

National Council on Disability



**Quarterly Meeting: People with Disabilities and Emergency Management
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**Quarterly Meeting Report
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Preface

NCD is an independent federal agency and is composed of 15 members appointed by the President, by and with the advice and consent of the Senate. NCD provides advice to the President, Congress, and executive branch agencies to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

In carrying out our mission during our quarterly meetings, we believe it is vital to hear from communities around the country on what works and what does not for people with disabilities. NCD held its first 2008 Quarterly public hearing/meeting in New Orleans from January 28 to the 30th. Among the agenda items for discussion were emergency preparedness issues and the disability community. What follows is a report outlining key issues raised and discussions from invited subject matter experts in the field of disability and emergency management and public comment.

This monograph represents the proceedings of our January 2008 quarterly meeting. It is part of a one-year research project on disability issues and disasters that NCD is conducting. The information in this monograph is being released at this time for use by people with disabilities, first responders, policy makers and communities who are actively involved in using lessons learned to improve their emergency preparedness efforts.

Introduction

Among the agencies represented at the NCD Quarterly meeting in NOLA were the American Red Cross, Salvation Army, and other local advocacy agencies. Following is a summarized brief from each agency.

American Red Cross (ARC)

Kay Wilkins, Chief Executive Officer of the Southeast Chapter of the American Red Cross, represented the ARC. She reported the following:

- There were 1,700 volunteers and 49 staff members at the chapter prior to Hurricane Katrina. Currently there are 100 volunteers and 29 staff members. The Friday before Katrina made landfall, the chapter activated the internal phone tree to alert the volunteers about the potential evacuation of New Orleans and to move host shelter areas above Interstate 12 beyond the area of greatest risk.
- Prior to Katrina, the chapter worked with the faith-based community on a program called Operation Brother's Keeper. ARC asked the faith-based community and congregations to identify the types of transportation opportunities available through their congregation and then to connect those in need of transportation with those who can provide transportation in the event of an

evacuation. Initially, the chapter believed Operation Bother's Keeper helped prepare them and communities for the worst-case scenario. However, as Katrina revealed, many people who did not evacuate and were rescued had no evacuation options and no transportation out.

- The Saturday before landfall, the chapter left the New Orleans area and moved to the Covington area, about 35 miles away. Volunteers and staff began opening the first of what would end up being 27 shelters by the time Katrina hit, the flood waters from the levees rose, and the days after people were rescued from their houses had started. In the 90-year history of the chapter, this is the most number of shelters to ever have been opened. The chapter began feeding and sheltering evacuees on August 26th and continued feeding in the city, including providing hot meals, along with ARC's partner organizations like Salvation Army, until April 15th.
- Katrina taught ARC a lot. Generally speaking, the ARC chapter spends about six months out of every year preparing for a hurricane evacuation in New Orleans. Despite testing plans as often as feasible, there were still lessons learned from Katrina. What the chapter failed to do was plan for a catastrophic event that would not only inundate the city, but also inundate a state, and by the time it was completed, inundate an area that was larger than the country of England.
- Post-Katrina, the chapter is currently working hard with the city of New Orleans to identify persons with no transportation, and to talk through what types of options may be available to those persons. Often, it's in that one-to-one connection, that one-to-one conversation, where the chapter can identify support systems and help individuals gain control of a situation where they feel they have no control.
- Another lesson learned is the need for a strong exit strategy including at the personal evacuation planning level. Every citizen of New Orleans needs to have a plan to safely evacuate. This includes individuals, business, and organizations. Part of ARC's efforts in the recovery phase is to build community resilience and emphasize personal evacuation strategies, having a disaster supply kit, and identifying and planning with support systems.
- The chapter is also working with the Mayor's Office on Disability and partnering with other organizations such as Resources for Independent Living to improve planning and advocacy for people with disabilities. With Resources for Independent Living, ARC is working with case managers to identify recovery assistance needs for people with disabilities. In addition, ARC is looking at ways to better utilize funds and develop plans incorporating the needs of people with disabilities. The chapter has tried to advocate with the Governor's Office of Disability Affairs and its advisory council. The chapter is urging them to establish a preparedness committee.

- Funding for the recovery efforts are dwindling. The American Red Cross' hurricane recovery program will stop in October of this year (2008). There is still much infrastructure that needs to be built, but funding is starting to disappear.
- In sum, the most important lesson learned from Hurricane Katrina is that everyone needs to be prepared. This includes making certain connections, establishing memorandums of understanding, and making sure residents have a disaster supply kit.

Salvation Army

The Salvation Army was represented by Major Michael Hawley, an officer serving as the Greater New Orleans Area Commander. He reported the following:

- In New Orleans, The Salvation Army has a four-story shelter on the corner of South Claiborne and Napoleon, within view of the Superdome. "At the time of Hurricane Katrina, the shelter was full of men and women who chose, for whatever reason, not to evacuate the city. In addition to the 200 or so occupied beds, the population increased over time as a number of people floating by were picked up out of the floodwaters." Ultimately 300 men and women scrounged for food and air in the hot, humid environment, but they were relatively dry and experienced some level of security on the second, third, and fourth floors of that building until they were evacuated from the roof by helicopter some days later.
- Overall, The Salvation Army incident commander had coordinated the deployment of hundreds of mobile kitchens from all over the country in multiple feeding sites throughout the affected area during the initial months. This included the mobilization of thousands of skilled and unskilled volunteers, officers, soldiers, and staff from all over the United States and Canada. It involved communication, as much as was possible, with emergency responders, functioning local agencies, vendors, and government through available means and ultimately meant we appointed men and women to serve as liaisons.
- Following the initial relief efforts, recovery efforts started. Mobile canteens had served the masses and returned home. Properties had been secured and made operational for warehousing, distribution, and long-term recovery caseworkers. Thousands of citizens were meeting weekly with staff -- case managers, emotional and spiritual case managers, and disaster volunteers. The Salvation Army was running multiple distribution centers, where furniture, appliances, clothing, mattresses, household and personal items, et cetera, were being given to people who had the capacity to use it. The list of supplies included wheelchairs, scooters, crutches, walkers, hospital beds, and other aids for people with a variety of disabilities.
- Unfortunately, and despite the need, at times services can't be provided rapidly enough – this was especially the case after Katrina. Consider the massive destruction: 183,000 homes in Louisiana qualified for significant recovery

dollars. Even on a good day, with the infrastructure of the community solidly intact, you may need 120 to 180 days to accomplish what's needed to replace or do the extensive repairs on a house, much less when you're working with systems that are broken, volunteer or contract labor pools that have to scrounge personally for a place to live so they can serve and work, or are constantly changing because their two weeks are up and they have to go back to school, work, or play. Each of these homeowners has had to make adjustments to their lifestyle, including for many of them finding somewhere else to live temporarily until their home is repaired.

- The wealthy had some insulation from the impact of the recovery because the damage impacted only a fraction of their holdings, but for those living paycheck to paycheck or those who had already been living with multiple families in their house because of their poverty, they may have to literally start over. There are also people who have been displaced, those who were not homeowners or landholders at all, who no longer had a place to live, or upon returning, found that rates had increased dramatically, effectively compelling them to relocate, leaving the familiar for unfamiliar territory.

Local Advocacy Centers

Talatha Denison represented the Mississippi Protection and Advocacy Center and served as a Katrina Aid Today project manager, a position that resulted from Hurricane Katrina. She reported the following:

- The Protection and Advocacy Center (P&A) had many lessons learned that were shared at the conference. A primary point is that agencies must have an emergency preparedness plan and that plans need to be tested and ready to put into action. All plans and exercising of plans should include contacting the agency staff, via a phone tree, or the chosen method of each agency. Three days after the storm, the agency was unable to locate workers. There was no power and they had to use radios sparingly to preserve the batteries because there was no sense as to how long the city would be without power. Most staff reported feeling trapped and stuck. In addition, after a disaster, agencies should consider not only reaching out to the local community and client-base, but to the larger surrounding communities.
- The agency also realized that a plan should be in place to protect client records, agency records, and a plan to evacuate those records if needed. It will be equally important to test the plans (i.e., see how well client and agency records can be backed-up and moved) before the actual event occurs.
- P&A staff members were able to access most of the shelters to locate clients and check on accessibility issues and needed services. By stating who they were as an agency and what the legal mandates of the agency are, it allowed staff to gain access. However, although P&A was able to gain access, not all agencies were and it also became difficult to coordinate services to people with disabilities and

be aware to not duplicate those services. Moving forward, disability agencies need to plan together, evaluate each situation, determine how to provide appropriate services, and ultimately to avoid duplication of services. In the beginning of the response, P&A was able to work with a few other agencies including LIFE and the Coalition for Citizens with Disabilities. Through working together as essentially a working group, agencies were able to share information regarding services and clients. This was very successful and an effort that needs to be continued in every disaster and emergency. It should be included in emergency preparedness efforts across the board.

- Another recommendation from P&A is to encourage disability agencies to become active members of the State and local Voluntary Organizations Active in Disaster (VOAD). P&A currently has a representative on the board of the Mississippi VOAD. P&A is the only disability agency at that table. It's important that disability agencies are a part of the VOAD system because it enables organizations to coordinate with other agencies, tap into available resources, and become more involved with planning, response and recovery.
- The issue of planning for both short-term and long-term needs is prominent concerns as well. Many of the problems caused by Katrina have not been resolved and are still prevalent today. For example, there was a need for equipment for people with disabilities, an immediate need after the storm and in shelters. By working with LIFE, P&A was able to obtain equipment in some cases including items such as hospital beds.
- After Katrina hit, Katrina Aid Today (KAT) was established to provide funding and coordination of long-term services and case management. P&A, along with many organizations, are an active part of KAT. Through the KAT program, the P&A case managers have served 1,713 individuals with disabilities and their families. This number refers to intake and assessments that have been completed. Out of the 1,713, about 818 cases have been closed. These cases have been closed for various reasons including recovery plans being met. Unfortunately, some recovery plans were not met because resources were not available and are still not available to meet recovery needs. A recovery plan basically charts the progress of what each individual will need to return home/stay home such as completely rebuilding a home or finding accessible affordable housing. There is no accessible affordable housing in Mississippi, so that makes a recovery plan addressing that issue impossible to achieve right now.
- One hundred out of 1,713 clients from the Gulfport Armed Forces Retirement Home, evacuated to Washington D.C. where they remain today. The National Disability Rights Network contact P&A to assist with some of the clients from the retirement home. However, the only assistance the agency was able to provide was information and additional answers. The agency was not able to move other types of services quicker such as expediting the rebuilding of the Gulfport home. Staff met with some of the clients who were relocated to D.C. and the number

- Initially, KAT provided enough funding for eight case managers at P&A, but funding was reallocated last year and the agency was able to hire eight more bringing the total to 16 case managers. However, as funding is dwindling, the agency lost eight staff members recently. Currently there are seven case managers from Mississippi P&A providing recovery case management. Through these KAT services, the agency has provided 2,099 referrals: 1,923 referrals have been utilized; 634 recovery plans have been developed; and 384 cases have been presented to the long-term recovery unmet needs committees by our agency. \$504,251 in resources has been received through the long-term recovery committees based on those presentations. \$1,662,896 and change has been provided in services that case managers have advocated for clientele. \$9,858 has been used from KAT donated funding for client needs.
- P&A also received donations, part of which has come from a group in Seattle called the Total Experience Gospel Choir, that has adopted the group. They've been to Mississippi twice to work directly with clients on refurbishing their homes or repairing and rebuilding in some areas, and sometimes they just go and visit with them to try to lift their spirits.
- In addition, a casino made a \$50,000 donation to P&A and other agencies in Mississippi. That money is primarily used for direct services for clients. Case managers have participated in 12 long-term recovery committees. To date, of the cases that have closed, 322 have been due to achieving their recovery plan. One hundred and eighty clients have stated that their primary needs were met. Two hundred twenty two of these people were unable to resolve due to lack of resources, which is almost half of what has been closed. 56 clients withdrew their request for services. 29 cases were transferred outside of our KAT consortium, and 43 of our clients relocated. Disability agencies in Mississippi have worked together following Katrina. LIFE, Coalition for Citizens with Disabilities, P&A, and others have worked together to address emergency preparedness and the recovery issues. Agencies rely on each other to meet the recovery needs of clients.
- Agencies consider the status of survivors still in crisis. There are 11,524 FEMA trailers still occupied in Mississippi. FEMA parks are currently closing at a rate of two per month in 2008. There's money available. The Mississippi Gulf Coast Community Foundation money is available through long-term recovery committees in the lower six counties. This money is accessible only through the long-term recovery committees. Thus it's only accessible by case managers representing clients. Case managers assess needs; verify needs, and present cases to the long-term recovery committees for support and for funding. Disaster case management is about to end in Mississippi. Katrina Aid Today ends

March 31 of 2008. Following behind that, in April of this year, some of the long-term recovery committee funding for case management also ends. And in Jackson County, Mississippi, which is one of the lower three counties, that completely wipes out the long-term recovery committee. And funding that we have received comes through those committees so it will be impossible to access it for recovery. Without disaster case managers, cases can't be worked and presented for funding.

1. Lessons Learned

Clearly there were many lessons learned that came out of the tragic event of Hurricane Katrina. This experience emphasized the importance for Cities, counties and individuals all across the country to be involved in their own personal disaster plan. It is important to recognize that Katrina was an anomaly and extreme event. Most disasters in the US differ in scale than Katrina. It is important to keep this perspective as we move forward and continue to face the challenge of disaster response and recovery and to learn from each experience. This section outlines lessons learned from Katrina, as well as from other recent disasters which panelists discussed during the conference.

1.1 Healthcare and General Services

This section briefly describes what happened in terms of people with disabilities during Katrina and why it's been so difficult now in terms of reconnection to services.

According to Kathy Kliebert, Assistant Secretary for the State of Louisiana Office for Citizens with Developmental Disabilities (OCDD), during Hurricane Katrina, it is estimated there were approximately 13,000 people with developmental disabilities evacuated from NOLA. Kliebert estimates that there were closer to 200,000 people with disabilities, evacuated in a short period of time. Since the evacuation happened so quickly, obtaining exact numbers of how many evacuees were people with disabilities is very difficult. It also indicates problems with the evacuation process and that left people without their medical records, medicines, adaptive equipment, and assistive technology. As a result, people were dispersed throughout the nation without essential information and equipment. Kliebert also reports that hospitals were severely affected with only two facilities operational during the storm and for months afterwards. As a result, people did not have access to many essential services immediately after the storm and for people with certain disabilities and/or medical conditions; this can have dire consequences on their health and safety.

Since people were re-located all around the country, it was difficult to help people reconnect. Many people with disabilities relied on human service organizations to help them reconnect. Specifically, it has been difficult reconnecting people with developmental disabilities because of the level of expertise needed to assist this community. Kliebert estimates that for the first few weeks, her organization was only able to locate about 10% of their clients; 10 weeks later, her organization was only able to account for about 70%. Kliebert states that they had a very poor tracking system in

terms of being able to locate people and communicating with clients making reconnecting clients to services extremely difficult.

Currently¹, it is believed by service providers that many people with disabilities still have not returned to the New Orleans area. Some service providers attribute this to housing problems acknowledging that the housing problems extend to the general population as well. However, for some people with specific disabilities, housing needs may include retrofitting homes and accessibility issues as well as access to certain social and medical support systems (i.e., dialysis centers, physicians, senior centers, etc.) In addition, some people with disabilities face needing housing that comes with some sort of voucher system or subsidy. Kliebert mentions that her agency was successful in obtaining permanent, supportive housing for people with disabilities. The units were specifically allocated for people with disabilities. What remain missing are the vouchers that allow for subsidies. This is particularly problematic because while there are some supportive, permanent housing, lack of vouchers and the ability to subsidize prevents people who receive SSI from actually obtaining the housing. This situation has made it difficult for some people with disabilities to return.

In addition to housing issues preventing people with disabilities from returning to New Orleans, there are other issues such as lack of service providers and workforce issues. It was reported by the developmental disability providers and community home providers specifically that some agencies simply have not returned. These agencies have found it difficult to obtain staff and the appropriate resources needed to provide services. As a result, some individuals are receiving services from providers located just north of New Orleans, other parts of Louisiana, and, in some cases, outside of Louisiana. The workforce has suffered as well both in terms of healthcare workers and direct support and personal care attendants for people with disabilities. Part of the issue has been funding to adequately pay trained staff, an ongoing issue. While some progress regarding salary increases have been made through legislation, competition is high in the area making recruitment and retaining personnel challenging. In addition, it had been reported that healthcare providers have left the area.

Several entities, such as the Department of Health and Hospitals, have been focusing intensely on recruitment. A study conducted by the Louisiana Public Health Institute indicated that, for the most part, major healthcare professionals have returned in sufficient numbers to the area. However, there seems to still be a lack of specific specialties. There are still waiting lists of people in need of specialists. Kliebert reports that some clients will wait months to see a neurologist. In addition, all healthcare providers do not accept Medicaid and clients cannot afford to see other providers. At the time of this report, Louisiana State University Medical School only has four neurologists on staff. For the 13,000 or so people with developmental disabilities, this is a significant problem. Longer wait times for neurologists also means that primary care physicians may try to medicate and provide services to a population they may not necessarily have the exact expertise to provide proper care. For example, a lack of expertise in developmental disabilities makes some of these practices potentially dangerous;

¹ This was reported at the time of the NCD Quarterly meeting on January 29, 2008.

specialists need to be involved, for example, when neurologists prescribe medications for those with developmental disabilities. Finally, there are longer wait times in emergency rooms and general physician care, which is problematic for people who are medically frail or have serious medical conditions and require a high level of attention.

1.2 Behavioral/Disaster Mental Health

It has been reported there is a major shortage of psychologists and psychiatrists in the New Orleans area. Again, wait times for those types of specialties can be upwards of four to six months for an initial appointment. If a client experiences a mental illness or behavioral crisis must wait, the potential danger to the client and even to the larger society may increase. Waiting for mental health care often is not an option for certain people. This has resulted in an increased need for inpatient beds for people with mental illness in psychiatric facilities, which are at a premium right now. There is also an increased incidence of post-traumatic stress. This is typical for many people with disabilities, and specifically in the aftermath of Katrina, there have been some real traumatic situations that many people with disabilities faced.

It was also reported that mental health issues are still on the rise in Mississippi as well as Louisiana. The further away from the disaster and the longer the recovery efforts take, the less hope people seem to have. Most people have stated they continue to deal with bureaucracy and red tape. Panelists confer that the changes have not occurred in terms of including the needs of people with mental illness in addition to the general disability population.

Kliebert reports the following efforts from her agency, Office for Citizens with Developmental Disabilities (OCDD):

- The agency continues to evaluate the healthcare shortages and is working to put incentives in place to recruit trained personnel in the area of disability. The agency is working with new providers to give them some expertise.
- The agency has an Operation House Call program that was started post-Katrina. The program trains residents by going into homes of people with disabilities and working with the families and learning about some of their experiences and understanding what it means to be a physician dealing with somebody with disabilities.
- Other activities include: pay increases, restructuring hospital capacity for home and community based services, an increase in federally funded healthcare clinics and other clinics in the area that are more community based and will have easier access for people with disabilities, an increase for waivers, working with school-based health clinics, and training on post-traumatic stress disorders in people with disabilities.

These types of efforts will provide a foundation on which people can mount a return with the support that they need. In addition, it will assist people already in the area who need

personal care support or other supports. It has also been reported that there has been some major funding to increase both mental health services and beds in this area. However, the damage to the infrastructure was significant. The ability to retain and obtain resources for people in this area has been difficult and is still difficult. The rebuilding has been very slow. One estimate states it will be 2015 before some of the infrastructure really comes back to the area.

1.3 Post-Katrina Rebuilding Efforts

The Advocacy Center from New Orleans works on behalf of individuals with disabilities to achieve access to public buildings and services and privately run public accommodations. Charles Tubre, from the Advocacy Center suggests that as with all other aspects of post-Katrina rebuilding, it is important that the physical reconstruction of buildings be achieved carefully and deliberately with attention to the needs of the individuals with disabilities. Federal and local laws require that accessibility and removable barriers for people with disabilities, that they be a part of the rebuilding process. Physical accessibility has ramifications beyond access to the structure itself. FEMA funds are being used to rebuild streets, schools, civic centers, and privately owned buildings. As rebuilding progresses, attention must be made to increasing accessibility to the community, to the system of this city, and other communities rebuilding after the storm. The entire community benefits as access to public works and structures will increase access to the employment, healthcare, and independence for people with disabilities. We must ensure that the federal, state, and local authorities who operate public buildings will fill their obligation to comply with the laws; the cost of complying with the relevant laws later will undoubtedly exceed that of getting it right the first time.

1.4 Building Capacity at the Local Emergency Management Levels

Most disasters in this country are responded to by local offices of emergency preparedness and not by federal teams. Although we hear more about the hurricanes, wildfires, earthquakes, and tornadoes that cause major destruction requiring federal assistance, these are not the most frequently occurring disasters that require the attention of the local offices of emergency preparedness. Charles Tubre from the Advocacy Center (New Orleans) suggests that it is these local offices where the experts should be offering guidance, expertise, and financial assistance. Most, if not all, local, parish, or municipalities' offices of emergency preparedness want to respond to all of its citizens in their communities, yet they are not given the tools and the finances to do so, especially when it comes to disability issues. The same person who leads the fire department or the police department runs many of Louisiana's local emergency preparedness offices. These men and women are stretched too thin to effectively focus on disability issues. They do not entirely understand these issues or they're afraid to address them due to lack of resources and fear, possibly unfounded, that they may not be able to afford them.

1.5 Preparedness

All agencies represented at the conference confer that personal as well as organizational preparedness are key issues. Advocacy agencies indicated that people

with disabilities need to be more involved with emergency preparedness training and feel it is still not happening enough. Preparedness should include the establishment of a database with people with difficulties and who cannot self-evacuate. In order to make this type of a database system work, it has to be maintained well so that the information remains current and useful. One reason for the biggest loss of lives of senior citizens and people with disabilities during Katrina was because no one prior to the storm had planned for these populations adequately, did not know their locations or how to reach out effectively to them across the country. In addition, there was a lack of effective communication between the aging and disability population who were not able to self-evacuate. Individual reports describe people with mobility disabilities (e.g., wheelchairs) requested rescue from emergency responders who were unable to reach them through the storm or flood. The loss of life within the disability and aging communities was devastating, a situation that should have been addressed prior to impact.

Preparedness efforts with these populations must include the consideration of durable medical equipment, auxiliary and assistive devices, and service animals. For example, a lack of accessible transportation and rescue transport meant that many were rescued without their wheelchairs, a debilitating consequence. Losing a wheelchair can take away from independence and a person's ability to be fully mobile. Some of these individuals who lost their wheelchairs were left in staging areas sometimes for days. As a result, secondary health complications arose and in some cases resulted in death.

Red Cross chapters meet with groups and talk to people one on one, partnering with local officials and telling the story, the very real story that the only way you're going to be assured of having the supplies you need to keep you and your family safe and to keep you independent is if you stock them yourselves. The best way people with disabilities to continue their own independence is to prepare as best they can. Some other recommendations include:

- In New Orleans, it was suggested that people with disabilities should let specific agencies know of disaster-related needs and the type of assistance necessary for evacuation, such as items like wheelchairs that need to remain with the person at all times.
- It is important to be able to communicate with government and other organizations the struggles people with disabilities have in both preparing for and recovering from disasters.
- Ensure agencies and organizations that can advocate get involved on a local level with various community supports. Together, these organizations can begin to identify who is in the community, who will need help, who will not have transportation, etc. As was suggested earlier, many areas now have local VOADs that bring organizations together for the purposes of disaster planning.

After Katrina, and based on lessons learned, the LIFE organization in Mississippi began working with and teaching people with disabilities how to create an emergency preparedness kit so that they will have their needs met. Mississippi continues to serve those with disabilities unable to return home. The disaster meant they lost social

security and Medicaid cards, medication, etc. Some did not have Social Security cards, Medicaid cards, enough medication, durable equipment, et cetera, with them, all which should be included in preparedness kits. LIFE had to try to meet all those needs as a result. Although a few organizations have begun preparedness efforts and are working with people with disabilities, it seems to not be a wide-spread process, which is problematic.

1.6 Building Trust in the Disability Community

Through testimony in the hearing it was noted that Hurricane Katrina was not only catastrophic in terms of people's lives lost due to the terrible displacement and the consequences of that for people with disabilities, but what it did was fracture the fabric of trust that people with disabilities as well as other citizens have in government resources in the time of emergency. That trust does not exist anymore or at best is fragile. Rapid reforms have been promised from the Bush Administration, but according to those still facing the aftermath of Katrina and other recent disasters for that matter, there is no or little evidence of significant gains made post-Katrina. It will take real reform and decades to improve trust within the disability and other communities as well.

1.7 Post Disaster Funding for the Disability Community

While there was a lot of funding sent to Louisiana post-Katrina, there was not a lot of money specifically for assisting people with disabilities. The money was not distributed and prorated in terms of specific services for people with disabilities except for some limited resources aimed toward housing. In terms of other resources, additional funding has gone to healthcare services, but again, not specific to serve those with disabilities. There was specific funding for people with mental health issues. However, because infrastructure was so devastated, it has made it difficult to provide these services. The infrastructure collapse has made it extremely difficult to utilize that money in an efficient manner.

There are some federal agencies that have assisted with getting particular processes started.

In terms of health issues, Substance Abuse and Mental Health Services Administration (SAMHSA) has provided funding through grants. The non-profit community has also been very helpful especially with getting healthcare professionals in the Louisiana area. Numerous agencies sent volunteer professionals such as doctors and nurses. While FEMA will try to support local areas affected by disaster, it also looks to the state to assist. The new National Disability Coordinator, Cindy Daniel, indicated that she will be looking into ways in which funding might support states regarding special needs.

1.8 Transportation Issues

Most panelists at the conference agreed that transportation is always an issue during disasters, especially for the disability, medical and aging communities. Transportation issues tend to center around evacuations and re-entry issues. However, during the recovery phase, if proper transportation infrastructure does not come back quickly, it can cause many ongoing issues. A local advocate from the Advocacy Center reported

that transportation has been horrendous for people with disabilities post-Katrina and is a big issue despite efforts by several agencies.

Coupled with housing, the second most important service severely impacted after the storm's aftermath is public transportation. Prior to Katrina, there were approximately 360 buses in the fixed route public transit fleet in New Orleans. As of this conference, there are less than 100. Fleet managers and agencies do not have the resources to maintain properly the buses. Part of the resource issue is tied into housing. If there is not enough affordable housing, then people cannot return and the workforce suffers. Essentially, transportation agencies do not have the maintenance crews that they had prior to Katrina to maintain the fleets including maintaining accessible transport. Pre-Katrina, there were approximately 124,000 daily riders on fixed routes. Today, there are only 23,000. New Orleans is supposed to receive 39 new low floor green diesel buses by the spring. This will hopefully help alleviate some of the ongoing transportation issues. The buses are more spacious, easier turning radius, and even if the mechanics of the ramp fail to be deployed automatically, they can be deployed manually, so you don't get caught on a bus that has some sort of mechanical or electrical failure. In addition to regular transportation, a majority of people with disabilities receives public transportation services from Paratransit, which is also overwhelmed.

During evacuations, which in the case of Katrina happened over a series of days and phases, there were many struggles to find adequate accessible transportation to take people to appropriate receiving centers. Registries are in place in various jurisdictions throughout the country to help identify people who may need assistance during evacuation, but registries are complex and don't always meet expectations. For example, the Houston Center for Independent Living (HCIL) reported that a plan had been devised to develop a database registry for evacuees who were seniors and people with disabilities and needed transportation assistance so that they could be picked up, brought to a staging area, and then to a receiving city. As reported by HCIL, the database at first was very medically oriented and intrusive asking more than transportation needs, such as medication information. Further there were shortages with accessible transportation, the primary transportation resource was school buses and MetroLift.

1.9 Housing

Housing is a major reason why people with disabilities cannot live as successfully as they did in New Orleans prior to Katrina. It was reported at the meeting that approximately 123,000 homes were damaged or destroyed in New Orleans as a result of the hurricane. 82,000 of those were rental units. An important fact is that New Orleans is traditionally a city of renters. Katrina destroyed 55% of rental units in the city. While there has been much loss, there are several programs that are just now getting into place that will bring some relief in terms of affordable housing. The Road Home small landlord rental program brings federal community development block grant dollars for property restoration. A small percentage of these units will be designated as both affordable and accessible. Community Development Block Grants (CDBG) built such incentives into the landlord programs and tied them to forgivable loans. Rental units

must remain at affordable prices for up to five years. Eventually, about 10,000 affordable rental units will be available. A small percentage of those units will be not only affordable but will be accessible, because built into these programs are incentives for landlords, forgivable loans, that if they agree to rent their properties at affordable prices for up to five years, then their loan under this program will be forgiven.

Housing, along with transportation, are the primary problems people with disabilities are currently facing in Mississippi. The cost of living has almost doubled on the coast after Katrina. A one-bedroom apartment, not necessarily accessible, rents for \$600 to \$900 post-Katrina. Section 8 rentals are also very limited. This has resulted in some tenants not being able to afford the increases as landlords have doubled their rents in some cases. Power bills have also increased. It was reported that some people have not been able to catch up on their utility bills following Katrina, especially those with disabilities who live on limited income.

The most current population counts puts 319,000 citizens back in New Orleans indicating the population has dropped significantly post-Katrina. According to Charles Tubre of the Advocacy Center, a number of those people were not citizens of the city prior to Katrina. Some estimate that as many as one-sixth (approximately 40,000-50,000 people) of the 319,000 current population may be those helping to rebuild the city (rather than returning residents).

Essential services were heavily impacted by the aftermath of Katrina such as public transportation, affordable housing, accessible housing, healthcare services, and community-based support workforce that it has made returning difficult for many but especially for people with disabilities. As a byproduct of the lack of affordable housing, the community-based care workforce is decimated. Pre-Katrina, there was a functioning community-based care workforce. Post-Katrina, because of the lack of affordable housing that specifically trained workforce has not returned to town. And even those who are here report problems getting to work because of the reduced number of public bus lines.

Kay Wilkins from ARC mentioned that the FEMA trailer villages are closing in the New Orleans area. ARC has been working with FEMA and HUD for the last six months on moving people from the trailers to more permanent housing. They have been working on holding housing fairs to bring in other case management agencies as well as HUD to identify options for these families as they move out of FEMA trailers. ARC continues to work with FEMA in Louisiana. However, it seems illogical to close the trailer villages when no one has anywhere to go.

Tony Koosis from the Houston Independent Living Center (HILC) also reported that housing is an ongoing issue. It was one of the organization's first points of advocacy specifically working with the housing committee to establish and provide accessible housing. The ILC developed a checklist based on the Uniform Federal Accessibility Standards (UFAS) so that people would have basic entry and ability to move around. There was a good organized effort to try to find accessible housing, but in the end,

people with disabilities took it upon themselves to find housing and make modifications later.

Mary Lamielle, Executive Director for the National Center for Environmental Health Strategies in New Jersey, and public health advocate stated that she fears for the health and vitality of the city (NOLA) and residents and land and waterways, fires, sewers, molds, pesticides, disinfectants, which all can cause a host of chemical injuries, including asthma in healthy people and chemical sensitivity. Add to that temporary housing that made people sick by toxic formaldehyde. It's a recipe for continued disaster. And of course no housing is available for those with chemical or electrical sensitivities.

The Musicians' Village Project is underway and provides 300 affordable units for musicians in New Orleans, a vital element of local culture. Other housing under development includes some tax credit developments, nonprofit development, and \$500 million planned HUD public housing mixed income development projects. However, construction will take several years.

1.10 Collaboration

It is critical that organizations and agencies, both NGOs and government entities, collaborate prior to, during and after a disaster. In addition, people with disabilities should be included in the collaborative efforts as volunteers, staff, planners, and organizations. For example, the Center for Independent Living (CIL) utilizes people with disabilities as staff, board members and volunteers. In addition, the CIL tries to recruit individuals with disabilities as AmeriCorps volunteers. Recommended organizations to collaborate with include: Centers for Independent Living (state and local if applicable), Departments of Rehabilitation Services, relief organizations, and government agencies (local and state) such as Aging, Disability, MRDD, etc. Some of these agencies assisted in locating consumers/clients, access to additional services and resources and equipment. Government agencies are especially helpful in terms of working with NGOs to gain access to areas where access would be prohibitive. For example, government entities can assist with ordering and loading trucks with necessary items, transportation of these items, and coordination. Since most government agencies are connected with emergency operations, they have direct access to many resources as well as the ability to deploy and coordinate as requested and necessary. Again, as mentioned earlier, VOAD organizations are also focused on greater collaboration among organizations in planning for disasters.

1.11 Shelters

Accessible shelters are a critical issue for people with disabilities during and following emergency evacuations. If people with disabilities cannot access shelters, a whole segment of the population will have no safe place to reside temporarily during a dangerous situation. This puts the lives of people with disabilities at risk. Specifically, some advocates at the conference argued that it should be the law that all shelters are accessible and that no one should be denied entry into disaster shelters. There are specific legal issues that need to be addressed most especially accessible sheltering.

All people should be entitled to a safe place to stay for the duration of an emergency or disaster.

NCD heard repeatedly throughout the conference meeting in New Orleans and as well as previous meetings in Boston and other cities since Katrina that organizations operating shelters, such as ARC and the Salvation Army, were either not allowing people with disabilities into the shelters or not making appropriate accommodations for people with disabilities. It seems while not all shelters were accessible, others were. Apparently it was a “mixed bag” in terms of accessibility to shelters and provision of reasonable accommodations. The Advocacy Center has been trying to deal with this issue for many years prior to Katrina. When Katrina hit, it was 15 years post Americans with Disabilities Act and therefore, many in the advocacy community believe that there is no excuse for shelters to not be fully accessible to individuals with disabilities.

The issue of access to shelters is an issue for many disability advocacy groups as well as other service agencies. In Texas, the Houston Center for Independent Living spent days trying to gain access to the Astrodome, and had great difficulty identifying the agency to grant such permission. When the Houston Convention Center was established the Houston CIL went directly to the facility, asked to speak to the person in charge, and was then granted permission. The Houston CIL spent about the next 45 days there with at least two staff members there full time, answering questions and providing assistance. There were many gaps in service that the agency identified as well. Additionally, when the request for wheelchairs was made to the CIL, they were able to get private donations of money including a major contribution from the Wheelchair Foundation of almost 300 manual wheelchairs. The Advocacy Center of New Orleans reported staff was turned away from local government and ARC run shelters. Some other organizations reported that they also offered assistance at shelters in Mississippi offering resources, DMEs and professional staff with expertise in disability. Some of the organizations were also turned away in Mississippi because they were not affiliated with government.

These agencies have experience working with the disability population and identifying services and resources, and once integrated into the shelter structure can be a tremendous asset to the recovery effort.

In terms of emergency shelters, it is important to have trained professional staff especially in the area of mental illness and the needs of the overall disability population. Providing information about what an individual with a disability needs to have in time of an emergency, a list of their medications such that they report to a staging area, they're transported out of harm's way to a shelter, the trained staff there would look at those medications, the list, and be able to provide the oversight or care of that particular population. It is hoped that would be true of people with physical disabilities as well as psychiatric disabilities. All of those issues were not addressed uniformly across the board no matter what the disability. Even for the elderly, the shelters were not suitable for their needs in terms of the kinds of cots they had, and other resources. It just did not work for fragile populations.

The issue of storing necessary equipment and assets for shelters also was raised during the meeting. Some participants felt that storing assets locally was the best approach. Others argued against that for logistical reasons. The counter argument rested on the idea that FEMA could provide funds to ship items including durable medical equipment (DME) from storage locations into the impacted area. Otherwise, storing items like wheelchairs could be problematic because of bulk. Charles Tubre of the Advocacy Center recommended that it may work better to have a memorandum of understanding between FEMA and suppliers of such equipment. If some durable medical equipment goes unused and unmaintained, it might not even be usable when it's needed. Rather than have regional depositories, have contracts with providers, just like FEMA does with its emergency transportable housing so that they can get that kind of thing online quickly. Perhaps a combination of such a memorandum of understanding coupled with an evacuation plan that would enable consumers to leave their homes in time of an emergency with their durable medical equipment would be another approach. Then it's not an issue when you get to the shelter that hopefully would be accessible.

Christy Dunaway, Executive Director from the LIFE organization in Mississippi reported the following experiences:

- LIFE staff members were deployed throughout the state to go to their local shelters mostly run by either ARC or FEMA in addition to “unofficial” shelters, like those in local churches that had been set up to meet burgeoning needs. LIFE staff spent time at these shelters to assess what the needs of people with disabilities who had to evacuate from coastal Louisiana and coastal Mississippi. This went on for several weeks. In terms of access to shelters, some allowed LIFE staff in while others did not.
- LIFE staff served well over 2,000 to 3,000 people in the first couple of months after Katrina in Mississippi because a lot of New Orleans people evacuated to Mississippi. Staff were only able to accomplish that because disability organizations were extremely generous not because of federal, state, or local governments. For example, the independent living program out of Houston contacted LIFE and provided funds and medical equipment. LIFE obtained other significant donations including 18-wheelers full of durable medical equipment, power wheelchairs, manual wheelchairs, hospital beds, and walkers. In addition, with assistance help from the Department of Rehabilitation Services, Mississippi provided warehouse space to store the equipment and helped distribute it. Primary assistance came from nonprofits and churches. Since Katrina, organizations have not seen any significant changes.

1.12 Hurricane Rita

Evacuation Issues

Coming off the heels of Hurricane Katrina prompted people to evacuate even in communities where government officials were saying they didn't need to evacuate. Within a few hours after the evacuation started, in Texas authorities made all the

highways going in one direction out and posted guards and sentries to make sure nobody would go the other way. One specific lesson learned from the evacuation included a need for more access to gas for refueling, and food locations along the evacuation route.

Initially, the State of Texas began to utilize the 2-1-1 system² and encouraged individuals with special needs to use it to register their location prior to landfall. Two days before the storm, the Center for Independent Living assigned volunteers and staff members to call all consumers and to let them know they could register with the 211 system and request transportation assistance. Unfortunately, 48 hours in advance of the hurricane, the 211 system had been turned off. This caused a lot of confusion and tied up local city and county lines. The State of Texas learned a lot from this experience and now begin the pre-positioning and pre-storm planning process 10 days in advance.

1.13 2007 California Wildfires

Experts at the conference confer that while there were improvements during the response and recovery efforts during the 2007 Wildfires, it still cannot be compared to the events of Hurricane Katrina. The FEMA National Disability Coordinator, Cindy Daniel, reported that she was able to put things in place before she was deployed to California during the wildfire response. The communication was already taking place while during Katrina, it was not. Working with other groups such as the Interagency Coordinating Council (ICC), Cindy Daniels was able to collaborate better including holding daily conference calls regarding what the needs were within the disability community.

The team was also able to go to shelters to assess the situation as well as working on obtaining durable medical equipment. People with disabilities were taken from wheelchairs to cots and sometimes lost their DMEs. The team worked hard to help people who lost DMEs get them back as well as work on educating relief workers that people could not be separated from their wheelchairs, canes, service animals, other DMEs, etc. In addition, the team was able to establish pet shelters next to general population shelters. Daniel's reported that there were no "special needs" shelters because, through collaborative efforts, people with disabilities were accommodated and provided for in established shelters. The team was able to transport people back and forth from the shelter to temporary housing, which was accessible. Currently (January 2008), FEMA has 400 people already with applications and being served. FEMA provided motorized wheelchairs, manual wheelchairs, raised toilet seats, grab bars, TTYs, hearing aids, and dentures.

² 2-1-1 is an easy to remember telephone number that, where available, connects people with important community services and volunteer opportunities. The implementation of 2-1-1 is being spearheaded by United Ways and comprehensive and specialized information and referral agencies in states and local communities. United Way of America (UWA) and the Alliance for Information and Referral Systems (AIRS) strongly support federal funding so that every American has access to this essential service. For more information, go to <http://www.211.org/>.

2. National Council on Disability: Next Steps

2.1 2008-2009 Research Project

NCD is conducting a one-year research project on disability issues and disasters. The project has been organized into different discrete topic areas that will be researched, analyzed and reviewed over the course of the year. These so-called mini-lit reviews, or chapters, will be drafted one at a time, and while in review the next topic area will be in progress, which will allow NCD to identify issues early on that should be further researched. To conduct the research a multidisciplinary approach is used to review a wide variety of materials. This means journals of medicine, journals of emergency management, journals from human services and social service delivery. It does not mean staying to one academic discipline but rather stretching it as far and wide as to potentially capture those references that might have been lost in the initial review process. This includes a review of existing materials, new and current materials (incorporated as they are being published), and after action reports including any disasters that occur during the course of the project.

The result of this project will be a robust annotated bibliography, which also includes a synthesis and analysis of the findings and recommendations. This is the first of its kind and will be a great resource, with a wealth of information for furthering the process of research.

3. Conclusion Analysis

- There are significant lessons learned resulting from Hurricanes Katrina, Rita, and the recent 2007 California Wildfires. Much of the information shared during this hearing not only indicates the challenges with response directly after Hurricane Katrina, but addresses the long term effects as can be documented at the time of this hearing, two and a half years later. There is still a pressing need for coordinating national efforts with FEMA, Department of Homeland Security, and DOJ, among others, to implement the identified needed services that people impacted by Katrina once had access to but no longer do. During the hearing, there was an indication that, to this day, a great deal of anger and disappointment is directed at both federal officials and state officials and certainly the municipal officials for their failure to plan for and respond to its citizens with disabilities after Katrina.
- Though there is new guidance available and new criteria developed around special needs planning, via the federal government, this has come to the states and locals without funding and resources to carry out what is specified in the guidance. The worry is that local jurisdictions are being set up to fail and not meet new criteria. There is also criticism of the NRF that provides a framework but does not set up mandates or provide clear direction to the states and local jurisdictions about how to operationalize the concepts.
- A theme that emerged from the hearing is the need for greater coordination among agencies and particularly more involvement and integration of disability

organizations in emergency planning efforts. The federally funded centers for independent living, Statewide Independent Living Councils, P&A services, other disability organizations, and others should be at the table when disaster plans are being made and when disaster relief is being coordinated. These efforts have to be coordinated with local and state emergency management officials, to ensure integration, collaboration, and cooperation before, during and after emergencies. For example, putting MOUs in place prior to the disasters for a range of services and resources with agencies including: specialized equipment; accessible transportation; access to shelters; providing assistance in recovery centers; etc.

- The importance of personal preparedness was stressed by several people through testimony during the hearing. It was stressed that people will be able to respond to and recover from disasters if they take steps to be prepared. Several suggestions were made that organizations and agencies that work directly with people with disabilities and other special needs spread the message and actively engage their clients in personal preparedness activities.
- There are many people with disabilities or other special needs that are still waiting for equipment, housing, healthcare, and need of other essential services, but many of the casework agencies are closing. Funding is now limited or no longer available to provide the assistance that is still needed.
- The lack of or limited access to critical infrastructure – such as transportation and housing – is still keeping people with disabilities (and others) from returning home. Without this infrastructure coupled with lack of specialized health care, mental health services, etc. people are not able to return to NOLA.

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