

## **United States Senate Special Committee on Aging**

Hearing on:

### **“Disaster Preparedness and Response: The Special Needs of Older Americans”**

Wednesday, September 20, 2017  
9AM  
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#### **Statement for the Record**

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Portlight Inclusive Disaster Strategies, Inc. is a nonprofit, nonpartisan, disability inclusive disaster relief organization established in Charleston, SC, in 1997. Portlight Strategies does not receive federal funding.

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## **“Disaster Preparedness and Response: The Special Needs of Older Americans”**

*By Paul Timmons, President, Portlight Inclusive Disaster Strategies, Inc.*

Chairman Collins and Ranking Member Casey:

Thank you for the invitation to speak before the Committee on this important topic. My name is Paul Timmons, President of Portlight Inclusive Disaster Strategies. I have been working in the field of disaster preparation and response for people who are aging and those with disabilities for 15 years and have led Portlight since 1997. In my time I will share with you some of my observations related to our most recent disasters and make a number of recommendations for improving disaster preparedness.

As the news media began to cover the story of the horrific conditions at the Hollywood Hills Nursing Home in Hollywood FL and the deaths of eight of their residents on September 13, Portlight Strategies had begun our 18<sup>th</sup> straight day of round the clock disaster response efforts to address the disproportionate impact of hurricanes Harvey and Irma on older adults and people with disabilities. Given that people with disabilities and older adults are two to four times more likely to die or be seriously injured in a disaster, the urgency of our work cannot be understated. The disproportionate rate of injury and death is due to poor planning, inadequate accessibility, and the widely shared but incorrect assumption that people with disabilities and older adults are “vulnerable,” “special,” or “at-risk,” simply because of their diagnoses or stigmatizing beliefs about disability and aging. In fact, older adults and people with disabilities are extremely valuable experts on emergency problem solving, with far more practice than younger people and people who don’t navigate inaccessible environments and programs on a daily basis.

Since August 26, our work at Portlight has been spent, around the clock, organizing lifesaving rescues with our partners, organizing delivery of food, water, generators, wheelchairs, medical equipment and supplies, sign language resources, addressing civil rights violations, answering non-stop calls to our hotline, and pointing people to lifesaving and life sustaining emergency resources to meet the critical needs of older adults and people with disabilities.

We have organized daily national, state, and issue specific public-private coordination calls between governments, the Red Cross, disability organizations, and stakeholders to optimize limited resources and minimize duplication of effort.

For every heartwarming tale of heroism (and there are many), we are navigating the devastating stories from people who have not benefitted from the considerable tax payer investments in local, state, and national emergency preparedness initiatives. Local resources, the most knowledgeable daily lifeline for people with disabilities and older adults, are rarely funded before, during, and after disasters, with federal funds and donations going to organizations without a local foot print or experience in meeting the daily needs of older adults and people with disabilities in the impacted areas.

What has happened since the Post Katrina Emergency Management Reform Act was passed in 2007?

Great progress was made for many years, primarily by heavily investing in whole community inclusive initiatives, with true partnerships between FEMA and disability and older adult led organizations.

People with disabilities and those who are aging need to be at the table when planning for disasters. There is no more important time for the adage “nothing about us, without us” to be a reality. At the local, state, and federal levels, and in non-profit agencies dedicated to disaster preparation and response, those who are aging and disabled need to be both participants and leaders. Right now, most planning occurs “FOR” people with disabilities and older adults, not “WITH” us. Moving forward we need to ensure there is substantial leadership and participation during emergency planning.

To truly include older Americans and Americans with disabilities in the planning process, the following issues need to be addressed in order to reduce injuries, avoid deaths, and ensure response is as effective as possible:

- Ensure communication about emergency services are broadcast and distributed in American Sign Language and clear, plain language in all cases when communication about a disaster is made to the general public;
- Ensure that all emergency response communications, including 911, 311, and 211 emergency and information lines are accessible;
- Ensure all building evacuation procedures include procedures for those who need mobility support, have sensory disabilities, intellectual disability, and anxiety and other mental health concerns, and that personnel are trained to implement those plans;
- Ensure that all transportation to evacuate older persons and those with disabilities are fully accessible, have personnel who know how to operate the vehicles and the accessibility features, and are available during the emergencies;
- Ensure access to food, water, medicine, and power;
- Ensure all information about what to do, where to go, and how to get help is available in accessible formats, including video with captioning, audio, and plain language formats;
- Ensure *all* shelters, including both general population shelters and “special needs” or “special medical needs” shelters, are ready to support older adults and those with disabilities and that personnel staffing those sites are trained to support people with disabilities and those who are aging;
- Ensure all shelters are accessible and have trained personal assistants, accessible showers and toilets, flexibility in meals to meet dietary restrictions and requirements, and equal access to communication;
- Ensure admissions to medical facilities and nursing homes are not substituted for meeting civil rights obligations to provide equal access to emergency services and programs in their community;

- Ensure that all tracking information systems are up-to-date and personnel know how both to use the systems and maintain confidentiality;
- Ensure there is equal access to emergency registries operated by state, federal, and non-profit emergency programs;
- Ensure voluntary registries are not only used in preparation for a disaster but are actually used as part of the response;
- Significant delays (up to 30 days, if the caller could even complete their call) in receiving “critical and immediate needs” assistance from FEMA and Red Cross, despite announcements to apply;
- Ensure individuals who use service animals are admitted to shelters and are able to stay with their animals while in shelters; and
- Ensure individuals who use mobility devices, sign language interpreters, personal assistants, communication devices, and health maintenance items are not separated from those devices and services.

Despite extensive planning, many of these items were not completed for the response to Harvey and Irma. We learned lessons from Katrina and Sandy but did not implement many of those lessons. Hopefully we will be able to implement more lessons from the most recent storms. The following are my priorities to improve responses to reduce injuries and save lives.

### **Recommendations**

1. Create an inclusive disaster relief fund for Independent Living Centers and other consumer controlled community disability and aging organizations to engage in emergency preparedness, response, recovery, and mitigation. Invest \$1 billion over five years to serve the people of their community before, during and after disasters. Those who are aging and those with disabilities are the experts on housing, access to health maintenance services, accessible transportation, getting people back to work, and keeping people out of nursing homes. Currently, Independent Living Centers and other consumer directed agencies receive no funding to do their emergency preparedness and disaster response, recovery and mitigation work. Funding for these efforts should not compete with first responders, public health, and state and local emergency managers. So it is essential to fund preparation and response work through separate sources.
2. Establish a National Center for Excellence in inclusive Disability and Aging Emergency Management. The initial focus of the Center should include community engagement, leadership, training and exercise development, evacuation, sheltering, housing, and universal accessibility. I suggest a budget of \$1 billion over five years to stand up the Center.
3. Direct the US Department of Justice, and provide the Department with resources, to monitor and enforce the use of all disaster funds to ensure compliance with the civil

rights requirements of the Rehabilitation Act of 1973, as amended and the Americans with Disabilities Act of 1990, as amended.

4. Provide Department of Homeland Security grant funds to specifically fund qualified and experienced statewide Access and Functional Needs Coordinators for all states and territories. These coordinators would serve as statewide subject matter experts across preparedness, response, recovery and mitigation to engage and coordinate whole community collaboration among disability leaders, community organizations, first responders, emergency managers, public health and safety, private sector and other stakeholders.
5. Conduct a study of the use of volunteers to determine efficacy in sheltering services to individuals with disabilities and older adults. Objectives of the study should include determining if the use of volunteers is adequate to comply with disability equal access and non-discrimination obligations.
6. Refresh the Post Katrina Emergency Management Reform Act to better define state and federal government obligations to plan for, respond to, recover from, and mitigate all hazards in compliance with disability civil rights laws.
7. Exempt the cost of disability related repairs and replacement from the FEMA Individuals and Households maximum Grant ceiling (currently \$33,300). Disability related repairs and replacement of durable medical equipment and other disability items includes replacing wheelchairs, customized vehicles, medical devices, entrance ramps, elevator installation to meet home elevation requirements, and other items that provide equal access for people with disabilities in recovering from a disaster.
8. Establish an American Independence Corps, similar to FEMA Corps made up of at least 5,000 citizen members with and without disabilities to carry out planning and preparation activities in each State, DC and Territory year round.
9. Direct FEMA and the Administration on Community Living to lead a coordinated effort across federal government agencies, the States, CBOs, foundations, and other sectors, with those who are aging and those with disabilities in leadership roles, aimed at achieving on-going planning, preparation, and implementation of these recommendations.

Implementing these recommendations will:

- Prevent, minimize, and rectify the institutionalization and/or loss of critical home and community based services for children, adults and older persons in the lead up to, during or following a disaster; and

- Increase the ready supply of accessible, adaptable, affordable, and disaster resistant permanent and temporary housing nationwide.

## **Conclusion**

Let me be very clear, most of the failures and shortfalls we address are a direct result of the failure to plan at the local and state level and the failure to place subject matter experts in leadership roles at every level coupled with failure to include people with disabilities and older adults as key stakeholders in planning efforts. This has been coupled with blatant disregard for the unwaiverable civil rights obligations associated with the expenditure of every federal dollar spent by government, grantees and contractors without any monitoring and enforcement by the federal government over its civil rights obligations. To further emphasize this point, there are no civil rights loopholes releasing anyone from their legal obligations in emergencies and disasters. Period.

Despite years of planning, people with disabilities and older adults in Texas, Florida, and the U.S. Virgin Islands, and other hurricane impacted states have, once again, paid the price for our collective emergency planning shortfalls. Many thousands are still without the basic necessities to meet their independence, safety, and health maintenance needs. Most have been denied their basic right to equal access to federally funded emergency programs and services. We receive daily requests to assist people without food and water. Some of the people calling are in high rise buildings without power. Callers are unable to obtain prescription medications, return home from evacuation placement in nursing homes hundreds of miles away, having extreme difficulty in reaching FEMA and Red Cross to request assistance and being informed about wait times of up to 30 days for crisis and immediate assistance funds for food, water and medication.

Effective practices for whole community inclusion must be led by experts in disability and aging inclusive emergency management. The people most knowledgeable about the needs in their own community are best suited to lead disaster response and recovery. We must find a way for these organizations to have adequate resources to do the complex and long-term work that is needed for people with disabilities and older adults to participate with government and the disaster business giants to get grants, donations, and tax payer dollars to optimize whole community inclusive disaster recovery.

Portlight Strategies and our national Partnership for Inclusive Disaster Strategies stand ready to assist the American people to get this right.

Thank you for allowing me this opportunity to share my experience and recommendations with the Committee and I stand ready to answer any questions you might have