

National Council on Disability on Hurricane Katrina Affected Areas September 7, 2005

In the aftermath of Hurricane Katrina, people with disabilities have unique needs that must be surveyed and responded to immediately. In order to evacuate the large number of survivors from the New Orleans area, as well as from other areas of Louisiana, Mississippi and Alabama, people with disabilities were often forced to abandon their wheelchairs, walkers and other medical equipment. People who are blind, who may no longer have a service animal or cane to help them navigate, will require assistance in navigating a new environmental landscape. People who are deaf or hard of hearing will need visual access to emergency information. People in need of personal assistance services may now no longer have access to such services both as the result of separation from attendants during the evacuation process or due to not knowing how to obtain and fund the cost of qualified individuals in the locations where they now find themselves and, consequently, nursing home care in an institutional setting is often seen as the only remaining viable alternative to living in shelters. People with mental health needs, whose access to treatment and medications may have been disrupted, are in critical need of treatment and/or medication. In addition, mental illness symptoms are often exacerbated in times of crisis, and many individuals, even those not directly affected by the hurricane, may need assistance in identifying and accessing available resources.

The Federal Government's Response

The Federal Emergency Management Agency (FEMA) has set up a registration process for people with disabilities and chronic health care needs, and every hurricane survivor with a disability must register to be able to receive the full range of federal disaster relief assistance. See <https://disasterhelp.gov/portal/jhtml/index.jhtml> or call 800-621-FEMA or 800-462-9029 or TDD/TTY 800-462-7585.

The Food and Nutrition Service, run by the US Department of Agriculture, has taken several actions to expedite and facilitate the Food Stamp enrollment and receipt for evacuees of Hurricane Katrina in their destination states, as identified on the webpage found at www.fns.usda.gov/fns/. This site's "Newsroom" section provides the latest efforts to date.

The US Department of Health and Human Services (HHS) has set up a waiver between all the states housing hurricane survivors who were already receiving Medicaid to have their Medicaid accepted in their current location. HHS has also set up an expedited process for Medicaid eligibility for those who may not be eligible due to their hurricane related situation. The Centers for Medicare and Medicaid Services are also offering the following relief immediately:

- Health care providers that furnish medical services in good faith, but who cannot comply with normal program requirements because of Hurricane Katrina, will be paid for services provided and will be exempt from sanctions for noncompliance, unless it is discovered that fraud or abuse occurred.
- Crisis services provided to Medicare and Medicaid patients who have been transferred to facilities not certified to participate in the programs will be paid.

- Programs will reimburse facilities for providing dialysis to patients with kidney failure in alternative settings.
- Medicare contractors may pay the costs of ambulance transfers of patients being evacuated from one health care facility to another.
- Normal prior authorization and out-of-network requirements will also be waived for enrollees of Medicare, Medicaid or SCHIP managed care plans.
- Normal licensing requirements for doctors, nurses and other health care professionals who cross state lines to provide emergency care in stricken areas will be waived as long as the provider is licensed in their home state.
- Certain HIPAA privacy requirements will be waived so that health care providers can talk to family members about a patient's condition even if that patient is unable to grant that permission to the provider.
- Hospitals and other facilities can be flexible in billing for beds that have been dedicated to other uses, for example, if a psychiatric unit bed is used for an acute care patient admitted during the crisis.
- Hospital emergency rooms will not be held liable under the Emergency Medical Treatment and Labor Act (EMTALA) for transferring patients to other facilities for assessment, if the original facility is in the area where a public health emergency has been declared.

More information about CMS emergency relief activities, including a detailed explanation of billing and payment policy revisions, and phone numbers for the state medical assistance offices can be found at www.cms.hhs.gov. Frequently asked questions and their answers on the site will be updated daily by 2pm. In addition, members of the Interagency Coordinating Council (ICC) on Emergency Preparedness and Individuals with Disabilities, a federal interagency group led by the Department of Homeland Security, participated in a conference call with consumer organizations to identify the most immediate needs of hurricane victims with disabilities, and have fielded comments and inquiries about surfacing problems.

More Needs to Be Done Immediately

However, more needs to be done to effectuate a coordinated Federal Disability Recovery Plan for Hurricane Katrina. In declaring a public health emergency, HHS Secretary Michael Leavitt identified as priorities for the survivors of Hurricane Katrina to include health care, housing assistance, childcare and education. While NCD recognizes that urgent needs and the necessary responses are continuing to emerge in the days after the disaster, it would like to offer the following recommendations in support of the Bush Administration's assistance to those affected by the disaster:

- NCD recommends that President Bush designate a high-level official within Department of Homeland Security/FEMA to resolve issues around disability access or related issues.
- NCD recommends that FEMA coordinate with HHS' Substance Abuse and Mental Health Services Administration (SAMHSA), which is equipped to train mental health workers and other human services providers who assist survivors following a disaster. <http://www.mentalhealth.samhsa.gov/publications/allpubs/ADM90-537/Default.asp> The

SAMHSA Disaster Technical Assistance Center was established to provide assistance to jurisdictions planning for or facing an emergency event. SAMSHA should also continue to work with mental health providers and consumers to develop and implement a plan for providing or continuing services.

- Many organizations and individuals have stepped up to provide donated equipment. For example, several Centers for Independent Living (CILs) are in the process of obtaining a substantial amount of durable medical equipment (DME). FEMA and the agencies working with people with disabilities need to know about these DME resources that have been obtained and about other disability-specific resources and services that will most definitely benefit incoming people with disabilities. NCD urges FEMA to assist with immediate shipment of donated equipment.
- NCD urges the Federal Communications Commission to work with agencies to designate Telecommunications Relay Services (TRS) personnel, Public Safety Answering Point (PSAP) personnel, and captioners as essential personnel to ensure that they can travel to and from their designated facilities to provide continuity of services for persons with hearing and speech disabilities. Without trained personnel to provide these intermediate services, individuals with hearing or speech disabilities will be denied their rights to accessible communications and will not have access to public alert and warning information during and after an emergency.
- NCD recommends that FEMA coordinate with HHS to ensure that comprehensive medical approaches are used to address the health care and medical needs of individuals with disabilities across the lifespan of the Hurricane Katrina disaster.
- NCD urges the Department of Transportation to coordinate with state and local governments to provide expedited eligibility to vocational rehabilitation services, paratransit services and specialized telecommunication assistance programs.
- A multi-agency, cross-disability proposal for disability specific funds should be developed to support on-going activities in the Gulf region.
- Shelters and facilities must be accessible to people with disabilities and to people who have expertise in providing services to people with disabilities. NCD recommends that the Justice Department issue a statement on the legal requirements for accessible shelters and facilities. NCD recommends that DHS issue a statement and operational guidance encouraging accessibility.
- NCD recommends that the Department of Education (DoEd) coordinate with state and local school districts to ensure that students with disabilities are included in DoEd's plans to work with states and local communities to welcome students with disabilities and get them enrolled into schools as quickly as possible. NCD urges the use of "emergency" assessment procedures by qualified school professionals to provide a record of general functioning for temporary provision of special education and related services. Plans for regular evaluation need to be established within a reasonable timeframe after enrollment by state and local school districts to avoid over identification of children from diverse racial and cultural backgrounds as children with disabilities. Counseling and other mental

health services need to be made available to all evacuated children and families through schools and collaboration with health departments.

- FEMA/CMS/HHS should immediately determine the location and status of residents of long-term care facilities, including nursing home and group home populations, and assess and respond to their immediate needs to ensure that they are receiving the necessary range of services and supports. NCD also recommends that CMS consider the impact of the implementation of Medicare Part D.
- HHS and HUD have each established toll free hotlines. HUD has established a single toll-free number (1-888-297-8685) to help disaster victims with all housing concerns. Assistance is available from 7 a.m. to 8 p.m., CST, seven days a week. HHS has established a crisis hotline for people in crisis in the aftermath of Hurricane Katrina. By dialing 1-800-273-TALK (1-800-273-8255), callers will be connected to a network of local crisis centers across the country that are committed to crisis counseling. Callers to the hotline will receive counseling from trained staff at the closest certified crisis center in the network. However, it is strongly recommended that these hotlines be made accessible to deaf and hard of hearing consumers immediately by also establishing a TTY/TDD telephone number. NCD also recommends that HUD consider housing vouchers and other low income housing be set aside for people with disabilities, and provide help in locating accessible housing.
- The Secretary of Veterans Affairs to request VA hospitals across the country to assist in providing outdated or unneeded wheelchairs and other useful durable medical equipment, currently in VA storerooms, to the relief effort. The VA should also coordinate with the network of veteran's homes and other veterans' organizations, like VFW and American Legion chapters, whose members could provide donations to, or assist with, equipment drives.

Subsequent Follow-Up Action

NCD's April 15, 2005 report *Saving Lives: Including People with Disabilities in Emergency Planning*, (http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm) provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement and emergency programs and services.

- Department of Homeland Security should establish a Hurricane Katrina Disability Access Advisory Group, made up of qualified people with disabilities and others with disability-specific disaster experience, who meet regularly with senior officials to: share real time information from the Gulf Coast region, as well as to discuss events and challenges and progress.
- Federal Government information web sites like DisabilityInfo.gov should have ongoing portals designated specifically for Hurricane Katrina disaster relief efforts, and these

portals should be accessible, accurate, timely, and updated regularly. To the greatest extent possible, these sites should incorporate state and local information that is relevant.

- The DHS Directorate of Emergency Preparedness and Response should integrate information on people with disabilities into Katrina-specific preparedness materials. It also should inform readers and information users on how to get access to more customized and regionally relevant materials.
- The DHS Office of Civil Rights and Civil Liberties should regularly issue guidance for state and local emergency planning departments to reinforce their legal obligation to comply with ADA and Section 504 and 508 of the Rehabilitation Act in planning for, operating, and managing programs and services such as Citizen Corps, shelters, and other Katrina disaster assistance and relief services.
- The FCC should develop stronger enforcement mechanisms to ensure that video programming distributors, including broadcasters, cable operators, and satellite television services, comply with their obligation to make Katrina emergency information accessible to people with hearing and vision disabilities, that it acts immediately on violations, and that it is proactive on Section 255 hearing aid compatibility.

The Federal Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities was established to ensure that the Federal government appropriately supports safety and security for individuals with disabilities in disaster situations. Chaired by the Secretary of Homeland Security, the purpose of the Council is to facilitate cooperation among Federal, State, local, and tribal governments and private organizations and individuals in the implementation of emergency preparedness plans as they relate to individuals with disabilities. The following recommendations from the Council's first annual report to President Bush (http://www.dhs.gov/interweb/assetlibrary/CRCL_IWDEP_AnnualReport_2005.txt) are salient as applied to our response to the Hurricane Katrina disaster and should be immediately acted upon:

- 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. In order to ensure that all persons are alerted to and warned about disasters or emergencies, accessible technologies are indispensable. The ICC is uniquely positioned to accelerate research that guides the development and integration of appropriate technologies into the Nation's emergency warning systems and practices. These technologies identified from research will guide contract procurement and technical assistance, and translate findings into guidelines. Findings will also result in information on promising new practices for alerting and warning individuals with disabilities.
- Ensure comprehensive medical approaches that address the health care and medical needs of individuals with disabilities across the lifespan of an emergency event. In order to ensure that health care providers and emergency responders have the appropriate skills to provide life-sustaining care to individuals with disabilities for both pre-existing and incident-caused health needs, they must receive training. Effective competency-based

instructional materials and training will increase positive outcomes for individuals with disabilities in times of emergency and over the duration of the recovery process. The ICC will work to ensure development of this type of instructional material and training.

- Direct homeland security funding to promote the full integration of people with disabilities in all aspects of emergency preparedness, response and recovery. There must be adequate funding to ensure that emergency planning includes people with disabilities. In the present environment, it is difficult for planners to find funds to meet their communities' needs for items ranging from evacuation devices to personal preparedness education materials. In January 2005, the Secretary of Homeland Security sent a letter to all Governors encouraging them to consider using a portion of their homeland security grants for such purposes. This effort should be replicated at the State, local and tribal levels to encourage the use of homeland security resources to achieve the goals of the Executive Order. To expedite the process, the ICC will develop a database of current funding streams devoted to emergency preparedness and people with disabilities.

Leaders and experts within the disability community, members of relief organizations, media professionals, and local, state, and federal officials must establish a cooperative relationship to address the catastrophic effects of tens of thousands of Gulf Coast residents with disabilities. The challenges ahead will be overcome only by clear communication and ongoing dialogue among these and other groups. That dialogue must, at a minimum, identify key needs of people with disabilities, develop effective and timely strategies for addressing those issues, and build relationships and delineate responsibilities among disaster mitigation organizations, the media, and disability organizations.

- **Disaster Preparation, Education, and Training.** Relief and rescue operations must have the appropriate medical equipment, supplies, and training to address the immediate needs of people with disabilities. Affected individuals will require bladder bags, insulin pumps, walkers, or wheelchairs. Relief personnel must be equipped and trained in the use of such equipment. In addition, relief personnel should provide training, particularly for personnel and volunteers in the field, on how to support the independence and dignity of persons with disabilities in the aftermath of Hurricane Katrina.
- **Universal Design and Implementation Strategies.** In the aftermath of Hurricane Katrina, a universal design approach to meeting the needs of people with disabilities will benefit many people without disabilities, such as the very young or the aged. A look at existing agreements among relief organizations and local, state, federal, and international governments will offer guidance in developing timely and effective strategies for universal design and implementation plans. The federal government could encourage or even mandate universal design and set standards.
- **Partnerships with the Media.** The media -- in partnership with disability and governmental organizations -- should incorporate ongoing advisories into emergency broadcasts in formats accessible to people with disabilities, recognizing that information may need to be conveyed through multiple mechanisms so that the information is available in both audible and visual formats. Such advisories should alert the public to ongoing threats (e.g., public health) resulting from Hurricane Katrina, and for identifying

responsible and timely solutions. The creation and repetition of accessible media messages is critical for empowering people with disabilities to protect themselves from the chronic effects of Katrina.

- **Partnerships with the Disability Community.** Disability organizations must join with Katrina relief and rescue organizations and the media to educate and inform their constituents of disaster contingency and self-help plans.

The Community's Response

The disability community has mobilized to provide its expertise in assisting with the response to the disaster. Among many things, the community has organized several conference calls, directly assisted survivors on the ground, engaged in fundraising efforts, advised governmental entities, developed workgroups for follow up actions, and established informational websites. While the strength and unity of the disability community's response has played a critical role in disaster recovery, the full force of their assistance has been hampered by the lack of relief organizations' coordination with community leaders in the provision of clear and systemic communications, independent funding and resource support and not fully including disability experts in the development and implementation of assistance and recovery plans. Below are a few examples of the actions and information dissemination of the disability community:

- <http://www.katrinadisability.info/> has been set up to provide information to people with disabilities and their families who have been affected by Hurricane Katrina. New information and resources will be added as it becomes available, so people should visit often for information and updates.
- California's Independent Living Centers, which are community-based non-profit organizations serving people with disabilities of all ages, have offered to serve as the collection points for new or used items to be delivered to the survivors who are disabled. "We know that many people who receive new replacement equipment, or recover from an injury or illness, keep the older items in case they're ever needed," according to Michael Collins of the State Independent Living Council in Sacramento, "The items gathering dust in garages and storage units around the state could make a real difference to a survivor who cannot move without assistance at a shelter." Since many people who are elderly, and children, need replacement items too, it is hoped that the agencies serving such age groups will join in the California collection drive. For anyone who would prefer to donate money that will assist local disability organizations in the Southeast, the California Foundation for Independent Living Centers is also accepting such donations at www.cfilc.org.

Because the deliveries of donated goods need to be coordinated with a local organization capable of temporary storage and effective delivery to the people who really need the equipment and supplies, it is being requested that advance contact be made with a recipient agency near the shelter sites. California's Independent Living Centers have made those contacts, and will coordinate shipment of the needed items. To find the location of the nearest Independent Living Center or community collection drive, call the

State Independent Living Council at (866) 866-7452 or view the address www.calsilc.org.

Contact: Michael C. Collins, Executive Director
(866) 866-7452 (Toll-free)
(916) 505-4273 (Cellphone)

- United Cerebral Palsy Association (UCP) has set up an emergency hotline for UCP of New Orleans. Concerned consumers and their families, employees and volunteers can call 800-872-5827 to receive information, as well as leave messages about their personal status. www.ucpgno.org

Additionally, United Cerebral Palsy has set-up a Hurricane Katrina Disaster Relief Fund to provide services to people with disabilities affected by hurricane Katrina and assist UCP affiliates throughout the region in restoring their operations as quickly as possible. Members of the public, who are able to help, are encouraged to make an online donation at www.ucp.org.

- The National Alliance on Mental Illness (NAMI) is providing a resource guide and a Katrina Hurricane Relief Fund to assist consumers and families affected by the hurricane. Included in this resource: How NAMI is responding to the tragedy as it relates to people with serious mental illness, NAMI's Hurricane Katrina Message Board, NAMI's email alerts, Resources and Links to support and information specific for people living with mental illness and their families.
http://www.nami.org/TextTemplate.cfm?Section=Hurricane_Katrina&Template=/ContentManagement/ContentDisplay.cfm&ContentID=26242&lstid=566
1-800-950-nami (6264)

- The Spina Bifida Association (SBA) has a Hurricane Emergency Life-Support Program including working with industry to secure essential equipment, working with its chapters to distribute supplies when the infrastructure in the region has been restored, and develop an Emergency Preparedness program for future emergency situations. Also links to SBA Chapter and Clinic Lists.

http://www.sbaa.org/site/PageServer?pagename=campaign_SBA_HELP
1-800-621-3141

- TASH (serving persons with severe disabilities) has put together the following information for TASH members and colleagues regarding efforts to assist disability related organizations and individuals with disabilities and their families in the Gulf States and the states receiving refugees from the storm and floods. We will be updating this page with additional information as we receive it. <<http://www.tash.org/katrinainfo.htm>>
410-828-8274
- The National Spinal Cord Injury Association (NSCIA) has distributed "Ways to Support Disability Related Relief Efforts for Hurricane Katrina." They include links for

information, organizations, and assistance

<http://www.spinalcord.org/news.php?dep=1&page=0&list=601>
1-800-962-9629.