

Written Statement of

Marcie Roth

Director

Office of Disability Integration and Coordination

Federal Emergency Management Agency

Department of Homeland Security



FEMA

**“Caring for Special Needs during Disasters: What’s being
done for Vulnerable Populations?”**

Before the

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Emergency Communications, Preparedness, and Response**

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Good Morning Madame Chairwoman, Ranking Member Rogers and distinguished Members of the Subcommittee. I am honored to appear before you today. I am Marcie Roth. I have served since June 2009 as the Senior Advisor for Disability Issues at the U.S. Department of Homeland Security (DHS), Federal Emergency Management Agency (FEMA). I am here today to speak about the strong emphasis this Administration has placed on providing people with disabilities and those with access and functional needs the necessary support in times of disaster. I also want to share with you FEMA's work as a result of this emphasis.

Prior to my appointment, I served for many years as the Executive Director and CEO of the National Spinal Cord Injury Association (NSCIA), where one of our duties was working on disaster relief efforts on behalf of all people with disabilities. I also co-chaired the Consortium for Citizens with Disabilities Emergency Management Task Force, which represents over 100 national disability organizations.

On the morning of August 29, 2005, I received a call that I will never forget and once I tell you about it, I hope you will never forget it either. My friend and colleague called to enlist my help because her sister-in-law, Benilda Caixeta, a New Orleans resident who was quadriplegic, paralyzed from the shoulders down, had been trying to evacuate from her Upper 9th Ward New Orleans apartment to the Superdome for three days.

Despite repeated requests to be evacuated, in her power wheelchair, which is a vital tool for mobility and independence, the paratransit system that serves the transportation needs of people with disabilities never showed up. Even calls to 911 had been fruitless. She was still in her home, she had not been able to evacuate, despite her very best efforts. I thought a few phone calls to the "right" people would help, and I was sure I knew who to call. I was wrong. After many calls to the "right" people, it was clear that Benny was not being evacuated.

I stayed on the phone with Benny for most of the day, assuring her that I was doing all I could to make sure help would be coming as soon as possible. She kept telling me she had been calling for a ride to the Superdome for three days, but, despite promises, no one came. 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. Sometimes things like this can't be prevented. Despite the magnitude of the catastrophe, this was not one of those times. Benilda did not have to drown.

In 2005, as many as 54.4 million people, or 18.7% of the population at that time, were people with disabilities. As it happens, the areas most severely impacted by the 2005 hurricanes were also those with especially high percentages of people with disabilities living in the community. Because a disproportionate number of people with disabilities live below the

poverty line, frequently have less mobility than the general population, and are often more dependent on external assistance, this population felt the impact of Hurricane Katrina quite severely.

In October 2006, the Post-Katrina Emergency Management Reform Act of 2006 (PKEMRA) provided a much-needed mandate to integrate the needs of people with disabilities and those with access and functional needs, into general emergency management planning, response and recovery. However, despite the numerous new requirements on planning for and meeting the disaster related needs of children and adults with disabilities, many of the same problems were seen again during Hurricanes Gustav and Ike just a few years later. Many people were still turned away from shelters, information was inaccessible to individuals who were deaf or blind, services required under disability rights laws were not being provided, and catastrophic but preventable health impacts were felt by previously stable and independent evacuees with disabilities.

However, with some responsible planning and smart investments, people with disabilities can begin to trust that their needs will be better met in future disasters. In addition, taxpayers, generous donors, and the general public can rest assured that we are maximizing our limited resources and minimizing any unnecessary waste in moving forward with this effort.

Integrated Plans

All successful actions start with planning. As FEMA's Administrator Craig Fugate said, at the Inclusive Hurricane Conference in Biloxi, Mississippi, "My experience tells me if we wait and plan for people with disabilities after we write the basic plan, we fail." The Administrator is challenging the emergency management community to not just plan for easy scenarios, but to plan for all who may be impacted by a disaster or emergency.

The DHS Nationwide Plan Review (NPR): The DHS Nationwide Plan Review (NPR) revealed major inconsistencies in the definition of the term special needs, including the current National Response Framework (NRF) terminology.

The consistent yet vague references to special needs lack the guidance to put direct community-wide planning tasks into actions that will fully support people with disabilities. When people with disabilities are thought of as 'special,' they are often thought of as marginal individuals who have needs, not rights. People with that label appear to need things done for them as recipients, not participants. If people with disabilities are more thoroughly integrated in local planning, their participation will help ensure that misleading stereotypes do not dilute the effectiveness of emergency plans.

National Response Framework (NRF): The NRF definition of special needs is, "populations whose members may have additional needs before, during, and after an incident

in functional areas, including but not limited to: maintaining independence, communication, transportation, supervision, medical care. Individuals in need of additional response assistance may include; those who have disabilities; who live in institutionalized settings; who are elderly; who are children; who are from diverse cultures; who have limited English proficiency or are non-English speaking; or who are transportation disadvantaged.”

Researchers have pointed out that this definition actually describes almost 50 percent of the population¹, and yet, until now, “special needs” planning has been handled as a separate activity, rather than as a central element of the planning required in every community to prepare for vital emergency management needs.

A better way to plan for the needs of people with disabilities and activity limitations is to use an orientation that considers major functional needs as vital to protecting life and safety, maximizing limited resources and promoting maintenance of independence and health. Functional Needs Support Services (FNSS) are defined as “services that are provided to individuals during an emergency in general population shelters or other integrated community facilities to enable them to maintain their independence in such settings”. FNSS includes reasonable modifications to shelter practices and procedures such as the planning for the inclusion of service animals, and also may include the acquisition or use of durable medical equipment (DME), consumable medical supplies (CMS), personal assistance services (PAS) and other goods and services as needed.

Children and adults requiring FNSS may have physical, sensory, mental health, cognitive and/or intellectual disabilities affecting their ability to function independently without assistance. Others that may benefit from FNSS include women in late stages of pregnancy, elders, and people needing bariatric equipment or communications assistance. Acute medical needs, not regularly addressed in the individual’s daily life, however, are not a part of FNSS and are addressed under activities conducted through medical facilities (hospitals, hospices, etc.).

Since Katrina, there have been significant changes in the NRF’s Mass Care Emergency Support Function-6 (ESF-6). FEMA is now the lead agency, with other federal agencies and the American Red Cross in a supporting role. FEMA’s Mass Care ESF-6 planning includes all activities needed to meet the access and functional needs of people impacted by a disaster. FEMA’s ESF-6 staff is working with FEMA’s Office of Disability Integration and Coordination (ODIC) to ensure that all planning meets compliance with the Americans with

¹ Kailes, J. (2005). Disaster Services and “Special Needs:” Term of Art or Meaningless Term? Kailes-Publications, 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293-7556, <http://www.jik.com/resource.html>, jik@pacbell.net.

Disabilities Act, the Rehabilitation Act, the Fair Housing Act, and other disability rights laws, not only in sheltering, but also in evacuation, housing, and recovery efforts.

Comprehensive Preparedness Guideline (CPG 101): FEMA is updating its CPG 101 to integrate the Comprehensive Preparedness Guideline 301 for Special Needs Planning, which will result in a single all-inclusive planning document. This is meant to provide clear and efficient guidance for state, territorial, tribal, and local emergency managers with one integrated plan – rather than a base general plan and secondary, auxiliary guidance on people with disabilities. The revised document is expected to be finalized soon.

FEMA’s National Disaster Recovery Framework and National Disaster Housing Strategy: These are being drafted to incorporate the needs of people with disabilities and access and functional needs, so they can more easily transition back into the community following a disaster.

Office of Disability Integration and Coordination

PKEMRA also required FEMA to appoint a Disability Coordinator. I have been serving as the acting Disability Coordinator since 2009. In February 2010, after a careful review of FEMA’s progress in serving children and adults with disabilities and responding to the national imperative for an inclusive approach to emergency management, FEMA Administrator Craig Fugate established the ODIC, with me as Director.

Mindful of the hard lessons of the past, as well as our national mandates regarding the integration of children and adults with disabilities, ODIC has played a lead role in promoting a shift in our national emergency management approach. This represents a shift away from a paradigm that views people with disabilities and other access and functional needs as separate or apart from the general population, and towards a notion that all segments of American society will be integrated and served through a single and inclusive emergency management approach.

Partnerships, Technical Assistance and Information Dissemination

In order to maximize FEMA’s capacity to serve individuals with disabilities and other access and functional needs in disaster situations, ODIC has worked actively to engage the many stakeholders involved in inclusive emergency management.

This work includes coordination with both internal FEMA program offices and relevant external parties. The vast spectrum of coordination projects include: forming new partnerships and relationships, providing technical assistance and information dissemination, incorporating

disability considerations into emergency communications, evacuation, transportation, sheltering, medical supply plans, Disaster Recovery Centers, and registration needs.

Some recent ODIC projects include:

- Established regular meetings with the National Council on Disability, the National Council on Independent Living, the DHS Office for Civil Rights and Civil Liberties, and others.
- Provided technical assistance and expert guidance on disability integration in multiple venues, including: FEMA Regional Offices, FEMA National Advisory Council, the National Disaster Housing Taskforce, the Pandemic Planning Guidance Workgroup, the Long Term Disaster Recovery Initiative, and the National Exercise Program's National Level Exercise 2011, which will include the National Council on Disability and state representatives.
- Engaged in an ongoing series of trainings, presentations, and meetings with government and private entities in order to get the word out about disability integration in emergency management, building capacity, and developing networks. Selected venues include: the Federal Communications Commission Broadband Opportunities for Individuals with Disabilities Initiative; the U.S. Department of Labor Perspectives on the Employment of Persons with Disabilities Conference; the Wireless Emergency Communications 2009 Conference; the International Association of Emergency Management Special Needs Subcommittee; The Iowa Special Needs Symposium; the National Council on Community Preparedness; the National Organization on Disability; the Access to Readiness Coalition; and the Citizens with Disabilities Emergency Management Taskforce.
- Utilized and reviewed disability related emergency preparedness guidance, such as the Framework of Guidelines: Preparing the Workplace for Everyone, developed by the Interagency Coordinating Council on Emergency Preparedness for Individuals with Disabilities, Workplace Subcommittee, which is coordinated by the Office of Disability Employment Policy at the Department of Labor.
- Provided 600 disability and emergency management stakeholder organizations and entities with updates on a variety of FEMA efforts such as: the disability response during the American Samoa Tsunami, H1N1 preparedness and response, earthquakes in Haiti and Chile (supporting USAID), and more.
- Began efforts to develop a cadre of disability subject matter experts who can assist in disaster response activities across the country.

- Participated in FEMA conferences related to logistics, mass care, and external affairs, providing counsel and expertise on disability integration into these FEMA programs.
- Established a Citizen Corps partnership with the National Council on Disability, and held a Citizen Corps Disability Law webinar on April 10, 2010.
- Participated in the creation of a FEMA Children’s Working Group, and established a focus within that group on children with disabilities. ODIC is participating in a summer 2010 Children’s Summit.
- Facilitated the development of a partnership between FEMA and the Department of Education so we can focus on inclusive preparedness curriculums for children in schools.

In addition, FEMA has collaborated with the National Commission on Children and Disasters to further identify and address the needs of children during a disaster, including children with disabilities. Thus far, FEMA has updated its FY 2010 Homeland Security Grant Program guidance to include how grant dollars may be used to support preparedness and planning activities for children. The guidance provides resources for grantees to incorporate children into their planning and purchase of equipment and supplies, and provides training to a broad range of child-specific providers, and exercise capabilities relating to children. In addition, FEMA’s Children’s Working Group collaborated with the American Red Cross, the Commission, and other pediatric experts to develop a shelter supply list which identifies the basic items necessary to sustain infants and toddlers in mass care shelters and emergency congregate care environments. That list has been integrated into numerous planning and guidance documents. FEMA signed an agreement with Health and Human Services to provide for the rapid deployment of case managers when requested by the State during a Presidentially declared disaster. FEMA’s Public Assistance Division has clarified certain child care services and facilities are eligible for reimbursement under the Stafford Act and a Fact Sheet has been disseminated to the Regions.

Emergency Communications

ODIC and FEMA’s Integrated Public Alert and Warning System (IPAWS) Program Office are collaborating to identify key resources and stakeholders that can facilitate improved emergency communications such as alerts and warnings. Examples of key ODIC and IPAWS Program Office stakeholder collaborations include:

- Developing a burgeoning relationship with WGBH-TV’s National Center for Accessible Media (NCAM) in our efforts to identify key industry contacts, and available resources currently being used to alert people with disabilities.

- Leveraging Gallaudet University’s research on new technology for Emergency Alerting Systems. IPAWS and Gallaudet University have jointly participated in collaborative technology demonstrations featuring the ALERTUS Alert Beacon System, currently in use at Gallaudet University.
- Coordinating with the National Council on Disability to gather Commercial Mobile Alerting System requirements pertaining to the disability community as well as identifying educational and training strategies on disabilities for emergency managers.

Evacuation and Transportation

Federal mass evacuation planning requires a coordinated concept of operations and a command and control system that provides federal support to state, local, or tribal authorities. FEMA’s Planning Division in the Response Directorate has recently begun to discuss with ODIC how to create regional and state response plans that better integrate the needs of all populations, including transportation during emergencies.² NORTHCOM and NORAD are assisting FEMA with planning and resources for the potential evacuation of people with disabilities and access and functional needs. FEMA has assisted state and local evacuation-specific planning for people with disabilities, access or functional needs.

Federal support may be required when people with medical needs must move to a facility with an appropriate care level. Various modes of transportation may be implemented to safely and effectively transport individuals with acute medical needs and people with mobility disabilities including emergency medical services (EMS), paratransit services, surface marine vessels, and rotary-wing and fixed-wing aircraft. FEMA’s ambulance contract remains fully mission-capable, including providing services to people with disabilities.

PKEMRA, by amending sections 501, 503 and 512 of the Homeland Security Act of 2002, assigned FEMA the responsibility of supporting state mass evacuation operations. To meet this requirement, FEMA created the National Mass Evacuation Tracking Systems (NMETS) expected to roll out this summer. NMETS is composed of both manual and computer-based systems that are designed to assist states in tracking the movement of transportation-assisted

² Mass Evacuation Plans are implanted within the framework and operating principles of the National Response Framework (NRF) and are pursuant to authorities including:

- Robert T. Stafford Disaster Relief and Emergency Assistance Act
- Post-Katrina Emergency Management Reform Act of 2006
- Americans with Disabilities Act (ADA) of 1990
- Executive Order 13166, Improving Access to Services for Persons with Limited English Proficiency
- Executive Order 13347, Individuals with Disabilities in Emergency Preparedness
- The Aviation and Transportation Security Act (ATSA), 2007
- The Safe, Accountable, Flexible, Efficient, Transportation Equity Act, 2007
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evacuees, their household pets, luggage and medical equipment during evacuations. The system can operate independently or be used to support multi-state, state-managed or local level evacuation operations. The systems are compliant with the Mass Evacuation Incident Annex to the National Response Framework (NRF).

Medical Supplies

FEMA is developing consumable medical supplies (CMS) capabilities to support people with functional support needs in general population shelters across all FEMA regions. ODIC supported Mass Care's "just-in-time" capacity so FEMA could provide durable medical equipment and consumable medical supplies upon request by a state. With input from disability subject matter experts, FEMA developed and implemented mechanisms to obtain durable medical equipment (DME) to support people with disabilities in shelters and other integrated congregate care environments.

Administrator Fugate directed the agency to identify a universal cot that could accommodate people with functional needs. As part of the process, FEMA held an "Industry Day" on June 14, 2010 for U.S. manufacturers of cots to provide specifications for a universal cot that can be used by people with functional support needs as well as the other residents of a shelter. Instead of purchasing separate items, we hope to move forward with one item that fits the needs of most individuals impacted by a disaster.

Sheltering

FEMA, together with a host of partners, is developing Guidance for Integration of Functional Needs Support Service in General Population Shelters. The guidance was created with the Department of Justice, the DHS Office for Civil Rights and Civil Liberties, the National Council on Disability, the Department of Health and Human Services, the American Red Cross, the National Council on Independent Living, state emergency management officials, and FEMA's Office of Disability Integration and Coordination, among others. The group continues to examine and re-evaluate ways that FEMA's disaster assistance programs can meet the needs of individuals with disabilities and others with access and functional needs, at all levels of service delivery.

FEMA is developing the FNSS guidance to states as well as Guidance for Personal Assistance Services (PAS) in General Population Shelters. The guidance also has a training curriculum that is being scheduled for all ten FEMA Regions in the coming months. The guidance will provide states and territories with more information on how to comply with federal laws regarding people with disabilities and the integration of people with disabilities into general population shelters. ODIC also partnered with FEMA's Mass Care Section to develop a multi-agency shelter assessment tool that incorporates disability considerations.

Over the past four years, FEMA has collaborated with the US Access Board, the Department of Housing and Urban Development, and DHS' Office of Health Affairs to revise FEMA specifications to meet Uniform Federal Accessibility Standards (UFAS) for Accessible Temporary Housing. FEMA has provided UFAS-compliant temporary housing directives for all Direct Housing Missions since 2007.

FEMA's current target baseline temporary housing inventory is established at 4,000 units, of which 10 percent are targeted as UFAS compliant. This target baseline inventory is being re-evaluated in consideration of production contracts that allow FEMA to produce additional UFAS-compliant units as needed.

FEMA's indefinite delivery, indefinite quantity (IDIQ) contracts allow for rapid ramp-up of temporary housing unit (THU) production. Each of the five contractors has the capability to produce 150 units per week within three weeks of a request by FEMA. Units produced under the contracts may be all UFAS-compliant if disaster housing needs require a large number of such units. FEMA's IDIQ contracts for THU installation and the template statements of work for local contractors to install THUs have specific language requiring the installation of accessible ramps and platform stairs. All FEMA contracts for the design and construction of group sites have UFAS requirements ensuring accessibility and integration and not segregation of applicants with disabilities.

Further, FEMA Interim Policy 9452.1 directs that housing group sites constructed, altered by, or altered on behalf of FEMA will include accessible routes and elements for common use areas. Moreover, this policy mandates that at least 15 percent of individual lots within any such site constructed or managed by or on behalf of FEMA must be designed to accommodate accessible units for eligible disaster survivors with a disability and or access and functional needs.

Disaster Recovery Centers (DRCs)

As part of the Disaster Recovery Center Services and Providers Policy (DAP 9430.1), FEMA established a DRC Access Agreement for the Agency's National Disaster Assistance Partners – non-governmental entities that offer services FEMA does not provide. These "Partners" have seamless access to all of FEMA's DRCs. Currently, FEMA is working on DRC Access Agreements with two additional disability groups, the National Council on Independent Living and National Disability Rights Network.

Communications Equipment

FEMA purchased equipment for its Regions to use in communicating emergency and disaster assistance information to persons with hearing limitations. This assistive technology equipment is for use by the Regions in Disaster Recovery Centers, congregate shelters and

other areas where disaster victims may gather. The equipment is sent in a waterproof storage case for durable use after a disaster. Additional items to assist with access for applicants with disabilities have been selected by each Region.

Registration

FEMA uses Teletypewriter (TTY) to take Registration Intake and Helpline calls from disaster survivors with hearing disabilities. The TTY is answered by a live agent during the hours of operation. When the 1-800 number is not manned by a live operator, the caller can leave a message and a Customer Service Representative will quickly return the call.

Disaster survivors who are unable to register with FEMA over the phone can register for disaster assistance online at www.disasterassistance.gov. FEMA's applicant guide, *Help After a Disaster* (FEMA Publication 545), is available in Braille and large print. Additionally, the applicant guide is available for download at www.fema.gov, and in the text version, which can be used in Acrobat ADOBE reader.

The disaster applicant guide has been translated into 20 languages and translated documents will be posted, in an accessible format, at www.fema.gov for public access. The registration intake interview includes question regarding the applicant's access and functional needs that may require FEMA's attention as a result of the disaster.

Staffing

Meeting the regional staffing needs for successfully achieving disability integration is complex, and involves budget decisions made some time ago. The Regional Administrators were presented with staffing options that included a variety of job titles including disability coordinator. It appears that most of the Regions chose to incorporate the tasks of a disability coordinator into positions that already exist and work with individuals on disaster assistance.

There are advantages and disadvantages to this approach. If we aspire to integrate disability into the entire emergency management process, then it would be ideal to have staff members working on general population needs while incorporating important disability issues. On the other hand, if these individuals do not have disability subject matter expertise, this may not be effective.

Alternatively, if we identify one position as a permanent disability coordinator, they may be 'stove-piped' into disability topics and individual case management and away from integrating the needs of every individual into the whole. At this point, those staffing decisions are in the hands of the Regional Administrators and we will work with their designated staff.

One way we intend to assist those regional staff working with disability integration issues is by providing training, capacity building, and the opportunity to share ideas. ODIC is planning a national conference to be held in Washington, D.C. in the early fall of this year that will bring these regional staff members together with their state counterparts and relevant subject matter experts to provide a strong beginning to this collaborative national effort.

Next Steps: The Work Ahead

While we are very proud of FEMA's and our partners' achievements in a short period of time, more needs to be done to incorporate disability and other access and functional needs considerations into all FEMA operations.

One of our upcoming initiatives will be a National Capacity Building Training Conference at the end of the summer, co-sponsored by the National Preparedness Directorate, Citizen Corps, and the DHS Office for Civil Rights and Civil Liberties. During this training, members of the disability and emergency management communities will participate jointly in an intensive cross-training and bridge-building conference. Participants will have post-training responsibilities to educate others in their communities about emergency preparedness that is inclusive of children and adults with disabilities and others with access and functional needs.

Additionally, ODIC plans to co-sponsor 20th Anniversary Celebrations with the National Council on Disability in order to get the word out about FEMA's emphasis on disability integration. ODIC welcomes the opportunity to work with the National Council on Disability in this and many venues as we move forward together.

Ultimately, FEMA and all of our partners must be driven by the determination to learn from the mistakes of the past and to deliver a better future to all those affected by disasters. We must not stand by and allow what happened to Benilda Caixeta to happen again to those who need and trust us for support in the face of disaster.

Madam Chairwoman, Ranking Member Rogers and distinguished Members of the Subcommittee, I thank you again for the opportunity to share with you FEMA's work on disability integration and coordination, and stand ready to answer any questions you may have.