

# Impact

Feature Issue on Disaster Preparedness and  
People with Disabilities

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Willy Martin stands in the home he owns as it's being reconstructed following Hurricane Katrina. With him is his Personal Care Attendant, Lyndelle Casby (middle), of Volunteers of America of Greater New Orleans, with whom Willy lived for a year after the storm, and Angela King, from VOA's national office. See story on pages 6-7.

## ***Katrina: A Story of Survival and Papa Joe's New Community***

by Jeff Ridgeway

The night that people along the Gulf Coast entered the shelters, evacuating cities in the path of Katrina, no one could possibly have known the carnage and devastation this storm would bring to their lives. To say that Katrina was a monster of a storm would be sugar-coating it. When daylight came and the storm was over it was time to begin the process of finding who was dead and who was alive, and what was still standing, if anything.

A few days after the storm, when the full effect of what was lost was truly being realized, I got a call asking if I could possibly get up to Tuscaloosa, Alabama the next day (I live in Mobile) where some of the evacuees were. Upon arriving in Tuscaloosa I was met by the advisor of People First of Alabama, Vicki Turnage, who began to fill me in on what People First had already started to do. People First members, with support from the Arc and Ability Alliance, had already obtained funds for the folks to visit a local mall to shop and have lunch. But there were many other immediate needs for our new friends.

One of the first things we did was to meet at a church that had opened their doors to the group. Almost every agency involved in the relief effort, the minister from the church, and representatives from agencies providing supports for individuals with disabilities came to the meeting. We asked evacuated self-advocates, staff, and their

*[Ridgeway, continued on page 34]*

### ***From the Editors***

*When disasters occur people with disabilities are often among those most in harm's way. In many cases this is because the planning and processes in place to respond to disasters and emergencies haven't made adequate provision for people with disabilities. In this Impact issue we seek to address that need for greater inclusion of people with disabilities in disaster preparedness, response, and recovery efforts by providing strategies, stories, and resources that we hope will be of use to disability service providers, advocates, individuals with disabilities, families, and policy-makers. Through personal stories, reflections on lessons learned from previous disasters, reviews of what works and doesn't work in policies and procedures, and a variety of preparedness checklists we hope to give readers information they can use to evaluate and improve disaster preparedness where they live, work, and participate in their communities. Whether it's doing personal emergency planning, organizing neighbors into a circle of support for one another in case of an emergency, ensuring that local and state disaster planning agencies include input from people with disabilities, or evaluating the disaster preparedness of the agency or organization in which we work, we can each take steps to make sure that when the next disaster or emergency occurs, no one is left behind.*

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## Including People with Disabilities in Emergency Planning: How Are We Doing?

by Hilary Styron

Hurricanes Katrina and Rita left more than 1,300 dead in their wake, caused more than \$80 billion in damage over 90,000 square miles, and forced mass evacuations from five states along the Gulf Coast. An estimated 600,000 households were displaced from affected areas and 50,000-100,000 remained in temporary housing six months later. As a result, 44 states and the District of Columbia received millions of evacuees, providing them with care and shelter

*Although strides are being made toward fully integrating people with disabilities in community life, substantial improvement is necessary to integrate people with disabilities in emergency planning.*

over an extended period. These events tested the nation's ability to respond to catastrophic events and demonstrated the importance of ensuring the effectiveness of federal, state, and local plans and the ability to quickly synchronize inter-governmental efforts.

### Launching a Nationwide Review

Following Hurricane Katrina, the National Organization on Disability (N.O.D.) Emergency Preparedness Initiative (EPI) deployed four Special Needs Assessment 4 Katrina Evacuees (SNAKE) teams into the Gulf region to evaluate conditions for people with disabilities in mass care settings. Our teams witnessed first-hand the human crisis unfolding for

all persons impacted by the storm, and reported real-time information specifically related to people with disabilities to Department of Homeland Security (DHS) and Federal Emergency Management Agency (FEMA) officials.<sup>1</sup> The SNAKE teams returned to Washington, D.C. on September 14, 2005, and the following day President Bush asked the DHS to conduct a review, in cooperation with local counterparts, of emergency plans in every major city in America. In response to President Bush's call for a nationwide plan review, Secretary Michael Chertoff further ordered that reviews include a rigorous examination of how communities plan to prepare, inform, evacuate and care for people with disabilities. As part of that effort, the DHS Office of Civil Rights and Civil Liberties (CRCL) led a team of subject-matter experts who used a detailed assessment tool specifically designed for the purpose of assessing the level to which states and urban areas are taking actions to address requirements associated with integrating people with disabilities into the emergency planning process.

In addition to these efforts, on September 29, 2005, Congress, in the Conference Report on H.R. 2360, DHS Appropriations Act of 2006, indicated the importance of having plans in place to deal with catastrophic events and the need to include people with disabilities in emergency management planning. Congress emphasized that it is imperative that states and urban areas ensure sufficient resources are devoted to developing plans for the complete evacuation of all residents, including people in hospitals and nursing homes, and residents without access to transportation, in advance of and after such an event.

### Nationwide Plan Review Findings

In June 2006, DHS and the U.S. Department of Transportation released the *Nationwide Plan Review Phase 2 Report* detailing the results of the review of urban and state emergency preparedness nationwide, including findings on emergency planning in relation to people with disabilities. The DHS review revealed major fragmentation, inconsistencies, and critical gaps throughout the plans. Few plans demonstrated in-depth planning and proactive thinking in preparing to meet the needs of people with disabilities before, during, and after emergencies. Most plans delegated critical responsibilities to third parties or other governmental entities without adequate coordination, oversight, or assurance of resources, and contained no indication that a delegated function would be executed in a timely and effective manner. More specifically, most plans failed to do the following:

- Address evacuation for persons with disabilities;
- Meet the need to keep together people with disabilities, family members, caregivers, and durable medical equipment;
- Establish tracking procedures that will assure reunification;
- Acknowledge that traditional emergency notification and communication methods are not accessible for people with certain disabilities;
- Ensure that the local or regional Red Cross is equipped with adequate disability-related knowledge, experience, training, and resources to serve people with disabilities who seek sheltering at mass care facilities;
- Require that communication in mass care shelters be accessible to people who are deaf, deaf-blind or hard of hearing, those who are blind or who

have low vision, and individuals with cognitive disabilities;

- Ensure that shelter personnel will not separate individuals with disabilities from their service animals (a practice generally prohibited under the Americans with Disabilities Act) or clarify that service animals are not pets;
- Include a way to re-integrate people with disabilities from these shelter facilities back into a more integrated setting at the earliest appropriate opportunity; and
- Illustrate better planning for the smaller percentage of persons who are medically fragile.

The review revealed that across state and urban emergency plans, “disability” was inconsistently defined and often treated as a sub-group of the umbrella of “special needs,” “at-risk,” or “vulnerable populations.” The term “special needs” often referred to an extremely broad segment of the population, including people with disabilities, minority groups, people who do not speak English, children, and the elderly. In practice, the term also included people who live in poverty or on public assistance; people without private transportation or who rely on public transportation; people who rely on caregivers for assistance in daily living and would need similar assistance in an emergency; and people who live independently or with caregiver(s) in homes, assisted living housing, nursing homes, supervised group homes, hospitals, and other health care facilities. These groups obviously represent a large and complex variety of concerns and challenges in relation to emergency planning and response. In addition, few plans incorporated state or urban area disability demographics documenting the prevalence of persons with disabilities in their communities. And few plans recognized that the state and local governments have legal obligations to those residents under the Americans with Disabilities Act and other authorities.

In response to these shortfalls in emergency plans nationwide, the report presented recommendations, including

the following (U.S. Department of Homeland Security & U.S. Department of Transportation, 2006):

- States should designate a specific state agency that is responsible for providing oversight and ensuring accountability for including people with disabilities in the shelter operations process.
- The federal government should develop a consistent definition of the term “special needs.”
- The federal government should provide guidance to state and local governments on incorporation of disability-related demographic analysis into emergency planning.
- Federal, state, and local governments should increase the participation of people with disabilities and disability subject-matter experts in the development and execution of plans, training, and exercises.
- Federal, state, and local governments should work with the private sector to identify and coordinate effective means of transporting individuals with disabilities before, during, and after an emergency.
- The federal government should provide technical assistance to clarify the extent to which emergency communications, including public information associated with emergencies, must be in accessible formats for persons with disabilities. This assistance should address all aspects of communication, including, for example, televised and other types of emergency notification and instructions, shelter announcements, and applications and forms for government and private disaster benefits.

As the findings illustrate, until emergency planners understand and address the prevalence and needs of persons with disabilities in their states and communities, as well as their commensurate federal civil rights obligations, inadequate preparation and implementation will continue to be the norm.

[Styron, continued on page 35]

## ***We Watch the City***

*We watch the City fall down*

*But we pick it up.*

*The Cost of Freedom*

*We pick it up.*

*Nothing said*

*We pick it up*

*We watch the City fall down*

*We pick it up*

*Because of Freedom*

*We walk hand in hand*

*God Save America*

*We pick it up.*

*We watch the City fall down.*

*We pick it up.*

*See the Capital standing strong.*

*Because of Freedom*

*We pick it up.*

*We are Americans.*

*We pick it up.*

*Because of Freedom*

*We pick it up.*

*Long live Freedom*

*We pick it up.*

*Long live Freedom*

*We pick it up.*

*Raise the flag*

*We pick it up*

*Across the nation*

*We pick it up.*

*We watch the City fall down*

*We pick it up*

*With the grace of God*

*We pick it up.*

- by Chester Finn, Self-Advocate from New York

Reprinted with permission from *We Watch the City: Stories in the Shadow of 9/11* video and booklet produced by the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

## Nobody Left Behind: Consumer Experiences of Emergency and Disaster

by Catherine Rooney

As part of the research project titled, Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments, conducted at the Center on Independent Living, University of Kansas, an online consumer survey was administered on the study's Web site. Anyone who had experienced a disaster or emergency situation and has a mobility impairment was eligible to fill-out the survey about his or her experiences. For the purposes of the survey, a person with a

*We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the 3rd floor by the stairwell for the firefighters to come get me.*

*But, no one came.*

mobility impairment was defined as someone who has moderate to complete difficulty in walking, or moderate to complete difficulty moving around using equipment.

Feedback from the survey included personal descriptions of the circumstances that persons with mobility impairments found themselves in during a disaster or emergency situation. These powerful statements provide insight into the shortcomings of the many current emergency management and response systems in the United States.

Overall, participants reported that evacuation plans in public areas are often not addressing the evacuation needs of persons with mobility impairments, as they are at times being left behind with-

out a plan of escape, or left at stairwells or elevators while others are escaping to safety. Other frightening and sometimes life-threatening situations occur when infrastructures fail. These include electrical power outages for extended periods of time and non-accessible transportation, shelter, and temporary lodging. The disaster recovery efforts for persons with disabilities are often not seen as a priority of others involved, thus placing persons with disabilities at risk of losing their independence, mobility, and health. The Americans with Disabilities Act (ADA) has been in existence for more than 15 years, yet disaster-related services can still be found to be inaccessible and disaster-related personnel uninformed of the needs of persons with disabilities and how to assist them.

### What Consumers Have Said

The following are consumer survey participants' statements recorded on the Nobody Left Behind research study's Web site as of May 15, 2005:

- I ambulate with forearm crutches and my leg stamina is limited. As a social service provider in NYC, I am in tall buildings often and [in] one in particular they had an evacuation drill. There were no plans or equipment to assist me. They told me to ignore the drill. I felt very vulnerable because I attend regular work meetings in this building. – New York City
- [After a hurricane] I did not use the shelters because they were not wheelchair accessible, and had no provisions for my service dog. – Miami, FL
- I have Juvenile Rheumatoid Arthritis and use a wheelchair. We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the 3rd floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled, and I used pure fear to get myself down the stairs and outside. It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency. – Los Angeles, CA
- My wheelchair ramp washed away in a flood and my house was left with three feet of mud everywhere. It was hard to use my electric wheelchair. I had money to pay for a ramp, but couldn't hire anyone, as they were busy elsewhere. – Texas
- We had a fire at work and the evacuation plan didn't work to get me out. Even so, management refused to change the plan. – Oklahoma
- At the temporary shelter I couldn't get to the bathrooms, as you had to walk up stairs. – Northridge, CA
- The disaster volunteer was not trained on accessibility issues. He said that the shelters should be accessible since the law requires it. He didn't understand the impact of me getting there [during the hurricane] only to discover that they were in violation of the law. – Alexandria, VA
- My only accessible route was on fire at my home. I had to escape via a non-accessible route. The fire destroyed our home. – Hagerstown, VA
- Disabled persons have the same freedom of choice as any other American. The paternalistic attitude was frightening beyond belief that I experienced [while trying to access disaster services and information after an earthquake]. – Glendora, CA
- We had to move out of our house for several weeks to have it repaired [after an earthquake]. All the places that people referred us to were not accessible to me in my scooter. – Los Angeles, CA

- It is really difficult to get the utility company to understand power is a need, if disabled. – Knoxville , TN
- The able-bodied community MUST get the message that it is critical to think through and develop a plan to evacuate people with disabilities. – New York , NY

The following are additional consumer survey participants' statements taken from the online survey:

- There were no evacuation plans for persons with disabilities who use wheelchairs at the City Mall during an evacuation of the mall [due to a bomb threat]. There were no personnel around to assist me. They all evacuated and left me there. The elevators were shut off during the evacuation. I had nightmares for several months. – Silver Springs , MD
- [Disaster personnel after an earthquake] did not know whether any of the options were wheelchair accessible or if they had electricity to keep my ventilators running and batteries charged if the power outage lasted beyond my ventilators' battery life.
- There were no disaster preparations for the work fire, no evacuation plan, or escape options except to walk down three flights of cement stairs, which is not an option. I was left at a stairwell because no one knew what to do. – Sacramento , CA
- Management refused to change evacuation plans [after a fire in the workplace], even though they didn't work. Buddies at work and family never confronted the shortfall. – Toledo , OH
- It was very frightening going back up into the building [after a fire caused by a bomb explosion] as I had waited on the 8th floor for 4 hours for the fireman to come and carry me down even when the fire was out, but there was still a lot of smoke. Now, I recommend that every floor have an evacuation chair. I fear being in a similar disaster and not knowing if it is simulated or real and being left in a stairwell because no one knew what else to do. – Sacramento , CA
- At my apartment building [during a blackout], I could not get upstairs until the electricity came back on or until I could get some people to carry me up. I waited in the lobby with my wife and another spinal cord injured neighbor and his girlfriend for several hours. Eventually, the superintendent and a doorman carried me and someone else carried my wheelchair. Unhelpful was a girl who worked in the building management office, who told me that I would not be carried upstairs because that would expose management to insurance liability in case anything happened. – New York, NY
- [During a power outage after a hurricane hit] I was unable to use my home oxygen machine, CPap machine, or electric bed, and I was trapped in my apartment building as the evaluators were down with no electricity, and I use a wheelchair. When I called for help, the [disaster volunteer] worker said I would have to go to the hospital or a shelter. He didn't know if the shelter was accessible or how I would get home after power was restored. ...My health declined without the use of my equipment. When my legs began swelling due to fluid problems, I called the paramedics. The issue became whether to go to the hospital and then the shelter and worry about how to get back home or stay at home. I had to sign a release [with the paramedics] to stay at home, as they wanted to document the choice in case I died from congestive heart failure. The reason I stayed was I couldn't get to my car or use the para-transit or public transit as I have to be able to get to the curb. – Alexandria , VA
- I was in a basement meeting when the earthquake hit. Everyone walked upstairs leaving me in the basement as the elevator won't function. One brave man came back downstairs and we positioned [ourselves] in as safe an area as we could until the quake emer-

gency team arrived. They eventually carried my chair and me separately upstairs. – Glendora , CA

- New directions should include planning for services by emergency preparedness personnel, as they tend to ignore that we exist right now. – Knoxville , TN

## Conclusion

More participants' statements on problems and issues encountered during disasters or emergencies, lessons learned, and recommendations on future directions for exploration to assist persons with mobility impairments to survive disasters and emergencies can be found on the Nobody Left Behind Web site at [www.nobodyleftbehind2.org](http://www.nobodyleftbehind2.org). To address these problems described by survey participants, changes need to be made, creative solutions explored and developed, and existing ADA regulations reinforced. These efforts will most assuredly make an improvement in the health, safety and well-being of all Americans and help assure that nobody is left behind in a disaster or emergency situation.

**Note:** The report from which this was taken was created by the Research and Training Center on Independent Living at the University of Kansas by a grant from the Centers for Disease Control and Prevention through the Association of Teachers of Preventive Medicine, TS#-0840.

*Adapted and reprinted with permission from "Report #1: Consumer Survey Quotes" (May 15, 2005), by Catherine Rooney, published by the Nobody Left Behind project of the Research and Training Center on Independent Living, University of Kansas, Lawrence. Retrieved June 6, 2007 from [www2.ku.edu/~rrtcpbs/findings/consumer\\_survey.shtml](http://www2.ku.edu/~rrtcpbs/findings/consumer_survey.shtml). Catherine Rooney is Project Coordinator of the Nobody Left Behind project, and may be reached at 785/864-4095, 785/864-0706 (TDD), or by e-mail at [catr@ku.edu](mailto:catr@ku.edu).*

## Experiences of Direct Support Professionals During Hurricanes Katrina and Rita

by Sheryl A. Larson and Angela King

On August 29, 2005, Hurricane Katrina struck, directly impacting every staff member of, and person supported by, Volunteers of America (VOA) of Greater New Orleans. In May 2006, the University of Minnesota interviewed Direct Support Professionals (DSPs) from two of VOA's programs – Supported Living Services (offering family and semi-independent living supports to adults and children with disabilities) and Community Living Services (offering group homes for adults and children with developmental disabilities) – to learn what happened during the hurricane,

*Many DSPs found it difficult or impossible to meet the demands of work and find time to secure new housing or benefits for themselves. But, many said, “If we don’t work the hours, who will?”*

what worked and did not work in the evacuation, why they returned to New Orleans, and suggestions for the future. Some of the findings are shared here.

### Background

Before Katrina hit, VOA New Orleans employed 180 Personal Care Attendants who supported 122 individuals living in their own homes or with family, and 100 Direct Care Staff who supported 75 individuals living in 12 group homes. On August 26, when administrators realized Hurricane Katrina was going to hit with life-threatening intensity, an evacuation was initiated and the organization began moving staff and the people they sup-

ported to safety. The evacuation, expected to last just three days, stretched for months as large parts of New Orleans and surrounding communities became uninhabitable.

The individuals receiving Supported Living Services in their own homes or in their family homes followed individual evacuation plans, leaving with family members, VOA staff, or on their own. They were scattered throughout the southern United States in Mississippi, Florida, Texas, Tennessee, Arkansas, and other parts of Louisiana. Accommodations were difficult to secure, and they stayed in cars, shelters, hotels, trailers, or with other family members. Some contacted VOA affiliates and were assisted in securing temporary living arrangements in unused transition or group homes. Some had to move again when Hurricane Rita hit.

For the residents and staff of the group homes, the evacuation included 50 DSPs and 75 individuals with disabilities, along with administrators and bus drivers, leaving in three buses and three vans. They, along with family members of staff, stayed in a Houston hotel for a week, then evacuated to the Astrodome for one day, finally ending up in dorms at the Lakeview Methodist Conference Center in Palestine, Texas for 64 days. When the flood waters receded, 69 individuals with disabilities remained at Lakeview with only 12 DSPs from New Orleans. To fill the staffing gap, VOA recruited temporary assistants from affiliates around the country.

### The Katrina Experience

Of the DSPs interviewed, 52% evacuated with one or more individuals from VOA, including 41% who left with individuals with disabilities and their own family members, and 11% who left with individuals with disabilities but not with

family members. An additional 24% evacuated alone, and 13% evacuated with family members but no people with disabilities. Some DSPs, who evacuated alone or with family, after checking in with VOA, learned they were needed and joined up with an evacuated person in another city.

DSPs packed three days of clothes and personal supplies for themselves, family members, and the people they supported. When the evacuation was extended, DSPs who provided supported living services purchased food, clothes, and supplies for the people they supported. Some DSPs kept receipts and were reimbursed, while others just absorbed the expenses. DSPs were thankful that VOA had made arrangements to directly deposit paychecks into their bank accounts throughout the evacuation.

DSPs experienced stress, trauma, anxiety, and confusion. In the beginning they didn't know where family members were, if they had evacuated or even if they had survived. They heard unsubstantiated stories of dead bodies hanging from trees, devastation of their homes, loss of their personal belongings, shootings, and lootings. DSPs were unable to connect with friends, family, and neighbors to confirm these reports due to the breakdown in the communication infrastructure. In the early stages of the disaster, cell phones would not work because of failure of the telephone service in the New Orleans area code. VOA had an 800 number set up in the Alexandria, Virginia office and fielded a large number of calls from staff, family members, and other people supported.

As some DSPs left to attend to their families, those who remained supported additional people. DSPs worked 24 hours a day, 7 days a week, with little or no time off. Some family members were hired to work as DSPs, and others worked for free so that the DSP could get a break. DSPs

had little opportunity to reflect on what was happening, talk about it, and grieve the multitude of losses they were experiencing. Their focus was on doing the work and helping their family members get through each day. DSPs worked months at a time with little personal privacy or freedom, working with strangers, and cohabitating with multiple families and the people with disabilities whom they supported. Many DSPs were only beginning their grieving and healing process at the time of the interviews.

### **The Recovery Experience**

When the DSPs returned to New Orleans, housing was in short supply. Some lived in group homes or in trailers in the yards of group homes, and some stayed with friends or families. In many instances, the DSPs, their families, and the individuals they supported lived together because they could no longer afford the rents being charged in New Orleans. They lived in crowded conditions with multiple families sharing small spaces; sleeping on the floor, in a bathroom or under a sink; sharing hard-to-secure FEMA trailers; or living apart from their families so they could continue working. Many found it difficult or impossible to meet the demands of work and find time to secure new housing or benefits for themselves. They had homes that needed gutting and repair, but did not have time to begin, let alone finish, such daunting tasks. But, many said, "If we don't work the hours, who will?"

By May 2006, 72 individuals receiving services from VOA had returned to six New Orleans area group homes supported by 50 DSPs. An additional 78 people were receiving services in their own homes, temporary shelters, or the homes of 76 Personal Care Attendants. By May 2007, more DSPs have returned to the area and to their jobs at VOA. More have gotten FEMA trailers and some have found permanent housing. Two disaster recovery assistance grants have provided resources to assist both individuals with disabilities and VOA staff to return to homes in the area.

### **Lessons and Recommendations**

One lesson learned from the New Orleans VOA experience was how difficult it is for an organization, during a large-scale disaster, to not only find shelter, food, and clothing for the individuals it supports, but also help employees meet these same basic needs. VOA affiliates around the country provided relief staff at their own expense, incurring costs well over \$200,000 in payroll and travel. Had VOA not been a large non-profit agency that could solicit donations it would never have survived these and other costs. FEMA did not recognize these expenses. VOA paid the Lakeview conference center from donations it raised; FEMA would not pay Lakeview because a county official in Palestine refused to designate their site as an official shelter. This indicates how badly the system is broken; even the Texas state Katrina office could not override this single person. Medicaid only allowed VOA to submit its regular billing for the group home clients and some slight increases in hours for its supportive living services. Clearly, there are large systemic issues that must be addressed.

Additionally, the DSPs interviewed made recommendations, based on their experience, for service providers to consider when making disaster response plans. They include:

- Create an open dialogue with DSPs. Listen to and act upon their concerns.
- Provide staff with credit cards or pre-paid cards that they can activate if evacuations last over three days.
- Have a long-term accommodation plan so that, in the event of longer evacuations, staff have a place to go to with the people they support.
- Give staff identification cards so they can "prove" they have an official role in the lives of people they support.
- Obtain out of state emergency contact names and phone numbers for all staff. In an emergency these individuals can be contacted about the whereabouts and well-being of the DSPs and the people they support.

- Have a national toll-free number, staffed 24 hours a day and housed outside the disaster area, so staff can call for assistance during evacuations.
- Provide technology for DSPs to communicate with management during a crisis, such as pre-paid cell phones.
- Develop an emergency per diem for staff and the people they support. Direct deposit this into their accounts so that staff do not have to worry about food, housing and transportation receipts in the midst of trauma.
- Provide personal, individual thank you's to each staff member during and after the disaster.
- Provide some type of "disaster pay" with additional money for each hour worked, in addition to regular pay.
- Create a national pool of relief staff.
- Ensure that critical information about people supported (e.g., medications, support plans, health needs) is available via the Internet or at a central location so it's available anywhere.
- Provide company vehicles to evacuate staff and people with disabilities rather than requiring staff to use personal vehicles.
- Work with FEMA and other federal agencies to plan for and make available staff housing during disasters.

**Note:** The study reported here was funded by the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Contract to Volunteers of America, Sponsor Award 95-P-92225/3-01.

*Sheryl A. Larson is Senior Research Associate with the Research and Training Center on Community Living, University of Minnesota. She may be reached at 612/624-6024 or larso072@umn.edu. Angela King is Director of Program Development with Volunteers of America, Alexandria, Virginia. She may be reached at 817/860-1559 or AMKing@voa.org. The full report from the VOA study, "You Know That It's Got to Be Dedication That I am Still Here," is published online at <http://rtc.umn.edu/docs/NOLAFinalReport.pdf>.*

## Personal Emergency Preparedness: Who Are Your People?

by Lynda Kahn and Jack Pearpoint

Most of us use planning processes to set directions in our lives: to help us think about our work, and where and how we'll live, learn and try new things. We also need to think about and plan for the unthinkable – for emergencies, disasters. We need to do it now, and we need to do it with *our* people.

*How about organizing “Our Neighborhood Emergency Planning Coffee & Brownie Party”? The strategy is simple. In an emergency, we can take care of each other better than any “system” on the planet, especially if we know each other.*

We all need to make “personal preparedness plans.” The practical literature agrees. Booklets, brochures, guides and resources from the Federal Emergency Management Agency (FEMA), the Red Cross, the National Organization on Disability (N.O.D.), and more give great information and summarize a few key steps. These steps are the core of each of our personal emergency preparedness plans (FEMA, 2004; N.O.D., 2005):

- Be informed
- Make a plan
- Assemble supplies and a kit
- Create a personal support network
- Practice with your network and team
- Maintain your plan and kit

There is, however, one fundamental concept underlying all preparedness

planning: *It's all about relationships.* We need people. First and foremost, we need to think about our *circles of support* and the people, connections, and relationships in our lives. Now is the time to recognize if *your* circles (and the circles of people we support and care about) need to be strengthened. If so, don't wait. Accept the challenge and nurture, build, and expand your relationships.

### **Big Systems and Personal Networks**

Building connections will really make a difference to safety and to life. This could not only enrich people's lives with more and deeper connections and relationships, it could save lives as well.

We all want to believe that “Katrina” will never happen again, at least not to us. Well, it may not be a hurricane, but chances are actually loaded in the other direction. Life happens to all of us, and for almost all of us, we will need some help at some point. Thus the question is how will we deal with life circumstances that will be out of our control, without being consumed by fear and just hiding under our beds.

There are choices we can make that will offer degrees of security. The range and complexity of the potential answers is bewildering, but in the thumbnail sketch there are two extremes: We can depend on “big systems” to take care of it for us, or we can build and strengthen our own personal networks of support. Clearly, both are necessary, but the revelations about recent disasters are decisive: Big systems don't do well taking care of the “little” guy or gal. Thus, while we all work to repair and strengthen the systems so they will serve us better, the smart money would be to get to work today building and strengthening our own personal networks and working together with them to create our personal preparedness plans.

### **What If...?**

What if we act on approaches that connect us? Our isolation from one another creates profound loneliness and despair. This is the greatest disability for any of us. What if we reframe and reorganize our energy? What if our actions engage and support folks with disabilities to share their gifts, including their capacity to bring people together? Here's our suggestion for a quick start.

How about organizing “Our Neighborhood Emergency Planning Coffee & Brownie Party”? Make it a fun event. Invite everyone; get to know each other. The strategy is simple. In an emergency, we can take care of each other better than any “system” on the planet, especially if we know each other. Having relationships with your neighbors is the ultimate security blanket. Within the first 24-48 hours, before bigger systems might even reach you, the people who will make the difference are your neighbors; personal contacts and connections; members of your local place of worship; and folks you know through belonging to clubs, classes or other memberships. They will make the difference. We need to be good neighbors! This needs to be the core of our plan. It is an emergency preparedness strategy, and it's simply a good idea.

Following the good neighbor strategy you can also join your local neighborhood watch, or neighborhood safety group. If there isn't one, you or someone you support could be the catalyst to get one started. Think of this as a community engagement strategy. Become an active contributor to your community. That's security. If you are a stakeholder with your people, and they with you, we will do what it takes to take care of each other. This is much more than “who is your emergency contact?” It's really the opportunity to engage in a series of conversations with your neighbors and

friends about how we get along together – and how we will take care of each other. Don't think of this as a single "meeting." There may be one "event," but if we think about this as a series of neighborly conversations that get richer over time, we are on a more secure foundation. Each simple encounter and conversation becomes a moment to appreciate, but equally a piece of the strategic plan to have people in your life (a mutual obligation) who will help each other out every day, and in an emergency.

### **Waiting or Mutual Caring?**

Some may wonder about the relevance of this "take charge of your life" approach for people who need various kinds of supports. Unfortunately, we have hard evidence from Hurricane Katrina, other disasters, and history that people with disabilities are too often left until "last." The dramatic death toll from Katrina for people with disabilities is brutal testimony. People waited for "big systems" to take care of them. Too often it didn't happen. Big systems were struggling to cope themselves. Communications failed. Transportation collapsed. Inter-agency struggles consumed valuable time and resources. We all know stories. The point is that in an emergency, unless we are very lucky, big systems are also in emergency mode and many of the people we know and care about will not survive until the big systems reorganize and get back into action. And even then, too often, people with disabilities will be low on the priority list for attention.

So, do we sit and wait for someone to take care of us when the evidence suggests it is chancy? Or, do we take charge and invest in making, renewing, and re-energizing our own personal networks that will make our daily lives more interesting, and give as much real security as there is for any of us in a serious emergency of any kind?

A frightening piece of research from New York City affirms this strategy. In a controlled experiment, an actor fell in the street with classic heart attack symptoms. Most people walked by. In the

second scenario, after the fall, the actor asked for help, and a few responded. In the third, the actor asked people to "dial Dr. X at hospital X." People responded with a clutch of cell phone dialing! Many of us want to help, but without appropriate cues, we become passers by.

In disasters, it is the same. Most of us are willing to help (at least a little) but we are paralyzed by our lack of understanding about what to do, and then we move on. When we know someone, when we have shared a cup of coffee, worshipped together, etc., we have a little knowledge about a real person and what might be helpful. If asked, and given a few clues, many, if not most of us, would be willing to reach out and give a hand to a fellow human. So the good news is that if we reach out and connect to people around us, build a network of relationships (perhaps even a few friends), there will be people who, if a crisis occurs, will think about helping each other out. They won't wait for instructions from a bureaucracy that is itself in crisis. They will be able to figure out that someone who needs assistance to get around or to eat will likely need a hand. They will show up with lunch and an extra blanket. No waiting required. We will just get on with taking care of each other. If the cell phones are down and the power is out, it still works because we know each other. We know where we live, we know likes and dislikes, we know dozens of personal anecdotes about each other that help us to know/guess what to do in a crisis, because we care about one another.

### **Building Our Circles of Support**

Efforts in emergency preparedness are aligned with the core values of community inclusion and membership. We are prompted again through these preparedness efforts to take stock of the very questions at the heart of individualized planning with people. Who is in your circle of support? Who's in the inner circle? Who can you count on, at least "three deep" (at least three people in each important location), in the different places where you spend your time. Who

will be part of your personal support network in the event of an emergency? Those trusted individuals and folks are the people you invite to be part of your planning process (the coffee party). They can assist you during an emergency. If we notice that these circles or relationships are thin, then we have identified important work to do. We need to build our circle of community connection.

None of this exempts us from doing the complex work of improving emergency response systems so they are sensitive to the individual needs of people who are likely to require a little extra assistance in an emergency. In fact, vigorously joining in that planning is critical so the real needs of people do not get put on the list last. Reaching out and engaging with public and private sector systems is one of the key community connections that each of us can make. But there is a second layer of organizing that each of us can do beginning today. We need to be "regulars" in our local places people gather for recreation, worship, social events. We need to join things, meet people, be present; and we need to be there before a crisis happens, so if something happens, friends and colleagues will notice our absence and take action immediately. And we can start today. We can build relationships and networks of support, and the good news is that we begin one conversation at a time – perhaps over coffee and brownies.

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*Lynda Kahn is a co-leader at Inclusion Press International in Toronto, a faculty member of the University of Massachusetts Department of Family and Community Medicine, and advisor to the Emergency Awareness/Preparedness Initiative at the University's Eunice Kennedy Shriver Center. Jack Pearpoint is founding Director of Inclusion Press and the Marsha Forest Center, Toronto. They may be reached at 416/658-5363 or [inclusionpress@inclusion.com](mailto:inclusionpress@inclusion.com).*

## When Disaster Strikes: An Emergency Preparedness Checklist for Service Providers

The following checklist was developed by United Cerebral Palsy to help community providers of services for individuals with disabilities to fully engage their organization, including staff, volunteers and the individuals they serve, in community, organizational and personal preparedness for emergencies and disasters.

### Community Emergency Planning

Your organization can play an important role in community emergency preparedness through the following:

- **Community Planning.** Participate in community emergency planning efforts. Ensure that both staff and people with disabilities are fully participating in the community planning process and effectively communicating the perspective of people with disabilities.

### Organizational Preparedness

The following are procedures to help ensure your organization is ready and survives an emergency or disaster:

- **Your services.** Identify the primary services you think you will continue to provide following an emergency.
- **Basic resources.** Identify the critical material resources necessary to maintain these operations.
- **Staff personal/family preparedness.** Encourage staff to have a personal, family or home emergency plan to increase the likelihood that staff and their families can cope with the disaster without outside help.
- **Essential personnel.** Determine which staff should automatically report to work in a disaster, and have back-ups.
- **Staff contact list.** Develop and post in a private but accessible place a list of staff home and contact telephone numbers for emergency use only. Ask each staff also to list contact information for someone out of the area who could serve the “clearinghouse” function for getting in touch.
- **Volunteers.** Develop your own volunteers, especially to cover in a disaster, and have backups.
- **Locating everyone.** Implement procedures to ensure that you will know where everyone is at all times, utilizing such strategies as a contact registry, a master schedule, a “buddy system,” wireless telecom devices, etc. – as well as recruiting emergency contacts who live at least 100 miles away to act as a clearinghouse for information on your staff and individuals served.
- **Important documents.** Implement procedures to ensure important documents pertaining to all the individuals you serve are available, utilizing such strategies as putting individuals’ permanent legal documents, or copies (birth certificates, immigration documents, guardianship decrees, etc.) in a safe, accessible, off-site, 24-hour location, and copies of other documents (SS cards, Government IDs, Medicaid IDs, Food Stamp IDs, prescriptions, DME info, etc.) in sealed freezer bags in emergency kits, with additional copies sent to out-of-area emergency contacts. As a backup, consider putting everything possible on a secure Web site.
- **Emergency kits.** Assign and train staff to ensure that home emergency kit(s) are put together, are in designated place(s), and are checked and updated regularly.
- **Posting special needs.** Post a list of individuals you serve and their specific needs in an accessible, but private, location.
- **Medications/equipment.** Assign and train staff to keep important medical and/or mobility equipment and assistive devices in consistent, convenient and secured places and in working condition. Have a back-up power plan for durable medical equipment and medications needing refrigeration.
- **Immediate shelter.** Identify temporary, accessible shelters (consider churches, nearby community centers, schools, other residential services, etc.). Develop mutual aid agreements.
- **Make assignments, train and cross-train staff for:**
  - Site security. Check and turn off gas, electricity and water if evacuating.
  - Fire suppression. Check for and suppress small fires and attempt to notify fire department.
  - Search and rescue. Ensure everyone has evacuated. Quickly search the facility for people who may be trapped or injured. Help if possible. Note and record situation for other responders, including names and location.
  - First aid. Administer first aid to injured persons
- **Assisting individuals.** Assign staff to specific individuals who are likely to need assistance in the event of an evacuation. Be sure they have a designated place(s) to go.
- **Accounting for people.** Assign staff to take a “head count” to ensure all staff and individuals served have evacuated, if necessary, or are sheltered at home, if possible.
- **Transportation.** Have an emergency transportation plan, including designating accessible emergency vehicles for people, and others who can carry equipment and supplies, as well as specific destinations.
- **Communications.** Have an emergency communications plan that

includes backup systems for remaining in contact if traditional communication systems are unavailable.

- **Organizational “buddy system.”** Identify neighboring agencies or businesses you can join with to share resources in an emergency in order to maintain a level of operations for both and ensure the ongoing support of people you serve.
- **Insurance.** Make sure you have the best disaster coverage you can obtain and afford, including indemnity for payroll and for loss of business or funding, if available.
- **Government funding.** Make an emergency agreement with government funders for interim continuation of funding during an emergency.

### Individual Preparedness

The following are procedures to help insure that the individuals you serve are prepared:

- **Health information.** Have multiple copies of a health information card, with one that stays with each individual, including information on medications, equipment, allergies, sensitivities, communication style, preferred treatment, medical and care providers, and important contact people.
- **Medication.** Have an emergency medication protocol that will ensure a 7-14 day supply of essential medications, maintaining extra supplies, current prescriptions and/or emergency agreements with medical providers.
- **Equipment.** Have an emergency durable medical equipment protocol, including attaching simple handling instructions to all equipment, with copies in emergency kit(s).
- **Service animals.** Have an emergency service animal protocol, ensuring service animals have animal emergency kits and current identification tags, with both the owner’s

home number and the out-of-area contact number.

- **“Carry-along” supplies.** Assign staff to maintain a small kit (fanny pack, backpack or bag) of “Carry-Along Supplies” that each individual you serve keeps with them at all times, containing:
  - His/her health information card.
  - Instructions on personal assistance needs and how best to provide them.
  - An emergency communication card (For individuals with cognitive disabilities, it might say something like: “I cannot read. I communicate slowly. Please speak slowly to me. I can point to or understand simple pictures and some words.”)
  - Reduced copies of important documents such as Social Security card, Medicaid card, government ID, etc.
  - Copies of prescriptions.
  - Flashlight on a key ring.
  - Emergency signaling device such as a whistle, beeper, bell, screecher, flashing light, etc.
  - Small battery-operated radio and extra batteries.
- **Practice, practice, practice.** Conduct periodic drills/practices, without fail. Staff and individuals served will turn over.
- **Back-ups, back-ups, back-ups.** Have all the back-ups you can, including relief staff, emergency on-call staff, joint staffing agreements with other providers, your own volunteers, pre-agreements with volunteer service organizations, etc.

*Adapted and reprinted with permission from “When Disaster Strikes: An Emergency Preparedness Checklist for Providers of Services and Supports for People with Disabilities,” published by United Cerebral Palsy (UCP), Washington, D.C. Retrieved June 6, 2007 from [www.ancor.org/issues/disaster/UCP\\_when\\_disaster\\_strikes\\_05-06.pdf](http://www.ancor.org/issues/disaster/UCP_when_disaster_strikes_05-06.pdf). For further information call UCP at 800/872-5827 or visit [www.ucp.org](http://www.ucp.org).*

### Resources for Information

*The following may be useful for further information about disaster preparedness in relation to people with disabilities:*

- **Support Coordinators Emergency Preparedness: Best Practices Guidelines** ([www.dhh.state.la.us/publications.asp?ID=77&Detail=1193](http://www.dhh.state.la.us/publications.asp?ID=77&Detail=1193)). A resource guide providing a framework for support coordination agencies to use in designing emergency preparedness procedures, and in supporting development of individualized emergency plans for individuals with disabilities. Developed by representatives from Louisiana’s support coordination agencies and the state’s Office for Citizens with Developmental Disabilities.
- **Higher Ground: The Dedication of Direct Support Professionals During and After Hurricanes Katrina and Rita.** A documentary on DVD telling the stories of some of the heroic Direct Support Professionals from New Orleans who, despite long hours, low pay, and tremendous stress and trauma, continued to provide support services during and after the storms while often not knowing the fate of their own families. Produced by the Research and Training Center on Community Living, University of Minnesota, in conjunction with Volunteers of America of Greater New Orleans. For further information go to [www.highergroundthemovie.org](http://www.highergroundthemovie.org) or call 612/624-4512.
- **We Watch the City: Stories in the Shadow of 9/11.** A documentary on DVD relating the experiences of New Yorkers with intellectual and other developmental disabilities and those who supported them in the aftermath of September 11, 2001. Produced by the Research and Training Center on Community Living, University of Minnesota. Ordering information available at <http://ici.umn.edu/products> or by calling 612/624-4512.

# Employers' Guide to Including Employees with Disabilities in Emergency Evacuation Plans

by Linda Carter Batiste and Beth Loy

Interest in emergency evacuation planning has increased dramatically since the September 11 terrorist attacks. In turn, the Job Accommodation Network (JAN) started receiving more calls from employers requesting information about their legal obligation to develop emergency evacuation plans and how to include employees with disabilities in such plans. This article addresses these issues.

## Legal Requirements

Although employers are not required to have emergency evacuation plans under the Americans with Disabilities Act (ADA), if employers covered by the ADA

the Occupational Safety and Health Act (OSH Act) or under state and local law.<sup>3</sup>

Whether mandatory or voluntary, many employers decide to develop emergency evacuation plans. The following provides steps for including employees with disabilities in those plans.

## Plan Development

The first step for including employees with disabilities in emergency evacuation plans is plan development. Plan development begins with identifying accommodation needs. One of the best ways to identify accommodation needs is to ask employees whether they have limitations that might interfere with safe emergency evacuation. The Equal Employment Opportunity Commission (EEOC) recently issued guidance that discusses what information employers are allowed to gather when developing an emergency evacuation plan.<sup>4</sup> According to this guidance, there are three ways that an employer may obtain information:

- After making a job offer, but before employment begins, an employer may ask all individuals whether they will need assistance during an emergency.
- An employer also may periodically survey all of its current employees to determine whether they will require assistance in an emergency, as long as the employer makes it clear that self-identification is voluntary and explains the purpose for requesting the information.
- Finally, whether an employer periodically surveys all employees or not, it may ask employees with known disabilities if they will require assistance in the event of an emergency. An employer should not assume, however, that everyone with an obvious disability will need assistance during an evacuation. For example, many indi-

viduals who are blind may prefer to walk down stairs unassisted. People with disabilities are generally in the best position to assess their particular needs.

The ADA requires employers to keep all medical information confidential. However, first aid and safety personnel may be informed, when appropriate, if the disability might require emergency treatment or if any specific procedures are needed for emergency evacuations.

In addition to requesting information from employees, employers may want to hold evacuation drills to help identify needs that employees are unaware of; conduct hazard analyses to help identify hazards specific to the workplace; develop a method to identify visitors with special needs; and contact local fire, police, and HazMat departments for guidance.

## Accommodations

Once accommodation needs have been identified, the employer should choose effective accommodation options. Often employees with disabilities are a good resource for accommodation ideas. In addition, employers should contact local fire, police, and HazMat departments to determine what services they can offer. Finally, employers can contact other resources such as JAN. JAN can provide specific accommodation ideas on a case-by-case basis. The following is an overview of frequently suggested accommodation ideas for emergency evacuation. Additional details about many of them can be found through JAN's Searchable Online Accommodations Resource (SOAR) at [www.jan.wvu.edu/soar](http://www.jan.wvu.edu/soar).

In the area of *general accommodations* the following are suggested:

- Employers should have emergency alarms and signs showing the emergency exit routes. These alarms and

*Since September 11, the Job Accommodation Network has received more calls from employers requesting information about their legal obligation to develop emergency evacuation plans and how to include employees with disabilities in such plans.*

opt to have such plans they are required to include people with disabilities.<sup>1</sup> Further, employers who do not have emergency evacuation plans may nonetheless have to address emergency evacuation for employees with disabilities as a reasonable accommodation under Title I of the ADA.<sup>2</sup> In addition, employers in certain industries may have obligations to develop emergency evacuation plans under

signs should be accessible and maintained in proper working order.

- Employers may want to implement a “buddy system” for all employees. A buddy system involves employees working in teams so they can locate and assist each other in emergencies.
- Employers may want to designate areas of rescue assistance. Section 4.3.11 of the Americans with Disabilities Act Accessibility Guidelines (ADAAG) ([www.access-board.gov/adaag/html/adaag.htm#4.3](http://www.access-board.gov/adaag/html/adaag.htm#4.3)) specifically addresses areas of rescue assistance. If these areas do not have escape routes, they should have 1) an operating phone, cell-phone, TTY, and two-way radio so that emergency services can be contacted; 2) a closing door; 3) supplies to block smoke from entering the room under the door; 4) a window and something to write with (lipstick, marker) or a “help” sign to alert rescuers that people are in this location; and respirator masks.

Frequently suggested accommodations for employees with *motor impairments* include:

- To evacuate individuals with motor impairments, employers can purchase evacuation devices. These devices help move people with motor impairments down the stairs or across rough terrain. If evacuation devices are used, personnel should be trained to operate and maintain them.
- Employers should remove any physical barriers (boxes, supplies, furniture) to insure a barrier-free route of travel out of the building.
- Employers may want to provide heavy gloves to protect individuals’ hands from debris when pushing their manual wheelchairs, a patch kit to repair flat tires, and extra batteries for those who use motorized wheelchairs or scooters. Arrangements should also be made to make wheelchairs available after evacuation.

Emergency evacuation accommodations for employees with *sensory impairments* may include the following:

- Employers should install lighted fire strobes and other visual or vibrating alerting devices to supplement audible alarms. Lighted strobes should not exceed five flashes per second due to risk of triggering seizures in some individuals. Section 4.28 of the ADAAG (<http://www.access-board.gov/adaag/html/adaag.htm#4.28>) specifically addresses alarms.
- Employers may want to provide alerting devices, vibrating paging devices, wireless communicators, or two-way paging systems to alert individuals with hearing impairments of the need to evacuate.
- Employers should install tactile signage and maps for employees with vision impairments. Braille signage, audible directional signage, and pedestrian systems are also available. These products may benefit other people who must navigate smoke-filled exit routes.
- Employers may also want to provide alpha-numeric pagers or other communication devices to individuals with speech impairments so they can communicate with personnel in an emergency.

Suggested accommodations in relation to employees with *cognitive disabilities* include:

- Employers should consider ways of communicating with people who have cognitive disabilities. For example, some individuals may benefit from pictures of buddies, color-coding of escape doors and areas of rescue assistance, and information on video/CD.

Suggested accommodations in relation to employees with *psychiatric conditions* include:

- Employers should consider the effects of training for emergency evacuation. Some individuals with psychiatric impairments benefit from frequent emergency drills, but for others practice drills may trigger anxiety. Notifying employees of upcoming practice drills and allowing them to opt out of participation may be a reasonable

accommodation. In this case, another form of training for emergency evacuation procedures may be needed, for example providing detailed written instructions.

Accommodation ideas for employees with *respiratory impairments* may include:

- Employees with respiratory impairments may have limitations exacerbated by smoke, dust, fumes, chemicals, and other odors and may benefit from products such as emergency evacuation hoods, masks, and respirators. Using areas of rescue assistance until emergency personnel arrive may also be an option.
- Employees with respiratory impairments may have breathing difficulties when walking distances and therefore have problems descending stairs. Employers may want to consider purchasing evacuation devices, relocating the employees’ workstations, and working with the employee to ensure availability of adequate medical supplies.

After effective accommodations are chosen, employers should decide who will be involved in implementing the evacuation plan, commit the plan to writing and share it with employees for feedback, practice the plan to make sure it works, and modify the plan as needed.

### **Plan Implementation and Maintenance**

The second step for including employees with disabilities in emergency evacuation plans is plan implementation. After the final evacuation plan is written, a copy should be distributed to all employees and key personnel. In addition, an evacuation drill should be performed to make sure all employees are familiar with the plan. Finally, it should be integrated into the standard operating procedures.

The final step for including employees with disabilities in emergency evacuation plans is plan maintenance. To insure that accommodations continue to be effective, the evacuation plan should be practiced and the accommodations updated

[Batiste & Loy, continued on page 34]

# Coping with Disaster: Helping Children with Cognitive Disabilities

by Anne F. Farrell and Daniel Crimmins

People respond differently to disaster. Some may appear unaffected, and others show distress, rage, and fear. Children's reactions vary according to many factors, including their ages, abilities, and experiences. The children most directly affected are likely to have the greatest difficulty coping, but children with prolonged indirect exposure (including seeing events on TV) may also have trouble coping.

Children exposed to trauma may respond in some predictable ways. For most, these responses will diminish over the next few months, especially if the child did not experience injury, loss of a family member, or further trauma. Some of the common reactions of children, including children with cognitive disabilities, are as follows:

- **Very young children (about 2-5):** sleep disturbance, difficulty separating from parents, fussiness, confusion, fears about safety, somatic symptoms (stomachaches), exaggerated startle to loud noise, and re-enactment of the events through play. These reactions will be most evident in children with greatest exposure to the trauma and when parents display a great deal of distress.
- **School-age children (ages 5-11):** worries about the safety of loved ones, attention to adult reactions, withdrawal or hyperactivity, repetitive play, impaired concentration and academic performance, sleep disturbances and nightmares, magical ideas about how the disaster might have been averted, and questions about why such disasters can happen.
- **Adolescents (12 to around 18):** sadness, outrage, risk-taking behaviors, substance use or abuse, sleep or eating disturbances, anger or rage, talk of retaliation, increased sense of alienation, shifts in peer groups, and focus on death. The adolescent think-

ing style tends to be all-or-nothing and teens are especially vulnerable to peer influences and failing to consider the consequences of their actions. As such, teens may be particularly vulnerable to impulsive responses.

## General Strategies for All Children

The following are general strategies to promote coping in children:

- **Natural supports work best.** Children with cognitive impairments, like other children, adapt best in their own environments and routines. There is comfort in the familiar, so allow children to go about routines of school, recreation, and play. Consider the community supports you would turn to in any time of need: extended family, religious faith, community organizations, and recreational activities that provide outlets for tension and opportunities to spend time together. Use your support network. Take care of yourself so that you can be available when children need guidance.
- **Education helps.** Educate yourself about the impact of trauma and how it changes over time. Knowing what to expect helps you be prepared to provide support. For example, expect children to misunderstand some of the things they hear and see. Be prepared to learn what they know and supply accurate and timely information. Teach older children that recovery is a process: it takes time, everyone responds uniquely, and there is no "right" way to feel. There are right ways to act, however, and children need good role models. Help them learn about federal, state, and community leaders whose responses are constructive and inspire confidence. Use reputable resources to guide your own education efforts.

- **Focus on doing.** When you demonstrate caring for yourself and others, you are engaged in coping. It is important to express feelings, but coping is also about learning, thinking, and doing. Some specific steps you can take are the following:

- *Limit further exposure to trauma.* Given how immersed we are in unfolding events, assume that children know about them. It is important, however, to limit ongoing exposure to the trauma. For younger children, turn off the television during the news. Set aside some time to look at newspaper stories and photographs and answer questions. For older children, watch the news together. Change channels if you feel the media coverage is not constructive. Talk about what you see while you are watching and afterward.

- *Address concerns about safety.* Discuss safety with children. Children will be assured by knowing steps authorities are taking to protect the public. Explain in concrete terms how our leaders are working together to restore normalcy. Be honest and calm about risk; don't promise that nothing like this will happen again. Explain that most of us will live long and grow old. Reassure children that you will do everything in your power to protect them.

## Additional Strategies for Children with Disabilities

Children with disabilities will benefit from all of the strategies listed above. Maintaining regular schedules may be particularly important for children who rely on routine as a coping method. Because of their information-processing differences, however, children with cognitive disabilities may also require strategies that address their unique needs:

- **Use language the child understands.** Speak at the child's language level, giving short explanations. Children often ask questions that adults don't have answers to, such as "Why did this happen?" It's also okay to admit there are things you don't know. Abstract terms may lead to misconceptions. Avoid statements like "This was tragic and many lost their lives. One of John's loved ones passed on in the collapse." Instead, say, "There was a big explosion and many people died. John's uncle was killed."
- **Check the child's understanding.** Ask often about what children are thinking and feeling. Encourage them to draw pictures if they are able. Draw, paint, or color with them. Provide choices of emotions they may be experiencing. Use pictures that represent "sad" or "upset" if they are not good at expressing themselves with words. Ask open-ended questions like "What have you seen and heard about the World Trade Center?" Prompt them with questions such as "What happened next?" Avoid yes/no questions that do not encourage children to talk more.
- **Expect misunderstanding.** Children with language and cognitive disabilities may be particularly vulnerable to misconceptions. Multiple television rebroadcasts may be confusing and children may become afraid that the attack continues or has started anew.
- **Correct misunderstandings.** A news report about requests for blood donations confused one child who could not understand why someone would take people's blood from them. Ask children about what they hear and tune in closely to their reactions, including facial expressions. In this case, you might show the child a photo of someone donating blood and tell how this helps. If you donate blood, show the child your Band-Aid and explain that no one hurt you.
- **Repeat your responses patiently.** Children may have questions about these events and ask them repetitively.

Use clear examples and repeat yourself as needed. If you are aware of misconceptions a child has, you are in a good position to help. Gently and carefully repeat correct information and be sure the child grasps what you mean. Later, check in again about the same information because misconceptions can be hard to shake. For example, one child came home from school crying. She said the grandparents of three classmates died in the World Trade Center attack. Her mother talked to a neighbor and learned that the child's teacher talked about the attack. Luckily, no one in the class was directly affected. The teacher asked whether any students remembered someone dying and three children said that their grandfathers had died previously. The child's mother corrected her misperception. Later when her father came home, the child repeated the story, again stating that the grandfathers had been killed in the attack. Two or three more conversations were necessary before the child grasped the difference. Gentle repetition reduced her distress and made it less likely she would repeat the story incorrectly.

- **Use pictures and talk together.** Each discussion offers an opportunity to help children understand and cope. Provide information to more than one sense at a time, allowing children to see, hear, touch, talk, and do. For very young and elementary-age children, show photos of recovery operations. Tell them how the firefighter or police officer pictured is helping. This can be done many times over the coming days. For older children and adolescents, talk about television and newspaper coverage every day. Expose them to leaders who appear strong, sympathetic, and reasonable.
- **Identify the human element of the tragedy if inappropriate questions are asked.** Some children may want to talk about aspects of the tragedy that may seem irrelevant or insensitive. A child with restricted interests might want to review details about the equip-

ment used in the recovery effort. Answer the questions, but remind the child that this is a sad time because so many people have died. If an attempt to redirect the child does not work, try to structure or contain this conversation. Provide times and places for the child to discuss this with you. Give the child guidelines for talking to others in a sensitive way. Offer "okay" topics such as the number of rescue personnel on the scene or which bridges and tunnels have reopened.

- **Look at what might be upsetting.** One child became upset when she heard a television show with gunshots. She thought that a war had started. If a child has a strong emotional response, look first at the immediate context. Another child had recently done something for which he was scolded. When the disaster of September 11th occurred, he felt that his being "bad" had caused it. Guilt can be inappropriately attached to an unrelated event.

Despite all of the above, some children with cognitive disabilities may develop stress disorders related to their exposure to a traumatic event. They should be referred to a mental health professional with appropriate training in both stress disorders and cognitive disability.

*Adapted and reprinted with permission from the guide, "Coping with Disaster: Suggestions for Helping Children with Cognitive Disabilities," by Anne F. Farrell and Daniel Crimmins, published by the Administration on Developmental Disabilities. Retrieved June 6, 2007 from [www.acf.dhhs.gov/programs/add/Sept11/addcoping.html](http://www.acf.dhhs.gov/programs/add/Sept11/addcoping.html). Anne F. Farrell is Assistant Professor in Family Development and Family Studies, University of Connecticut, Stamford; she may be reached at 203/251-8590 or [anne.farrell@uconn.edu](mailto:anne.farrell@uconn.edu). Daniel Crimmins is Associate Director for the University Center for Excellence in Developmental Disabilities at the Marcus Institute, Atlanta. He may be reached at [crimmins@marcus.org](mailto:crimmins@marcus.org) or 404/419-4060.*

## Congregations Who Care - Prepare: Preparing Faith Communities to Assist During Disasters

The congregations of America are more aware of the need to prepare for a human-made or natural disaster than they were prior to September 11, 2001. Through television and other media, the nation is powerfully and graphically alerted to hurricanes, tornadoes, floods, blizzards, earthquakes, terrorist attacks and wildfires, as well as the resulting destruction, homelessness, injury and

*There are a number of specific steps a congregation can take to assist people with disabilities to prepare for a disaster, and to prepare its faith community to assist people with disabilities during a disaster.*

death that follow. Sadly, we have learned that children and adults with disabilities and their families are more vulnerable during and after these disasters.

People, with and without disabilities, can reduce the impact of disaster by taking precautionary measures to prepare in case an event occurs. In November 2001, the National Organization on Disability (N.O.D.) launched the Emergency Preparedness Initiative (EPI), a program to address the special concerns of the nation's disability community and to ensure that people with all types of disabilities are included in emergency planning at all levels (the Web site of this award-winning program is [www.nod.org/emergency](http://www.nod.org/emergency)). EPI is the sister program of N.O.D.'s Religion and Disability Program (R&DP), which works with congregations, national faith groups, and seminaries (the R&DP Web site is at [www.nod.org/religion](http://www.nod.org/religion)).

Following the terrorist attacks in the fall of 2001 and the recent hurricanes in the Gulf Region, congregations have fulfilled their scriptural mandate to offer hospitality and help those in need. People of all faiths have contributed millions of dollars and countless hours assisting older adults and people with disabilities. Congregations of all faiths have provided transportation, medical care, housing, food, clothing and tutoring to Americans with physical, sensory, psychiatric and intellectual disabilities. People of faith from America's congregations continue to make a critical difference in disaster recovery.

There are a number of specific steps a congregation can take to assist people with disabilities to prepare for a disaster, and to prepare its faith community to assist people with disabilities during a disaster. They include the following:

- **Coordination:** A congregation can join with other congregations and volunteer groups to assess preparedness efforts in their community and plan for disaster before it happens. This planning, grounded in cooperation, will reduce duplication of services. Congregations can be guided through this planning process by joining National Voluntary Organizations Active in Disaster (NVOAD). A visit to its Web site at [www.nvoad.org](http://www.nvoad.org) offers information about the coordinating and advocacy services offered by NVOAD or an affiliated state VOAD member.

Also, consult EPI's Interactive Map of Disability and Emergency Preparedness Resources ([www.nod.org/EPIResources/interactive\\_map.html](http://www.nod.org/EPIResources/interactive_map.html)). The map houses information on your regional branch of FEMA, your state Citizen Corps and American Red Cross Chapters, as well as links to your state and local Emergency Management Agencies, and is a good place to start gathering the information most useful to you.

This type of coordination and planning must be very specific. For example, during and after a disaster, one congregation could provide the services of two sign-language interpreters and store extra hearing aid batteries; another congregation, which has a religious education program for children with mild to severe disabilities, could offer the services of the professionals who staff the program; another congregation, which operates a shelter for people without homes, could offer its wheelchair accessible restroom and shower; another congregation with a parish nurse might offer her services; and a congregation that provides meals could store the equipment that children and adults with disabilities might need, including flexible straws, adaptive silverware and dishes, sodium and sugar-free snacks and beverages, gluten-free products and tables that can easily be raised to accommodate a wheelchair user.

- **Education:** A congregation or a cluster of congregations could sponsor an Emergency Preparedness Town Hall Day or Awareness Day similar to a Health Fair. Resources and materials to be distributed at these events can be found on the EPI Web site at [www.nod.org/emergency](http://www.nod.org/emergency). Likewise, any time there is a celebratory fair, congregations can staff a booth with information about emergency preparedness for people with disabilities, including information about the TV and radio Emergency Alert Stations and National Oceanic and Atmospheric Administration (NOAA) weather radios with audible, flashing and vibrating alerts. Central to the message for everyone is that it takes more time to evacuate if you have a disability or a family member with disability.

These events can be publicized using energizing words such as "Get

Informed,” “Get Involved,” “Create Partnerships,” and “Make a Plan.” Because congregations are trusted to disburse health and safety information, they are ideally positioned to promote an emergency preparedness message.

- **Training:** A congregation can sponsor several members for Citizen Emergency Response Training (CERT) that is offered by the Department of Homeland Security’s Citizen Corps program ([www.citizen corps.gov](http://www.citizen corps.gov)). CERT is offered nationwide to people with and without disabilities who are trained to understand triage and the chain of command following a disaster, as well as to do basic search and rescue and first aid. Or a congregation could encourage its members to obtain American Red Cross training ([www.redcross.org](http://www.redcross.org)). Once again, this gives a congregation an opportunity to be informed, involved and prepared.

- **Personal Planning:** A congregation, through its ordained and lay leaders, can make sure members prepare personally for a disaster. One of the congregation’s leaders, who happens to have a disability, could lead a seminar on this subject and distribute the N.O.D. Emergency Preparedness Initiative brochure, found on the Web site at [www.nod.org/emergency](http://www.nod.org/emergency), entitled “Prepare Yourself: Disaster Readiness Tips for People with Disabilities.” People with disabilities know best their own abilities and needs before, during and after a disaster. Using a simple checklist, people with disabilities and their families can identify resources, make a plan, create a “ready kit” and a “go kit.” Each person, with and without a disability, can decrease the impact of a disaster by taking steps to prepare before an event occurs.

N.O.D.’s Religion and Disability Program, in cooperation with the Emergency Preparedness Initiative, is recruiting congregations to become part of our “Congregations Who Care – Prepare” pilot project. If you are a congregation currently working with your members to prepare for disasters, and are interested in learning how to incorporate people with disabilities into your plans, please contact us. Similarly, if you are a congregation currently working to improve inclusion of people with disabilities, and are concerned about disaster readiness for your congregation, let us serve you in your journey toward preparedness for all people! Please contact Rik Opstelten for further information at 202/293-5960 or via e-mail at [OpsteltenH@nod.org](mailto:OpsteltenH@nod.org).

*Adapted and reprinted with permission from “Congregations Who Care – Prepare,” published by the National Organization on Disability (N.O.D.). Retrieved June 6, 2007 from [www.nod.org/congregationsprepare](http://www.nod.org/congregationsprepare).*

## Resources for Information on Disability and Disaster

The following resources may be useful for further information about disaster preparedness, response, and recovery in relation to people with disabilities.

- **The Take and Go Emergency Book** ([www.dhh.state.la.us/publications.asp?ID=77&Detail=1193](http://www.dhh.state.la.us/publications.asp?ID=77&Detail=1193)). A practical booklet for use by individuals with disabilities in personal emergency planning. Includes planning worksheets to fill out. Developed by persons with disabilities and their families in collaboration with the Louisiana Office for Citizens with Developmental Disabilities.
- **Disaster Preparedness for People with Disabilities** ([www.redcross.org/services/disaster/beprepared/disability.pdf](http://www.redcross.org/services/disaster/beprepared/disability.pdf); or in print from your local Red Cross chapter, item #A5091). This in-depth guide is designed to help people who have physical, visual, auditory, or cognitive disabilities

to prepare for natural disasters and their consequences. Individuals with disabilities and those who work with, live with, or assist a person with a disability can use this booklet, which contains information and checklists that can help users organize a personal disaster plan.

- **It’s Not Flu as Usual: What Faith-Based and Community Organizations Need to Know About Pandemic Flu** (<http://healthyamericans.org/reports/flu/brochures/FluBrochureFaith.pdf>). A brochure from the Trust for America’s Health that includes a checklist for preparing for and responding to a pandemic, and common sense prevention precautions.
- **Disaster Preparedness for Families of Children with Special Needs** ([www.fifionline.org/disaster\\_plan.php](http://www.fifionline.org/disaster_plan.php)) This resource from the Florida Institute for Family

Involvement includes checklists, tips, and information for families preparing for a variety of emergencies or disasters. Available in English and Spanish.

- **Emergency Preparedness: Taking Responsibility for Your Safety – Tips for People with Disabilities and Activity Limitations** (<http://lacoa.org/esppub.htm#Spec>). This guide is for anyone who has trouble walking, hearing, seeing, breathing, understanding, learning or responding quickly. It includes checklists and worksheets for identifying the areas in which a person might need assistance during a disaster, their current level of emergency preparedness, emergency contacts, and necessary emergency supplies. Produced by the County of Los Angeles Office of Emergency Management, it’s available in English and Spanish. Additional resources are also on the Web site.

## ***Serving and Protecting: The Role of Disability and Aging Organizations in Disaster Planning***

by June Isaacson Kailes

All too often in emergencies, the concerns of people with disabilities and seniors are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans, great urgency surrounds the need for responding to these concerns in all planning, preparedness, response, recovery, and mitigation activities. Prior planning will help prevent poor performance.

### ***Lessons Learned but Not Applied***

Lessons documented regarding disability and aging populations during previous disasters often don't get incorporated into subsequent planning, preparedness, response, and recovery activities, hence

***Disaster response commonly reflects no use or under-use of help from disability and aging organizations.***

they are not learned (United States Government Accountability Office, 2006). Segments of disability communities continually report problems participating in and benefiting from emergency services over many decades (National Council on Disability, 2005). The 2005 hurricanes in the Gulf States reinforced these documented lessons regarding management, policy, and training issues identified in many previous large-scale disasters such as Hurricane Andrew, the Loma Prieta and Northridge earthquakes, and the September 11th terrorist attacks. The catastrophic scope and impact on seniors, people with disabilities, and those with medical needs in the Gulf States underscores and amplifies the issues and makes them all the more

evident (National Organization on Disability, 2005).

Although local, state, regional, and federal government agencies play a major role in disaster planning and response, these recent events confirm what has been recognized for decades: traditional response and recovery systems are often not able to successfully meet many human needs. The usual approach to delivering emergency services cannot provide many of the essential services needed by people with disabilities and activity limitations (National Council on Disability, 2005; National Organization on Disability, 2005).

### ***The Importance of Disability and Aging Expertise***

Disability and aging organizations represent a vast array of national, state, regional, and local human and social service organizations, faith-based organizations, and neighborhood associations that are critical to the disaster response and recovery process. Disaster service workers could never adequately replicate the expertise, skill sets, and resources of these organizations. Disability and aging organizations have unique and credible connections with the people they support and experience with delivering services to them. Their unique skills and understanding are invaluable. But unfortunately, they are an often overlooked resource for emergency planning, preparedness, response, recovery and mitigation activities. For example, one shelter manager involved in the Katrina response complained about the length of time it took to locate assistive devices: "...it would have been nice to have 'someone' local provide a list of resources in the area, rather than taking staff hours on phones all day trying to find equipment." Knowledgeable disability and aging organizations could have accomplished this

task more efficiently, freeing shelter management staff for other activities, had they been plugged into the system with an assigned task and role (National Organization on Disability, 2005).

Disaster response commonly reflects no use or under-use of help from disability and aging organizations (and sometimes ignored offers of help). There is often no designated entity or individual to "own" and coordinate disability and aging issues. Disability and aging community-based organizations report difficulty in gaining access to emergency management authorities to coordinate response and service delivery. This leads to well-intentioned but misguided actions, only adding to the management difficulties on the ground (National Organization on Disability, 2005).

To correct this situation, disability and aging organizations must be included as partners in working with local, regional, state, and national public and private response agencies. And while structural changes are needed on the part of emergency response agencies to bring this about – such as establishment of a point person at the executive level of the agency to provide leadership, guidance, and coordination of all emergency preparedness, response, and recovery operations in relation to disability and aging populations – there are also steps that disability and aging organizations can take to establish or strengthen that partnership. Three strategies community organizations can engage in are 1) cross training, 2) integration of disaster work into their missions and funding, and 3) advocating for creation of a state point-person position.

### ***Cross Training***

A first step in increasing partnerships between disability and aging organizations and emergency response agencies is to

share knowledge with each other. Disability and aging advocates and service providers need to strengthen their understanding of emergency management systems if they are to have a role in shaping plans and responding to disasters. To improve effectiveness they need to participate in activities that provide orientations to emergency management organizations and structure, as well as to the roles of traditional recovery organizations such as FEMA, the American Red Cross, and other Voluntary Agencies Active in Disaster (VOAD). Likewise, emergency managers in government agencies need to strengthen their understanding of disability and aging populations and of the organizations that serve them. Toward these ends emergency response agencies and disability and aging organizations should engage in cross orientation, training, and planning activities.

### **Integration into Mission**

A second way in which disability and aging organizations can be effectively involved in emergency preparedness is through integrating disaster planning,

## ***Disability and aging organizations can take steps toward establishing collaborative relationships with emergency management agencies.***

preparedness, response, recovery, and mitigation activities into their missions, along with allocating and seeking funding to support such activities. By establishing disaster activities as a priority, organizations strengthen their position as a partner in emergency preparedness, response, and recovery. They equip themselves to be an asset to emergency response agencies and to engage in activities such as augmenting govern-

ment services during disasters, participating in community networking and planning (including building relationships with other disability and aging organizations to coordinate efforts), sharing back-up staff and resources across agencies during disasters, participating in their community emergency response teams and citizen corps, and becoming an integral part of the community response system. Disability and aging organizations can also, by integrating disaster preparedness into their missions, be involved in creating and compiling guidance materials for emergency response agencies on the needs of people with disabilities, and in developing and distributing emergency preparedness materials for people with disabilities, their families, and support staff, including materials that have disability specific content and are accessible to people with limitations in hearing, vision, mobility, speech and cognition. And they can help those whom they serve to develop individual and family emergency preparedness plans.

### **Advocating for a State Point Person**

In addition to the previous suggestions, disability and aging organizations can advocate strongly for the creation of a structure in state emergency services that ensures inclusion of people with disabilities. One proposal is creation of a state-level position that could be titled Access and Functional Services Coordinator within a state office of emergency services (Kailes, 2007). The position would provide oversight to ensure that state and local emergency planning incorporates the diverse needs of people with disabilities and functional limitations in all preparedness, response, recovery and mitigation activities. It could facilitate appointments of qualified representatives from disability and aging organizations to local and state emergency planning committees, provide sustained funding incentives that allow disability and aging organizations to integrate disaster work into their missions, and oversee Functional Assessment and

Service Teams (FAST), which are corps of trained personnel from disability, aging and other community organizations who are ready to respond to and deploy to disaster areas to assist people with disabilities and functional limitations. Creation of such a position in each state could help to facilitate collaboration between disability, aging, and emergency organizations, and keep the partnership process and momentum going.

### **Conclusion**

Emergency management systems need help with the very specific and often complex needs of people with disabilities and seniors. Well-intentioned emergency medical and public service personnel cannot adequately address the complex and additional needs of this population without a deep and thorough understanding not only of disabilities and of aging, but also of the values and goals of independent living and self-determination, and absolute clarity about the human and civil rights of people with disabilities and seniors. Disability and aging organizations can take steps toward establishing a collaborative relationship with emergency management agencies to ensure this understanding and clarity exists, and that the concerns and needs of people with disabilities and seniors are effectively addressed in times of disaster.

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*June Isaacson Kailes is Associate Director with the Center for Disability Issues and the Health Professions at Western University of Health Sciences, Pomona, California. She may be reached at 310/821-7080 or through her Web site at [www.jik.com/disaster.html](http://www.jik.com/disaster.html).*

# The Impact of Building Design on Evacuation of Persons with Disabilities

by Keith Christensen and Patricia Salmi

Individuals with disabilities represent a significant, although often overlooked, portion of the population in emergency evacuations from buildings. Americans with Disabilities Act guidelines require that provisions for accessible evacuation or exit must be made; however, failures in meeting the evacuation needs of individuals with disabilities continue to occur (Christensen et. al., 2007). These failures may be attributed to evacuation policy and planning that emphasizes

*Universal Design is a useful tool for evaluating and designing buildings to better support the emergency evacuation needs of individuals with disabilities.*

helping an individual with disabilities adjust to the environment, rather than adjusting the environment to accommodate the individual (Hahn, 1985). During evacuations, it is the design of the environment that creates the majority of evacuation barriers. For individuals with disabilities, their families, and service providers, it is important to evaluate environments for clear and easy movement to safety during emergencies.

Universal Design is a useful tool for evaluating and designing buildings to better support the emergency evacuation needs of individuals with disabilities. Universal Design is an approach to make buildings usable by the broadest group of users possible, and is based on seven design principles: equitable use, flexibility in use, simple and intuitive, perceptible information, tolerance for error, low

physical effort, and size and space for approach and use (Story et. al., 1998). The list of suggestions in this article incorporates Universal Design principles and can be used by individuals, their families, and service providers to evaluate buildings for clarity and ease of movement to safety during times of emergencies.

## Spatial Organization

Spatial organization or building layout is critical during building evacuation, either facilitating or inhibiting movement to safety, and relates to the Universal Design principles of equitable use, simple and intuitive, flexibility in use, and tolerance for error. Key points to look for in spatial organization include:

- **Destination zones.** Determine if a larger building or building complex has destination zones, which are the easily-identified areas in a building. Examples of this might include a food court in a shopping mall or a cafeteria or central atrium in an office complex. Destination zones can be useful in designating areas for sheltering people within the building and for providing orientation points in giving directions; they should be clearly marked and discussed during emergency evacuation practices.
- **Equitable means of accessible exit.** The same options for getting out of a building should be available for all of the population, including those with disabilities. While it is allowable by building codes, providing alternate accessible emergency exits can be very confusing. To avoid confusion, every emergency exit should be accessible. If it is impossible to make the exit accessible, on the second floor of the building for example, safe areas for sheltering people within that area need to be provided. These areas

should be located in close proximity to the inaccessible exits to permit better visibility of individuals who might need assistance.

- **Spatial overview opportunities.** Does the building have spatial overview opportunities, which are places where one can “look over” the area. Spatial overview opportunities allow people to gain building information quickly about various parts of a building, including exits and corridors that lead to exits as well as paths that lead to destination zones and/or places of shelter within a building, and reduce the possibility of errors during exiting.
- **Spatial layout.** How is the building laid out? Is the layout confusing? Is it easy to get lost? Symmetrically laid out buildings (i.e., one side mirrors the other) need clearly differentiated sides (i.e., the sides need to be clearly marked in different manners). Confusing layouts in which it’s easy to get lost benefit from the judicious use of color, lighting, landmarks, and signage to clearly mark exiting areas and destination zones designated as places of shelter. Also helpful in differentiating spatial layout are architectural features such archways, columns, and windows (and possibly doors) that make a particular space memorable.

## Use of Signs

Signs are useful in communicating necessary information and are an important element for emergency building evacuation related to the Universal Design principle of perceptible information. The following describes building sign placement and desirable characteristics:

- **Placement of signs.** Building information signs, including signs provid-

ing direction to destination zones, should be clearly visible from the path of travel, above eye level, and lit appropriately. Evacuation signs should appear at regular intervals, particularly at decision points, to let people know they're going the right direction.

- **Readability of the information.**

All information signs should be readily legible in adverse conditions. The text of the sign should be large, easily readable, and have a high contrast with the background. The signs should be carefully lit to prevent any glare that causes them to be unreadable. The text should be paired with a graphic image that is clearly understood, a feature that is useful to non-readers. Additionally, raised images, text, and Braille should be incorporated in the sign in a consistent manner. Color should be used only as a reinforcing cue and related to the environment. For example, if there is more than one destination zone and/or exiting area, use signage that is paired with a graphic and reinforced with a color such as orange. The orange color should be obviously repeated in the destination zone as well as the accompanying exit.

## Landmarks

Use of landmarks is important during evacuation and provides useful and accessible building information to people with disabilities. Desirable characteristics of landmarks that help mark a path and make the space memorable include the following:

- **Distinctive landmarks.** Landmarks that are distinct in shape, color, and appropriately lit are memorable and can serve to orient people in the space, as well as provide an effective way to direct them to exits.
- **Types of landmarks.** Distinct destination zones and large artwork can serve as landmarks, especially if they are colorful, well-lit, provide an interactive feature, and contain distinct

architectural features such as decorative columns, archways, or photographs.

- **Landmarks and signs.** Landmarks should be paired with appropriate signage to convey important information and guide evacuation decisions.

## Conclusion

Exiting a building during an emergency can be a difficult experience for anyone. By following the recommendations provided and the principles of universal design, buildings can more readily accommodate the broadest group of users, to the greatest extent possible. Building universally designed exit features into environments not only makes good sense, but also offers the promise of increasing the safety and welfare of all, including persons with disabilities.

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*Keith Christensen is a Senior Research Associate and Landscape Architect with the Center for Persons with Disabilities, Utah State University, Logan. He may be reached at 435/797-3997 or keithc@cpd2.usu.edu. Patricia Salmi is a Research Associate with the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Minneapolis. She may be reached at 612/625-0171 or salm0054@umn.edu.*

## Resources for Information

The following may be useful for further information about disaster preparedness in relation to people with disabilities:

- **Emergency Evacuation: Safe Egress of Persons with Disabilities from Transit Systems ([www.projectaction.org](http://www.projectaction.org)).** This fact sheet provides information for transit agencies and for people with disabilities about planning for safe evacuation from public transportation during an emergency. Prepared by Easter Seals Project ACTION and the National Organization on Disability Emergency Preparedness Initiative.
- **Project Safe EV-AC (<http://evac.icdi.wvu.edu>).** The Web site of this project at West Virginia University has resources for emergency responders as well as people with disabilities and those who support them. The focus is improving evacuation from buildings, vehicles, and other settings during emergencies by providing training materials on the evacuation and accommodation of people with disabilities.
- **U.S. Access Board, Resources on Emergency Preparedness and Evacuation (<http://www.access-board.gov/evac.htm>).** This Web site on emergency preparedness includes extensive resources on accessibility issues in evacuation planning and response. It's operated by the Access Board, a federal agency committed to accessible design, that develops and maintains accessibility requirements for the built environment, transit vehicles, telecommunications equipment, and for electronic and information technology under several different laws, including the Americans with Disabilities Act (ADA).
- **ADA Checklist for Emergency Shelters ([www.ada.gov/pcatoolkit/chap7shelterchk.htm](http://www.ada.gov/pcatoolkit/chap7shelterchk.htm)).** This checklist from the U.S. Department of Justice, Disability Rights Section, evaluates the accessibility of shelters.

## Emergency Preparedness at Home for People with Disabilities: Guidelines

Protecting yourself at home when disaster strikes requires planning by both you and others who live with you for at least 72 hours. This checklist can help you get started.

### Get Information

- Find out how you would be warned of an emergency. If the warning is by means not accessible to you, suggest or arrange alternatives.
- Determine aid that might be available to you in an emergency.
- Contact your local fire department or emergency management office to see if they maintain a register for people with disabilities so help can be provided quickly in an emergency.

*Protecting yourself at home when disaster strikes requires planning by you and others who live with you*

### Create a Plan

- Talk to your landlord, service provider, family and/or roommates to discuss what plans are in place for emergencies that might occur.
- Discuss provisions that have been made to assist you in an emergency.
- Discuss what preparations you can make to prepare yourself for different kinds of emergencies.
- Learn what you will need to know for each of these emergencies (e.g., how to evacuate or shelter-in-place, where emergency equipment is located, where a designated meeting place is, where you will be evacuated to, etc.).
- Learn what to do for each kind of emergency. For example, if you use a wheelchair, can you access the “safe area” for a tornado (usually the basement), or do you need to go to an alternate place?
- Be self-reliant. Assume responsibility for your safety – even if your building has a plan that takes into account your disability.
- Learn escape routes and how to exit the building without help if necessary.
- Establish two evacuation routes in case the primary one is blocked.
- Practice evacuating the building on your own as well as in the building’s drills.
- Determine alternative “safe areas” with input from the fire marshal.
- Arrange how your family can contact you and how you can contact them if you must leave your home suddenly.
- Find a secure place to store things you may need that can be easily accessed in an emergency.
- Obtain and use health and information cards with critical information such as your ID, people to contact, and any medical issues affecting you.
- Determine any special aid you may need from emergency responders in relation to your disability.
- Acquire a cell phone with a GPS. Program in emergency numbers so they can be activated without speech.
- Consider acquiring a medical alert system that will allow you to call for help if you are immobilized.

### Prepare a Disaster Kit

Assemble supplies you might need in an evacuation. Store them in an easy-to-carry container such as a backpack or duffel bag. Tailor this kit to your specific needs. Your emergency kit should include these items:

- Battery-powered radio, flashlights, lighter, candle, matches and extra batteries.
- A first aid kit, medications and copies of prescriptions.
- Water purifying tablets.
- Change of clothing, sturdy shoes, and rain gear.
- Personal hygiene items.
- Special equipment you may need such as augmentative communication equipment, insulin supplies, cane, food and water for sight dog, etc.
- Hearing aid batteries.
- The style and serial numbers of medical devices you use.
- Blanket and a sleeping bag.
- A list of family, physicians, and a relative or friend who should be notified if you are injured, along with a back-up contact person living outside the immediate area.
- Important documents including contacts, ID cards, and bank account numbers, as well as cash.

*Adapted and reprinted with permission from “Emergency Preparedness at Home for People with Disabilities,” published by the Center for Disability and Special Needs Preparedness, Washington, D.C. Retrieved June 6, 2007 from their Web site at [www.disabilitypreparedness.org](http://www.disabilitypreparedness.org). They may also be reached at 202/338-7158, x 201.*

## Getting Ready for an Emergency in Maine: Training By and For Self-Advocates

by Kelly Baston and Laurie Kimball

People with disabilities are among those most likely to be adversely affected in an emergency. Yet, when Adult Developmental Services at the Maine Department of Health and Human Services (DHHS) wanted to offer emergency preparedness training for the people they serve, they were surprised to find very little material out there for this audience. Believing that people with intellectual and developmental disabilities need to learn what to do for themselves to be prepared for a storm, flood or even a pandemic flu, Maine set out to create a co-trainer model that would meet that need.

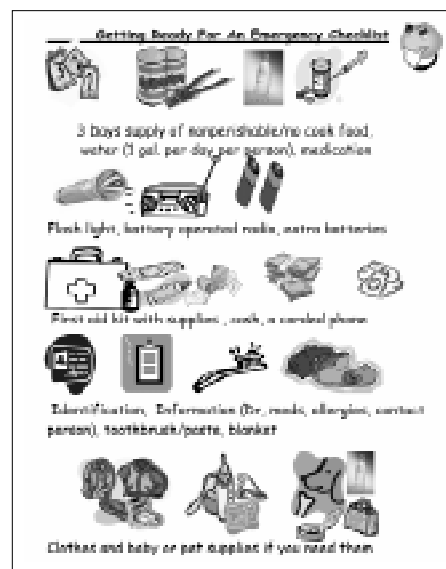
We knew that people with disabilities would be the best creators and teachers of material for our audience, so initially DHHS contracted with Mobius, Inc., an agency that supports people with disabilities, to work with self-advocates to compile material for the curriculum. Maine's self-advocacy group, Speaking Up For Us (SUFU), was approached and SUFU members got involved because they realized the crisis potential if people did not know the facts. In Maine there are regular floods, ice and snow storms, and power outages. SUFU believes self-advocates need to know for themselves what to do when these things happen because knowing what to do can provide the power that helps people to be safe and not panic or be scared. SUFU members were asked to identify the important training topics and some possible consultants/trainers, and interested members were hired as consultants to help refine and co-teach the curriculum with the Regional Training Coordinator for DHHS. A draft PowerPoint slide show was pulled together from available resources on emergency preparedness and brought to self-advocacy groups for comment. Co-trainers selected one concept to discuss for each slide, and chose graphics that would be meaningful. They also created a key, and a consistent

approach in the notes, so trainers who could not read would be able anticipate what was coming up. Trainers reviewed formats for written information recommended in an emergency, and created their own forms based on one from the Red Cross. The result, *Getting Ready for an Emergency*, is a presenter's manual and PowerPoint slide show for a workshop co-taught by two trainers, at least one of whom is an individual labeled with an intellectual disability.

At the end of each workshop, participants are familiar with the basic aspects of emergency preparedness: identifying an emergency, the importance of being prepared, listing items important to have in an emergency, how to decide about evacuation, and important written information to complete. Participants receive "go bags" purchased by DHHS to use to evacuate if they need to. They also leave with a graphic list of selections to put in a "go bag" or an emergency kit at home.

Training has been conducted in about 15 locations across the state, reaching more than 100 self-advocates, family members and supporters. The response at training events has been quite favorable, with most participants asking for more opportunities to learn. While it is difficult to gauge the effectiveness of the training at this point because it's so new, during a recent storm with high winds, flooding, and power outages the DHHS regional office did not receive the usual deluge of calls asking for help figuring out what to do or how to get ready. While this is good news, DHHS is looking to other ways to measure and build upon the outcomes of the workshops.

Although the first round of training targeted individuals who live alone, it was clear from the start that everyone can benefit from the information. Some support staff who were present were misinformed about what to do, and they were able to learn accurate information.



A handout from "Getting Ready for an Emergency."

On other occasions, participants told of times their staff became incapacitated in an emergency and they needed to act to protect them both. Whether or not people have staff or full-time support, they need to know for themselves so they will be safe and won't get stuck or be scared. For these reasons, both SUFU and DHHS would like to expand the audience for this training in the coming year and are currently discussing the best way to deliver it to as many people in as many locations as possible. We anticipate offering workshops at regional SUFU conferences, as well as to local self-advocacy groups. The curriculum is also being made available to others who would like to offer it in their areas. We expect the instructor's manual and PowerPoint slides to be available online for people to download in Fall 2007 at [www.maine.gov/dhhs/bh/index.html](http://www.maine.gov/dhhs/bh/index.html).

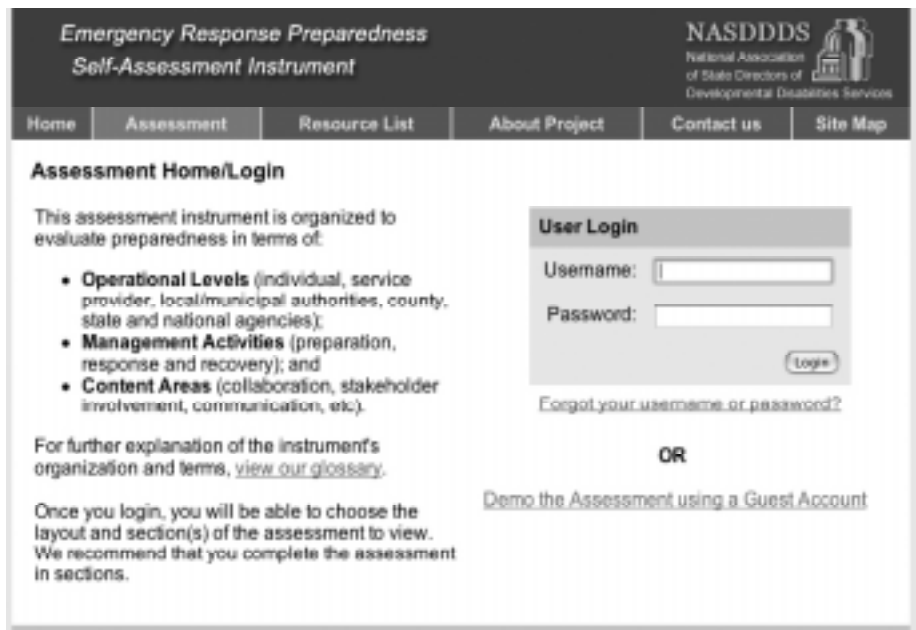
*Kelly Baston is a member of Speaking Up For Us of Maine, and a co-trainer for the curriculum. Laurie Kimball is Training Coordinator with Adult Developmental Services, Maine DHHS, Portland. They may be reached at 207/822-0271 or [laurie.kimball@maine.gov](mailto:laurie.kimball@maine.gov).*

## Emergency Preparedness: A New Tool for Assessing State's Readiness

by Charles Moseley and Patricia Salmi

In the days and weeks following the devastation wrought by hurricanes Katrina and Rita, state developmental disabilities agencies across the country stepped forward with offers to provide staffing, housing, funding, and other direct assistance to the Gulf Coast states. The National Association of State Directors of Developmental Disabilities Services (NASDDDS) received countless calls and e-mails from members with offers of assistance. A special membership teleconference was hurriedly convened to inform the state agency officials of the actions they could take to assist their sister agencies. During this call, state leaders learned of the extreme challenges facing the affected states, and began to identify critical emergency preparedness lessons that could be learned by all state disability agencies from the tragic aftermath of these storms.

In the weeks that followed NASDDDS began compiling existing state and national emergency preparedness materials, recommendations, and best practice examples to assist member state agency officials as they assessed their emergency response plans and capabilities. While a great deal of resource material was available, it soon became clear that most of the information on preparedness was of limited applicability to the needs of individuals with intellectual disabilities and, as a result, of little use to state developmental disability agency officials. In response, the NASDDDS board of directors launched an initiative to develop new tools to assist member agency officials to design and build state-specific emergency preparedness plans that address the unique characteristics and needs of individuals with intellectual and developmental disabilities. The outcome of that work is the Web-based *NASDDDS Emergency Response Preparedness Self-Assessment Instrument* (<http://rtc.umn.edu/erp/main>).



The opening screen of the online self-assessment instrument.

The *NASDDDS Emergency Response Preparedness Self-Assessment Instrument* is a flexible self-assessment tool for state officials to use to determine the extent to which their agency's current emergency preparedness plans address issues that are critical to the support and protection of individuals with intellectual and developmental disabilities during periods of disaster or crisis. The instrument was developed by a partnership between NASDDDS and the Research and Training Center on Community Living at the University of Minnesota, under the guidance of an *ad hoc* advisory committee composed of nine state developmental disability agency directors and other officials with extensive emergency planning experience. The instrument has been designed with the following characteristics as central features: (a) it is easy to use and applicable to the range of programs and services furnished by state developmental disabilities agencies; (b) it fits within the broader context of emergency preparedness plans developed by state

and federal emergency management agencies, statewide mutual aid compacts, and national and local authorities; and (c) it fully addresses the challenges associated with protecting disaster victims and potential victims with intellectual and developmental disabilities who live and work in a wide range of community settings and situations.

The organization of the instrument reflects the need for it to be used by states that have a variety of disaster preparedness planning approaches. Some states, for example, first organize their planning according to management activities, such as preparing, responding and recovering. Others plan around operational levels that describe the responsibilities of individuals, service providers, and government entities. And other states structure their emergency response planning around specific content areas such as collaboration, communication, and transportation. The instrument therefore is structured according to the following categories, allowing users to

directly access the assessment format that best meets their needs:

- **Management Activities:** Preparing, responding, recovering.
- **Operational Levels:** Individual, service provider, local/municipal authorities, county/regional authorities, state agencies, national emergency agencies and entities.
- **Content Areas:** Collaboration with state emergency management agency activities; stakeholder involvement; communication and coordination; workforce (duties, roles, responsibilities, availability, training needs); power generation (heat, light, air conditioning, refrigeration); transportation (before, during, after); identification and tracking of clients and staff members; evacuation; specialized supports for individuals with developmental disabilities; and shelter.

In contrast to text-based materials that provide a single format for all users, the NASDDDS instrument is a Web-based tool that can be easily adapted to the specific organizational format of a state's emergency preparedness plans. All survey items are placed in a searchable database that permits users to rearrange the format to best meet their needs. Structuring the self-assessment in this way offers a simple and straightforward approach that makes it easier to access the information both across and within categories. Rather than having to page through the entire document one section at a time, a user can "click" on a level – "preparing" for example – and be able to access all items pertaining to "preparing" across all operational levels and content areas. Users can follow the questions from one category to another or navigate to a different section altogether. Links to relevant resource materials are embedded within each question so that users have immediate access to extensive references and additional information.

Users begin working with the tool by selecting one of the three initial organizing patterns (i.e., Operational Levels, Management Activities, or Content

Areas). They next identify the specific areas to be reviewed within those categories. Then, the program generates a series of questions regarding the extent to which the various emergency response plans address a particular issue. Users are asked to indicate whether the topic being described is (a) adequately addressed by their state's emergency planning documents, (b) addressed but needs improvement, (c) is not addressed, or (d) the user does not know. Users are then able to select one of the following for each question: "Flag this item for future action," "comment about my state's readiness to address this issue," "view supporting resources for this evaluation statement," or "make comments." The program keeps track of the answers provided in the self-assessment and provides a summary for each specific area as well as an overall summary report.

The instrument has been field-tested in six states and will be available for access online by all states in early September 2007. Although developed for the use of state developmental disability agency officials, the instrument's broad scope, comprehensiveness, and ease of use has earned it high praise from others involved in the field-testing process, including provider agency officials and other stakeholders. State agencies, community service providers, and others interested in exploring its usefulness for evaluating their emergency preparedness plans in relation to individuals with intellectual and developmental disabilities can find more information, as well as a demonstration version of the instrument, at <http://rtc.umn.edu/erp/main>.

*Charles Moseley is Director of Special Projects, National Association of State Directors of Developmental Disabilities Services, Alexandria, Virginia. He may be reached at 703/683-4202 or [moseley@nasddds.org](mailto:moseley@nasddds.org). Patricia Salmi is a Research Associate with the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Minneapolis. She may be reached at 612/625-0171 or [salm0054@umn.edu](mailto:salm0054@umn.edu).*

## Who's in Charge? Locating Emergency Planning Agencies in Your Area

*Individuals, families, and organizations who want to learn more about emergency plans for their communities, and about how to have a voice in the planning process, may find the following resources useful in locating those who are in charge:*

- **Ready America ([www.ready.gov](http://www.ready.gov)).** This Web site of the Department of Homeland Security includes an interactive map that leads to state and local government resources with information on preparedness in their areas.

- **National Organization on Disability's Interactive Map of Disability and Emergency Preparedness Resources ([www.nod.org/EPIResources/interactive\\_map.html](http://www.nod.org/EPIResources/interactive_map.html)).** This Web resource of N.O.D.'s Emergency Preparedness Initiative is an interactive online map of federal, regional, state, and local disability and related emergency management resources. Users can click on the map to view a list of links to disability and emergency preparedness resources in their states.

- **Citizen Corps ([www.citizen corps.gov](http://www.citizen corps.gov)).** Citizen Corps is the Department of Homeland Security's grassroots effort to provide opportunities for citizens to get emergency response training, participate in community exercises, and volunteer to support local first responders. These opportunities are offered through state and local Citizens Corps Councils. This Web site includes links to the local and state councils across the country as well as to partner programs.

- **PandemicFlu.gov ([www.pandemicflu.gov](http://www.pandemicflu.gov)).** This Web site of the U.S. Department of Health and Human Services includes an interactive map with links to each state's pandemic planning information and contacts, along with other information.

## ***Katrina is Not Over: Stories From the Arc of Mississippi***

by Matt Nalker

I was asked a few days ago if I was happy Katrina was over. The person who asked me that question had no clue what he was saying. It was clear to me he was not affected by the storm nor did he have anyone close to him affected or he would never have uttered such an ignorant statement. People lost everything!

A lot of people are still living in FEMA trailers, mucking out their homes with little to no help. People with disabilities are still on extended stays with other

***Some thought a man with disabilities wanting to spend his money on camping supplies during hurricane recovery was silly, but seeing looters taking off with others' sentimental belongings it made perfect sense that he would camp out to protect his possessions.***

family members or sister organizations further up state, their homes as they knew them never to be the same. Some of the luckier ones who got only eight feet of water in their homes are able to get back to normal after stripping the house down to the studs and getting the proper inspection then re-sheetrocking and insulating and basically rebuilding the entire home while living in a FEMA trailer in the driveway and, yes, truly considering yourself lucky. Normal life has an entirely new meaning to most people affected by the storm.

Today, normal for our local chapter of The Arc in Gulfport Mississippi means meeting regularly to discuss the need to charge for services they were able to provide for free for 50 years. Although their sheltered workshop only sustained minor damage, the city of Gulfport and many, many of its members lost most of everything they owned. Let that marinate for a minute – “Everything they owned!” The priority of the day for almost a year or longer for many of these people was not disability policy or quality of services for the people we represent, it was food and shelter and basic necessities for all. Now that was true inclusion.

I remember a call in the office a few months after the storm reporting that a man with a cognitive disability and a wheelchair user used his FEMA dollars to buy camping gear. The well-intended reporter was aghast that someone in his condition would not use the money to better himself in other ways. As a person-centered organization we went out and actually asked the man what he was doing and if we could offer assistance in doing it. He had been in a shelter watching the news and saw the many reports of looters taking things from the rubble; he was not going to let that happen to him. When we arrived he was determined to camp out at his home-site and spend his days rolling through the rubble, stacking up pictures, furniture, clothes and other various stuff that was his before the storm. He had the need to protect his stuff and there were people who believed that because he had a disability, he should not be allowed to do so. In the end, he purchased his camping supplies, and ended up camping out at his home and protecting his property – just as so many of the other Katrina victims did. The only difference in his case and his neighbors, was that he was there with the proper supports who ensured his safety and independence.

In another case we were able to help a family of 11 who fled Louisiana and evacuated to our city. The mother, son and daughter, along with their 75-year-old aunt, spent three days on the road sleeping, eating, and barely surviving a 200-mile journey into the unknown. When they arrived in Jackson they found themselves in a hotel for one night and then kicked out due to insufficient funds to stay. They quickly reunited with the rest of their family in another hotel, sharing space with the other six members in two hotel rooms for the eleven. Just as before, the management needed them to leave due to insufficient funds. Back in survival mode they met with management to no avail. While in the hotel office they met a past advocate of The Arc of Mississippi who was there with her church handing out bottled water. She was told their story and we were called. The son was a wheelchair user in dire need of assistance. You see, they left Louisiana in the middle of the night and forgot his foot pegs for his chair. His feet had been dangling for days and the pressure had swollen his feet to basketball size proportion. Not being from Jackson, and still being in survival mode from sleeping in the car for days and not knowing about the status of their home back in Louisiana, this family was in dire straits. As a mission run person-centered organization, we were able to help support this family for 10 months in their own hotel room, get them the medical attention the entire family needed, and most importantly make several trips back home to get their home ready for their return to Louisiana, where they live today. This family and so many others have profoundly impacted the supports and services we provide as a primarily advocacy organization.

The purpose of this article is to give a perspective from an agency that has experienced recurring disaster preparation

and recovery, and to tell about the lessons learned that could benefit other agencies. My lesson is to always be person-centered and find out for yourself what the real issues are so you can help make proper decisions to help with the situation. Some thought that a man wanting to spend his money on camping supplies during hurricane recovery was silly, but driving down the demolished streets of Bay St. Lewis and seeing the

looters taking off with others' sentimental belongings, it made perfect sense that he would want to camp out to protect his possessions. Some may assume that 10 months is far too long to stay in a hotel when your home was damaged, but until you visit the devastation and see for yourself what thousands of homes still look like, you cannot understand. I'm glad we were able to be honest about what we were able to provide

and that we were able to partner with many agencies to experience the outcomes we all wanted for the people we still get to represent.

Katrina is NOT over and we are still learning lessons from it.

*Matt Nalker is Executive Director of The Arc of Mississippi, Jackson. He may be reached at 601/982-1180 or by e-mail at matt@arcms.org.*

## **FIVES: Facility Information, Vacancy, and Evacuation System for Long-Term Care Facilities in Texas**

*When Hurricane Katrina came ashore in Louisiana in August 2005, it left hundreds of thousands of Louisianans homeless. Many of those displaced by the storm ended up in Texas shelters, in what the Federal Emergency Management Agency (FEMA) called "the largest relocation in American history." Many others, some of whom were medically fragile, ended up in hospitals and nursing homes.*

*Less than a month later, Hurricane Rita came ashore on the Texas-Louisiana coast. This time, hundreds of thousands of Texans evacuated, but with shelters and health care facilities already filled with displaced people from Louisiana, available space was at a premium. While state emergency responders, local jurisdictions, and response organizations like the Red Cross worked together to develop shelter space for the general public, employees of the Texas Department of Aging and Disability Services (DADS) worked day and night to locate appropriate shelter for evacuees in need of long-term care.*

*DADS' employees called thousands of long-term care facilities daily to determine their status. Staff called facilities near the coast to ensure that they had viable evacuation plans, and inland facilities were polled to find vacant space that was appropriate for use by evacuating facilities. While this procedure*

*worked at an acceptable level, it was extremely labor-intensive, and, because of time constraints, facilities were contacted only once daily, except in unusual situations.*

*Once the worst of the crisis was past, DADS staff reviewed their response efforts to see how the job might be done better in the future. One area in which the need for improvement was glaring was communication with, and collection of information from, long-term care facilities.*

*As part of the effort to streamline agency-facility communication, DADS developed a Web-based "Facility Inventory, Verification, and Evacuation Status (FIVES)" application. FIVES is designed to help long-term care facilities help each other during large-scale disaster events that require facilities to evacuate their residents. (See <http://fives.dads.state.tx.us/>).*

*Using FIVES, providers can record their vacancies as well as information related to their evacuation status. Users can generate online, real-time FIVES reports showing Texas vacancies by provider type, county, city, and other variables. With this information, providers that need to evacuate their facilities can easily identify other facilities that have the capacity to accept evacuees.*

*Each facility is responsible for its own*

*evacuation plan. During an evacuation event, it is the responsibility of each facility to use FIVES to do the following:*

- *Update its vacancy data.*
- *Identify potential partners that are able to accept evacuees.*
- *Make arrangements with those partners to transfer residents.*
- *Update their evacuation status when the facility is evacuated.*

*DADS expects long-term care facilities to become familiar with the FIVES system before the next hurricane or emergency occurs, and to practice using it by entering their current number of vacancies. Although DADS has not yet used FIVES during an evacuation event, DADS incorporated FIVES into a functional hurricane exercise in June 2007, and more than 600 facilities accessed the site and entered their facility data.*

*Contributed by Bo Platt, Disaster Coordinator with the Texas Department of Aging and Disability Services, Austin, Texas. He may be reached at 512/438-5744 or at bo.platt@dads.state.tx.us.*

## Responding to Disaster: Lessons From Louisiana's Disability Services System

by Kathy Kliebert

On August 27, 2005 as Hurricane Katrina threatened the southeastern coast of Louisiana, developmental disability service providers felt prepared for the storm and began implementing evacuation plans. Less than a month later, Hurricane Rita hit the southwestern coast. Our developmental disabilities agencies had significant experience and practice in hurricane evacuation and had disaster plans that were considered comprehensive and effective. These plans included

*What neither the developmental disabilities services system, nor most of Louisiana's citizens, were prepared for was the aftermath of the two storms.*

detailed procedures regarding staff responses and multiple assurances for health and safety of people receiving services. What neither the developmental disabilities services system, nor most of Louisiana's citizens, were prepared for was the aftermath of the two storms.

### **After the Hurricanes**

Following the storms, communication from almost every source failed, making it virtually impossible for people to connect to their family members and the outside world. Important information that needed to be dispersed to people with disabilities, their families, providers and others could not be relayed. Support coordinators could not get in touch with participants; participants could not get in

touch with providers. Agencies did not have adequate tracking systems to ascertain the current location of people. People who went to shelters often moved to other locations before we were able to assess, take action, and track these subsequent moves. The lack of available communication and the inability to track and coordinate program participants, providers, and staff significantly impaired the ability to reconnect people to the supports and services they needed. Almost a week after the initial hurricane, we were still unable to locate over 75% of people receiving waiver services and 50% of those receiving ICF/DD services. Four months later, we still had not accurately identified locations of 13% of waiver participants.

People who were not receiving services or who had limited family support struggled both in the evacuation process and in the aftermath. Transportation for people with physical disabilities was severely lacking, resulting in people remaining in homes with tragic consequences. People without identification were transported to unknown destinations; many were unable to provide information to assist with their identification and service provision. People were transported without necessary medical supplies and adaptive equipment. People were placed in nursing homes because of the lack of more appropriate shelter. Efforts to move people out of shelters were stymied by expensive or unavailable housing. Accessible housing was no longer an option. Over 20 months later, we still have people with developmental disabilities living in other states who desperately want to return to Louisiana; however, they are unable to obtain housing. No agency or system in Louisiana was prepared for the enormity of the disaster and our ability to respond was often slow and frustrating.

### **The State Agency Response**

At the Office for Citizens with Developmental Disabilities the challenges we faced in responding to these storms were overwhelming. First, we quickly recognized our essential functions during this disaster were very different from our traditional ones, and entirely new roles were established for almost every employee in our office. Our staff's efforts became focused on the following:

- Location and relocation of people with developmental disabilities.
- Reconnection of people to services.
- Management of prolonged evacuations of large institutions.
- Receipt and distribution of donations.
- Reestablishment of local offices.
- Distribution of emergency resources.
- Crisis response to those in shelters who have disabilities and mental health issues.

My personal efforts were focused on directing these activities, as well as working with our Medicaid bureau and coordinating with federal agencies on emergency rules, policy exceptions, and other administrative tasks to ensure people could continue to receive services and providers could continue to be paid for services. The disaster made it impossible to follow previously established rules, and exceptions were made on almost a daily basis. Louisiana is fortunate that the Medicaid agency is in the same department as our agency, so we were able to work collaboratively to devise creative solutions to assure access to care and the continuity of services. No statewide disability service system had ever been faced with such extensive dispersion of people, loss of direct support staff, extended shelter stays, loss of infrastructure, non-functional communication, extended evacuations, and loss of providers and housing.

## What We've Learned

The experiences of Katrina and Rita taught us that we must have a comprehensive disaster response system that can address each of the realities listed above. We recognized that there are at least seven essential components of this comprehensive response:

- *Policies and Procedures.* One of the key elements of an effective response is to have policies and procedures that clearly delineate and require specific responses by our developmental disability state and local governmental entities, providers, support coordinators, family members and advocacy agencies. Every stakeholder in the system must take responsibility for some part of the response effort in order for it to be effective. As we have moved forward in our recovery phase, we directed a statewide effort of individuals with disabilities, family members, providers, advocates and state employees to re-vamp our disaster strategies by utilizing our “lessons learned.” These groups have developed best practices manuals for providers and case managers. They also developed a “Take and Go Emergency Booklet” for people with disabilities and their families. We revised our statewide agency procedures to include all the things we learned about the many failures in communication systems, tracking systems, records management, billing systems, rules and regulations. Additionally, revisions of our new response system have required increased monitoring of individual and provider disaster preparations in order to assure that new procedures have incorporated newly established best practices.
- *Communication Systems.* It is critical that the response plan include procedures which will provide immediate communication methods that are practical and effective for stakeholders. We established new communication strategies to include more of the satellite, Internet and text-messaging systems since these worked well during the storms.
- *Effective Transportation and Shelter Access.* An effective system response must assure that wheelchair accessible transportation is immediately available to assist in evacuation from affected areas. People with disabilities must be able to immediately access living situations such as shelters or other temporary living environments. Evacuation sites that can be easily accessed and utilized for extended periods of time are being designed in Louisiana and should be a part of any effective plan.
- *Tracking System.* An efficient data system that can track and locate people for reconnection to family and services is essential to a viable, successful plan. We are working to develop an innovative tracking system that will track people from place to place in a non-intrusive manner and will work for those that have limited communication.
- *Repatriation Options.* The ability to have emergency contingency plans for community based options in time of disaster must be addressed. It is critical to have access to emergency waiver or other community living options so that people can utilize those when family and community support systems disintegrate in the face of disaster. The lack of those options will ultimately mean unnecessary utilization of nursing homes and large facilities. Additionally, the ever-expanding barrier of accessible and affordable housing is an issue that must be faced if we are to be able to have a realistic plan for moving people back into disaster areas which have sustained significant loss of housing.
- *Location of Residential Settings.* Our disaster planning now includes a critical review of the areas in which state funded public and private residential settings are located in order to assure not only safe evacuation, but also health and safety in the aftermath. This planning resulted in the conversion of a large developmental

center (serving 242 people) which was located in the “Red Zone (Critical flooding zone)” to a community based operation that serves 32 people in supported living and community homes. Review and consideration of relocating residential sites that are high risk for significant disaster is an excellent preventative strategy to consider.

- *Workforce.* The issue of our dwindling direct support workforce becomes even more critical in disaster situations. Response plans should include carefully planned disaster pay schedules as well as recruitment and retention strategies when the workforce leaves the area or is unable or unwilling to remain in an evacuation site.

This list is not all-inclusive; it is just an overview of those elements we found critical based on our experiences.

## Conclusion

It is important to note that this article does not refer to the damaging winds or extensive flooding that were part of this particular disaster. Louisiana’s disaster really occurred because of the destruction of infrastructure. Such destruction could happen anywhere and from a number of causes. Our developmental disabilities services system sustained significant impact, and we are working to rebuild it and improve our disaster response, in the midst of a long-term care reform effort. While these challenges seem overwhelming, Louisiana is fortunate to have a committed group of stakeholders that includes public and private providers, self-advocates, advocacy groups, and dedicated state employees. We know that they can be relied on to work with us to not only rebuild our system, but also to make it stronger and more responsive to people.

*Kathy Kliebert is Assistant Secretary of the Office for Citizens with Developmental Disabilities, Baton Rouge, Louisiana. She may be reached at 225/342-0095 or [kklieber@dhh.la.gov](mailto:kklieber@dhh.la.gov).*

## ***Improving Disaster Preparedness: Strategies from California's Disability Services System***

by Carol Risley

There is no single best approach to addressing the needs of people with disabilities in preparing for, responding to, and recovering from a disaster. There is much to do because of the historic lack of attention – so much that the task often appears overwhelming, leading to lack of any action at all. And the larger the population, the more daunting the task. Nonetheless, it is not a matter of if a disaster will occur, but when. Thus, it's not a question of what to do, but rather the need is to begin to do something to help people prepare themselves, and to help existing emergency response systems to modify themselves to meet the needs of people with disabilities in our communities and states.

***To improve communications within and between the state and local services systems, the developmental services system is becoming part of an existing automatic emergency alert system currently in place for public health emergencies.***

California's Department of Developmental Services provides supports and services to 212,000 people with developmental disabilities, all of whom (but for 2,800) live and receive services and supports in a wide range of community settings. Each person has a service coordinator provided through a network of non-profit regional centers, along with direct service providers to support them. While some of the services and support settings

are licensed facilities, at least 22,000 people receive supported or independent living services, thus they may not be with other people 24 hours a day. For those individuals there is an urgent need to become personally prepared for an emergency and able to either support themselves in a shelter-in-place situation or to transport to a shelter. For those living in licensed facilities, there is a need for those facilities to ensure the preparedness of those they serve and their staff.

In response to this range of needs, California is pursuing several strategies:

- To improve communications within and between the state and local services systems, the developmental services system is becoming part of an existing automatic emergency alert system currently in place for public health emergencies. This system will provide for timely and updated emergency/disaster alerts, both from state and local support systems. A key benefit in joining this network is that it will allow for alerts coming down from the State to local entities, but more importantly for alerts to be issued from local government to the network of non-profit regional centers, thus incorporating the developmental services system into local emergency response systems. As all emergencies are local, integration of the system of services supporting people with disabilities will have the effect of bringing more attention to their needs in local planning and response activities. Further, the system is adding communications technology to enhance the effectiveness of communications when traditional systems are not functioning. In addition to land lines, cell phones, and e-mail, California is adding satellite telephones and will be exploring options for use of HAM radio networks.
- California has just completed a comprehensive review of existing emergency preparedness plans in the developmental services system and identified many best practices as well as areas that require additional attention. Working with the regional centers, best practices will be shared among centers and providers, and guidance will be developed to assure plans address all key areas needed to maximize coordination, readiness, response, and recovery. Because of the vast size and population of California it is essential that plans address coordination between centers in the event one or more centers are rendered inoperable, so others can assume responsibility for supporting the consumers during the recovery process.
- Working with the California Office of Emergency Services, for the first time consumers with physical, sensory and cognitive disabilities are becoming part of the Standardized Emergency Management System (SEMS) working committees, thus integrating their needs and input into existing planning and response efforts.

On the local level, many consumer organizations, regional centers, and providers are engaged in a variety of activities addressing the eventual emergency/disaster that will impact their lives. Regional centers, in cooperation with local first responders, are sponsoring emergency preparedness meetings for consumers and providers, thus bringing the emergency response systems into conversation with people with disabilities. As available and accessible transportation is a key to evacuation in any disaster, some cities are conducting planning meetings with people with disabilities to better understand their needs and identify available transit resources. These conversations have enlightened both sides as to

what might be expected from traditional transit systems and promoted the development of creative strategies. Use of transit system data to identify riders is one potential way to address the concept of registries for people with disabilities without having to develop new, costly and controversial systems. Some providers, as part of their service design, are discussing emergency preparedness and assisting consumers to better understand the issues and how to prepare.

Areas in which further widespread work is needed include the following:

- Development and distribution of consumer-friendly written and video materials for use in thinking about and creating a personal plan to ensure safety and security, and to assist consumers during an emergency or disaster. Implementation of consumer readiness planning needs to occur with assistance from peers,

***Working with the California Office of Emergency Services, for the first time consumers with physical, sensory, and cognitive disabilities are becoming part of the Standardized Emergency Management System (SEMS) working committees.***

families, service coordinators, advocates, service providers, and friends so that each person has a personal emergency preparedness plan. It is not enough to simply gather and distribute commercially prepared materials about emergency planning, hang them on the refrigerator and expect understanding and implementa-

tion in an emergency. Plans must be developed by and with consumers to be realistic and ensure ownership, and then they must be practiced so they become routine.

- The availability of “to go” kits to assist with sheltering-in-place or sheltering elsewhere for people living in independent situations. History shows that staff who normally support consumers often will not be available or able to provide supports during an emergency situation, thus consumers may be on their own for some period of time. Consumers should have kits with essential supplies and information about the individual and their needs; the kits will serve as tools to maintain their health and safety and enhance the likelihood of appropriate treatment by emergency personnel. One of the greatest barriers in assuring these kits meet the needs of consumers is related to maintaining an up-to-date, adequate supply of necessary pharmaceuticals. Most consumers use Medicaid or Medicare to address their medical needs and California needs to explore how that system can become more flexible and allow for these essential kit items.

This is by no means a comprehensive report on all the activities being pursued at many levels to enhance the readiness, survivability, and recovery for people with disabilities when the next emergency hits California. It is, however, an indication that the issue has become a priority, and with continued consumer leadership and support from the service system will become part of our way of life, not just remembered after each event occurs.

*Carol Risley is Chief of the Department of Developmental Services, Office of Human Rights and Advocacy Services, Sacramento, California. She may be reached at 916/654-1888 or [crisley@dds.ca.gov](mailto:crisley@dds.ca.gov).*

## **Resources for Information**

*The following may be useful for further information about disaster preparedness in relation to people with disabilities:*

- **Disaster Resources for People with Disabilities and Emergency Managers ([www.jik.com/disaster.html](http://www.jik.com/disaster.html)).** This Web site from disability policy consultant June Isaacson Kailes provides extensive resources on individual preparedness; legal issues and disability rights; planning, policy, and training; and the role of community organizations. It also includes a working document on creation of state level coordinator positions for facilitating inclusion of people with disabilities and disability organizations in all areas of emergency planning and response.

- **PrepareNow.Org ([www.preparenow.org](http://www.preparenow.org)).** This Web site of PrepareNow Partners, an alliance of San Francisco Bay Area groups supporting the needs of vulnerable people in disaster preparedness/response, has an information library of practical tips in English and Spanish for use by service providers, advocates, individuals and families. It includes tips for people with specific types of disabilities.

- **Gender and Disaster Network ([www.gdnonline.org](http://www.gdnonline.org)).** This Web site contains extensive international resources on the experiences of women and girls in disasters, ways in which they often experience additional vulnerability (including gender-based violence), and gender inequality in disaster planning and recovery. It also includes stories of women's leadership in recovery efforts.

- **National Organization on Disability Emergency Preparedness Initiative ([www.nod.org/emergency](http://www.nod.org/emergency); 202/293-5960).** The Web site of this N.O.D. initiative has extensive resources for people with disabilities, community leaders, emergency managers/planners, and disability service providers.

## Establishing Information-Sharing Partnerships: The Connecticut Approach

by Daniel A. Micari and Dennis J. Mitchell

The events of September 11, 2001 focused public attention on existing emergency preparedness, response, and recovery practices. Government entities across the country were asked to review, and if necessary, develop and/or revise their response to a catastrophic event. In Connecticut, the governor asked each state agency to develop comprehensive plans to address such events.

*Innovative and balanced strategies that respect the individual's right to privacy, while addressing their needs in a time of crisis, can be arrived at.*

People involved in emergency preparedness and response must appreciate the likelihood that many community members may have cognitive disabilities that might diminish their ability to understand or respond to an emergency. With so many community members having a disability that may impact their ability to independently execute appropriate self-preservation actions, planning for emergencies and their aftermath is a challenging undertaking. In support of this effort, many of Connecticut's 169 towns, supported by the state's Department of Emergency Management and Homeland Security (DEMHS), have developed or are considering developing a *Special Needs Registry*.

A Special Needs Registry represents a method whereby people indicating their need for special support during an emergency voluntarily list themselves, informing the local emergency authority of their presence. Towns employ such registries as an information source to support pre-

emergency planning efforts. Registries are also used to alert citizens of impending emergencies. Additionally, emergency responders use registries to identify and prioritize emergency service efforts, such as evacuation, transportation, sheltering, and health care during and following a disaster. Community emergency management personnel in Connecticut consider such registries an extremely useful tool.

The Connecticut Department of Mental Retardation (DMR) provides services and supports to over 19,000 individuals and their families through a network of public and private providers. DMR realized early on that our support role, in the event of an emergency, could include the sharing of clients' Protected Health Information with state and municipal emergency response personnel. Additionally, and perhaps more importantly, it would be essential for state and local emergency responders to have access to such information prior to an emergency event. Emergency management officials' ability to access and analyze this information would be essential to the development of local emergency plans that would be responsive to the needs of all citizens.

To bridge any information gaps about the special needs of our clientele in an emergency, DMR and DEMHS established a collaborative relationship in 2002. Since then, DMR has participated in over a dozen DEMHS emergency drills associated with nuclear safety, homeland security, and natural disasters. At each, DMR brings to the attention of state, local, and/or federal emergency personnel the emergency management needs of the clients of the department. Additionally, a DMR Emergency Management Liaison Team is continually present at the DEMHS Emergency Operations Center during emergency management events.

Also in 2002, DMR developed a Special Operations Plan for Emergency Relocation for persons served in group resi-

dences and day programs operated or funded by DMR. The plan has been tested during local, state and federal emergency management exercises. Some key components of it are:

- *Emergency Individual Fact Sheet* with critical information about the person, should they need to be evacuated and/or relocated. It includes the names and addresses of the individual, their physician, and their pharmacy; as well as critical dietary, medical and other information. In addition, a Medication Administration Record (e.g., Kardex) is transported with the individual at the time of relocation.
- *Individual Identification Badge* to be attached to the individual's clothing. It is a reduced copy of the Emergency Individual Fact Sheet with the person's photograph. The badge contains information necessary to insure their safety should they be in the care of others who do not know them.
- *DMR's Emergency Management Database* containing essential emergency information regarding clients of the department and service providers. It is a means for DMR to establish and maintain operational communications and continual access to vital information during a widespread emergency or significant disaster that could threaten the health and safety of those we serve. It is updated monthly, and certain information shared monthly with DEMHS, who shares it with municipal emergency management directors.

Additionally, DMR, with the support of DEMHS, has surveyed municipal emergency management directors as to what information about people they might need to plan for and execute emergency evacuation and relocation. Survey results will help shape information release forms to be signed by department clientele, authorizing DMR to release information

*[Micari & Mitchell, continued on page 34]*

## Preparing for Pandemic Flu: A Minneapolis Congregation's First Steps

by Bill Weir

In 2006, the First Unitarian Society of Minneapolis created a standing committee on emergency preparedness, which I chair. The committee believes that the principal threat for which most people are not prepared is a pandemic influenza outbreak, commonly called "bird flu" or "avian influenza." Because of this concern, the task force has two main goals: 1) to protect the people in our First Unitarian Society community from the risk of bird flu, and 2) to explore ways to serve our members in the event of a bird flu pandemic.

*The committee believes that the principal threat for which most people are not prepared is a pandemic influenza outbreak.*

What is the threat? If pandemic flu develops, the Minnesota Department of Health projection in a worst-case scenario is that 1.25 million Minnesotans could become ill, with 20,000 deaths (Hull, 2006). The number of sick would significantly overwhelm the healthcare system. In light of that, our key concern is how to best help our congregation of people with and without disabilities become adequately prepared, and to encourage preparedness within our denomination. Among the steps we've taken toward that end are the following:

- Our committee originated a Bird Flu E-mail Discussion List that has been publicized throughout our denomination as a place where participants can discuss how congregations and individual members can better pre-

pare for a possible bird flu pandemic. It is also a place to share articles and information about pandemic influenza. (The list sign-up is at <http://lists.muusja.org/mailman/listinfo/birdflu>).

- One of our members, Peter Raynor who is also a professor of Public Health, has drafted a Pandemic Flu Planning Overview, which continues to be reviewed, updated and circulated for comment within our committee and to interested others via the e-mail discussion list. The overview identifies steps the congregation could take at each of five phases: 1) pre-pandemic (now), 2) circulating animal virus in state/region with potential human risk, 3) single or limited cases in humans in state or region with no human-to-human transmission, 4) single or limited cases in humans in the U.S. with low human-to-human transmission, and 5) widespread cases anywhere with high human-to-human transmission.
- Members of our committee and congregation have participated in emergency preparedness activities in the wider community. For instance, we had a representative on the statewide advisory group for CodeReady, the public information campaign rolled out in May 2007 by the State and its many private-sector partners to improve readiness to cope with all hazards, including pandemic flu, throughout the state (for more information see [www.codeready.org](http://www.codeready.org)). Another member attended a conference titled "The Church and Pandemic Preparedness" hosted by Central Lutheran Church in Minneapolis, and reported back to our committee about the information shared.
- Our committee has been in conversation with our congregation's Caring

Circles regarding how they can best work with our ministers in reaching out to help affected members of the congregation if a pandemic comes. Caring Circles is a group of people who are an adjunct to the minister in providing visits, phone calls, cards, transportation, and so on at times of loss and other types of life challenges.

- We share information with the congregation on an ongoing basis about simple steps people can take to keep themselves and their neighbors in the congregation healthy during any cold and flu season, as well as year-round. We, for example, include in our congregation newsletter reminders to prevent the spread of colds and flu by covering your cough, washing hands regularly and thoroughly, and so forth.

It would take much more space to share the many more details on how congregations and their members with and without disabilities can prepare for and respond to a possible pandemic. We'd invite people to visit the resources posted on our Bird Flu E-mail Discussion List and to consider joining the discussion (<http://lists.muusja.org/mailman/listinfo/birdflu>). We all hope a severe pandemic never comes, but expert scientists, especially epidemiologists, are concerned that it may come soon and may be devastating, especially to those who fail to prepare.

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Hull, Harry. (2006). Avian flu is coming! *Minnesota Medicine*, 89. Retrieved 5/29/07 from [www.mmaonline.net/publications/MNMed2006/January/avian-Hull.htm](http://www.mmaonline.net/publications/MNMed2006/January/avian-Hull.htm).

*Bill Weir is a member of First Unitarian Society of Minneapolis and chair of its Committee on Emergency Preparedness. He is a retired minister with a Masters in Healthcare Administration. He may be reached at [weirwilliam@msn.com](mailto:weirwilliam@msn.com).*

[Ridgeway, continued from page 1]

families what they needed. They were all ages, from grade school to senior citizens. They numbered 65. Twenty-five were from group homes and apartments, and ten staff and their families were from St. Bernard Parish in New Orleans. In that meeting I saw something happen that I don't know if I'll ever see again. In a meeting of 24-28 people all representing their own version of government, and members of the local and state People First groups (who actually called the meeting), the red tape book was thrown over in the corner. We focused on the immediate needs with one mind and voice. I'm glad the Good Lord let me live long enough to see that.

After all the assignments were divided up, everyone chipped in from their departments, offering computers, clothes, information on loved ones, beds, cigars/cigarettes, jobs, apartments and homes, fax machines, copiers, and e-mail access. After that day we met in small meetings, but still kept working on welcoming our new friends to the community and supporting them to begin to rebuild their lives. Boxes began to arrive with clothes, shoes, school supplies for the kids, and much more. Ladies from the community brought food. A van was loaned to the evacuees for transportation to places like Wal-Mart to get the things they needed right away.

I met a lot of the survivors. One particular man named Joe, "Papa Joe" everybody called him, stands out. People First had put together a survey to find out just what folks needed, both immediate and long-term. I noticed that on the "want" question he wanted a brown hat with a wide brim, so I asked Vicki to stop by a western store on the way home. The next day Papa Joe got his brown hat with a wide brim. How could I not make sure he got his hat – this man had just lost everything he had except the clothes on his back. The smile on his face when he opened up that box was worth 10 million bucks to me.

When I left, the kids were in school, some of the people were in day programs, and some had jobs so they didn't have to sit doing nothing. (We really

hated to use day programs, but it was what we had, and sometimes we have to use what's out there, especially during this emergency.) The church is not a home, but we are trying to embrace our new neighbors in our community and advocate for them to have their homes back and support them in their steps to the rebuilding of their lives.

While it was most certainly tragic that so many lost homes, jobs, even loved ones to the storm, what was senseless, irresponsible, even on the brink of torturous, was the poor response from officials because of bureaucratic red tape. Today I call on every member of Congress to go forth and call for a drastic reduction in red tape in getting help to the people who need it when they need it and where they need it, without the breakdown of communications and delay of help. Let's not let another American die waiting.

*Jeff Ridgeway is Past President of People First of Alabama, and originally wrote this article in December 2005. He can be reached at 251/414-5364 or by e-mail at [jridgeway11@bellsouth.net](mailto:jridgeway11@bellsouth.net).*

[Batiste & Loy, continued from page 13] periodically. In addition, a system for reporting new hazards and accommodation needs should be developed; a relationship with local fire, police, and HazMat departments should be maintained; and new employees should be made aware of the plan. Finally, all accommodation equipment used in emergency evacuation should be inspected and maintained in proper working order.

#### Notes

1. Title I of the ADA applies to private employers with 15 or more employees, state and local government employers, employment agencies, labor unions, and joint labor-management committees. Federal employers are covered by the Rehabilitation Act of 1973. Both laws prohibit employers from discriminating against people with disabilities in regard to any employment practices or terms, conditions, and privileges of employment.

2. Title I of the ADA requires employers to provide reasonable accommodations to the known limitations of employees with disabilities. For additional information on reasonable accommodation, see *Enforcement Guidance: Reasonable Accommodation and Undue Hardship Under the ADA* at <http://www.eeoc.gov/policy/docs/accommodation.html>.

3. The OSH Act does not require that all employers have emergency action plans; however, the Act does require that employers from particular industries have emergency action plans (e.g., metal, chemical, and grain handling facilities). Employers must check particular industry

codes to see if emergency action plans are required and what elements are necessary.

4. *Fact Sheet on Obtaining and Using Employee Medical Information as Part of Emergency Evacuation Procedures*, <http://www.eeoc.gov/facts/evacuation.html>.

*Adapted and reprinted with permission from "Employers' Guide to Including Employees with Disabilities in Emergency Evacuation Plans," by Linda Carter Batiste and Beth Loy, published by the Job Accommodation Network (JAN), West Virginia University, Morgantown. Retrieved June 6, 2007 from [www.jan.wvu.edu/media/emergency.html](http://www.jan.wvu.edu/media/emergency.html). A checklist for use by employers can be found with the online version of the report. The report was funded under a contract supported by the Office of Disability Employment Policy of the U.S. Department of Labor.*

[Micari & Mitchell, continued from page 32] about their emergency management needs to local and state emergency personnel. This form will indicate the information will be updated at least monthly by DMR, and that recipients of the information must keep it secure and ensure it is used only for the purpose of emergency planning and response. Status of individual release form information will be maintained by DMR in the emergency management database.

We, as service providers, must actively ensure the emergency management needs of those we serve are addressed. This includes establishing partnership and information-sharing relationships between people with special emergency management needs and government entities. We have found that innovative and balanced strategies that respect the individual's right to privacy, while addressing their needs in a time of crisis, can be arrived at through ongoing dialogue between people with disabilities, service providers, and emergency management personnel.

*Daniel A. Micari is Director of the Division of Quality Management, and Statewide Emergency Management Director, for DMR. He may be reached at 860/418-6081 or [daniel.micari@po.state.ct.us](mailto:daniel.micari@po.state.ct.us). Dennis J. Mitchell is Statewide Emergency Management Coordinator for DMR. He is at 860/418-6105 or [dennis.mitchell@po.state.ct.us](mailto:dennis.mitchell@po.state.ct.us).*

[Styron, continued from page 3]

### Additional Findings

As DHS and others have found, while most Emergency Operation Plans (EOPs) make scattered references to people with disabilities, sorely lacking is any consistency of approach, depth of planning, or evidence of safeguards and effective implementation. Most jurisdictions significantly underestimate the amount of advance planning and coordination that is required to effectively address the integration and accommodation of individuals with disabilities. A 2004 survey of emergency managers conducted by EPI revealed that 76% do not have a paid expert on staff to advise on special needs issues and 73% said that no funding had been received to address and plan for special needs issues (N.O.D. & Harris Interactive, 2004). The 2004 survey also revealed that 42% of emergency managers had preparedness materials for people with disabilities; however, only 16% of those 42% had those same educational materials available in an accessible format. In addition, SNAKE team findings revealed that 85.7% of community-based organizations that provided services to people with disabilities and seniors in areas affected by Hurricane Katrina did not know how to access their emergency management system prior to the storm.

Although strides are being made toward fully integrating people with disabilities in community life, substantial improvement is necessary to integrate people with disabilities in emergency planning and readiness.

### Principles for Improvement

To increase the effectiveness of emergency preparedness in relation to persons with disabilities, individuals who have disabilities, their families, service providers, and advocates, as well as their communities as a whole and government leaders at all levels, must recognize and act upon the following principles:

- Through personal and community planning, all people must have the

same opportunity to survive natural and human-made disasters.

- Emergency workers can be provided the tools, equipment, and training to maintain the independence of persons with disabilities in an emergency event.
- Persons with disabilities can develop a realistic and successful emergency plan through educating themselves and emergency workers on how to best help them during an emergency.
- All transportation, reception centers, shelters, and medical services can be accessible for all people, and all people can maintain dignity and self-respect.

Some recommendations for implementing these principles include:

- Increase the rate of participation of people with disabilities in emergency planning.
- Increase the rate of participation of people with disabilities in emergency preparedness, response, and recovery drills and exercises.
- Direct DHS funding to promote the full integration of people with disabilities in all aspects of emergency preparedness, response and recovery.
- Ensure that during an emergency, Telecommunications Relay Services (TRS) personnel, Public Safety Answering Point (PSAP) personnel, and captioners can travel to and from their designated facilities to provide continuity of services for persons with hearing and speech disabilities.
- Integrate the needs of individuals with disabilities into the National Response Plan (NRP) and National Incident Management System (NIMS).<sup>2</sup>
- Coordinate evidence-based federal research into the effectiveness of audio, visual, and/or tactile protocols and technologies related to emergency preparedness, alerting, warning, and response for individuals with disabilities.<sup>3</sup>

- Ensure comprehensive medical approaches that address the health care and medical needs of individuals with disabilities across the life-span of an emergency event.

### Conclusion

One of the most important roles of government is to protect its citizenry from harm, including helping people prepare for and respond to emergencies. Making local, state, and federal government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility. People with disabilities throughout the country will continue to risk suffering and death in disproportionate numbers unless we dramatically improve disability-related emergency planning processes and readiness.

#### Notes:

<sup>1</sup> Special Needs Assessment 4 Katrina Evacuee (SNAKE) Report and findings are available at [www.nod.org/emergency](http://www.nod.org/emergency).

<sup>2</sup> The NRP/NIMS is currently under review and special needs are being fully incorporated into these guidance documents.

<sup>3</sup> The Federal Communications Commission has established the Commercial Mobile Service Alert Advisory Committee (CMSAAC) to address these issues (<http://www.fcc.gov/pshs/cmsaac.html>).

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*Hilary Styron is Director of the Emergency Preparedness Initiative of the National Organization on Disability, Washington, D.C. She may be reached at 202/293-5960 or [epi@nod.org](mailto:epi@nod.org). Additional information regarding the content of this article is available by visiting the EPI Web site at [www.nod.org/emergency](http://www.nod.org/emergency). For specific information or to speak with someone about issues surrounding special needs preparedness planning in your community, please contact EPI at 202/293-5960.*

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## **Impact**

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*Issue Editors:*

Chas Moseley, National Association of State Directors of Developmental Disabilities Services, Alexandria, Virginia

Patricia Salmi, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Minneapolis

Christopher Johnstone, Global Resource Center, Institute on Community Integration, University of Minnesota, Minneapolis

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For additional copies or information contact:  
Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • 612/624-4512  
icipub@umn.edu • <http://ici.umn.edu>.

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