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Michael Chertoff
U.S. Department of Homeland Security
Washington, D.C. 20528

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Dear Secretary Chertoff,

The Consortium for Citizens with Disabilities (CCD) is a coalition of 105 national disability organizations with expertise in disability policy, advocacy and service delivery. As the Consortium's task force devoted to the emergency relief and disaster preparedness needs of well over 54 million Americans with disabilities, we are committed to participation in the ongoing national dialogue on emergency preparedness and the inclusion of the needs of people with disabilities and their families in preparedness, response, recovery, and mitigation efforts from the local to national levels.

Over the many years that the Task Force and its individual members have engaged collaboratively with governmental and nongovernmental entities to work toward a shared goal of high capacity and high competency in the inclusion of people with disabilities and their needs in preparedness efforts, it has unfortunately been our ongoing experience that this inclusion has been misunderstood, underestimated, and insufficiently considered. For this reason, the Task Force is writing to you directly, Secretary Chertoff, to provide a response to the Draft National Response Framework currently under consideration and in so doing, convey some of our broader core concerns about the current status of including people with disabilities in preparedness and response planning.

The Framework describes its intended audience as “government executives, private sector business and nongovernmental leaders and emergency management practitioners.” We believe that these very leaders must possess an accurate understanding of the breadth of characteristics of such a large component of general American society: persons with disabilities, who the Centers for Disease Control determined in 2006 account for as much as 25% of the overall population of some states. With such a significant segment of the population, we believe that persons with disabilities and their emergency management and disaster relief needs must be accurately represented in the Framework so that decision makers have a clearer understanding of the population, and its diversity and complexity, in order to develop and implement best practices and fully integrate persons with disabilities in preparedness and response planning.

To this point, we must comment on a misnomer present within the Framework, one we find unfortunately prevalent throughout the preparedness and response industry. This concerns the term *special needs*. Our review of the Framework Core Document finds uses of the term *special needs* (though, unfortunately, only six times), and its source definition in the glossary to be inadequate in defining the specific *functional and medical needs* of people with disabilities. Popularly, *special needs* is used so broadly, referring to everyone from non-English speakers to children to those who are transportation disadvantaged (and this could be everyone in a disaster!), that the phrase carries not enough specificity about whom it is truly referring. As advocates for persons with disabilities, we cannot allow this insufficient focus on such a significant portion of the population to stand in a federal document intended to guide leadership at all levels and prevent unnecessary loss of life. Despite heated debate over many months, led by experts from across the country, we find it egregious that the term *disability* is only used twice in the Framework Core Document as currently drafted. It is the *functional and medical needs* of people with and without disabilities that must be considered by emergency managers and first responders, and as long as these *functional and medical needs* are considered “special” and as long as they remain ill-defined, the National Response Framework fails to provide adequate structure to meet the additional needs of 25% of the population.

Similarly, in the Framework’s section titled “Incident Management: The Who,” there is reference to individuals, families, and caregivers of those with *special needs*. While consideration of caregivers is something we wholly support, our frustration with the expression *special needs*, based on its long track record of ambiguity, misapplication and misinterpretation, causes us to rather suggest that the document should simply refer to *personal assistants and caregivers*.

The Framework seeks “to incorporate public sector agencies at all levels, private sector business and nongovernmental organizations.” We believe that preparation at the local level is key, particularly to mitigating barriers to civic participation, including within response preparedness, for persons with disabilities. We therefore ask you to use the Framework to emphasize to local officials that such a significant portion of their population will be considered and engaged in response planning. Likewise, businesses and NGOs must be clearly directed that their services must be fully accessible and nondiscriminatory.

Within the Framework’s Response Doctrine Five Key Principles, the document says, “Preparedness involves a combination of planning, resources, training, exercising and organizing in order to build, sustain and improve operational capabilities.” Again, stemming from our experience in service to governmental and nongovernmental bodies concerning persons with disabilities, we feel the Framework has missed a key opportunity: preparedness also involves *learning*. Direct input from people with disabilities, including those with sensory, physical, mental, intellectual and cognitive disabilities, must be fully included for successful organizational learning. Pointedly, we believe that leadership at all levels must receive a

message from the Framework that learning from constituents with disabilities and disability experts is essential for success and mandatory for sufficient achievement. This emphasis will be particularly critical in the Framework Core Document's chapters on Roles and Responsibilities and Planning.

Throughout the document, there is a clear emphasis on the importance of personal preparedness by individuals and their families. Our member organizations work actively to assist individuals and families to prepare for an emergency. However, the emphasis in the Framework fails to acknowledge that for many people, this is an impossible and potentially dangerous expectation. While many people with disabilities have been able to adequately prepare for future emergencies, many people are disenfranchised and do not have a support system in place to assist in their planning. Many lack the tools for even basic survival on a daily basis. Public and private healthcare systems do not allow individuals to maintain a stockpile of extra medication, equipment and supplies. The disproportionate poverty among people with disabilities severely limits their ability to maintain the basic supplies they need on a daily basis, much less what they will need in an emergency and for many people with disabilities transportation remains a daily challenge in the best of times. For people who are homeless, those who reside in nursing homes and a significant segment of the 54 million Americans with disabilities living in our communities, adequate personal preparedness is an unreasonable expectation and unobtainable objective, and it's emphasis in this document, without acknowledging the systemic challenges faced by many people with disabilities, adds to the existing stigma that fuels public, responder and policy maker misunderstanding about their responsibility to prioritize the functional and medical needs of people with disabilities.

We believe that any federal guidance intended for all levels of governmental and nongovernmental action in national response must address:

- What to do and how to interact with people with various disabilities including communication access issues: e.g. how to assist an individual with mental illness and those who can not communicate without assistive technology
- How to make shelters and relief operations accessible to people with physical, mental, sensory (hearing and vision) and intellectual and cognitive disabilities
- How to comply with and enforce civil rights laws and ordinances, including the Americans with Disabilities Act and fair housing laws
- How to access, engage and utilize disability experts and public and private entities, including nonprofit organizations, that provide services and supports to people with disabilities and are extremely knowledgeable about addressing emergency management issues

We acknowledge that there is additional information contained in the annexes and other supporting documents, and we will submit comments that express our concerns with those documents as well, however, the objective of the Framework is to present an "overview of key response principles, roles and structures that guide the national response." It is supposed to describe how "communities, States, the Federal Government and private-sector and nongovernmental partners apply these principles for a coordinated, effective national response." Furthermore, it is supposed to describe "special circumstances where the Federal Government exercises a larger role, including incidents where Federal interests are involved and catastrophic incidents where a State would require significant support." It is described as having real value especially in "how these elements come together and are implemented by first responders, decision makers and supporting entities to provide a unified national response."

Until the needs of 25% of the population are more adequately and specifically addressed, this document further jeopardizes the safety of millions of Americans who are relegated to second class or “special” status.

Disability experts and our constituents are well aware that in an emergency, special means second. People with disabilities have died or experienced unnecessary health crises as a direct result of the failure to adequately plan for and provide resources and experts to address their needs. The National Response Framework draft does not achieve its stated mission and as representatives of 54 million Americans with disabilities we cannot endorse this document in its current form.

Despite the absence of almost all of our previous input, CCD has already played a significant role in the planning discussions that led to the development of this document and we remain entirely willing and able to provide expert input into creating a framework that adequately meets the needs of the entire population, not just those who are not considered “special.”

Sincerely,

Curt Decker, Co-Chair
David Morrissey, Co-Chair
Marcie Roth, Co-Chair

Consortium for Citizens with Disabilities
Emergency Relief and Disaster Preparedness Task Force

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The Consortium for Citizens with Disabilities is a Coalition of more than 100 national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. (A list of members is available at www.c-c-d.org.) Since 1973, the CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society. The Emergency Management Task Force was established in 2005 and has more than 25 member organizations.