

Marcie Roth –Testimony Opening Remarks for June 15, 2010

Good Morning Madame Chairwoman, Ranking Member Rogers, Chairman Thompson, and distinguished Members of the Subcommittee. Thank you for convening this important hearing. I am honored to appear before you today.

I am Marcie Roth. In June 2009, President Obama appointed me as Senior Advisor for Disability Issues at the U.S. Department of Homeland Security (DHS), Federal Emergency Management Agency (FEMA). In February, 2010, after a careful review of FEMA's progress in serving children and adults with disabilities, FEMA Administrator Craig Fugate established the Office of Disability Integration and Coordination (or O.D.I.C.), organizationally located directly under his office. It's a great honor to serve as its Director.

My office plays a lead role in promoting a paradigm shift in the way we think about children and adults with access and functional needs in our national

emergency management approach. This shift is away from an approach that views people with disabilities as separate from the general population, and towards one that integrates all segments of American society in our preparedness initiatives.

As we approach the 20th anniversary of the Americans with Disabilities Act (ADA), I am proud of FEMA's role in reinforcing the importance of the ADA's integration mandate into our nation's emergency management policies and practices. The name of my "Office of Disability Integration and Coordination" reinforces this point, and shapes the work that we do. ODIC is not a siloed office, rather we exist to provide support across the agency and in support of our partners.

Let me give you a personal example of how the lack of an integrated approach led to an unnecessary death during Hurricane Katrina.

Prior to my appointment at FEMA, I served for many years as the CEO of the National Spinal Cord Injury Association, and co-chair of the Consortium for Citizens with Disabilities Emergency

Management Task Force representing over 100 national organizations serving millions of people with disabilities.

On the morning of August 29th 2005 when Hurricane Katrina was making landfall in the Gulf, I received a call from a colleague whose sister-in-law, Benilda Caixeta, was trapped in her home in New Orleans. Benilda, was quadriplegic, paralyzed from the shoulders down and she had been trying to evacuate from her upper 9th ward New Orleans apartment to the Superdome for three days.

There had only been minimal pre-planning for a person who uses a wheelchair, to be evacuated during an emergency. The local paratransit system designed to serve the accessible transportation needs of people with disabilities, never arrived despite Benilda's repeated calls. Even her pleas to 911 had been fruitless. So she was still in her home that morning.

As I learned of her situation I thought I could use my connections to get some help to her. I was wrong. It was too late to evacuate, so I did the next best thing.

I stayed on the phone with Benilda for most of the day, assuring her that help would come as soon as possible. I was on the phone with her that afternoon when she told me, with panic in her voice, “the water is rushing in” and then her phone went dead. We learned five days later that she had been found in her apartment, dead, floating next to her wheelchair.

Knowing that this death and countless other unnecessary tragedies could have been averted is why I came to FEMA and why we are working so hard to implement comprehensive strategies for inclusive emergency planning.

When I began to address this process of integrating the needs of the whole community, the first obstacle I encountered was to explain who we mean by ‘people with access and functional needs’.

Historically, emergency management has planned primarily for “easy”--individuals with their own resources rather than “real”, including people requiring assistance with physical, programmatic, or communications access.

Mindful of the hard lessons of the past and our national mandates regarding the integration of children and adults with disabilities, I am faced with continual references to people with ‘special needs’. The problem with this nomenclature is that it leads to segregation and unequal services for people with disabilities. No one wants to be ‘special’ during an emergency; they want to receive the same services as everyone else. And they should.

In addition, the term “access and functional needs” is much more useful as a description because it describes everyone who may require accommodations throughout the lifecycle of a disaster. This includes elders, people with language and communication access needs, pregnant women, people with mental health needs and others who must be anticipated and accommodated in federal, state, tribal and local emergency plans.

Over the past 11 months, we have already begun to make significant progress. Our accomplishments include our new document, “Guidance on Planning for Integration of Functional Needs Support Service in General Population Shelters” (FNSS).

This guidance will help municipalities comply with federal laws designed to assist people with disabilities to maintain their independence, health and functioning. Training will be provided in each FEMA region beginning on July 19th.

Other accomplishments include integrating the access and functional needs of children and adults with disabilities into preparedness initiatives including CPG 101 and our role as co-sponsor for the 20th Anniversary Celebration of the Americans with Disabilities Act with the National Council on Disability. Administrator Fugate and other senior leaders will participate.

Another upcoming initiative is an intensive capacity-building conference between FEMA’s Regional Offices, state emergency managers and members of

the disability community to focus on disability integration, in planning, policies, and operations

Ultimately, FEMA and all of our partners must be driven by a commitment to inclusive practices that bring disability community leaders to the table along with the rest of the team as we bake the needs of children and adults with disabilities into all we do. We are determined to learn from the mistakes of the past and to deliver a better future to all who may be affected by disasters. We must not stand by and allow what happened to Benilda Caixeta to happen again. In the face of a disaster, we are all vulnerable, we are all at risk. The needs of our communities will be best served by planning and practices that are inclusive. We will all be stronger as we succeed.

Thank you Madam Chairwoman and distinguished Members of the Subcommittee, for the opportunity to share FEMA's progress with disability integration and coordination with you. I stand ready to answer your questions.