



Survival Coalition

of Wisconsin Disability Organizations

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TESTIMONY OF INVITED SPEAKER

WISCONSIN LEGISLATIVE COUNCIL SPECIAL COMMITTEE ON DISASTER PREPAREDNESS PLANNING

Good morning!

My name is Michael Steinhauer and I am the managing partner of The Steinhauer Group, LLC a management and clinical consulting firm in Madison helping long term care facilities, specifically nursing homes and assisted living organizations achieve their goals through assuring regulatory compliance, best practices, quality improvement activities and workforce development.

My firm is also a member of the Survival Coalition of Wisconsin Disability Organizations, the largest coalition of its kind advocating for equal, civil rights for those with disabilities, and supporting all initiatives that allow people with disabilities to live in the least restricted environment and under person-directed care. I speak to you representing the Coalition.

I currently help lead two initiatives addressing disaster planning: one on the State level serving on the Expert Panel for Healthcare Facilities organized by DHFS and the Division of Public Health under Dennis Tomczyk in the Hospital Bioterrorism Unit. I assisted in writing the States' formal policy on the evacuation of long term care facilities. Second, I sit on the Dane County Special Populations Disaster Planning Committee, where we are gathering information and resources to create a meaningful strategy to address disaster planning for those with disabilities.

My colleague Nancy Anderson and I are here to address you about inclusion and integration of people with disabilities and their advocates participating at every planning level throughout our state.

Both of these experiences have been rewarding personally and professionally but concurrently they have also left me with an empty feeling not being convinced that adequate planning resources are directed to addressing the unique challenges facing those with disabilities during a disaster. I note efforts to date address institutional acute and long term

care facilities in our planning and for that aspect of our population we are organizing well. My primary concern today centers around meeting the needs of those with disabilities who reside in the community. These folks are generally much more isolated than those residing in institutions and with memories of wheelchairs floating down the streets of New Orleans, it is now their time to be included in the planning process!

The Americans with Disabilities Act (ADA) of 1990 requires that emergency preparedness and response programs be accessible to people with disabilities. But there is currently no standardized federal preparedness plan for disabled people, and many state and local emergency management offices do not have appropriate plans in place to account for special needs.

I'll quote Hilary Styron, Director of the Emergency Preparedness Initiative for the National Organization on Disability who said recently, "There isn't ownership clearly defined by the federal government as to who is responsible for disability planning." I think that is also true at the State level in Wisconsin and Nancy will address that.

While President Bush's 2004 executive order created the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, the council is only instructed to "encourage" state and local jurisdictions to consider special needs in its planning.

Traditional evacuation plans, which often rely on at least some walking, driving, seeing and hearing, are not appropriate for many people with disabilities. We need more responsive plans, and for government to require planners to include people with disabilities and their advocates a part of the planning process. Although some states have adopted measures that have begun to account for the needs of people with disabilities, such as a reverse 9-1-1 system and more accurate records on the locations of people with disabilities, significant gaps still exist.

In my view the major difficulty in planning for disasters for people with disabilities is that there is no "one-size-fits-all" approach. This requires the person with a disability to plan on being more self-reliant than others during and after a disaster. The elements and exercise of personal and family preparedness will address this fact, but only as planned for and supported by the overall state, county and local planning efforts. Therefore it is paramount that the disabled and their advocates be full, active partners in all aspects of emergency preparedness, response, and recovery.

We seek your active support in a multi-step process to achieve this goal.

- 1) People with disabilities are experts on their own needs and the agencies that serve them are experts with unique skills and community knowledge to contribute. Full inclusion in planning must be fulfilled. This Council should recommend the funding of projects that include or have a history of collaboration between mainstream organizations and disability groups. Please support and demand funding for small or under-funded

agencies with strong roots in the disability communities and emergency/disaster expertise to cover the costs of their full participation in emergency planning.

2) Identify those with disabilities living in the community. The Council should make efforts to support funding efforts to create community-wide rosters of disabled people likely to need assistance in an emergency.

3) Make information and warning systems accessible to those with disabilities e.g., Braille, large print, audio tapes, relay system, sign language services, etc. Please support and require the means of ensuring that (a) opportunities for input and dialogue are ongoing, and (b) that reviews and testing of the plans, policies and procedures are built into the process.

4) Make sure that emergency supplies and shelters reflect the diverse needs of the disability communities for equipment and assistive devices or that there are funds to meet such needs. Please support and make available grants for specialized supplies such as accessible evacuation equipment; disaster supply kits that address disability related needs; tiered shelters and equipment for the disabled, and delineated staff to be used before, during or after a disaster.

Wisconsin has the resources to quantify and specify the ingredients necessary for a well rounded disaster planning protocol for its citizens with disabilities. There must be exceptional plans that meet the diverse needs of those with disabilities residing in our exceptional state.

We count on your leadership to make this happen. I would be pleased to answer any questions you may have. Thank you.

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