

Emergency Preparedness and Response for People with Disabilities

“For people with disabilities, proper planning could be lifesaving.”¹

The Pennsylvania Developmental Disabilities Council believes that appropriate and effective management of emergencies **of all types** across the life cycle of disasters (preparedness, response, recovery, and mitigation) is essential for people with disabilities, their families, and their support systems. Pennsylvania is prone to some types of weather disasters such as snow storms, hurricanes, tornadoes, and flooding at the rate of 15 declared emergencies in the period 1998 to 2008. The state has also experienced forest fires, a nuclear accident, an act of terrorism, and flu pandemics in our history. At the time of this writing, attention to prevention and emergency preparedness is being renewed by state and local officials in anticipation of the threat of the H1N1 “swine flu” in Pennsylvania.

Emergency preparedness includes being ready to respond to an unusual problem that can range from minor to very serious. Communities, governments, businesses, public places, and private citizens need to be informed and prepared to deal with various types of emergencies and their aftermath to ensure the best outcomes. Being prepared for an emergency is everyone’s responsibility and can make the difference in how well individuals and their communities fare in disaster and recovery. The presence of an estimated 54 million Americans with disabilities living and working in our communities highlights the importance for plans to understand and meet the needs of all people.

In response to the national conversation about the need for information on emergency management laws, policies, programs and practices that affect people with disabilities, the National Council on Disability (NCD) published a report titled Effective Emergency Management: Making Improvements for Communities and People with Disabilities.² The report describes issues at all levels and makes recommendations for action.

When describing emergencies, there are four levels;

- Routine Dispatch Problem – a minor emergency involving first responders (example: injury, lost pet)
- Incident – an emergency the local responders can handle (example: lost child or adult, Amber Alert, house fire)
- Disaster or catastrophe – an incident involving much destruction and many injuries or deaths (example: flooding, wildland fires, tornadoes)
- National/International Disaster – a disaster of substantial size and seriousness (example: flu pandemic, terror attack, major hurricane, tsunami)

Generally, the response and recovery process in the event of an emergency starts with local government’s resources, supplemented by neighboring communities and volunteer agencies. If overwhelmed, local government turns to the state for resources such as the National Guard and help from state agencies. The damage is assessed by various

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entities and the losses and recovery needs are determined. If needed, the Governor can ask the President for federal help to deal with and recover from the emergency. Federal help can include search and rescue, and the provision of electrical power, food, water, shelter and other basic human needs. Federal assistance is also used to prevent or reduce the effects of anticipated disasters, such as making vaccines available or building levees along rivers.

The Pennsylvania Developmental Disabilities Council highlights several areas where emergency preparedness, response and recovery could be improved for individuals with disabilities, their families and their support systems. They include communication and information exchange, inclusion of individuals with disabilities in disaster planning, and defining system and government responsibilities.

Communication and Information Exchange

The Pennsylvania Developmental Disabilities Council is interested in supporting efforts aimed at raising awareness of the need for emergency preparedness for individuals with disabilities at home, at work, at school and in the community. It is essential that people with disabilities, their families and support systems are informed about how to prepare for emergencies and are able to prepare effectively based on their unique needs. They may need assistance to inform First Responders about themselves and their issues, outreach from trusted sources to dispel fears and myths about what will happen in an emergency and information about being prepared for a disaster.

For many years, providers, individuals with disabilities and their families have aimed to blend in to their communities and not stand out as “special” or different. Succeeding at this may make it more difficult to be “found” and provided with the accommodations needed to be safe. Some individuals fear being stigmatized or being victimized if they make their disability, needs, or vulnerability known. Others are not comfortable sharing information without assurance that it will remain confidential except for its intended purpose of aiding first response efforts. A balance must be struck between these values that respect individuals while enabling first responders to provide effective services. Efforts such as identification and location registry programs can only be effective if there is a high degree of trust established with the systems that operate them.

The Council believes that communication about preparedness must be effective and useful for people with disabilities and their families, providers and communities. Information must be in accessible, understandable and accommodating formats free of technical jargon and acronyms. In addition, outreach and materials must accommodate different cultures and languages in order to be effective. Information must be easily located for planning purposes and when urgently needed.

The response to an emergency is carried out by volunteers and professionals who have been trained to deal with many different situations, to act quickly, and to assist large numbers of people, if needed. In order to be most effective for people with disabilities, first responders must understand behavioral, communication and accommodation issues of this population. First Responders are in that role because they want to be

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helpful to people and desire to leave no one behind but often lack the complete information they need to do so. The Council supports the provision of resources so that all individuals involved in emergency management can receive more extensive training in regard to specific disabilities, community living, service animals, and appropriate communication and interaction with people with disabilities.

System and Government Responsibilities

The Council supports the Consortium for Citizens with Disabilities (CCD) position on emergency management for vulnerable populations including individuals with disabilities.³ State and local governments must comply with all civil rights laws in all emergency- and disaster-related efforts, including sheltering, communications, mass care, transportation, and housing that they provide directly as well as through third parties, such as the American Red Cross, private non-profit organizations, and religious groups. The CCD calls on Congress and the Administration to foster coordination between federal, state, and local governments, as well as contractors, in planning for and responding to disasters inclusively for people with disabilities. Further, they urge the provision of resources needed by community service agencies in both preparing for and during times of emergency so they are not using their already limited resources to prepare for and recover from a catastrophe.

People with disabilities must have access to assistance to be fully prepared for a disaster. As personal preparedness recommendations can be costly and difficult for low-income individuals and their families to afford, resources to locate and/or pay for preparedness items, e.g. ready kits, vaccines, accessible alarm accommodations, medication supplies and crank radios, are essential.

The Council believes that federal, state and local governments bear responsibility to ensure that emergency plans and communication in public buildings and venues include drills, clearly stated expectations, and the capacity to safely assist all individuals with disabilities. Because of the unique role government plays in disaster response, it should be a leader and model in preparedness in its buildings and in the safe evacuation of its workforce and visitors to its public venues. Drills must include actual evacuation practice for all individuals and should address mobility and communication issues of persons with disabilities in order to be effective. Evacuation plans must be readily available and understandable to all. The use of emergency shelters must take into account the unique challenges inherent in assisting people with mobility, cognitive, and sensory disabilities. Emergency plans at all levels must be continually reviewed to incorporate lessons learned from previous events and drills and to take advantage of evolving technologies.

The Council believes that federal, state and local governments bear responsibility to ensure that essential human services can be provided to vulnerable populations in an emergency and its aftermath. Communication and information to human service agencies and facilities should support and encourage their emergency preparedness planning through policy directives, elimination of financial disincentives, and the review of contingency planning standards in monitoring instruments. Specific areas that require attention to ensure successful outcomes include:

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- Standards and information regarding continuity of operating programs for the service system including financial, communication, and human resources logistics
- Policy and procedure to ensure continuity of operating programs for public administration of human service programs including financial, communication, and human resources logistics
- Arrangements for providers to have access to operating cash if normal finance and banking is interrupted
- Formal arrangements with other localities or states for evacuation or temporary service locations
- Financial and service delivery policies that support service provision in an emergency
- Support and assistance to carry out and learn from drills and contingency plan testing, including the intentional sharing of best practices as it evolves

Inclusion of Individuals with Disabilities in Disaster Planning

The Council believes that people with disabilities, seniors, and their advocates must be included and treated as full partners in emergency preparedness response planning at the federal, state and local level in coordination with FEMA, PEMA, and Regional Task Forces. It must be mandatory to include stakeholders in planning efforts while providing full ADA compliant venues and supporting services, e.g. sign language or captioning. Planning groups should be educated about the needs of individuals with disabilities and accept recommendations on the most effective methods of outreach to various communities. Planning efforts that include stakeholder input must be seen as a continuum with benchmarks for improvement and sustainability of effort. The planning process must include people with disabilities in all forms of learning, including table top, functional, and field exercises.

In conclusion, action is urgently needed to improve inclusive emergency management through the life cycle of disasters that is effective for all people with disabilities. The stakes are high for all citizens during a disaster but people with disabilities and other vulnerable populations should not pay the highest price due to a lack of effective emergency planning. The needs of the masses during an emergency are not at odds with the needs of individuals with disabilities if creativity, adequate resources, effective communication, good planning and sufficient learning from practice are used.

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¹ <http://disabilities.temple.edu/programs/eprep/>

² http://www.ncd.gov/newsroom/publications/2009/NCD_EmergencyManagement_HTML/EffectiveEmergencyManagement.html

³ http://www.c-c-d.org/task_forces/emer_prep/Final%20Principles.pdf