



Serving the Hardest Hit

Centering People with Disabilities in Emergency Planning and Response Efforts

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It's often said that natural disasters don't discriminate—that no individual is more or less likely than another to fall victim to a large-scale natural disaster. But the truth is that people with disabilities—particularly those living in disaster-vulnerable, low-income communities¹—endure disproportionate harm.² For the purpose of this issue brief, the term “disability” includes those with physical and mobility disabilities; sensory disabilities such as Deafness or Blindness; and learning, mental health, neurodiverse, and intellectual or developmental disabilities. It also includes people with a chronic illness and/or in recovery for substance use disorders, as well as those with a history of these conditions. All these categories could include individuals aging into disability.

Indeed, in the United States, people with disabilities are 2 to 4 times more likely to die or sustain a critical injury during a disaster than people without disabilities.³ This increased level of risk is due to the difficulty that individuals with disabilities have evacuating without assistance,⁴ accessing lifesaving medical equipment during power outages,⁵ and accessing accurate emergency information and effective emergency services.⁶ The still-unfolding damage from Post-Tropical Cyclone Florence,⁷ the recent wildfires ravaging the western United States,⁸ and the one-year anniversary of Hurricane Maria's reverberating trauma⁹ in Puerto Rico are all potent reminders of the heightened perils those with disabilities face during extreme weather events.

The now nearly 1 in 4¹⁰ Americans with disabilities have complex access requirements and functional needs during times of natural disaster. Unfortunately, these needs have failed to gain significant notice. The noise of a White House intent on neglecting its responsibility to the health and safety of vulnerable U.S. communities during disasters and of price gouging¹¹ for lifesaving medication in the wake of emergencies, as well as the always prematurely fading media spotlight¹² on the never-ending aftermaths faced by disaster-torn communities, serve to detract from making the needs of people with disabilities a national policy priority.

In light of overwhelming scientific trends pointing to the increasing frequency and strength of extreme weather events—and as the nation observes National Emergency Preparedness Month this September—federal and local leaders must create a long-term preparedness, response, and recovery framework that centers the needs and supports the resilience of the disability community.¹³ Of the roughly 10 million people living in parts of the country forecasted to be directly affected by Florence’s high winds, storm surges, floods, and power outages, close to 3 million have disabilities.¹⁴ And while local officials and agencies made concerted efforts to ensure that individuals with disabilities had adequate time and resources to reach safety ahead of the storm,¹⁵ community emergency evacuation and shelter plans still too often fall short. These shortcomings result in greater exposure to harm and potentially life-threatening conditions for these vulnerable residents.¹⁶

Natural disasters such as Post-Tropical Cyclone Florence and Hurricane Maria affect people with disabilities of all ages. In addition to harming individuals with existing disabilities, storms also affect those who acquire disabilities¹⁷ as a result of disaster-induced trauma.¹⁸ Effective preparedness, response, and recovery infrastructures require a fundamental rethinking of disability programming—from early childhood education to aging services, all of which require a trauma-informed framework to meet the needs of affected individuals.¹⁹ A recent study conducted by The George Washington University (GW) revealed that at least 2,975—not 64, as previously reported—people, the majority if not all of whom were likely U.S. citizens—lost their lives²⁰ due to Hurricane Maria, making it the second deadliest hurricane²¹ in U.S. history. This underscores the urgent need to dramatically reform the nation’s preparation for and response to emergencies.

The Trump administration’s FEMA failures and detrimental rollbacks

Thus far, the Trump administration has shown an outright disregard for the challenges of living in areas vulnerable to extreme weather for people with disabilities, people of color,²² and aging residents.²³ Recently, the president went so far as to declare that his administration’s response to Hurricane Maria “was an incredible, unsung success,”²⁴ and further insulted the families of the nearly 3,000 people who lost their lives because of Maria by flat-out denying GW’s death toll findings.²⁵ Commissioned by the Puerto Rican government, the independent study detailed that of the 2,975 residents who died in Puerto Rico, the vast majority were those living in poverty and seniors²⁶—many of whom were likely residents with disabilities²⁷ who faced deadly mobility barriers to safety. Furthermore, researchers at Harvard University estimated that roughly one-third of the Hurricane Maria-related deaths in Puerto Rico were caused by either delays in receiving vital medical services or the inability to obtain care altogether.²⁸

The disability community already started the 2018 hurricane season at a point of disadvantage. The Trump administration has been adamant in its desire to push responsibility for disaster preparedness, response, and recovery to the states.²⁹ However, not all states have personnel designated in the upper levels of the emergency management agencies to focus on meeting the needs of the disability community. Moreover, on June 1, 2018, the Federal Emergency Management Agency (FEMA)—despite its previously admitted shortcomings³⁰ and capacity shortfalls—reduced the number of Disability Integration Advisors (DIAs) it sends to states in federally declared disaster areas. Previously, FEMA sent approximately 60 DIAs per disaster; it now sends just 5.³¹ DIAs are central to providing guidance, training, and technical assistance throughout disaster response and recovery as part of the federal government’s obligation to protect the civil rights of people with disabilities and ensure equal access to assistance before, during, and after disasters.³²

The reduction in DIAs is just one of several rollbacks this administration has undertaken. A 2018 U.S. Government Accountability Office (GAO) report found that despite FEMA’s efforts in Puerto Rico having been the “largest and longest single response in the agency’s history,” more than half the agency’s staff “did not hold the title of “‘Qualified’” based on FEMA qualification standards for the jobs that they were assigned. According to the GAO, FEMA’s own internal review showed that the overall “staff shortages, and lack of trained personnel with program expertise led to complications in its response efforts, particularly after Hurricane Maria.”³³

Disasters and extreme weather events magnify existing inequities

Every day that response and recovery policies are not inclusive of individuals with disabilities, millions of U.S. residents are needlessly put in harm’s way. When there is a lack of proper planning and qualified personnel on the ground to help individuals with disabilities and their families access necessary services and supports, what often results are violations of the civil rights of people with disabilities. As witnessed in Hurricane Irma,³⁴ multiple homeless individuals who were thought to have mental illnesses were tracked down and arrested and committed against their will. Proper planning, service coordination, and engagement with the disability community could have and should have prevented this.

Furthermore, for people with disabilities in low-income communities, the harms caused by a major natural catastrophe are magnified, and the likelihood of full recovery is virtually slim to none, as noted in a recent analysis of nearly a century’s worth of data by the National Bureau of Economic Research.³⁵ In the study, researchers observed that inequality worsened in disaster-prone areas as residents with the economic means to evacuate did so, meaning that community members who were already financially insecure had to shoulder the increased, inequitable burden of both greater exposure to severe weather events³⁶ and a higher probability of falling deeper into poverty.³⁷

Despite passing a \$89.3 billion disaster relief package in February to help communities recover and rebuild from the 2017 hurricanes and wildfires, Republican leaders in Congress have taken little if any action to meaningfully tackle the current federal preparedness and response infrastructure. At the time of this publication, they have yet to convene a full committee hearing to revisit what went wrong with the federal response to hurricanes Harvey, Irma, and Maria in light of the new official death toll in Puerto Rico.³⁸ Neither a Senate nor a House public hearing has been scheduled to consider the George Washington University study; to publicly examine the Federal Emergency Management Agency's response and recovery failures, as documented by both the Government Accountability Office's and the agency's own recent reports; or to determine how best to move forward and ensure that these deadly mistakes are not repeated. Congressional committee chairs also have not scheduled hearings on the Army Corps of Engineers' standards for dams and levees, flood risk assessments, or new floodplain mapping to help answer the difficult questions being raised on whether areas chronically prone to flooding³⁹ should remain inhabited as the severity and urgency of climate change becomes glaringly clear.⁴⁰

Restoring and improving the federal emergency infrastructure for inclusive disaster preparedness and response

Following the George W. Bush administration's reprehensible, mismanaged response to Hurricane Katrina, no fewer than nine congressional hearings were held to get to the bottom of what went wrong in order to ensure adequate oversight in the future and prevent the United States from again experiencing that level of avoidable devastation and loss of life.⁴¹ Out of those hearings came the Post-Katrina Emergency Management Reform Act of 2006, which reorganized the Federal Emergency Management Agency.⁴² The agency adopted a more inclusive mission and established a better-integrated emergency management framework to remedy response gaps, better address unmet needs, and reduce community-specific vulnerabilities to disaster threats and hazards.⁴³ This included the establishment of the new position of director of the Office of Disability Integration and Coordination (ODIC) and required disability inclusive emergency preparedness, response, and recovery plans.

Under the Obama administration in 2010, FEMA established the ODIC to further incorporate the access and functional needs of individuals with disabilities in all aspects of community emergency planning and management.⁴⁴ The ODIC ensured that each of FEMA's 10 regions had a coordinator whose role was to help organize and direct grass-roots advocates and local, state, and federal governments in linked activities and efforts. Clear coordination and communication between local, state, and federal officials ensured that FEMA's Disability Integration Advisors could connect community-based disability organizations—such as Centers for Independent Living, Developmental Disabilities Councils, and Protection and Advocacy agencies—with the necessary government officials to carry out activities such as distributing wheelchairs or helping individuals connect with home- and community-based service providers.

Furthermore, a number of individuals acquire disabilities as a direct result of a natural disaster and need help managing the bureaucracy around obtaining services and support. DIAs are there to provide that assistance and address the immediate unmet needs of disaster survivors, whether it be retrofitting a home for accessibility or finding a therapist specializing in trauma-informed care.⁴⁵ Such needs are the true legacy of disasters such as Hurricane Maria, as survivors adjust to their new normal⁴⁶ of life with a disability or chronic health condition for years to come.⁴⁷

Under former President Barack Obama, FEMA also entered into a partnership with Portlight Inclusive Disaster Strategies,⁴⁸ an organization led by people with disabilities that centers self-determination in disaster preparedness, response, and recovery. It shares operational best practices, augments data collection efforts, and participates in ongoing training and technical assistance activities to improve response efforts for people with disabilities. In their current iterations, FEMA and its state-level partners lack the capacity and expertise required to meet the needs of communities in disaster-vulnerable areas, let alone the needs of individuals with disabilities and their families.⁴⁹ These challenges are only worsened by the Trump administration's continued mismanagement, removal of key staff members and draconian budget cuts.⁵⁰

With peak hurricane season in full swing and extreme weather events striking at unprecedented levels and rates, state and federal leaders cannot afford to delay taking action to improve emergency response and recovery efforts any longer.⁵¹ As the death and devastation tolls of Florence rise⁵² and reports of fatalities involving people with disabilities continue to emerge,⁵³ policymakers must address the gaps in the current preparedness, response, and recovery infrastructure laid bare by the storm and past disasters. These natural catastrophes continue to disproportionately affect the health and resilience of communities vulnerable to more severe and urgent climate change effects. As federal, state, and local officials determine the appropriate emergency and disaster relief measures to employ in the immediate future, this brief offers the following topline recommendations that should be enacted to ensure that people with disabilities, particularly in low-income communities, have the information and supports they need to adequately prepare and safeguard their lives from impending, life-altering extreme weather events:⁵⁴

- Ensure that evacuation services and shelters are fully accessible to people with disabilities, including individuals who have service and emotional support animals.
- Make certain that current communication and planning strategies to share critical information during emergencies and disasters prioritize and reflect the diverse needs of people with disabilities and other at-risk communities.⁵⁵
 - Require the use of certified American Sign Language (ASL) interpreters at all press conferences detailing news related to an ongoing emergency.
 - Ensure that disseminated preparedness, response, and recovery information is available in alternate formats—including Braille and through highly qualified ASL interpreters.

- Require the creation of state integration specialists within state emergency preparation agencies to make sure that no population, especially individuals with disabilities, is overlooked.
- Coordinate evacuation processes for nursing homes, hospitals, and prisons to ensure that those who are under state supervision have access to the supports and services necessary to evacuate safely.
- Provide Centers for Independent Living and other disability service providers access to federal funding for response and recovery efforts.
- Enact processes and policies to avoid the implementation of the Baker Act, which results in the involuntary institutionalization and incarceration of low-income people and people with disabilities.⁵⁶
- Restore the number of Disability Integration Advisors sent out for each disaster to a minimum of 60.

Conclusion

Extreme weather risks and vulnerabilities⁵⁷ for people with disabilities are escalating in a rapidly changing climate.⁵⁸ Storms are becoming more powerful, heat waves are longer and hotter, and floods are more frequent and dangerous. Centering people with disabilities in all emergency preparedness, disaster response, and recovery efforts is not only a moral imperative—the changing climate demands it. To be truly inclusive of and responsive to the diverse needs of people with disabilities during disasters, federal, state, and local leaders must fundamentally reimagine their current preparedness and recovery framework, as well as their disability programming—from early childhood education to aging services. The hard lessons learned recently in Puerto Rico⁵⁹ and from the Northern California wildfires⁶⁰ demonstrate that when people with disabilities are not at the table, they are disproportionately harmed. Clearly, what’s at stake is the long-term health, well-being, and resilience of the disability community.

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