

ILRU Network

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Hurricane Survivors with Disabilities Lives of Isolation

We at ILRU interviewed survivors of Hurricane Katrina several months following their flight from the New Orleans area. Now part of a great modern Diaspora, they live in cities and towns spread across many states. Most are isolated from their new communities and especially from others with disabilities. They have had few opportunities to tell about their escape, rescue, and resettlement. They demonstrate a deep need to talk with others about their experiences.

These interviews highlight the failure—or complete absence of—disaster assistance for people with disabilities. What happened to those we interviewed and thousands of other people with disabilities must not be repeated. We in the disability community must continue, and double, and triple our efforts to ensure we are ready. We must ensure our communities are ready to meet their obligation to people with disabilities. The same is true for service organizations such as the United Way and Red Cross.

ILRU's Jacquie Brennan and I will continue to seek out survivors of Hurricanes Katrina and Rita, listen to their stories, and write about their experiences. Their stories must be told so we all will remember and so we all will change what we do in preparing for disaster.

--Richard Petty, IL NET Director

Independent Living Research Utilization (ILRU) at TIRR assisted more than 3,000 people with disabilities affected by Hurricanes Katrina and Rita. ILRU is a nationally-recognized center engaged in disability research, education, consulting and publishing. Located in Houston, where many Katrina survivors were first brought and where many remain, ILRU's Director, Lex Frieden, and staff began their support of survivors just hours after the first hurricane struck.

Hurricane Katrina hit the Gulf Coast on August 29, 2005. By the next day, ILRU's involvement had begun. Calls were made to Centers for Independent Living in the Gulf Coast states to begin to determine the status of staff and consumers, the physical structures of the Centers, and the various areas served. Within a few days, Centers around the country were responding to requests for specific equipment and financial needs at the affected Centers. It soon became clear that the magnitude of the crisis required that ILRU staff offer an additional level of support — direct support for people with disabilities, many of whom were in the midst of their flight from New Orleans, southeastern Louisiana, and southern Mississippi. With a few exceptions, such as the well-organized Houston relief effort, most relief organizations were lacking in experience and capacity to offer disaster support to those with disabilities, leaving thousands in unpleasant, uncomfortable, dangerous, and even life-threatening circumstances.

Callers expressed the same concerns that all people did, with or without disabilities—food, clothing, housing, and money. Individuals with disabilities, however, had an additional layer of difficulty. Many had to evacuate without their wheelchairs, walkers, and/or adaptive devices. Some were on medications they had to leave behind or they had run out. Others had special dietary needs that were not being met in shelters or through food banks. Few had transportation to pharmacies for medication or special supplies. Some were awaiting needed surgery and then had no idea where to turn to have it done in a new place. The forms FEMA sent were inaccessible to many with sensory, cognitive or dexterity disabilities. They were overwhelmed and confused, as were all evacuees.

ILRU had not previously offered direct support of people affected by disaster, but every person on staff made disaster support their top priority in the first days and weeks following the first hurricane. The ILRU toll free telephone line normally used for ADA technical assistance was opened for disaster assistance calls. ILRU informed officials of the Federal Emergency Management Agency (FEMA) that ILRU would assist callers with disabilities and ILRU's emergency assistance was also announced to other service organizations, including centers for independent living. Staff answered phone calls from people with disabilities, most of whom were referred to ILRU by FEMA. They sought out needed resources and developed a disaster recovery manual that those answering calls used to assist survivors. They continued support of Centers for Independent Living. ILRU's Director, Lex Frieden, played an important national role working with government agencies and other national organizations in mobilizing resources for survivors.

By September 22, another Gulf Coast disaster loomed. ILRU staff found themselves in the midst of the largest ever urban evacuation as Hurricane Rita approached the Texas coast. Although Houston was spared a direct hit from Rita, the hurricane plowed into eastern Texas and western Louisiana, leaving thousands more, many of whom were people with disabilities, homeless or in need of extensive support. ILRU again responded by providing the same kind of support to this new group of persons affected by disaster. ILRU continues to offer support to hurricane survivors with disabilities. Many are still experiencing considerable difficulty threading their way through confusing government regulations and still need referrals to local assistance as they seek more permanent living arrangements. Many still need help connecting with needed disability related resources. Many have faced, or narrowly escaped, eviction as FEMA has changed (and changed again) its policies on rental assistance.

In March, 2006 ILRU's Program Director Richard Petty, and Legal Specialist and Individual Disaster Assistance Coordinator Jacquie Brennan, sought out several survivors with disabilities with whom they had been in contact earlier and interviewed them to learn how they were dealing with the extended aftermath of their evacuation and

resettlement. For this article, the authors contacted people who had lived in the New Orleans area. This article focuses on this group because most of the people still unable to return to their homes were those who had lived in New Orleans or southeastern Louisiana. Callers affected by Hurricane Rita who called ILRU appear to have returned to their homes or to nearby areas. ILRU received few calls from victims in Mississippi and Alabama, many of whom contacted agencies in that region, notably the Southeast Disability and Business Technical Assistance Center in Atlanta. The names of those interviewed have been changed to maintain confidentiality.

Just as with the calls that came to ILRU during the months after the hurricanes, those interviewed longed to talk with someone—anyone—about their experiences. They spoke of their deep sense of loss—of friends and of the unique community that was New Orleans. They told of being isolated from the communities in which they now live.

Several described the chaos and danger in New Orleans—swimming to safety in flooded streets, not having food and water, shootings, and violence. The harrowing experiences described in calls and in some of these interviews add credence to the many reports that people with disabilities died because they could not escape the city.

Most of those interviewed spoke of the inefficiencies and confusion of FEMA. Many callers have reported being separated from wheelchairs and durable medical equipment, but none interviewed experienced this. There have also been persistent rumors of service animal users being separated from their animals, but this has not been confirmed in any of the calls received by ILRU or in these interviews.

Callers described both positive and negative experiences in shelters, although the experiences of those who were evacuated to larger cities seem to have been somewhat better. Most of those interviewed said they did have good care when they arrived at large shelters in Houston, Austin, Dallas, and Little Rock. The continuing support through city-run and volunteer organizations in relocation cities has often been good according to those interviewed.

Leonard Christopher

As a lifelong resident of New Orleans, Mr. Christopher had gone through many storms and he thought Katrina was going to bypass the city. He had worked as a cook, sometimes on offshore rigs, for more than 30 years, and was not afraid of a “little storm.” Still, with all the dire predictions about Katrina, when there was a call for an evacuation on Sunday, August 27, he evacuated. First, he went to a neighborhood shelter. A bus took him from there to the Superdome, where he stayed one night. As did others interviewed, he witnessed shootings there and found the Superdome frightening. When the military arrived, those who were sick were separated from the rest and he was able to leave on one of the first buses because he had diabetes, high blood pressure, and heart problems. He was taken to the Astrodome in Houston. Shortly after his arrival, he collapsed and was taken to a hospital where he stayed for two months. When he was released, he

moved into an apartment complex for individuals with disabilities. He would prefer to live in the community, as he did before the disaster, instead of a segregated complex, although he says he is grateful that he has a place to live in Houston. He receives SSI and food stamps. On January 1, his SSI check increased to \$603/month due to an annual cost of living adjustment. The maximum allowable income to receive food stamps is \$600, so he was no longer eligible. At the time of the interview, he had no food in the house. Many hurricane survivors receive SSI and were hit especially hard by the same loss of food stamps.

Mr. Christopher has no contact with his former friends and neighbors from New Orleans. He has not made new friends in Houston. He feels isolated and alone. He has begun to develop psychiatric problems for which he is seeking treatment.

Eve Peterson

Ms. Peterson evacuated from New Orleans to Little Rock, Arkansas where she now lives in a mid-town, mid-rise apartment building sandwiched among shopping malls and busy thoroughfares. This new home is different from the tightly-packed, close-knit, inner city New Orleans neighborhood where she had lived. She has met few new friends, although she reports some contact with other evacuees who live in the same apartment building. She is also isolated from other people with disabilities, having made no connections in the Little Rock disability community. She was not aware of, and had not contacted, the local center for independent living.

In her new home she has found excellent medical care — better, she believes, than the care she received in New Orleans. Her apartment is near several large hospitals, including a teaching hospital where she has frequent appointments to address uncontrolled blood pressure and the lingering effects of brain trauma she experienced several years ago. She receives SSI and Medicaid. Like other evacuees, the recent increase in SSI benefits left her ineligible for the food stamps she had been receiving.

In New Orleans, she did not own a car. She had no good way of leaving the city, so she stayed -- as was true for thousands of New Orleanians. As the city began to flood, Ms. Peterson went from her home to the convention center in New Orleans where she stayed for several days. The only food there was spoiled. There was no medical care. She saw a person shot and killed just a few feet away from her. Military personnel, stationed there to keep order, inexplicably played the projected red dots of laser sights across her and other unarmed evacuees. When she was evacuated from the convention center, she went directly to Little Rock; she did not know where she was being taken until she arrived.

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belonging to a community, of
connection with long time friends.
--Elaine Peterson*

Like many other evacuees, she does not have an automobile. This has made it difficult now for her

to travel to grocery stores, pharmacies, and other stores where she can purchase basic necessities. (The shopping malls near her don't have grocery or drug stores.) She catches rides to food stores and other shopping with neighbors. Otherwise, she spends much of her time in her apartment, remembering the violence and chaos of her New Orleans experience. She also has nightmares about her experiences.

Ms. Peterson deeply misses her teenage children, who now must live with other relatives, her family, and her New Orleans neighbors. She has lost the sense of belonging to a community, of connection with long time friends. She begins to cry as she talks about how she longs to return to her small apartment on New Orleans Street in her home town.

Barbara Turner

Before Katrina, Ms. Turner lived in Jefferson Parish in an apartment with her youngest son. Two older sons lived nearby. She was not in Louisiana when the storm hit and avoided the danger and trauma of the evacuation. A week before the storm hit, she had gone to Arizona to baby-sit temporarily for her niece's children. Although she avoided the danger and the evacuation, she did not get a chance to save any of her belongings. The things she most mourns are the Mother's Day presents lovingly made by her sons when they were young and treasured by her for years. Other evacuees describe sadness at the loss of photographs and family mementos.

Ms. Turner moved to Houston to live with one of her three sons who evacuated from Jefferson Parish. Her son has found work and she is alone during the day. She has not met any of her neighbors and says she experiences deep loneliness and depression. She is isolated and, as she put it, starving for company. Unlike others interviewed, Ms. Turner has experienced few problems directly related to her primary disability, which is the result of a previous stroke and heart attack. Ms. Turner wants to have her own place again someday and longs to return to Jefferson Parish, but fears she may never be able to afford to do so, even if it is rebuilt.

Mary McDonald

Ms. McDonald, who was a resident of Jefferson Parish, now lives in Houston. In Houston she misses her former neighborhood, neighbors, and friends. In her Jefferson Parish neighborhood "everyone knew everyone else" and friends took care of one another. She doubts she will ever have that same kind of neighborhood experience again. She lives with family, but has lost contact with many friends.

The mold in her home and the lack of electricity and water contributed to her becoming ill. --Mary McDonald

Ms. McDonald lived independently in Jefferson Parish in a rented home. She lived in the same neighborhood all her life. She did not want to evacuate, having weathered several hurricanes in

her 58 years, but her son was worried about her and insisted that she come with him and his family to a nearby hotel that he believed would withstand the storm. Ms. McDonald was terrified during her three days at the hotel. She is blind and wanted to be in more familiar surroundings. When the storm came through, windows were blown out of the hotel and they had to stay in the hallways. On Monday after the storm had passed through, they went back to their neighborhood and started cleaning up. She was attempting to bail out two feet of water from her home when neighbors urged her to leave because there were reports that levees were failing. Ms. McDonald was fortunate to have access to private transportation; many Katrina victims did not. Her son drove the family to Baton Rouge, where they slept in the car because there was no place to stay. They returned the next week and again began cleaning up, but had to leave a second time. The mold in her home

and the lack of electricity and water contributed to her becoming ill. She and her son then left for Houston, where they now both live.

Ms. McDonald takes 13 different medications and, when she evacuated, she remembered to take them all with her. She forgot to bring any

identification papers, though, and that caused her much difficulty and delay in getting medications and services. She now receives Medicaid in Texas and expects to stay in Houston if her son does.

Blanche Johnson

Ms. Johnson now lives in Austin, Texas. She came directly to Austin after staying six days on the streets of New Orleans while awaiting evacuation. More than once she swam through flood waters to save herself. Then, she and others scrounged for water and food on the streets, unwilling to remain in the dangerous New Orleans convention center, where she witnessed a shooting, violence, and death. The week before the hurricane struck, Ms. Johnson had surgery on her neck. Still in need of medical care, she went without any until she arrived in Austin. Others with her on the streets in New Orleans had no medical care. She witnessed the death of several small children, probably the result of dehydration and exposure. During that time, her nephew died because he could not receive dialysis and other medical care he needed. His home was not damaged. She said he “just went home to lay down to die.” She expresses anger that officials were holding press conferences a few blocks away while her nephew and others lay dying without medical treatment, food, or proper care.

In Austin Ms. Johnson lives in a housing complex for people with disabilities. She says the complex managers have not been entirely welcoming of hurricane survivors. She believes they’ve tried to impose paper work and identification requirements on her that they haven’t required for others. They have pointedly asked, “When will you be leaving?” On more than one occasion, she has called on the Austin city housing authority to come to her defense and they have done so. Over time, she believes she has come to be more welcome. She is pleased with the medical care she receives, as well as the support she has from volunteer organizations and the city of Austin. She had some contact with the local center for independent living. She wants to talk about her experiences, yet has few opportunities to do so. This is one of the reasons she welcomed the interview. Although still isolated, Ms. Johnson is beginning to make friends in her complex and surrounding area. Unlike others interviewed, she plans to make her home in the place to which she evacuated. She says, “I will make a new life here.”

Debra Jones

In New Orleans, Ms. Jones worked hard to provide for her five children. As a single mother, she never had quite enough of anything to go around, but she was making it. Then Katrina hit. After two terror-filled nights at the Convention Center, a bus brought her and her children to Houston. Initially, she had no place to live, but she did receive a voucher for a suburban apartment. With no furniture, she and her five children slept on the floor. She had to pile clothes on the floor. Her living situation was chaotic. With no radio or television, her five children, all under the age of nine, were bored and restless. Without a car, in a new city, in a new suburban

location, she was isolated from shopping, her children’s schools, and therapy sessions for her child Katie, age three, who has Down Syndrome. Ms. Jones grew more isolated every day. Eventually, a Down Syndrome support group came to her rescue and provided her with furniture, including a television and VCR. They took her to register for more services through FEMA, helped her enroll her children for school, and arrange for their transportation. Ms. Jones is still overwhelmed and experiencing depression. She misses living in close proximity to family as she did in New Orleans and wants to go back if her neighborhood is rebuilt.

Conclusion

All those interviewed continue to deal with the emotional aftermath of their experiences. Their descriptions of depression, isolation, nightmares, and anxiety are consistent with commonly described post-trauma reactions. They have had little help addressing these issues. This points to a continuing unmet need for post-trauma emotional support, whether through formal mental health systems or informal networks such as peer counseling. As people with disabilities, they are isolated in their new homes not only from the larger community, but also from others with disabilities. They came from a city known for its close-knit population and as they have been dispersed across states and regions, they have lost—perhaps forever—that deep sense of connection and community.

The experiences of those interviewed adds to the overwhelming evidence that far more must be done to help individuals, organizations, and communities prepare for disaster. Communities must prepare for effective evacuation of people with disabilities, many of whom are likely to be without transportation. Unless this is done, people with disabilities will continue to be at high risk of being left behind in the panic of evacuation. Clearly, individuals must receive assistance in preparing personal evacuation plans. Service organizations must equip themselves to provide effective support to people with disabilities. Governments at all levels must plan for evacuation and emergency assistance for large numbers of people with disabilities. The disability community is challenged to take on the important advocacy role that will cause these service organizations and governments to meet their obligations to those with disabilities.

The logo for ILRU NetWork features the letters 'ilru' in a bold, lowercase, red font, followed by 'NetWork' in a bold, uppercase, black font. The 'i' and 'l' are connected, as are the 'r' and 'u'.

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