STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES
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Testimony of the Office of Protection and Advocacy for Persons with Disabilities

The Energy and Technology, Public Safety, Labor and Planning and Development Committees' Joint Public Hearing Regarding the Aftermath of Tropical Storm Irene

Presented by James D. McGaughey
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Good morning and thank you for this opportunity to provide information about the experiences of people with disabilities who have been in contact with our Office following Tropical Storm Irene, and to also share our insights about some lessons that experience can teach us.

Our Office has been involved in efforts to shape emergency responses for people with disabilities since 2005. That was the year that Hurricanes Katrina and Rita hit the Gulf coast, and it became clear from both the media coverage and from after-action reports that people with disabilities had fared very badly. After several months of stressful struggling to help people mourn, find family members and locate caregivers, replace expensive mobility equipment and service animals, reconstruct treatment records, re-establish support systems, connect with new mental health providers and begin to find accessible places to live, my counterparts in Louisiana and Texas issued a plea to all Protection &Advocacy agencies to become more involved in preparedness planning in our respective states. And so, working with a lot of other people and organizations, our Office has done just that. I have served on committees and task groups with staff from DEMHAS, the Red Cross and several local emergency managers to develop guidelines for Universally Accessible Shelters, to improve the accessibility of emergency communications, and to reach out through the DEMHAS Regional Emergency Preparedness Teams to local emergency managers and responders. Most recently, I have been serving on a committee that is co-chaired by DEMHAS and the Red Cross to develop a state-wide mass care sheltering plan. In addition, our Office has developed accessibility guides, offered to assist municipalities to review their facilities and plans to ensure accessibility, and has co-sponsored personal preparedness training sessions with the Department of Social Services' Aging Services Division. With our DD Network partners, we also developed, and with DEMHAS' help we published a *Guide for Including People with Disabilities in Disaster Preparedness Planning.* (http://www.ct.gov/opapd/lib/opapd/documents/adobe/guide_final.pdf.)

We haven't done these things alone. Other disability interest groups have also provided trainings and engaged in advocacy activities as well. Our collective message has been consistent and fairly simple:

1. The demographics in Connecticut communities have shifted significantly over the past 30 years as an increasing percentage of the population is aging, preferably "in place", and younger people with

significant disabilities are no longer being kept in hospitals, nursing homes and other institutions. Disaster planning must take this demographic reality into consideration – preparedness planners must understand that the numbers of people with age-related disabilities, the numbers of families raising children with complex medical conditions, the numbers of people using personal care assistance to live independently, the numbers of people who have cognitive, communications and psychiatric disabilities who are living in their own homes, scattered throughout towns and cities have all grown dramatically. For both practical and legal reasons, it makes no sense to plan for "the general population" and "the special needs population" as if they were two separate groups, and it is an especially bad idea to assume that people living with disabilities are "patients" who need to be transported to health care facilities in a disaster.

2. The second part of the message is aimed at seniors, families and people with disabilities living independent lives in their communities: prepare yourself for an emergency. Make realistic plans, develop a kit of essential supplies, do not count on help being able to get to you quickly.

As we look at the experience with Tropical Storm Irene, the good news is that we can see that those messages have had some impact. Our Office has been conducting an informal survey over the past several weeks, and, though the information gleaned is far from comprehensive, we have found that at many people did have personal or family preparedness plans, and that in many cases home health and human service agencies that support people in Connecticut communities had helped prepare people to weather the storm, and found ways to continue to provide support throughout the week following the storm. Families and neighbors rallied together and people helped each other. Nonetheless, there were enough problems reported to allow us to learn some lessons. More specifically:

1. People reported considerable confusion about where, how and with whom one can "register" oneself as a person or family that might need some particular type of assistance in the event of an emergency. There is no uniform way this is handled amongst municipalities or even at the State level. People may think that because they filled out a "special needs" registration form for the Enhanced 911 system that they also signed up for the CT Alert Emergency Notification System (which is also sometimes called "reverse 911"). Or, vice versa. Similar confusion exists about notification to electric power companies about one's need for uninterrupted power to operate ventilators, oxygen concentrators, suctioning devices, etc. Does the notification mean only that power will not be shut off for failure to pay the bill, or does it mean that the company knows it should not cut power to your home in the event it must de-energize lines for repairs? And, what if it has to do so anyway? Does that notification mean that restoring power to your home will be considered a priority? And what about people living in senior/disabled housing? Do they have to register individually, or will the power company automatically consider them a priority for restoration of service? What about registering with local emergency services? Having worked extensively with local emergency managers and responders from across the state, I am well aware that there are lots of problems with operating and maintaining "registries". In some towns they are formally kept, tied to the municipality's Emergency Notification System, and updated by confirming contacts annually. Others are much less formal and much less likely to be kept current. Residents who inquire

are sometimes directed to the local fire chief, sometimes to a first selectman. And some towns keep no registry at all. There are lots of differing opinions about the value of registries, about the resources necessary to maintain them, and about who should have access to information in them. I do not pretend to know what is best. My point is that there is considerable confusion about these issues, and that confusion does not serve people well. We need to examine these questions, consolidate whatever information and processes we can, and develop a solid, uniform message so that people who want to identify their needs in the event of an emergency know exactly what to do.

2. In some places it appears there were significant disconnects between human service support agencies, home health agencies, and vendors of medical equipment and supplies on the one hand, and local emergency managers and utility companies on the other. The result was that could not get answers to questions, and often didn't even know who to ask. This could be remedied by involving all concerned in local planning exercises. In fact, in those areas where that has happened, things went appreciably better. Here are some examples of this problem:

    - One agency that supports people with cognitive disabilities, most of whom live in their own apartments in shoreline towns, did not know how to advise people concerning evacuation and sheltering. The problem was that each town communicated very different and, in some cases potentially confusing information and directions. One town announced that all residents south of Route 1 should evacuate, but then chose to locate its daytime public shelter in a building that was, itself, south of Route 1. The overnight shelter in that town was in a different location, and did not open its doors until 10:00 pm. In contrast, the next town did not communicate any evacuation instructions, but did keep a shelter open day and night for several days. The support agency's managers had trouble tracking and re-communicating the town by town evacuation and sheltering information, and felt their clients, who typically receive several hours of support each day, were likewise confused.

    - Three days after the storm hit, one home health agency that had made considerable advanced preparation and was diligently serving hundreds of people in multiple towns in Eastern Connecticut received a call from an emergency management official in one of those towns asking for assistance identifying and reaching out to "shut-ins". The official was unaware of the fact that the agency had already been doing exactly that, and did not know how home health agencies operate. Had the home health agency been included in regional planning and table top exercises, it would not have felt it was operating by itself, and the extent of its services and client population would have been known to local emergency planners.

    - A supplier of home oxygen equipment had distributed extra oxygen tanks to its customers prior to the storm, but knew that those tanks would only last for a limited time. Many of its customers use electrically powered oxygen concentrators (a.k.a "oxygen generators") to refill their own tanks. The company could not, however, get information from anyone about how long the power would

be out, and couldn't rely on usual telephone communications from customers to keep them informed. They tried to make the rounds and check on people, and they also contacted fire departments to whom they also supplied oxygen cylinders to offer assistance to anyone they heard of who needed oxygen. If they had been included in regional planning exercises, they would have had a much better idea of who to contact for information, and emergency planners would have had a much clearer picture of peoples' needs.

3. Make Universally Accessible Sheltering a reality. In the post-Katrina world, a lot of emphasis has been placed on trying to improve our capacity to evacuate people and provide public shelters. Because there had been so much trauma and loss of life amongst people with disabilities during that disaster guidelines on inclusive sheltering for local and state governments have been developed by FEMA and the U.S. Department of Justice. The DOJ has also pursued ADA enforcement actions against municipalities that persisted in patterns of disaster planning that relegated people with disabilities to segregated sheltering. This is much more than a matter of legal compliance. Research and operational experience has shown that if we want people to heed evacuation orders and utilize public shelters, we have to understand their concerns. So we now know that we have to let them bring pets with them, that we have to allow families and support circles to shelter together, that we have to assure people that their functional needs – including their need to bring mobility devices and recharge their batteries - will be met, and, perhaps most importantly, we must be able to assure them that they will not find themselves being sent to a medical or long term care facility simply because they have disabilities. Many seniors and younger people with disabilities dedicate their lives to staying out of nursing homes, and any suggestion that that is where they will end up if they heed an evacuation order will result in non-compliance and possible tragedy. It was disappointing to note, therefore that only one of the municipalities that opened a public shelter advertised it as being accessible; that while some affirmatively said they had facilities for pets, others persisted in issuing the old, largely failed advice to "leave pets on the second floor of your home with extra water and food", and that some towns chose sites for shelters because they had emergency generator capacity, but, after they opened, found out that the generators were only wired into circuits for refrigeration and lighting, and could not be used to charge batteries on wheelchairs, computers, cell phones or other devices. And, it was especially distressing to learn that one municipality requested assistance from the State Department of Health in placing shelter guests with disabilities into nursing homes because it wanted to close the shelter and power had not been restored to those people's homes. Fortunately, power was restored to their homes before they could be sent to nursing homes, but the fact this was considered an acceptable alternative is distressing. This isn't to say that all shelters were deficient – the way that some were located, staffed and operated reflected a very clear understanding of all these issues. Clearly, some local emergency managers have been paying attention. But, it is also clear that part of Connecticut's after action analysis of Tropical Storm Irene should include an examination of the issue of accessibility and capabilities of public shelters with an eye to getting everyone to pay attention to those issues.

4. We need to rethink our planning assumptions and our personal preparedness messages about sheltering-in-place. Congregate shelters served relatively few Connecticut residents during Tropical Storm Irene, and most closed soon after it was safe for people to return to their homes. Most of us chose to stay home, or returned home and "shelter in place". In fact, for most of Connecticut, shelter-in-place scenarios are far more likely to occur than events which require widespread evacuation and congregate sheltering. Yet relatively little attention has been paid to planning how best to support people who are sheltering in their homes. In fact, the personal preparedness messages we are sending, which emphasize acquiring sufficient water, non-perishable food and other supplies to last only three days - may be misleading. We were fortunate that Irene hit during warm weather, when there was no need to heat homes and clean up and restoration efforts could proceed unimpeded. It is foreseeable, however, that a severe winter storm could create just as much disruption to transportation, electric power and communications infrastructure – disruption that could take even longer to remedy. For many of us, "Sheltering in place" for a prolonged period without heat or emergency communication capability is not a viable option. Planners must begin to reckon with this reality. At a minimum, we need to give more explicit information concerning the potential duration of events in particular regions of the State, and encourage personal preparedness plans to take that potential into consideration.

Thank you for this opportunity to share our experience and views. If there are any questions, I will try to answer them.