

Report #1: Consumer Survey Quotes
Nobody Left Behind
Research and Training Center on Independent Living
University of Kansas
May 15, 2005

As part of the research project titled, Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments, an on-line consumer survey was administered from the study's main website (www.nobodyleftbehind2.org). Anyone who had experienced a disaster or emergency situation and has a mobility impairment was eligible to fill-out the survey about his or her experiences. For the purposes of the survey, a person with a mobility impairment is defined as someone who has moderate to complete difficulty in walking, or moderate to complete difficulty moving around using equipment.

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

Participants reported that evacuation plans in public areas are often not addressing the evacuation needs of persons with mobility impairments, as they are at times being left behind without a plan of escape, or left at stairwells or elevators while others are escaping to safety. Other frightening and sometimes life-threatening situations occur when infrastructures fail. These include electrical power outages for extended periods of times and non-accessible transportation, shelter, and temporary lodging. The disaster recovery efforts for persons with disabilities are often not seen as a priority of other involved. Thus, placing persons with disabilities at risk of losing their independence, mobility, and health.

The Americans with Disabilities Act has been in existence for more than 15 years, yet disaster-related or local services can still be found to be inaccessible and disaster-related personnel uninformed of the needs and how to assist persons with disabilities.

To address these problems described by survey participants, changes need to be made, creative solutions explored and developed, and existing ADA regulations reinforced. These efforts will most assuredly make an improvement in the health, safety and well being of all Americans and help to assist that Nobody is Left Behind in a disaster or emergency situation.

The following are consumer survey participants' statements recorded on the Nobody Left Behind research study's website on "Speak Out (I)" <http://rtcil.org/speakout1.htm>, as of May 15, 2005.

"I ambulate with forearm crutches and my leg stamina is limited. As a social service provider in NYC, I am in tall buildings often and [in] one in particular they had an evacuation drill. There were no plans or equipment to assist me. They told me to

ignore the drill. *I felt very vulnerable because I attend regular work meetings in this building.*” – New York City

[After a hurricane] “I did not use the shelters, because they were not wheelchair accessible, and had no provisions for my service dog.” – Miami, FL

“I have Juvenile Rheumatoid Arthritis and use a wheel chair. We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the 3rd floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled, and I used pure fear to get myself down the stairs and outside. *It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency.*” – Los Angeles, CA

My wheelchair ramp washed away in a flood and my house was left with three feet of mud everywhere. It was hard to use my electric wheelchair. I had money to pay for a ramp, but couldn't hire any one, as they were busy elsewhere.” – Texas

“We had a fire at work and the evacuation plan didn't work to get me out. Even so, management refused to change the plan” – Oklahoma

At the temporary shelter I couldn't get to the bathrooms, as you had to walk up stairs. – Northridge, CA

“The disaster volunteer was not trained on accessibility issues. He said that the shelters should be accessible since the law requires it. He didn't understand the impact of me getting there only to discover that they were in violation of the law” – Alexandria, (Hurricane)

“My only accessible route was on fire at my home. I had to escape via a non-accessible route. The fire destroyed our home.” – Hagerstown, VA

“Disabled persons have the same freedom of choice as any other American. The paternalistic attitude was frightening beyond belief that I experienced [while trying to access after disaster services and information].” – Glendora, CA (Earthquake)

“It is really difficult to get the utility company to understand power is a need, if disabled.” – Knoxville, TN (Severe Storms)

“We had to move out of our house for several weeks to have it repaired. All the places that people referred us to were not accessible to me in my scooter.” –Los Angeles, CA (Earthquake)

“The able-bodied community MUST get the message that it is critical to think through and develop a plan to evacuate people with disabilities.” – New York, NY

The following are additional consumer survey participants' statements taken from responses from the on-line survey.

"There were no evacuation plans for persons with disabilities who use wheelchairs at the City Mall during an evacuation of the mall [due to a bomb threat]. There were no personnel around to assist me. They all evacuated and left me there. The elevators were shut off during the evacuation. I had nightmares for several months." – Silver Springs, MD

"[Disaster personnel] did not know whether any of the options were wheelchair accessible or if they had electricity to keep my ventilators running and batteries charged if the power outage lasted beyond my ventilators battery life." (Earthquake)

"There was no disaster preparations for the work fire, no evacuation plan, or escape options except to walk down three flights of cement stairs, which is not an option. I was left at a stair well because no one knew what to do. – Sacramento, CA (Work Fire)

"Management refused to change evacuation plans [after a fire in the workplace], even though they didn't work. Buddies at work and family never confronted the shortfall." – Toledo, OH

"It was very frightening going back up into the building [after the incident] as I had waited on the 8th floor for 4 hours for the fireman to come and carry me down even when the fire was out, but there was still a lot of smoke. Now, I recommend that every floor have an evacuation chair. "I fear being in a similar disaster and not knowing if it is simulated or real and being left in a stairwell because no one knew what else to do." – Sacramento, CA (Work Fire Caused by Bomb Explosion)

"At my apartment building, I could not get upstairs until the electricity came back on or until I could get some people to carry me up. I waited in the lobby with my wife and another spinal cord injured neighbor and his girlfriend for several hours. Eventually, the superintendent and a doorman carried me and someone else carried my wheelchair. Unhelpful was a girl who worked in the building management office, who told me that I would not be carried upstairs because that would expose management to insurance liability in case anything happened." – NY, NY (Blackout)

[During a power outage after a hurricane hit, I was unable to use my home oxygen machine, CPap machine, or electric bed, and I was trapped in my apartment building as the evaluators were down with no electricity, and I use a wheelchair.] "When I called for help, the [disaster volunteer] worker said I would have to go to the hospital or a shelter. He didn't know if the shelter was accessible or how I would get home after power was restored. ...My health declined without the use of my equipment. When my legs began swelling due to fluid problems, I called the paramedics, The issue became whether to go to the hospital and then the shelter and worry about how to get back home or stay at home. I had to sign a release [with the paramedics] to stay at home, as they wanted to document the choice in case I died from congestive heart failure.

The reason I stayed was I couldn't get to my car or use the para-transit or public transit as I have to be able to get to the curb." – Alexandria, VA

"I was in a basement meeting when the earthquake hit. Everyone walked upstairs leaving me in the basement as the elevator won't function. One brave man came back downstairs and we positioned [ourselves] in as safe an area as we could until the quake emergency team arrived. They eventually carried my chair and me separately upstairs." – Glendora, CA

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

More participants' statements on survival tips, problems and issues encountered during disasters or emergencies, the types of increased participation due to the disaster or emergency experience, lessons learned, and recommendations on future directions for exploration to assist persons with mobility impairments to survive disasters and emergencies can be founded in Reports #2-6 of this consumer survey.



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**For more information, refer to
www.nobodyleftbehind2.org**

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