THE IMPACT OF HURRICANES KATRINA AND RITA ON PEOPLE WITH DISABILITIES: A LOOK BACK AND REMAINING CHALLENGES

National Council on Disability 1331 F Street, NW, Suite 850 Washington, DC 20004 202-272-2004 Voice 202-272-2074 TTY 202-272-2022 Fax

Lex Frieden, Chairperson

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Synopsis

Hurricanes Katrina and Rita devastated the lives of many people who lived in the Gulf Coast region. Fortunately, millions of Americans opened their homes and their hearts to hurricane survivors while local, state, and federal government employees worked around the clock to evacuate and rescue people. With almost a year since the Hurricanes made landfall and wreaked havoc on the lives of many, we now have a clearer understanding of what went right, as well as what went wrong, with the response and recovery efforts. As this report will demonstrate, people with disabilities were disproportionately affected by the Hurricanes because their needs were often overlooked or completely disregarded. Their evacuation, shelter, and recovery experiences differed vastly from the experiences of people without disabilities. People with disabilities were often unable to evacuate because transportation was inaccessible. For example, most evacuation busses did not have wheelchair lifts. Moreover, people with visual and hearing disabilities were unable to obtain necessary information pertinent to their safety because said communication did not comply with federal law. To ensure that people with disabilities do not experience similar injustices during future catastrophes, emergency plans must acknowledge and address the difficulties experienced by people with disabilities discussed within this report, as well as include people with disabilities in rebuilding efforts. The National Council on Disability (NCD) offers these findings on the impact of Hurricanes Katrina and Rita on people with disabilities to guide the President, Congress, and other emergency planners to develop inclusive emergency preparedness and response plans.

Introduction

Scope

This paper focuses on the effects of the hurricanes on people with all types of disabilities. NCD recently released another report that addressed in detail the specific challenges for people with psychiatric disabilities. Please refer to *The Needs of People with Psychiatric Disabilities During and After Hurricanes Katrina and Rita: Position Paper and Recommendations* for a more detailed report about the population of mental health consumers affected by the hurricanes. Additionally, although the focus is on the emergency preparedness and response to Hurricanes Katrina and Rita, many of the problems addressed in this paper are systemic in nature and were not caused solely by the hurricanes. The challenges faced by people with disabilities during and

after the Hurricanes, while unique in scope and proportion, were similar to the challenges people with disabilities face on a day-to-day basis. Therefore, many of the findings and recommendations related to Hurricanes Katrina and Rita echo NCD's previous research on improving the daily quality of life of people with disabilities. When America embraces the twin principles of inclusion and accessibility for everyday programs, policies, and infrastructure, Americans with disabilities surely will be counted among the survivors of the next disasters. NCD made detailed recommendations for disaster preparedness in its 2005 report, *Saving Lives: Including People with Disabilities in Emergency Planning*. Since Hurricanes Katrina and Rita, many interested policymakers and emergency planners have used NCD's research to make their emergency plans more inclusive of people with disabilities. Some of the key recommendations from that report, along with recommendations based on lessons learned from Hurricanes Katrina and Rita, are included in this report under the Recommendations for Emergency Preparedness section.

The Population of People with Disabilities Affected by the Hurricanes

Almost immediately after Hurricane Katrina devastated the Gulf Coast, the National Council on Disability (NCD) estimated that there were roughly 155,000 people with disabilities over the age of 5 – or about 25 percent of the cities' populations – living in the three cities hardest hit by the hurricane: Biloxi, Mississippi; Mobile, Alabama; and New Orleans, Louisiana. NCD urged emergency managers and government officials to recognize that for hurricane survivors with disabilities, their needs for basic necessities were "compounded by chronic health conditions and functional impairments... [which includes] people who are blind, people who are deaf, people who use wheelchairs, canes, walkers, crutches, people with service animals, and people with mental health needs."

It is difficult to determine precisely what percentage of hurricane-related deaths were people with disabilities. However, it is clear that a disproportionate number of the fatalities were people with disabilities. One statistic from the American Association of Retired Persons (AARP) provides some insight into the extent: "73 percent of Hurricane Katrina-related deaths in New Orleans area were among persons age 60 and over, although they comprised only 15 percent of the population in New Orleans." Most of those individuals had medical conditions and

functional or sensory disabilities that made them more vulnerable. Many more people with disabilities under the age of 60 died or were otherwise impacted by the hurricanes.

Evacuation and Rescue

Emergency Alerts and Communication

NCD's pre-Katrina report, *Saving Lives: Including People with Disabilities in Emergency Planning*, revealed several barriers to accessible emergency information during disasters, including the failure of broadcasters and emergency management agencies to comply with legal obligations to provide accessible emergency information.⁵ For example, when Hurricane Georges hit the New Orleans area in 1998, sign language interpreters were rarely available at news releases and when they were, TV stations cut the interpreters out of the picture. "All I saw was an elbow," said one deaf hurricane survivor.⁶ Many people with sensory disabilities faced analogous barriers to emergency alerts during Hurricanes Katrina and Rita, sometimes with lethal results.⁷ People with disabilities often experience similar barriers to the use and enjoyment of telecommunications technology on a daily basis, not just during disasters like Katrina. In NCD's 2004 report, *Design for Inclusion: Creating a New Marketplace*, NCD investigated the extent to which telecommunications and information technologies are currently accessible to people with disabilities and how the market is preparing the new wave of accessible, universally designed technology.⁸ As barriers to the daily use of information and telecommunications technology decrease, so will the barriers to emergency communication.

Before and During the Hurricanes

Effective communication, which is essential during emergencies, was not available to people with disabilities – especially to those with sensory disabilities – during the Hurricanes.

According to a recent Congressional hearing on the impact of Hurricanes Katrina and Rita on people with disabilities, NCD Vice Chairperson Patricia Pound, testified that people with hearing disabilities often could not comprehend evacuation instructions and other similar directions in shelters. Furthermore, testimony by a broadcast technology expert revealed that most people initially received critical emergency information about the storm from television; therefore, without closed captioning or sign language interpretations of the televised emergency information, people with hearing disabilities often remained unaware of the scope or nature of

the impending emergency. Moreover, effective communication was troublesome for people with visual impairments because television broadcasts typically did not provide audio descriptions of visual displays of critical information, such as maps or lists of affected areas.

Some area residents with hearing disabilities, aware that public emergency alert systems had failed them in the past, relied on new technologies, such as cell phone text messaging (SMS services), to receive important information. However, with 160-mph winds, many cell phone users lost service when cell phone towers were damaged. Even had the televised information been accessible to people with hearing disabilities prior to the hurricane's landfall, once the hurricane hit, people with hearing disabilities had even less access to emergency information, which is exemplified by someone who recently testified before Congress that when the hurricane made landfall, "...power goes out, our homes go dark, and people are without television, cable, satellite, and the Internet. There is limited, if any, cell and hard-wire phone service. In these circumstances, radio becomes the primary, and in many cases, the sole lifeline and communication tool to a community and its residents." Thus, with radio as the primary communication "lifeline," people with hearing disabilities were left in the dark.

On a federal level, several government agencies took some positive steps to ensure that communications were accessible to people with disabilities during the emergency, but those steps were insufficient. During Hurricane Katrina, the Federal Communications Commission (FCC) issued a reminder to local broadcasters that they had an obligation to comply with existing communications accessibility laws. While NCD applauds the FCC's reminder to local television stations, ¹² it must be acknowledged that the single FCC reminder proved insufficient to encourage broadcasters to provide closed captioned or interpreted information. Initially, several Homeland Security web sites, including the Federal Emergency Management Agency (FEMA) web site, were inaccessible to people with vision impairments, as they were not compliant with Section 508. ¹³ When DHS was made aware of the non-compliance, the Department quickly remedied the problem, thus ensuring access to pertinent information to all people. Furthermore, the nation's Emergency Alert System – which requires emergency information to be fully accessible to people with disabilities – was never activated by the President or by local authorities during either of the Hurricanes. ¹⁴

Post-Hurricane Developments

Many of the accessibility issues that plagued people with disabilities during the Hurricanes continue to persist today. The acting director of FEMA recently stated that FEMA is uncertain "how in the world we're going to notify all these people [still living in over 50,000 FEMA trailers and mobile homes, with no access to television or the Internet]." According to a researcher at the Brookings Institution, "[evacuees] are living in situations that are very vulnerable to damage, and they're also living in situations completely cut off from any source of communication... It's really hard for them to be aware of any pronouncements..." Without access to television and the Internet, people with hearing disabilities who live in FEMA trailers are less capable of receiving critical emergency alerts now than before Hurricanes Katrina and Rita.

Although the accessibility of emergency communication continues to be an issue, some government agencies and private entities have made considerable progress since Hurricanes Katrina and Rita. For example, the Weather Channel significantly increased the amount of programming that will be captioned and will also caption its emergency broadcasts that are sent to local areas affected by the dangerous weather conditions.¹⁷

In another step forward, the Department of Commerce partnered with a non-governmental organization, the National Center for Accessible Media (NCAM), "to develop and encourage adoption of standardized methods, systems and services to identify, filter and present content in ways that are meaningful to people with disabilities leading up to, during and after emergencies." NCAM is cataloguing suggestions from people with disabilities and communication experts to develop effective standardized alert systems. Although the project is not yet complete, NCAM has already unearthed a range of possible emergency alert modifications. NCAM found that emergency alerts should be broadcast throughout a range of media – television with captioning, pagers, cell phones, Internet, Bluetooth, PDAs, etc. People with hearing disabilities have also suggested many creative solutions such as including emergency alerts as streaming text on satellite radio receivers in cars, in lieu of the titles of music tracks; streaming text alerts on buses; utilizing highway bulletin boards that display traffic updates and Amber Alerts; requiring the state to provide emergency pagers for people on fixed

incomes, similar to programs that provide TTY access. ¹⁹ The NCAM project is reportedly almost half complete.

The President recently ordered the FCC, DHS and the Commerce Department to overhaul the national Emergency Alert System (EAS), noting that the system relies on outdated technology and that broadcasters' participation in local alerts is completely voluntary. The EAS is a federal system first created in 1951 to help the President communicate critical information to the American people during emergencies. The President's order expands the scope of communications media that participate in the EAS to include electronic devices such as PDAs and cell phones. The order also makes broadcaster participation for local alerts mandatory. The revisions have the potential to drastically improve the accessibility of emergency alerts for people with disabilities.

Shortly after Hurricanes Katrina and Rita, the FCC implemented some changes to the emergency alert requirements that align with NCD's recommendations in Saving Lives: Including People with Disabilities in Emergency Planning. For example, in November of 2005, the FCC amended its EAS rules "to ensure that persons with disabilities have equal access to public warnings" (emphasis added).²¹ Effective December 31, 2006, the order requires all emergency alerts to include a "visual message" containing all key emergency information. The visual message cannot interfere with other visual messages, such as closed captioning.²² In this order, the FCC "encourages," but does not require, FEMA and state emergency centers to include "fully accessible" audio and visual formats of emergency messages. 23 The order also expanded emergency alert obligations to include digital content providers, whereas only analog and cable content providers were required to broadcast emergency alerts prior to the order. Though the FCC has not yet provided guidance to content carriers as to what steps need to be taken to provide the mandated "equal access to public warnings," the order included a Further Notice of Proposed Rulemaking (FNPR) that solicited comments and input on "how [the FCC] may, consistent with this order, make alerts more accessible to people with disabilities."²⁴ NCD applauds the President and the FCC for the forward-looking revisions to EAS requirements.

Emergency Transportation

According to reports that NCD collected from individuals with disabilities in the Gulf Coast and from advocacy groups based in the region or who traveled to the region, many people with disabilities were unable to evacuate from their homes, nursing homes, or hospitals because they lacked accessible public transportation or other requisite assistance.²⁵ Many of the transportation challenges faced by people with disabilities during the Hurricanes were magnified versions of daily barriers to accessible transportation. One of the most poignant examples of the failure of transportation infrastructure to evacuate people with disabilities was articulated by Marci Roth of the Spinal Cord Injury Association, in her testimony before Congress. She testified:

[On August 29] Susan Daniels called me to enlist my help because her sister-in-law, a quadriplegic woman in New Orleans, had been unsuccessfully trying to evacuate to the Superdome for two days. ...it was clear that this woman, Benilda Caixetta, was not being evacuated. I stayed on the phone with Benilda, for the most part of the day... She kept telling me she'd been calling for a ride to the Superdome since Saturday; but, despite promises, no one came. The very same paratransit system that people can't rely on in good weather is what was being relied on in the evacuation... I was on the phone with Benilda when she told me, with panic in her voice "the water is rushing in." And then her phone went dead. We learned five days later that she had been found in her apartment dead, floating next to her wheelchair ... Benilda did not have to drown [emphasis added].²⁶

Benilda's story is similar to those of many other people with disabilities who were unable to evacuate themselves. Some people who were able to reach bus stops arrived to find buses that were not lift or ramp equipped. As NCD reported in its 2004 report, *Livable Communities for Adults with Disabilities*, compliance with ADA transportation provisions is a "work in progress." Laudably, 83 percent of buses were ADA compliant by 2001 as compared to 35 percent in 1990 when the ADA was enacted, but that progress is insufficient. Often, when a person with a disability encounters a non-compliant bus, the consequence is a five or six hour increase in transit time, due to the wait for another accessible bus. However, during the hurricane crisis, the consequence of non-compliance was sometimes fatal, rather than merely time-consuming.

Often, local evacuation plans failed to adequately provide for the transportation needs of people with disabilities for two reasons: first, many local planners reported that they were unaware that people with disabilities have special evacuation needs; and, second, when local planners were aware of the need to plan for people with disabilities, the plans failed because they did not

involve people with disabilities in the planning process. For example, during the Katrina evacuation, many people with disabilities could not evacuate because to do so would require them to abandon support services and personnel. Moreover, since emergency transportation and shelters could not care for them, many people with disabilities were forced to stay behind. For example, Karen Johnson stayed in New Orleans to help her parents, who have disabilities and could not be evacuated. Holdouts like Karen and her parents were "getting dehydrated... running out of food... [and surrounded] by human remains in different houses." Other people with mobility disabilities who were forced to abandon wheelchairs could not wait in lines for evacuation buses for hours at a time, and thus were unable to evacuate from threatened cities. 31

Following the Hurricanes, the General Accountability Office (GAO) highlighted some of the cities that successfully prepared for the evacuation needs of people with disabilities. One commonly successful strategy was for local governments to conduct studies to identify people with unique transportation needs. Second, local emergency management officials reached out to existing citizen and advocacy networks to help them to prepare an evacuation plan and to inform the affected population.³² The GAO found that successful local evacuation plans included:

- "additional planning of pickup routes"
- "extra time to load and unload evacuation vehicles"
- "special resources, such as buses equipped with wheelchair lifts"
- "emergency management plans that clearly articulated methods" for evacuating PWD, including the roles of school boards, local and regional emergency management officials, transit agencies
- "Encouraged citizens who have special... needs to voluntarily register" with local emergency management; emergency managers should have a plan to maintain and administer this registry
- "Conducted regular exercises" of evacuation plans³³

The GAO continues to investigate Katrina-related evacuation issues. GAO's forthcoming report on the evacuation of transportation disadvantaged people, which it is developing through dialogue with NCD and other disability advocacy groups, is due to be completed in the fall of 2006. The Department of Transportation has prepared evacuation materials targeted at disability populations, and has created a website to provide information on the transportation needs of people with disabilities in the event of a disaster.³⁴

Evacuation of Institutions, e.g., Nursing Homes and Hospitals

Some of the most visible and alarming evacuation failures were the failures of some nursing homes to evacuate their residents, resulting in the deaths of at least 68 nursing home residents.³⁵ While the decision whether to evacuate nursing homes and hospitals is certainly complex and weighty, the reckless abandonment of nursing home residents to the mercy of floodwaters showed a disregard for the value of human life. The deaths of the nursing home residents highlighted problems with the evacuations of nursing homes. However, many New Orleans nursing homes had notoriously abusive records prior to the Hurricanes. The New Orleans Times-Picayune reported that at least 33 residents in Louisiana nursing homes had died from abuse or neglect between 1999 and April, 2005 – shortly before the tragic deaths following Hurricane Katrina.³⁶ In the six years immediately preceding the Hurricanes, the majority of Louisiana nursing homes were cited for harming or endangering residents. In one particularly harrowing incident, red ants had eaten away the top layer of skin over much of one resident's body before she was finally taken to a hospital for treatment.

The tragedy of the New Orleans nursing homes highlights the pre-existing national dilemma regarding the civil rights of people with disabilities within institutions. According to NCD's 2005 report, *The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise?*, one and a half million Americans reside in 17,000 nursing homes, and 30 percent of those facilities have been cited for harming residents or placing them at risk of serious injury or death. Studies suggest that 80 percent to 85 percent of abuse in institutions goes unreported. Policymakers cannot solve the problems associated with the emergency evacuation of institutionalized persons without addressing the systemic violation of their civil rights.

Emergency management officials on the federal and state level still have not prepared plans to ensure that nursing homes are evacuated in the event of an emergency. While state and federal governments are not strictly responsible for the evacuation of private nursing homes, ³⁷ federal and state entities can do more to ensure that they are effectively evacuated. The federal government's National Disaster Medical Systems (NDMS) supplements state and local efforts to evacuate hospitals. NDMS establishes agreements with hospitals to accept evacuated patients. During Katrina, NDMS evacuated over 2,900 people from hospitals and nursing homes. However, nursing homes are outside the ambit of NDMS responsibility and therefore NDMS has

not established similar agreements with nursing homes to accept evacuees.³⁸ Additionally, to receive federal funding through Medicare and Medicaid, nursing homes must maintain emergency evacuation plans as part of their accreditation. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) also requires evacuation plans prior to accreditation.

Emergency Mass Shelter and Food

While many organizations provided food and shelter in response to the hurricanes, the American Red Cross had the most visible and official role as shelter and food provider. Under the National Response Plan, the American Red Cross is responsible for providing temporary emergency mass shelter and food. While the American Red Cross is not a federal agency or entity, the organization does receive significant support from the federal government to help fulfill its emergency-related obligations. Much of the work by the American Red Cross during and after the hurricanes is laudable – the Red Cross mobilized nearly 245,000 volunteers and opened about 1,300 shelters across the nation.³⁹ The scope of the disaster tested and exceeded the limits of the American Red Cross' capacity to respond to disaster. It is important to recognize that some of the challenges faced by people with disabilities who sought assistance in shelters are inherent in any disaster response – the initial general confusion, an inadequate number of trained personnel, etc. However many of the most significant problems could have been avoided with more inclusive emergency planning. Many shelters refused to admit people with disabilities or inappropriately referred them to special needs shelters. Also, many evacuees with disabilities could not access shelter services, including medical care, communication, restrooms, food and shuttle services.

Access to Shelters

Marcie Roth of the National Spinal Cord Injury Association heard reports that American Red Cross shelters were refusing access to people with disabilities. Concerned, she contacted the Red Cross national headquarters. Roth quoted an employee from American Red Cross headquarters as saying, "Our shelters are not for them. There are places for them, run by local health departments, but still busloads of them kept being dropped off at our American Red Cross shelters. We can't hardly serve the **INTACT** people...." (emphasis in original)⁴⁰ Later inquiries

confirmed that American Red Cross implemented a policy to refuse shelter access for people with obvious disabilities. Sometimes, people with disabilities were referred to "special needs" shelters. Families were sometimes split up when Red Cross officials refused to allow family members with disabilities to access the general shelters. In other instances, people with disabilities were admitted to the general shelters but segregated from the general population by physical barriers.

Some areas established "special needs" shelters to accommodate people with disabilities. At their peak, special needs shelters served about 9,600 people. ⁴⁴ The American Red Cross did not operate the special needs shelters. The special needs shelters were intended to serve individuals who are homebound, chronically ill or who have disabilities that require medical or nursing care, and have no other place to receive care. The existence of special needs shelters does not relieve managers of general shelters of their legal obligation to provide reasonable accommodations for people with disabilities in general shelters. According to the U.S. Department of Justice, Civil Rights Division, "One of the most important roles of … government is to protect their citizenry from harm, including helping people prepare for and respond to emergencies. Making … government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility."⁴⁵

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

Despite some of the negative experiences with special needs shelters, some special needs shelters were adequately staffed, stocked and prepared to serve the appropriate population. The AARP identified an effective special needs shelter program in Duval County, Florida, that had access to critical medical supplies and support personnel. The county implemented an "Adopt-A-Shelter"

program that partnered with area hospitals and medical supply companies to ensure that special needs shelters are fully stocked prior to disasters, to develop an inventory for special needs shelters, and to provide those resources in the event of an emergency. Successful special needs shelter programs also include intake procedures to ensure that the correct people are admitted to special needs shelters while people with disabilities who are capable of living independently are sheltered in accessible general population shelters.

Accessibility of Shelter Services

In one of the most well known shelters, the Cajundome, one frustrated on-site volunteer repeatedly complained to Red Cross officials and shelter managers about the lack of accessible medical services for people with mobility disabilities. In a letter to the Red Cross, he wrote:

I have told Cajundome officials, medical staff, and Red Cross personnel about this problem. But I have been unsuccessful in getting it resolved. I have seen many frail people struggle to climb or descend the stairs in order to get medical attention, and I have personally seen two very exhausted men in wheelchairs almost decide to forego triage or other medical attention because of the difficulty of accessing this unit.⁴⁷

One advocate reported, "[m]ost callers are still living in inappropriate, inadequate and sometimes dangerous environments, out of money, out of medication and emotionally devastated." Several non-profit organizations, such as Centers for Independent Living (CILs) and other advocacy groups, rushed to provide people with disabilities in shelters with the resources that the shelters lacked, such as teletypewriters, wheelchairs, walkers, oxygen, and other essential support resources. The Department of Education offered grants to CILs to replenish resources used to help people with disabilities displaced by the storms. However, many advocacy groups that reached out to Hurricane survivors are still struggling from the financial strain of providing the supplies that the shelters did not provide.

The inadequacy of supplies within shelters was exacerbated by the frequency with which shelters were closed down and evacuees were sent to other locations. For example, Selena, a quadriplegic who lived in her own home in Alabama before the hurricanes, was evacuated to a crowded and understaffed special needs shelter where she was forced to sleep in her wheelchair due to a lack of beds. That shelter was short-lived, and she was evacuated to a bed-and-breakfast that opened its doors to evacuees. People with disabilities are grateful that so many private citizens,

businesses and charities opened their doors when the shelters failed them; however, for Selena, the bed-and-breakfast was inadequate because it did not have accessible bathrooms or other facilities. As a result of her evacuation experiences, Selena developed life-threatening bedsores and is now living in a nursing home, having lost her pre-hurricane independence due to the destruction of her home.⁴⁹

Most shelters did not provide information in an accessible format to people with sensory disabilities. According to Hilary Styron of the National Organization on Disability, "Over 80 percent of the shelters did not have access to TTY; 60 percent of the shelters did not have captioning TV capabilities. Less than 30 percent had access to sign language interpreters." People who were deaf or hard of hearing could not use phones to contact family members or arrange for housing or other relief services. People with vision impairments reported that they were told that critical information was posted on walls in shelters, or handed out via fliers.

Despite the inaccessibility of many shelters to people with disabilities, other shelters succeeded and can be used as models for further success. The National Organization on Disability (NOD) identified several exemplary general population shelters that were accessible to people with disabilities. In one town, a city mayor designated a convention center as a general shelter and ensured that the shelter included interpreters for the deaf, accessible shuttle services, Internet access, employment opportunities, and information on how evacuees could find accessible housing.⁵¹ NOD emphasized that the operators of those shelters were not experienced emergency managers; rather, the key to their success was their attitude of inclusiveness.

Disaster Recovery and Rebuilding

In the immediate aftermath of the storms, hurricane survivors received an immense outpouring of support from people across the country. Most disaster planning tends to focus on the immediate and visceral rescue and relief needs of disaster survivors, such as the provision of food, medicine, and shelter. After a disaster passes and media attention wanes, disaster survivors face the long-term challenge of disaster recovery. Many of the long-term disaster recovery issues of Hurricanes Katrina and Rita, such as the devastation to employment and education, received little media coverage.

Short-term Housing, e.g. Apartments and Trailers

The two most common forms of short-term housing for disaster survivors were apartments and trailers. People with mobility disabilities often had difficulties securing accessible apartments and even trailers provided by FEMA were not accessible. Even trailers that were purportedly "accessible" because they had ramps at the entrances often were located in gravel fields; inside, there was insufficient space to turn a wheelchair; bathrooms were inaccessible; and people in wheelchairs could not enter the kitchens to prepare food. Some disability advocates in Texas found that emergency officials were so focused on getting individuals out of shelters and hotels that they failed to prescreen temporary apartments to ensure that the apartments were accessible. Legislation pending in the Senate, bill S2124, would require DHS to conduct a survey of the accessibility of emergency shelters and FEMA housing.

Long-term Housing

With rebuilding efforts well underway, people with disabilities are beginning to face new challenges. Even before the hurricanes, affordable and accessible housing was difficult to find for people with disabilities. As NCD noted in its 2004 report, *Livable Communities for Adults with Disabilities*, approximately 1.8 million people with disabilities who receive Supplemental Security Income (SSI) experience "severe housing problems." NCD reported several factors that contribute to the "lack of affordable, accessible housing," including:

- The high costs of land, materials, labor, and "retrofitting" existing housing with accessibility features
- Land use and building regulations in local communities that discourage multi-unit housing development
- Public resistance and sometimes outright opposition to building new housing or converting older buildings into housing suitable for a range of incomes and abilities
- Few incentives for private developers to build affordable and accessible housing
- Lack of demand from the general public for accessibility features such as wider doorways because they do not see the value of such features or assume they would raise the price of already expensive housing⁵⁴

There are some indications that the same causes of "severe housing problems" prior to the hurricanes are being repeated in the reconstruction of the Gulf Coast. Commenting on the FEMA guideline that New Orleans homes should be raised three feet when reconstructed, a federal FEMA coordinator said, "[t]his will enable people to get on with their lives." This statement is

unfortunately indicative of policymaking that ignores the needs of people with disabilities. Requiring homes to be raised three feet likely will exacerbate the pre-Katrina scarcity of "affordable, accessible housing." Daniel Sutherland, director of the DHS' Office of Civil Rights and Civil Liberties (OCRCL), promised to investigate the promulgation of the guideline. While NCD applauds OCRCL for investigating the matter, the promulgation of this FEMA guideline is yet another indication that DHS should have an independent office or officer who reports directly to the Secretary of DHS.

Some legislators have recognized that the reconstruction of the Gulf Coast represents an ideal opportunity to create livable communities for people with disabilities. For example, Senator Harkin introduced the Emergency Preparedness and Response for Individuals With Disabilities Act (S2124), which would amend the Stafford Act to increase available funds by \$10,000 or loan amounts by 10 percent for people who rebuild homes that meet accessibility standards. This legislation – or proposals similar to it – serves dual purposes: first, it helps people with disabilities rebuild their homes with accessible features; and second, it encourages the construction of accessible single-family homes in the region.

It is essential to rebuild community services in addition to accessible homes. The predicament of Charles, a New Orleans resident, is typical of many people with disabilities who were living independently prior to the hurricanes but cannot return home until their community's services are restored:

Charles, a man with a good job, his own home in New Orleans, and flood insurance, hasn't been able to bathe in ten weeks. He's quadriplegic and homeless. The lack of personal care has landed him in the hospital twice. He now has a staph infection as a result of his last hospitalization. His insurance will pay over one hundred thousand dollars to repair his accessible home, but his community is destroyed. There's no public transit system, no grocery store, no health care system. He can't afford to keep paying the mortgage and taxes on a home he can't live in; and he can't afford to move to Baton Rouge where he could continue working and access health care and other disability related services. A hundred thousand dollars won't pay off his mortgage and it won't allow him to buy a new home in Baton Rouge. The cost of housing is just too high there.⁵⁸

The reconstruction efforts in the Gulf Coast provide Congress and the President with a unique opportunity to reshape the region in a manner that maximizes livability and accessibility for

people with disabilities. Rather than "reconstructing" the Gulf Coast as it was, now is the time to construct a new, accessible Gulf Coast. Some of the hallmarks of a livable community include:

- Affordable, appropriate, accessible housing
- Accessible, affordable, reliable, safe transportation
- Physical environments adjusted for inclusiveness and accessibility
- Work, volunteer, and education opportunities
- Access to key health and support services
- Access to civic, cultural, social, and recreational activities

NCD urges Congress, the President, Gulf Coast officials and other interested parties to review NCD's *Livable Communities* report in detail to guide reconstruction.

Employment

After meeting the critical short-term needs of evacuees, such as housing and food, volunteers and government officials turned toward the long-term employment concerns of evacuees. As noted by the National Organization on Disability, "the quickest way to get recovery moving is to provide employment and consistency to individuals whether they have disabilities or not." Among the estimated 502,000 Americans who lost the jobs as result of Hurricanes Katrina and Rita, many were people with disabilities. Even before Hurricanes Katrina and Rita, high unemployment and underemployment was and continues to be a serious problem for people with disabilities across the nation. Please refer to NCD's recent report *The Social Security* Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems for an in-depth analysis of employment-related issues.

Local and federal entities worked to improve employment opportunities for hurricane survivors, including those with disabilities. For example, Congress passed the "Katrina Emergency Tax Relief Act of 2005," which expanded a work opportunity tax credit for two additional years for businesses who hire people displaced by the hurricanes. Shortly after that, President Bush signed into law the "Assistance for Individuals with Disabilities Affected by Hurricanes Katrina and Rita Act of 2005," providing \$25.9 million in vocational rehabilitation funds for hurricane survivors; to help already cash-strapped states, those funds were released without the traditional requirement that the states provide matching funds. Furthermore, the Department of Labor (DOL) announced an initiative called "Pathways to Employment" to help survivors find employment and training opportunities through "the nationwide network of 3,500 One-Stop

Career Centers located across the country." The DOL also deployed additional Disability Program Navigators (DPNs) to hurricane-affected states. DPNs are individuals trained to help people with disabilities utilize the One-Stop Career Centers and to navigate the web of government and community employment services. Local businesses set up information centers in shelters to recruit evacuees, and volunteers tried to assist evacuees find employment. Local employment efforts had mixed results for people with disabilities. A group of Texas disability advocates reported that some employment programs were not successful for people with disabilities because volunteers did not know how to match people with disabilities with appropriate employment options. Descriptions of the people with disabilities with appropriate employment options.

In addition to those who lost their jobs because the hurricanes destroyed their places of employment or forced them to move, many people with disabilities were in the process of trying to obtain employment when the hurricanes hit. Employment agencies lost contact with their clients with disabilities, and it took some time to resume their activities. The experience of the Louisiana Rehabilitative Services was typical of vocational services throughout the region:

The Louisiana Rehabilitative Services is attempting to locate and resume services to individuals with disabilities who were receiving services through their agency prior to the hurricanes. To our knowledge, there is no other agency in the state currently addressing employment needs of persons with disabilities affected by the hurricanes. This has not been a priority for our office because the needs for housing, medication, and direct supports have been so pressing. As these needs are addressed, we expect that employment will become a greater priority among advocacy organizations and state agencies serving persons with disabilities. 66

Furthermore, many more people with disabilities were displaced from their employment training programs.⁶⁷

Effective long-term relief efforts "must focus not just on rebuilding infrastructure but restoring... employment..." It is essential that "[e]mployment programs... be aware that they are subject to federal employment and disability discrimination statutes." Moreover, "[c]ompanies and other organizations employing or training persons with disabilities must identify the needs of individuals ahead of time so that they can return to work as expeditiously as employees or trainees who are not disabled."

Education

Hurricane Katrina displaced approximately 247,000 students from Louisiana, 125,000 from Mississippi, and 3,000 from Alabama; additionally, Hurricane Rita displaced about 86,000 students from Texas' schools. Over 200,000 school age children, 135,000 of whom are from Louisiana, have been rendered homeless because of Hurricanes Katrina and Rita. Some estimates indicate that 12 percent of the displaced students have disabilities. Advocacy, Inc., of Texas estimated that Hurricane Rita displaced about 2,200 children with disabilities under the age of five – many of those children will need early intervention services – and about 5,000 school-aged children with disabilities. One of the most crucial challenges for disaster recovery efforts is to continue the education of student-evacuees while rebuilding educational services in the Gulf Coast.

"Attendance at a school becomes an oasis of normalcy" for children who were traumatized by the hurricanes' devastation. However, over five months after Hurricane Katrina, only 15 percent of New Orleans schools had reopened and those that had reopened reported operating difficulties. Many student-evacuees were able to integrate into new school systems. Nevertheless, the temporary nature of shelter or emergency housing caused many students to be transferred from school to school numerous times. This likely will have a deleterious effect on the academic success of these students, because studies indicate that children require between four and six months to academically "catch up" each time they transfer schools.

For student-evacuees with disabilities, the transfer to other school systems has been particularly problematic. Some student-evacuees with disabilities were unable to register for school because they had not secured housing in the evacuation area and therefore could not provide documentation. However, the McKinney-Vento Homeless Assistance Act⁷⁸ allows students to attend school despite the lack of formal documentation. Many student-evacuees with disabilities did not bring documentation about the nature of their disability or about their IEPs when they fled from the hurricanes, and some schools denied them the provision of necessary educational services.⁷⁹

Conversely, the state of Alabama decided to "take the parents at their word" and provided special education services to evacuees to the best of the schools' abilities, despite the lack of formal

documentation. Similarly, Fort Worth district officials temporarily waived documentation requirements. Several Texas school districts hired additional staff in anticipation of an influx of students with special needs, estimating that between 10 and 15 percent of student-evacuees would have some type of learning disability. Parents of students with disabilities have expressed deep gratitude for the he efforts of local school officials who reached out to their children. When she had to evacuate with her 11 year old son with ADHD, Latanya Biagas was concerned that her son would not have the resources he needs to adjust to his new school in Texas. However, thanks to school officials who planned in advance to accommodate the needs of special needs evacuees, Biagas said, "I'm comfortable [here]. The people at the district have been nothing but nice to us. That's why I want to stay here and make it our home."

On a federal level, Congress and the President jump-started various efforts to help children with disabilities return to school as quickly as possible. The Department of Health and Human Services released \$15 million in aid to help displaced kids re-enroll in Head Start programs. ⁸³ The Office of Special Education and Rehabilitative Services (OSERS) provided \$2 million to Gulf Coast ILCs. OSERS also earmarked \$150,000 for data collection on hurricane-related evacuation issues; \$300,000 for the ILRU program in Houston; and funded the NOD's Emergency Preparedness Initiative. OSERS continues to work with Gulf state officials to improve educational services to students with disabilities who were impacted by the hurricanes. ⁸⁴ Senators Enzi and Kennedy introduced a bill that authorized immediate aid to restart schools in the Gulf Coast region and waived NCLB's "highly qualified" teacher requirements in Louisiana, Mississippi, and Alabama for one year; the bill included special provisions to ensure IDEA compliance as school restarted. ⁸⁵

Healthcare

Access to healthcare was a problem during the evacuation and rescue phase and continues to be a problem during recovery from the hurricanes. In the immediate aftermath of the storms, evacuees arrived to find understaffed shelters with little or no medical supplies. Many emergency managers and health care professionals were unsure to what extent existing civil rights laws, such as HIPAA, applied during the crisis. The US Department of Health and Human Services (HHS) 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 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 offered the following relief:

- Health care providers that furnish medical services in good faith, but who cannot comply
 with normal program requirements because of Hurricane Katrina, were paid for services
 provided and were exempted from sanctions for noncompliance, unless fraud or abuse
 was occurred.
- Crisis services provided to Medicare and Medicaid patients who were transferred to facilities not certified to participate in the programs were paid.
- Programs reimbursed facilities for providing dialysis to patients with kidney failure in alternative settings.
- Medicare contractors paid the costs of ambulance transfers of some patients being evacuated from one health care facility to another.
- Normal prior authorization and out-of-network requirements were 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 were waived as long as
 the provider was licensed in their home state.
- Certain HIPAA privacy requirements were waived so that health care providers could talk to family members about a patient's condition even if that patient was unable to grant that permission to the provider.
- Hospitals and other facilities were granted flexibility in billing for beds that had been dedicated to other uses, for example, if a psychiatric unit bed was used for an acute care patient admitted during the crisis.
- Hospital emergency rooms were 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.⁸⁶

Steps are being taken to ensure that medical care is provided in future emergencies, and HHS has prepared a toolkit to help emergency planners and first responders appropriately access and use health information about people with disabilities, consistent with the law.⁸⁷ While the planning for the provision of emergency medical care has improved for future disasters, healthcare access continues to be a serious problem for Gulf Coast hurricane victims.

Many Katrina and Rita survivors lived at or below the poverty level prior to hurricanes and received a variety of healthcare aid from the government including Medicare, Medicaid, SSI and SSDI. Many hurricane survivors have been unable to reestablish their healthcare support network. Now, many hurricane survivors – who lost critical documents in the storms – are at risk of losing their Medicaid due to a new law that requires proof of citizenship to receive benefits.⁸⁸

Recommendations for Emergency Preparedness

In conjunction with the recommendations delineated in NCD's *Saving Lives: Including People* with Disabilities in Emergency Planning report and other pertinent NCD reports on inclusive transportation and community design, NCD makes the following recommendations:

Administration

- FEMA should require that temporary housing, e.g. trailers, meet universal design principles and accessibility guidelines.
- FCC should promulgate guidelines for broadcasters, cable operators, and satellite television services, to comply with their new "equal access to public warnings" requirement for the recently expanded Emergency Alert System.
- FCC should develop stronger enforcement mechanisms to ensure that programming distributors comply with their legal obligations to make information accessible to people with disabilities and that FCC immediately investigates and responds to violations during emergencies.
- FEMA should establish procedures to reimburse public organizations that exhausted critical resources during Hurricanes Katrina and Rita and in future disasters. Many organizations, e.g. Centers for Independent Living (CILs), donated equipment and medical supplies to hurricane victims and these centers are now hard-pressed to meet the day-to-day needs of their clients.
- HHS should strengthen the Medicare and Medicaid accreditation requirement that nursing homes maintain comprehensive evacuation and emergency response plans, and HHS should strengthen its post-accreditation reviews of evacuation plan compliance.
- DOJ should use its CRIPA authority to investigate civil rights violations that take place during emergencies against persons with disabilities in nursing homes, hospitals and other institutions.

Congress

- Congress should amend the Stafford Act to increase the funds or loan amounts that are available to hurricane victims who rebuild their homes according to accessibility standards, e.g. S2124, HR4704.
- Congress should establish an office or person within DHS who is solely responsible for disability issues and who reports directly to the Secretary, e.g. S2124, HR4704.
- Congress should waive the Medicaid citizenship documentation requirement for hurricane survivors.
- Congress should adopt the principles embodied in *Livable Communities* to guide the provision of reconstruction funds, promoting a Gulf Coast that includes:
 - Affordable, appropriate, accessible housing
 - Accessible, affordable, reliable, safe transportation
 - Physical environments adjusted for inclusiveness and accessibility
 - Work, volunteer, and education opportunities
 - Access to key health and support services

- Access to civic, cultural, social, and recreational activities
- Congress should require the inclusion of people with disabilities in the creation of the National Response Plan, e.g. RESPOND Act HR5316 that would require NCD to review and revise the National Response Plan.
- Congress should consider how NDMS may be expanded or modified to include the critical evacuation needs of nursing home residents.
- Congress should consider how nursing home accreditation programs, e.g. Medicaid and Medicare or JCAHO, could be strengthened to ensure the evacuation of people in nursing homes in times of emergency.

Communities and City Governments

- Establish voluntary self-registries to facilitate the provision of emergency services people with disabilities, such as evacuation.
- Include people with disabilities in emergency planning at all levels.
- Ensure that emergency plans are well coordinated among other state, federal and non-governmental entities.
- Develop a communications plan to ensure that people with disabilities are familiar with local emergency preparedness plans.
- Establish an office or person who is solely responsible for disability issues.

Non-Profit and Community Based Organizations

- The American Red Cross should establish an office or person responsible solely for disability issues who reports directly to the Red Cross CEO.
- The American Red Cross should ensure that shelters and other emergency services are compliant with the ADA and Sections 504 and 508 of the Rehabilitation Act. NCD recognizes that the American Red Cross does not have the licensure to meet the needs of "individuals who require care in an institutionalized setting," but the "reality is that people with special needs will show up at public shelters... the American Red Cross needs to be prepared to assist these individuals until they can be moved somewhere else" and cannot avoid the legal responsibility to admit people who do not require care in an institutionalized setting.
- The American Red Cross should continue to improve its volunteer training programs to ensure that shelter staff is familiar with disability issues.
- Community based organizations that wish to donate resources, e.g. wheelchairs and medical supplies, to disaster stricken areas, should coordinate with federal agencies and national organizations to distribute supplies in an efficient manner.

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