note 34.

<sup>48</sup> "Jenny" interview, note 27; Marshall interview, note 8.

<sup>49</sup> Denison interview, note 34.

<sup>50</sup> Mitchell interview, note 22.

<sup>51</sup> *Id.*

<sup>52</sup> 28 C.F.R. 35.130(d)

<sup>53</sup> Interview with Eileen Elias, Deputy Director, Office on Disability, Department of Health and Human Services.

<sup>54</sup> Hopkins interview, note 4.

<sup>55</sup> Secretary Michael Chertoff, Remarks at the National Council on Disability Seminar on the Americans with Disabilities Act, Washington DC (July 26, 2005) [www.dhs.gov/dhspublic/interapp/speech/speech\\_0257.xml](http://www.dhs.gov/dhspublic/interapp/speech/speech_0257.xml).

<sup>56</sup> Robert A. Eckels, Testimony to the Senate Homeland Security and Governmental Affairs Committee hearing on "Recovering from Hurricane Katrina: Responding to the Needs of the Displaced, Today and Tomorrow" (September 28, 2005) <http://hsqac.senate.gov/index.cfm?Fuseaction=Hearings.Details&HearingID=273>.

<sup>57</sup> *Id.*

<sup>58</sup> The manual is available at [www.mhselfhelp.org/resources](http://www.mhselfhelp.org/resources).

<sup>59</sup> Mitchell interview, note 22.

<sup>60</sup> See *Crisis Intervention Team (CIT)*, Memphis Police Department, <http://www.memphispolice.org/communit.htm>.

<sup>61</sup> See *EPI Press Conference regarding report on SNAKE teams' assessment of Katrina response and Rescue efforts*, National Organization on Disability (October 5, 2005)

[http://www.nod.org/Resources/PDFs/katrina\\_snake\\_briefing.doc](http://www.nod.org/Resources/PDFs/katrina_snake_briefing.doc).

<sup>62</sup> New Orleans Office of Emergency Preparedness Website,

[http://www.cityofno.com/Portals/Portal46/portal.aspx?portal\\_46&tabid=4](http://www.cityofno.com/Portals/Portal46/portal.aspx?portal_46&tabid=4).

<sup>63</sup> A search of the New Orleans Office of Emergency Preparedness web site using the search term "mental illness" returns the following results: "Web Pages: Health Department—Homeless Healthcare; Announcements: No Results Found; Events: No Results Found; Links: No Results Found; Documents: No Results Found; Services: No Results Found; News Stories: No Results Found." Press releases are limited to announcements relating to missing persons. New Orleans Office of Emergency Preparedness 2006, <http://www.cityofno.com>.

<sup>64</sup> Dr. Daniel Fisher, Director, National Empowerment Center

<sup>65</sup> Downing interview, note 19.

<sup>66</sup> *Id.*

<sup>67</sup> According to constitutional law scholar Erwin Chemerinsky, Congress could utilize the commerce clause to pass interstate Samaritan laws (personal communication).

<sup>68</sup> The best information came from a private report by the National Organization on Disability, called *Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project* (2006)

[http://www.nod.org/Resources/PDFs/katrina\\_snake\\_report.pdf](http://www.nod.org/Resources/PDFs/katrina_snake_report.pdf).

<sup>69</sup> See *Saving Lives: Including People with Disabilities in Emergency Planning*, NCD (April 15, 2005)

[http://www.ncd.gov/newsroom/publications/2005/saving\\_lives.htm](http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm).