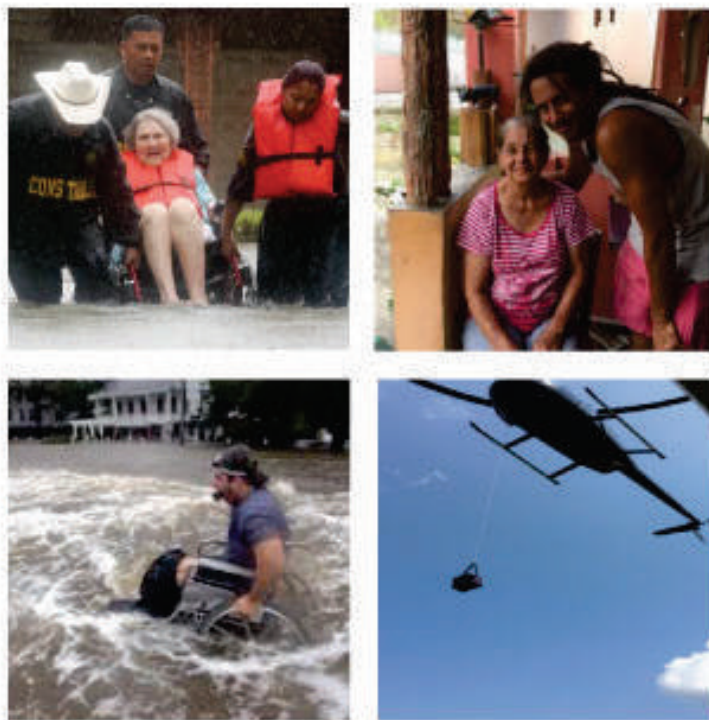




## Getting It Wrong: An Indictment with a Blueprint for Getting It Right

Disability Rights, Obligations and Responsibilities Before, During and After Disasters

Edition 1; May 2018



*Figure 1: A collage of four images: A) A woman using a wheelchair is assisted through heavy flooding; B) Two people smile for the camera during disaster recovery efforts; C) A man using a wheelchair maneuvers through heavy flooding; D) Supplies are dropped from a helicopter.*

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## Dedication

We dedicate this report to children and adults who have an equal right to participate in and benefit from publicly funded emergency preparedness and disaster response and recovery programs and services. It is especially dedicated to individuals who, despite this right, lost their health, independence and even their lives throughout the disasters of 2017 and 2018.

We also dedicate this report to disability advocates and allies across the country who continue to work in partnership to GET IT RIGHT.

## Acknowledgements

This After Action Report was the product of many hours of input from key informants and stakeholders who shared their first-hand observations, personal experience, insights and recommendations. Many were disaster survivors themselves, others were working on the ground in disaster impacted communities, and still others served in leadership roles with entities charged with various aspects of disaster response and relief.

Other invaluable information was drawn from the thousands of callers to the Hotline as well as the hundreds of stakeholders who participated in teleconferences and at the Department of Homeland Security Office for Civil Rights and Civil Liberties (DHS CRCL) listening session held in Houston, Texas. As of the date of publication of this report, additional listening sessions have been conducted by DHS CRCL in California and Florida, however the transcripts of these sessions are not yet available. Additional listening sessions are also scheduled for the US Virgin Islands and Puerto Rico, as well.

The After Action Report was made possible by the generous donations to Portlight Inclusive Disaster Strategies from disability community leaders and a broad spectrum of allies. **Portlight’s support to the Partnership for Inclusive Disaster Strategies, including funding for this report, has been invaluable.**

The Partnership extends its appreciation to all individuals who have contributed to this After Action Report.

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- Amber C. Christ, Senior Staff Attorney, Justice in Aging, Los Angeles, California
- Janet Collazo, Executive Director, Protection and Advocacy System Puerto Rico
- Teresa Favuzzi, past Executive Director, California Foundation for Independent Living Centers
- Lex Frieden, Professor of Biomedical Informatics, Professor of Rehabilitation, University of Texas, Health Science Center at Houston, Director, [Independent Living Research Utilization \(ILRU\)](#), Professor of Rehabilitation, Baylor College of Medicine, Houston, Texas
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- Todd Holloway, National Council on Independent Living
- Frederick Jefferson, Founder, Man II Man support group for fathers of children with autism
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- [Carol Salas Pagan, PsyD](#), Director, Puerto Rico UCEDD
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**Marcie Roth** is a national and global expert on whole community inclusive emergency preparedness and disaster response, recovery and mitigation. Her focus on disability inclusive emergency management began as an advisor to the White House on the rights of disaster survivors with disabilities in the immediate aftermath of the September 11, 2001 terrorist attacks. She is widely recognized as a strategic and transformative governmental and non-governmental leader with a 40-year record of success for advancing equal access, civil and human rights and inclusion initiatives, yielding promising practices and measurable outcomes benefitting the emergency management needs of individuals, families, organizations, businesses and communities.

Roth is the President of Inclusive Emergency Management Strategies LLC and CEO of the [Partnership for Inclusive Disaster Strategies](#), providing global disability rights leadership through a variety of contracted and collaborative projects committed to a shared mission of disability rights, equal access and full inclusion for the whole community before, during and after disasters. Her primary focus is on building a global collaborative of community leaders and emergency management

stakeholders working together to prepare for emergencies and recover from disasters. Her expertise includes providing tools, resources, training and technical assistance to prepare for, respond to, recover from and mitigate all hazards, optimizing universal design and accessibility as a critical life-saving and life-sustaining foundation for building and sustaining community-wide resilience.

Ms. Roth served a presidential appointment to the U.S Department of Homeland Security Federal Emergency Management Agency (FEMA) from 2009 to 2017, serving as Senior Advisor to the Administrator and congressionally mandated Disability Coordinator for the agency. While at FEMA, she established the Office of Disability Integration and Coordination (ODIC), serving as its Director. Under her leadership, ODIC led national transformation towards integrating the access and functional needs of the whole community throughout emergency preparedness and disaster response, recovery and mitigation.

Ms. Roth was charged with establishing and building FEMA's Disability Integration Cadre to ultimately include 285 deployable disability integration specialists while managing over 400 disaster deployments, frequently serving as lead advisor to the presidentially appointed Federal Coordinating Officer and collaborating with affected state and local emergency management leadership and stakeholder groups. She also led the work of the Department of Homeland Security Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, established through a presidential executive order in 2004 and she has represented the U.S. government internationally as an expert on whole community inclusive global disaster risk reduction since 2012. Roth is recognized as a global authority on disability inclusive disaster risk reduction serving as a leader throughout the development and implementation of the post-2015 Global Development Agenda and the Sendai Framework for Disaster Risk Reduction 2015-2030.

Ms. Roth was 2017 Hilton Foundation Fellow, addressing the disproportionate impact of climate change on individuals with disabilities and their communities. She recently completed the development of a comprehensive eLearning course on [Disability Inclusive Disaster Risk Reduction](#) for the United Nations Economic and Social Commission for Asia and the Pacific, and her most recent publication, [A Resilient Community is One That Includes and Protects Everyone](#), was published in the February 2017 issue of the Journal, "Bulletin of the Atomic Scientists".

In addition to her original studies in Special Education, Ms. Roth is a Harvard University Kennedy School of Government Senior Executive Fellow with a degree in Public Safety Administration from the University of Maryland University College. In addition to advocating for her own disability accommodations in the healthcare system, she has navigated complex disability rights issues as a parent. Her early disability rights career began in Connecticut, and she relocated to the Washington DC area immediately following the passage of the Americans with Disabilities Act.

[June Isaacson Kailes](#) has a Disability Policy Consulting practice and is the Associate Director of the [Harris Family Center for Disability and Health Policy](#) at Western University of Health Sciences, Pomona, California. June's consulting and publications focus on building disability actionable competencies in the worlds of health care and emergency management to ensure people with disabilities and others with access and functional needs are integrated and included in service delivery processes, procedures, protocols, policies and training.

June is one of just a handful of people with disabilities who focused on disability related emergency issues decades before Hurricane Katrina. As far back as the 1970s and 80s, June documented the deep and dramatic lack of equal and inclusionary emergency services for people with disabilities.

June works internationally, as well as with local, state, and federal governments, and with community-



based organizations. Her breadth and depth of experience in access and functional needs and her work as a writer, trainer, researcher, policy analyst, advocate, subject matter expert and expert witness is widely known and respected. She has the unique ability to blend and bridge two worlds: disability-lived experiences and emergency management experience.

She has worked nationally with FEMA, the Centers for Disease Control, Department of Homeland Security, and Health and Human Services on policy, planning and training issues.

In the emergency management world, June is a pioneer, leader and innovator. Examples of her impact and influence include: researching and writing "[Southern California Wildfires After Action Report](#);" developing inclusive emergency management plans that close service gaps, prevent civil rights violations, and emphasize and incorporate standard operating procedures, field operation guides, just-in-time checklists, and exercises; offering training that replaces the ambiguous disability etiquette, sensitivity and awareness, with focusing on maximizing impact, actionable disability practice competencies and measurable skill sets needed to provide equally effective services; conceiving, promoting, and moving the emergency management world from the vague "special needs" focus to operationalizing an access and [functional needs approach](#) to planning and response and fostering a clearer understanding of who is included in the large numbers and diversity of disability; originating and working with the State of California to adopt and implement the use of Functional Assessment Service Teams (FAST); and documenting the critical need to re-evaluating the use of [emergency registries](#) in order to avoid [symbolic planning](#).

[Melissa Marshall J.D.](#) has had a lifelong career in disability rights. She is the Principal of Melissa Marshall Disability Consulting, LLC. Her most recent efforts have focused on the legal rights of children and adults with disabilities before, during and after disasters. Throughout the 2017-2018 disasters, Ms. Marshall has managed the Partnership for Inclusive Disaster Strategies Hotline and has provided the Partnership with both policy expertise and operations coordination.

She was the founding Executive Director of the Disabilities Network of Eastern Connecticut, a Center for Independent Living; the first director of the Connecticut Protection and Advocacy for Persons with Mental Illness (PAIMI) national program;. She also served as the Executive Director of the Connecticut Business Leadership Network, a coalition of corporations committed to maximizing employment for people with disabilities, and as Executive Director of Advocacy Unlimited, a peer-led organization which educates people with mental health conditions in forensic institutions and in the community about their legal rights.

Ms. Marshall has promoted compliance with the Americans with Disabilities Act since its enactment. This has included providing intensive ADA and Rehabilitation Act training to corporations, non-profit organizations, college and universities. She assists state agencies, municipalities, school districts and state colleges and universities in conducting ADA Self-Evaluations and Transition Plans. She has worked with Senator Richard Blumenthal in his capacity as Connecticut Attorney General on ADA-related Supreme Court amicus briefs.

Her expertise includes developing and presenting extensive training curricula to mitigate disability bias to corporations, non-profit organizations, college and universities and public schools. She is the author of *Getting It: Persuading Organizations and Individuals to be Comfortable with People with Disabilities*, published by People with Disabilities Press.

Ms. Marshall received her Bachelor's degree from Hampshire College where she is thought to be the first person to major in Disability Studies. She graduated from the University of Connecticut School of Law and is admitted to the Connecticut Bar. She is in the process of writing a second book on the

history of the disability rights movement through the lens of her life and career experience as a person with a disability.

## Executive Summary

This After Action Report is an unvarnished account of the devastation from poor planning and failed execution throughout the 2017- 2018 disasters as reported by people with disabilities and allies with first-hand knowledge. The report also documents promising and good practices that can be refined, customized and replicated. Most importantly, it contains recommendations for “getting it right” before the next disasters strike.

Equal access to disaster services has been promised to children and adults with disabilities since passage of the Rehabilitation Act of 1973, however the promise remains unfulfilled. This is despite extensive legal protection; despite countless “lessons learned” documents, produced over thirteen years that have elapsed since the nation’s failed response to hurricane Katrina; and, despite claims that actionable emergency plans exist, children and adults with disabilities were consistently denied equal access to disaster-related programs and services throughout the catastrophic disasters of 2017 and 2018.

These equal access failures extended to all aspects of disaster response and recovery including:

- Alerts, warnings and notification
- Actionable information and instructions
- Evacuation
- Sheltering in the most integrated setting
- Health maintenance and acute medical care
- life-saving and life-sustaining goods and services
- Food and potable water
- Registering for disaster services including FEMA and state/territory emergency programs
- Temporary and permanent housing
- Return to home, school, work and community life
- Disaster recovery and mitigation investments

The federal government failed people with disabilities in the disasters. This lack of commitment to the civil and human rights of disaster survivors with disabilities was repeatedly demonstrated. The US Department of Health and Human Services (HHS) is the lead for the nation’s emergency health and medical response. Yet, supplemental oxygen was denied to thousands of disaster survivors living in the community in Puerto Rico. When HHS was repeatedly pressed to address this urgent need, they were unable to identify the accountable senior executive responsible for the solution, leaving many disaster survivors without access to oxygen. This was further exacerbated when the USNS Comfort was identified as a potential provider, however oxygen was not supplied. Further, a protocol for patient admission and care was never communicated to medical providers and disaster survivors needing the urgent care that deployment of the Comfort promised.

Despite FEMA’s long standing commitment to whole community inclusion, they failed to engage and include disability stakeholder organizations with a wealth of experience and resources that directly benefit disaster survivors and communities. This exclusion resulted in siloed efforts, which is the antithesis of the intent of the National Preparedness System and the priorities of the US Department



of Homeland Security and FEMA. The impact of government-centric actions diminished valuable resources that could have been exponentially optimized through public-private partnership.

Despite massive systemic failures, it is vital to acknowledge the many dedicated FEMA, HHS and other federal government employees who went to extraordinary lengths. These exemplary public servants committed to support equal access to disaster-related programs and services even when they were discouraged by their leaders. The members of the Partnership for Inclusive Disaster Strategies and disability leaders across the country recognize their dedication and commend their service.

Local, state and territory governments also failed people with disabilities. They failed to plan for providing accommodations to support their autonomy, health, independence and safety in evacuation and integrated community sheltering. As a result, disaster survivors with disabilities but without acute medical needs were repeatedly diverted to hospitals and institutions for the convenience of the emergency personnel, public health providers and shelter planners who had failed to adequately plan for their accommodation needs.

Failure was also starkly demonstrated when states activated the Disaster Supplemental Assistance Program (DSNAP), but delayed activation of this life-sustaining resource in areas known to have the highest level of poverty and disability.

There were state, territory and municipal employees who worked tirelessly to provide equal access to disaster survivors with disabilities. Municipal offices on disability issues and disability commissions such as the Houston Office for People with Disabilities and the Houston Commission on Disabilities distinguished themselves in their diligent effort to ensure that adults and children with disabilities received equal access to disaster-related services. The Florida, Texas and California Governor's offices provided a knowledgeable representative to collaborate and problem solve with stakeholder organizations.

Predictably, years of inadequate planning have devastated communities affected by disasters. This quickly reached a crescendo in Texas, followed by Florida, the US Virgin Islands, Puerto Rico and California. Among the most egregious failures was the denial of equal access to disaster programs and services for individuals with legal protection from discrimination. Many of the generalized failures, such as long-term interruption of power, poorly executed government services, inadequate housing solutions, and continual delays driven by political agendas had a massively disproportionate impact on children and adults with disabilities. They were separated from their loved ones and their community, became ill, were unnecessarily institutionalized, and some lost their lives.

As devastating as the effects of inadequate planning and execution have been for children and adults with disabilities, there were many emergent promising and good practices observed, with potential for refinement, customization and replication to benefit other communities.

The most significant drivers of real solutions and positive outcomes were the powerful voices and actions of disability leaders. Their relentless commitment to collaboration with other stakeholders was often the only hope for saving lives and preserving civil rights in the midst of chaos. This teamwork began as soon as the devastation of hurricane Harvey became apparent and included convening hourly and daily teleconferences among an ever-widening network of stakeholders. A hotline was immediately established, publicized and staffed with knowledgeable disability experts from across the country available around the clock to assist with life-saving and life-sustaining immediate needs of disaster impacted individuals with disabilities. Processes for obtaining, matching, shipping and distributing disability-related supplies, medical equipment and assistive devices were refined and

technological solutions were established to optimize limited resources. Fortunately, private donations made it possible to support local disability organizations in disaster-impacted communities as these organizations are always the experts on the needs of individuals with disabilities in their community. When these organizations were unable to function as a result of the disaster it was the collaboration of disability partners and the leadership of Portlight Inclusive Disaster Strategies that deployed disability experts, including native language speakers, into communities in need of urgent help for basic survival and to rebuild organizational capacity.

The civil rights of children and adults should never depend on the “charity” model of disaster relief. However, in the absence of solid government actions to comply with its unwavering obligations, the generosity of individuals and organizations was the only recourse for filling the gaps created by the government’s failures.

This After Action Report was the culmination of a five-month process ending in publication in conjunction with the 2018 Getting it Right Disability Inclusive Disaster Strategies Conference in May, 2018. However, the rest of the story is still being written.

As of the date of publication of this After Action Report, many families are still in temporary shelters without any road map for their future. Thousands of children and adults are still without power, families are displaced and countless individuals who formerly lived in the community are now languishing in nursing homes and other institutions. People who experienced homelessness before the disasters and others who were on the verge of homelessness are all trapped in a web of service eligibility exclusions. Disaster survivors with disabilities who are undocumented continue to experience the very worst circumstances because of ongoing violations of their basic human rights. Some children with disabilities are not back to school so their parents have not been able to return to work. These and other workers, many of whom have had to relocate, have contributed to an interruption in vital disability, health care, education and other community services. This employment gap is further exacerbating the disproportionate impact of the disasters on individuals with disabilities and their families. FEMA has been well aware of the deficiencies in their registration process for years. Despite this, the failure to provide an opportunity for registrants with disabilities to receive accommodations remains. Eligibility denial and a convoluted appeals process compound the barriers to equal access to FEMA assistance. Stakeholder efforts to assist with improvements have been further stymied by a lack of data transparency which further siloes any effort for collaborative problem solving.

Billions of dollars in disaster relief funding have been appropriated. Each of these federal dollars must meet equal access requirements for individuals with disabilities and disaster recovering communities. These funds must also be invested in compliant mitigation, planning and readiness initiatives. Disasters are devastating for communities, recovery from them provides an opportunity to plan for and sustain the kind of whole community resilience that is inclusive of children and adults with disabilities and many others who currently have or may acquire access and functional needs in the future. Without whole community inclusion, true resilience will remain elusive.

This After Action Report represents a snapshot in time. Resource limitations prevented the authors from fully examining the still emerging failures orchestrated by FEMA, the American Red Cross, and the US Department of Health and Human Services (HHS) Office of the Assistant Secretary for Preparedness and Response and the HHS Administration for Community Living.

In particular, next steps must include an in-depth analysis of the consequential shortfalls observed throughout the activation of Emergency Support Function (ESF) #8 – Public Health and Medical Services and the resulting impact on individuals with disabilities and communities. Additionally,

potential gaps and missteps in the use of federal funds for conducting and assisting in the delivery of disaster services must be reviewed for compliance.

As recovery from the disasters of 2017-2018 continues, much more work lies ahead. The outcomes for children and adults with disabilities and disaster-impacted communities continue to unfold and these must also be fully analyzed.

The Partnership for Inclusive Disaster Strategies plans to publish a second edition of this report to further examine the current circumstances of disaster survivors with disabilities and the process of their recovery one year later.

## Recommendations by Section

### Part II: Building and Sustaining Effective Community Partnerships

- Community Partnership Competencies: [Recommendations 1.1 through 1.10](#)

### Part IV Findings

- Deficiencies in equal access in areas critical to disaster survival and community resilience: [Recommendations 1.1 through 1.3](#)
- Equal Access to Department of Homeland Security (DHS) Programs and Services: [Recommendations 2.4 through 2.25](#)
- Equal Access to Programs and Services of the Department of Health and Human Services (HHS) : [Recommendations 3.1 through 3.3](#)
- Maintaining Health: [Recommendations 3.4 through 3.9](#)
- Meeting the Durable Medical Equipment Needs of People with Disabilities: [Recommendations 3.10 through 3.14](#)
- Health Plans: [Recommendations 3.15 through 3.25](#)
- Emergency Plans for Long Term Care Facilities: [Recommendations 3.26 through 3.30](#)
- Unnecessary Institutionalization: [Recommendations 4.1 through 4.11](#)
- Equal Access to Effective Communication: [Recommendations 5.1 through 5.11](#)
- Equal Access throughout Planning and Execution: [Recommendations 6.1 through 6.5](#)
- Emergency Registries: [Recommendations 7.1 through 7.5](#)
- Equal Access to Evacuation Services: [Recommendations 8.1 through 8.6](#)
- Sheltering: [Recommendations 9.1 through 9.6](#)
- Disaster Recovery Centers (DRCs) and Remote Registration for FEMA Assistance: [Recommendations 10.1 through 10.5](#)
- Food and Water Distribution: [Recommendation 11.1](#)
- Distribution of goods: [Recommendations 12.1 through 12.3](#)
- Housing: [Recommendations 13.1 through 13.3](#)
- Intersectionality and equal access to disaster programs and services: [Recommendations 14.1 through 14.3](#)
- Equal Access to Education for Students with Disabilities: [Recommendations 15.1 through 15.4](#)



*Figure 2: A person and a wheelchair are lifted into a helicopter*

## **Part I: Introduction**

## ***Part I - Section 1: Purpose of this Report***

The purpose of this After Action Report is to capture the broad experience of children and adults with disabilities across a vast swath of the country who were devastated by the federally declared disasters from August 2017 through January 2018. This report is an indictment of catastrophic failures and an unabashed call to action. This report documents the experience of disability advocates and allies who have come together, in partnership, to demand accountability from federal, tribal, state and territorial governments to comply with and enforce civil rights laws ensuring that children and adults with disabilities have equal access to emergency programs and services before, during and after future disasters.

Despite lessons that were allegedly learned and addressed after hurricanes Katrina, Sandy and other disasters; children and adults with disabilities and older adults were once again disproportionately impacted by the disasters of the late summer and fall of 2017 and early 2018. This impact was in large part because of a failure to plan for and provide equal access to programs and services as mandated under the Rehabilitation Act of 1973, [29 U.S.C. § 701](#) et seq (Rehabilitation Act) and the Americans with Disabilities Act of 1990 as amended 42 U.S.C. § 12101, et seq (ADA).

Hurricanes Harvey, Irma and Maria and the California wildfires once again left people with disabilities at increased risk of unnecessary institutionalization and without equal access to disaster programs and services. Because of this lack of parity, modification and accommodations, the Partnership for Inclusive Disaster Strategies determined that an After Action Report was needed. The report captures the experiences of individuals with disabilities, disability service providers, advocacy groups, public health and public safety providers, other community organizations and a broad array of stakeholders. Recommendations are delineated for improvements throughout the emergency and disaster cycle, optimizing strategies, solutions and outcomes. This is imperative to whole community readiness and resilience and is integral to addressing the deprivation of the civil rights of children and adults with disabilities before, during and after disasters.

The repeated assaults of the catastrophic disasters in 2017 and 2018 validated the suspicions of disability inclusive emergency management experts that there would be a significant disproportionate impact on people with disabilities in future disasters. Gaps and shortfalls were obvious when the profound lack of equal and inclusionary services throughout emergency preparedness initiatives across the nation became evident in response and recovery. Disability experts understand that emergencies degrade and/or break critical personal support systems and tools for community living. These include personal assistance providers, equipment, assistive technology, supplies, and customized environments that typically work, though often precariously. When supports are disrupted or broken they exacerbate impacts of disasters on people with disabilities. Despite this, many government and non-government After Action Reports (AARs) allude to disability issues through a medical lens or are entirely silent. This report spotlights issues needing immediate attention and provides specific recommendations for strengthening whole community outcomes inclusive of people with disabilities and others with access and functional needs.

In disasters, people with disabilities continue to lose their health, their independence and sometimes their lives. In fact, [according to the United Nations<sup>1</sup>, people with disabilities and older adults are two to four times more likely to be injured or lose their lives in a disaster](#). In spite of decades of data

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<sup>1</sup> [UN Disability-inclusive Humanitarian Action](#)

acquisition, lessons observed, and information documented regarding predictable needs, this knowledge has still not been effectively integrated into plans, policies, procedures, training, and exercises. The 2017/2018 disasters were no exception. Only when these shortfalls are consistently recognized, applied, and their results measured, can we claim them as lessons learned.

It is no surprise that the disproportionate impact of the recent disasters on people with disabilities were not new or unforeseeable. Recommendations include suggestions for changes to policy and practices so that people with disabilities have equal access as mandated under federal laws including; the Rehabilitation Act , the Americans with Disabilities Act, the Individuals with Disabilities Education Act and other statutes. This report also documents promising and good practices that should be replicated in planning for future emergencies and disasters.

## ***Audience***

The anticipated audience includes federal, tribal, state, territorial and local governments, policy makers and emergency planners, non-governmental organizations, community and advocacy groups, public health and public safety, first responders, health plans, long term care facilities and older adult and disability service community providers and advocates public/private partnerships, business and industry and faith- based groups.

## **Portlight Strategies and the Partnership for Inclusive Disaster Strategies**

Portlight Strategies and the Partnership for Inclusive Disaster Strategies (the Partnership) share a mission to provide advocacy, community engagement, disaster services in support of disability community leaders, and to foster universally designed and inclusive emergency planning, disaster response, relief, recovery and mitigation for disaster survivors with all types of access and functional needs. Our core values of equal access, inclusion and independence continually guide our work.

### **The priority focus of Portlight Strategies is:**

- Disaster response and relief

### **The priorities of the Partnership include:**

- Community engagement and organizing
- Advocacy and public policy leadership
- Training and education
- Technical assistance before, during and after disasters.

## **Partnership for Inclusive Disaster Strategies Members**

### **National Members**

- AAPD- American Association of People with Disabilities

- ADAPT
- ADA Legacy Project
- APRIL- Association of Programs for Rural Independent Living
- AUCD - Association of University Centers on Disabilities
- The Disability Rights Center
- DREDF- Disability Rights Education Defense Fund
- DAP- Disaster Accountability Project
- General Honore LLC
- Harris Family Center for Disability and Health Policy
- ILRU-Independent Living Resource Utilization
- Inclusive Emergency Management Strategies LLC
- Institute on Disabilities at Temple University
- NAD- National Association of the Deaf
- NCIL- National Council on Independent Living
- NCEHS- National Center for Environmental Health Strategies
- NDRN- National Disability Rights Network
- Niagara University
- Pacific ADA Center
- RESNA- Rehabilitation Engineering and Assistive Technology Society of North America
- Road to Freedom Bus Tour
- Shepherd Center
- SMG- Solutions Marketing Group
- UMASS- School for Social Inclusion and Global Development
- Western University of Health Sciences
- WID- World Institute on Disability

### **State Members**

- Arizona State Independent Living Council
- California Foundation for Independent Living Centers
- Connecticut State Independent Living Council
- Idaho State Independent Living Council
- Trach Mommas of Louisiana
- New York State Independent Living Council
- Oregon State Independent Living Council
- Washington State Independent Living Council
- West Virginia State Independent Living Council
- WI Council on Physical Disabilities Emergency Preparedness Committee

### **Community Members**

- The Ability Center of Greater Toledo, OH
- ACI-Alliance Center for Independence, NJ
- Appalachian Center for Independent Living, WV
- All About You Homecare, NY
- Center for Disability Rights, NY
- Center for Independence, WA
- CIDNY- Center for Independence of the Disabled, NY



- City of Decatur Fire and Rescue, GA
- Concepts of Independence, NY
- Disability Action Center, Moscow, ID
- Disability Resource Center, Pendleton, OR
- Eden I&R, Hayward, CA
- ILCNSCA- Independent Living Center of the North Shore and Cape Ann Inc., MA
- LIFE, Inc.- Living Independently for Everyone, IA
- LIFFT- Living Independently for Today and Tomorrow, MT
- L.I. Center for Independent Living, Inc, NY
- Progressive Independence, OK
- Regional Center for Independent Living, NY
- Resources for Independence - New Orleans & Baton Rouge, LA
- SKIL Resource Center, KS
- Westchester Disabled on the Move, NY
- White Apple Institute

## **Overview of the August 2017 through January 2018 Disaster Response**

When hurricane Harvey made landfall in Texas in August, 2017, the Partnership became aware of the immediate needs of individuals with disabilities and older adults and their families who needed emergency rescue and actionable information about immediate life-saving and life-sustaining steps.

Additionally, The Partnership recognized the need to engage and support stakeholders who were invested in immediate strategies for solutions to complex circumstances to achieve positive outcomes for disaster survivors with disabilities.

This required that disability advocacy groups, public health, first responders, community leaders and local, state, tribal, territorial and federal stakeholders had a consistent forum for collectively identifying urgent needs and optimizing resources to solve problems. It was against this backdrop that Portlight and the Partnership implemented strategies for addressing individual and stakeholder needs by establishing a Hotline, regular local and national stakeholders calls and an immediate resource for the equipment and supplies disaster survivors need to maintain health safety and independence.

### ***Hotline***

The Hotline was initially established by The Partnership as a real-time resource for addressing the urgent and immediate needs of disaster survivors. The Hotline began responding to calls on August 26, less than 24 hours after hurricane Harvey made landfall in Texas. The Partnership and the Portlight disaster response and relief initiative quickly expanded response capabilities by adding 20 expert volunteers to meet the surge in calls. Early needs focused on rescue, evacuation and the immediate sheltering of children and adults with disabilities.

Shortly, additional requests followed for transportation, temporary housing, food and water, power interruption related support, sign language interpreters, language translators, medical treatment, including dialysis and replacement of lost and damaged medical supplies, equipment and medication.

The team of expert volunteers worked around the clock and represented many areas of the country. This included an organization of and for parents of children with tracheostomies and complex medical and disability related needs who served as Hotline experts in procuring and distributing consumable medical supplies and equipment to disaster survivors with disabilities. Other volunteers came from Centers for Independent Living who provided staff with disaster response and independent living expertise. This included providing Spanish speaking and deaf staff for direct communication including via video phone.

Portlight provided resources to bring the Cajun Navy and their rescue capabilities onto the team to respond to the many calls the Hotline was receiving for water rescue of children and adults with disabilities. In addition to water rescue, the Cajun Navy also assisted in getting life-saving medication from one child who had a few extra doses in San Antonio to a 9-year-old boy with epilepsy whose family was cut off from all ground transportation by the flooding in the Lumberton, TX area. They also air dropped specialty formula in the middle of the night that was desperately needed for several infants in a flood impacted hospital neonatal intensive care unit in Beaumont, TX. Then, they air dropped life-saving supplies to several children at home without the G-tube formula they needed. The value and contributions of the Partnership were well demonstrated by this collaboration between disability organizations and on-the-ground volunteer rescuers and was integral to countless other life-saving efforts.

As of the publication of this report, the Hotline has responded to over 3,200 calls. The Hotline team continues to respond to callers from Texas, Florida, Puerto Rico, the US Virgin Islands, California and other disaster impacted areas. Outcomes for Hotline calls have been continually monitored with caller requests resolved more than 90% of the time from August 25, 2017 until the publication of this report.

## ***Stakeholder Calls***

All disasters are local and the experts on meeting the needs of disaster survivors with disabilities are local disability leaders. The Partnership is committed to supporting these local leaders as the primary stakeholders in identifying barriers to equal access, developing strategies, implementing solutions and assessing results.

Given the imperative for maintaining the role and voice of local disability leadership, The Partnership supports the establishment of working groups that meet via teleconference on a daily basis to bring local, state, tribal, territorial and national stakeholders together.

The Partnership convened the first national stakeholder teleconference less than 24 hours after hurricane Harvey made landfall in Texas. As more disasters struck, stakeholder participation expanded, with hundreds of participants joining the calls.

As hurricane and flood warnings, evacuation orders, and emergency declarations followed in Louisiana, the US Virgin Islands, Mississippi, Florida, Georgia, South Carolina, North Carolina, Virginia, and Puerto Rico, additional state and territory teleconferences were added. Later, as the California wildfire alerts were issued, the Partnership expanded the daily teleconferences further to support California disability leaders to establish their stakeholder teleconferences. In every case, the Partnership moved out of the role of convener as soon as local leadership regained capacity (staffing, power and connectivity) to lead.

By January, 2018 disaster specific teleconferences were reduced and a weekly national call became a central meeting place for all stakeholders. These meetings became a forum for sharing issues, promising practices and problem solving strategies as well as new policy initiatives for recovery, mitigation, and readiness and whole community inclusive resilience in advance of the next disaster.

## **Methodology**

The Partnership has utilized methodology comparable to that which was used in Kailes 2008 AAR.

Findings are derived from an analysis of information and data collected from multiple differentiated sources. These included:

- Key informant interviews conducted in a semi-structured method, allowing interviewees to respond conversationally to open-ended questions. Interviews were 10 to 75 minutes in length and conducted by phone from January through March 2018, see Acknowledgments;
- Calls to the Hotline from disaster survivors and family members and associates of disaster survivors;
- Transcript of DHS Office for Civil Rights and Civil Liberties Listening session hosted by the Houston Office for People with Disabilities and the Houston Mayor's Commission on Disabilities;
- Letter from the members of the House Committee on Homeland Security to Acting HHS Secretary Elaine Duke and FEMA Administrator Brock Long (Appendix A);
- Letter from Cameron Quinn, Officer for Civil Rights and Civil Liberties, Department of Homeland Security (DHS), Regis Phelan, Acting Director Office of Equal Rights (FEMA) and Linda Mastandrea, Director, Office of Disability Integration and Coordination (FEMA) to Wes Maul, Florida Division of Emergency Management expressing concerns that people with disabilities were not receiving equal access in the disaster (Appendix B);
- Reports on hurricane Harvey and Irma from the National Council on Independent Living (NCIL), (Appendices C and D);
- [Testimony from Paul Timmons, President Portlight Inclusive Disaster Strategies, Inc. at September 20, 2017 hearing of United States Senate Special Committee on Aging on "Disaster Preparedness and Response: The Special Needs of Older Americans"](#) (Appendix E);
- March 2018 Statement from National Council on Independent Living (NCIL) to the American Red Cross;
- April 2018 Letter from National Council on Disability to FEMA (Appendix F);
- Stakeholder teleconferences;
- Daily reports from Portlight and Partnership deployed teams in Puerto Rico and the US Virgin islands as well as from local partners; and

- Relevant websites, social media posts, media accounts and emails generated during and after these events.

## ***The Disasters***

In the span of just over 5 weeks, between August 25 and October 8, 2017, US states and territories prepared for five hurricanes and then responded to massive destruction from three of them.

Hurricane Harvey made landfall as a Category 4, later impacting the Louisiana coastline, parts of Mississippi, and Alabama, bringing catastrophic flooding. Hurricane Irma followed on September 6 as a Category 5 hurricane over the US Virgin Islands. Irma went on to impact Puerto Rico and then made landfall twice in Florida, first as a Category 4 in the Florida Keys and then as a Category 3 on the Florida Gulf Coast. Six million Floridians were under a mandatory evacuation order with the hurricane sweeping across the state, and causing massive damage throughout. Several other states issued emergency declarations in advance of the storm. Irma’s impact was subsequently felt in Georgia, Tennessee and South Carolina.

Concurrent to Irma, hurricane Jose posed a threat of landfall from September 6 to September 25.

On September 20, hurricane Maria made landfall as a strong Category 4 hurricane. Worldwide, it was the most intense tropical cyclone of 2017 and its damage across Puerto Rico was catastrophic.

On October 8, hurricane Nate made landfall twice as a Category 1 hurricane in Mississippi and Louisiana. This was the 4th hurricane to make landfall in 39 days.

While the impacted states and territories in the eastern part of the US were responding to the immediate needs of hurricane survivors, California was impacted by a series of wildfires with catastrophic impact beginning on October 8, in the northern part of the state, followed by additional devastating fires throughout December and January of 2018. The damage from the fires, followed by heavy rain, precipitated massive and deadly mudslides in January, 2018. The impact of the wildfires made this the largest and most destructive fire season in California history.

“The ability for a community to rebound after a disaster is more dependent on the cohesion and sense of interconnectedness that is shared throughout that community, more so than the infrastructure that is in place.”

Predictably, like previous catastrophic events, the disasters of 2017 and 2018 had a disproportionate impact on people with disabilities. Once again, despite the lessons observed in previous disasters, children and adults with disabilities did not have equal access to disaster programs and services.

“The ability for a community to rebound after a disaster is more dependent on the cohesion and sense of interconnectedness that is shared throughout that community, more so than the infrastructure that is in place.” (Source: [domesticpreparedness.com](http://domesticpreparedness.com))

The approach used in all of the recent disasters by disability advocates and service providers is a “join us - we have activated” approach that flips the old paradigm of waiting to be invited or asking permission to join the emergency management response table. Disability community leaders are now inviting emergency management to the table to participate in true whole community inclusive response and recovery. When these emergency response invitations are not accepted, everybody loses.

“If you want to solve a big problem, you need to go from taking credit, to sharing credit, to multiplying credit. The systems that all work, multiply credit. Multiplying credit is just another way of making everyone in the system feel ownership. And the byproduct is both resilience and propulsion.”

— Thomas L. Friedman, [Thank You for Being Late: An Optimist's Guide to Thriving in the Age of Accelerations](#)





*Figure 3: Seven people pose for a group photo during disaster relief efforts.*

## **Part II: Building and Sustaining Effective Community Partnerships**

Disability community led partnerships were established, convened and expanded throughout the Harvey/Irma/Maria Hurricanes and the California wildfire and mudslide responses in 2017/2018. These replicated a promising model of disability inclusive community engagement effectively launched in previous events such as the California wildfires in 2007, Alabama and Missouri tornadoes in 2011, hurricane Sandy in New York, New Jersey and Connecticut in 2012 and 2013, Louisiana floods in 2015 and 2016, West Virginia after 2016 floods, and many more.

In California, Functional Assessment Service Teams (FASTs) were also deployed in 2017, a model first established in 2007 to integrate the expertise of the disability services into shelter-focused emergency services. The vision entailed “doing better and working smarter together” through building partnerships with disability service organizations community based organizations government: local (towns, cities, counties and states) and Voluntary Organizations Active in Disasters (VOAD) members such as the American Red Cross.

These teams were to be inclusive of community disability services, not just those that are “for and about” people with disabilities, but most importantly those who are “of, by and with” people with disabilities.

In each disaster included in this After Action Report, expanded partnerships were encouraged, supported, and facilitated by two national disability organizations: the Partnership for Inclusive Disaster Strategies and Portlight Inclusive Disaster Strategies. These national organizations have a shared mission to support disability inclusive community engagement, immediate and urgent disaster response and relief, provide resources in support of local disability community leaders, and foster universally designed and inclusive emergency planning, disaster response, relief, recovery and mitigation for disaster survivors with all types of access and functional needs. Twenty-five national disability organizations worked together with the Partnership daily to support local disability organizations and to identify and address the immediate and unmet needs of thousands of disaster survivors with disabilities and others with access and functional needs.

These national stakeholder organizations included:

- ADA National Network
- ADAPT
- Association of Programs for Rural Independent Living
- Association of University Centers on Disabilities
- BCFS
- Board Resource Center
- Coalition for Inclusive Emergency Preparedness
- Disability Rights Advocates
- Disability Rights Education and Defense Fund
- Disaster Accountability Project
- Friends of Disabled Adults and Children
- Harris Family Center for Disability and Health Policy at Western University of Health Sciences
- Independent Living Research Utilization
- National Association of the Deaf
- National Council on Independent Living
- National Disability Rights Network
- National Low Income Housing Coalition
- National Association of Councils on Developmental Disabilities
- Paralyzed Veterans of America



- Partnership for Inclusive Disaster Strategies
- Pass It On Center
- Portlight Inclusive Disaster Strategies
- Save the Children
- The American Association of People with Disabilities
- Trach Mommas
- United States Association for Augmentative and Alternative Communication
- World Institute on Disability

## **Stakeholder Engagement Process throughout Disaster Operations**

In anticipation or upon first notice of a disaster, the Partnership and Portlight reach out to local disability leaders in the potentially affected areas. When those local leaders can initiate collaborative information sharing and disaster operations meetings, the Partnership and Portlight support their efforts with technical assistance and resources. When local leadership capabilities are overwhelmed or unavailable, the Partnership and Portlight will initiate collaboration, bringing together as many stakeholders as can be identified and reached.

The Partnership takes a relationship-based approach to organizational management using frequent and regularly scheduled teleconference meetings. These meetings focus on collaborative tactical planning, including anticipating and solving problems. The strong interpersonal relationships and friendships among Partnership members are augmented by shared values, a culture of deep mutual respect, and similar organizational missions focused on increasing equity and improving quality of life for people with disabilities and their communities. Many individual representatives of the organizations that comprise the most active Partnership members are themselves people with disabilities, meaning that in addition to their unique qualifications as expert disability inclusive community representatives, members share a flexibility, persistence and commitment to finding creative solutions that often develops in response to the lived disability experience. This effective collaboration approach has yielded impressive outcomes for disaster survivors with disabilities impacted by hurricanes Harvey, Irma, Maria and the California wildfires and mudslides.

In addition to strong internal collaboration, the Partnership collaborates with diverse stakeholders, some of whom have never worked together before, including local, state, tribal, territorial and federal emergency management, public health and public safety agencies, grassroots advocacy organizations, disability, aging, faith-based and community organizations, National Guard, business and industry representatives, elected officials and other entities. Setting and maintaining a tone of welcoming and shared commitment to the local community is at the heart of effective partnerships. Concurrent to this is a consistent and unwavering focus on achieving and sustaining equal access and full inclusion for children and adults with disabilities and others who also have access and functional needs before, during and after disasters.

In Houston, daily coordination calls were organized less than 48 hours after Hurricane Harvey made landfall, led by Maria Town, Director of the Houston Mayor's Office for People with Disabilities. The Partnership and Portlight provided logistical support and FEMA offered accessible teleconferencing resources. Additional daily coordination calls were established or supported by Partnership leaders in Louisiana, Alabama, Mississippi, Florida, Georgia and South Carolina in anticipation of and response to hurricanes Irma, Jose, Maria and Nate. Establishing contact proved to be impossible in the US Virgin Islands and Puerto Rico, so Portlight deployed disability leadership teams to both islands. These teams located local disability organization leaders and began to address the immediate life-saving and life-sustaining needs of children and adults with disabilities on all of the impacted islands.

At the core of these efforts is a firm commitment to support local disability leadership. Providing local disability leaders with access to adequate support and resources before, during and after disasters is vital to whole community resilience.

Community Partnerships were enhanced during teleconference meetings as participants shared information, situational awareness and problem-solving strategies. The roles of participants included:

- Supporting disability community service providers and advocates in assuming leadership roles
- Addressing systemic service delivery problems
- Filling service gaps by mobilizing and optimizing resources
- Preventing duplication of services
- Situational awareness and de-conflicting reports
- Identifying civil rights violations and providing or pursuing immediate solutions to fix these situations. This can entail applying policies processes, procedures, and protocols that make real and usable the civil right to physical, equipment, programmatic and communication access.
- Preventing and diverting inappropriate admissions to medical facilities and institutionalization, assisting people who were caught in the institutional net to move back to their community living.
- Problem solving and marshalling resources to meet urgent needs and anticipate known future needs such as:
  - Surmounting geographical and logistical challenges to provide evacuation / rescues / accessible transportation, health care.
  - Delivery of food, water, generators,
  - Organizing matches of critical needs with delivery of items lost, left behind or needed: equipment, technology supplies, mobility devices (wheelchairs, canes, crutches, walkers, shower chairs, raised toilet seats, tracheostomy care)
- “Just in Time” training and technical assistance regarding understanding how federal emergency response, recovery, mitigation and benefit programs work. For example, understanding eligibility requirements and how to navigate state and federal programs such as FEMA’s Individual Assistance and Transitional Sheltering Assistance.

Federal and state involvement with the whole community is well-documented as an imperative for meeting local disaster response and recovery needs in federally declared disasters such as the catastrophic disasters in TX, FL, USVI, PR and CA. [The National Preparedness System including the](#)

[National Response Framework, National Disaster Recovery Framework and the Federal Interagency Operational Plans](#)<sup>2</sup> contain explicit references to collaboration.

“Engaging the whole community is critical to successfully achieving a secure and resilient Nation, and individual and community preparedness is a key component. An effective partnership relies on engaging all elements of the whole community and, when appropriate, international partners. Engaged partnership and coalition building includes clear, consistent, effective, and culturally appropriate communication and shared situational awareness. Participation within these partnerships should include advocates for all elements of the whole community. The most effective partnerships within a community capitalize on all available resources —identifying, developing, fostering, and strengthening new and existing coordinating structures to create a unity of effort.”<sup>3</sup>

However, federal and state involvement of partners with disability stakeholders was extremely uneven. Dozens of federal and state employees with a role in disability integration in disasters were invited and encouraged to participate on every teleconference. The only consistent federal attendees were from the US Department of Homeland Security Office for Civil Rights and Civil Liberties. They had representatives on almost every call, accepted every request for information, and provided important updates. The Officer for Civil Rights and Civil Liberties, who came on board the day Hurricane Maria made landfall, conducted telephone and on-site listening sessions to give disaster survivors and disability organizations the opportunity to raise a myriad of troubling civil rights and civil liberties issues.

Individual FEMA Disability Integration Advisors were very willing to work with the Partnership. However, they often reported that they were prohibited by their leadership from attending teleconferences and sharing updates that would have optimized coordination of limited resources and improved outcomes for disaster survivors with disabilities.

The US Department of Health and Human Services (HHS) Office of the Assistant Secretary for Preparedness and Response (ASPR), responsible for Emergency Support Function #8, Public Health and Medical Response, chose not to participate despite consistent invitations. The HHS Administration for Community Living (ACL) and representatives from the US Department of Justice did attend occasional teleconferences, but rarely participated or provided information. Despite requesting and being provided with specific, written examples of immediate life-saving and life-sustaining needs, neither ACL nor any other HHS representative provided responses.

Disturbingly, it was discovered in March 2018 that FEMA had been regularly attending the weekly national stakeholder coordination calls, but never identifying their presence. They remained silent as life-saving and life-sustaining issues were raised and the group grappled with finding solutions, absent their input, guidance or situational awareness.

Key informants repeatedly reported that community partnerships were the single most powerful tool for optimizing favorable outcomes, but these same informants consistently noted that the absence of federal involvement was in stark contrast with the federal government’s stated value of whole community partnerships in emergencies and disasters.

The involvement of state government was also limited throughout response and recovery in most declared states and territories. California has a full-time access and functional needs chief in the Governor’s Office of Emergency Services. His participation was fairly consistent and there was some

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<sup>2</sup> [FEMA National Preparedness System](#)

<sup>3</sup> [FEMA Overview of the National Planning Frameworks](#)

participation from local emergency management and other state agency representatives from CA. Florida also has a full time emergency management and public health position, but Florida was consistently represented only by a member of the Governor's staff, with the occasional inclusion of Department of Health representatives. There was never a representative in attendance from Florida's Division of Emergency Management. In Texas there isn't a specific position with responsibility for disability inclusive emergency management, and there wasn't any involvement from the Texas Division of Emergency Management. The Executive Director of the Texas Governor's Committee on People with Disabilities was the sole representative from the state. There were no participants from the territorial governments of Puerto Rico or the US Virgin Islands.

The lack of existing relationships between disability leaders and emergency managers was very apparent in every impacted community, state and territory. This gap has the potential for continued catastrophic outcomes for children and adults with disabilities, older adults, people with temporary health conditions and others who also have access and functional needs. It also has a detrimental impact on whole community resilience due to the failure of emergency management to optimize the considerable resources of disability organizations.

### **Community Partnership Inclusion and Sustainability Challenge**

Disability services and advocacy organizations impacted by the disaster were suddenly bombarded with immediate, life-saving] needs of people they regularly support, and the significant disaster related needs of community members with disabilities who are new to their services.

As in previous disasters, collaboration between local, state, national and federal government and non-government stakeholder organizations increased and evolved quickly when surrounded by and immersed in disaster response, relief and recovery. Many relationships preexisted while others were quickly developed. Disability services and advocacy organizations were rarely included in these collaborative community response and relief efforts without assertively pushing their way into emergency operations, public health and established groups of community organizations active in disasters as the needs of their constituents with access and functional needs emerge.

Among the most devastating results of these gaps were the large numbers of children and adults with disabilities living at home who were sent to hospitals, nursing homes, hospice facilities and other acute care facilities during evacuations.

Partnership Hotline callers, participating stakeholder organizations and media reports all confirm the large numbers of children and adults with disabilities who were not appropriately accommodated throughout alerts, evacuation, sheltering, access to emergency programs and services and temporary housing. All indications are that countless numbers of children and adults with disability civil rights protections were denied equal access to the emergency supports and services provided to the rest of the community.

The clearly stated obligation to meet the disability civil rights of disaster survivors with disabilities, without exception, is found in federal guidance, including the National Response Framework.

“Given the scope and magnitude of a catastrophic incident, waivers, exceptions, and exemptions to policy, regulations, and laws may be available in order to save and sustain life, and to protect property and the environment. However, any such waivers, exceptions, and exemptions must be consistent with laws that preserve human and civil rights and protect individuals with disabilities and others with access and functional needs.”

This was also reiterated (see Appendix B) to all disaster declared states and territories by the Department of Homeland Security and Department of Health and Human Services, However, thousands of disaster survivors with disabilities did not seem to benefit from their right to be served in the least restrictive environment or accommodated in the most integrated setting.

Monitoring and enforcement of these obligations was essentially non-existent, failure to engage disability organizations as subject matter experts in accommodating disaster survivors with disabilities, provide equal access to emergency programs and services, and medical rather than independent living approaches to disaster response, relief and recovery have contributed to what appears to be very different outcomes than those explicitly described in the National Planning System.

Concurrently, after the disaster and the immediacy, headlines and memories start to fade and attention and commitment to ongoing engagement diminishes. Long dry spells where disasters have not occurred contribute to a waning of interest as other priorities compete for precious time and resources and overshadow the commitment to whole community inclusive preparedness and planning.

Moving forward, in the absence of disasters or any incentives to prioritizing preparedness for the next disaster, the challenge is that many organizations who have not experienced a disaster will not view engaging in emergency planning and coalition building as a priority. Most stakeholder organizations neither seek nor receive funding, training and technical assistance for disaster readiness, much less to address future response, relief and recovery needs of disaster survivors and whole community inclusion initiatives.

Concurrently, the organizations who identified and implemented promising and good practices are not provided with resources to capture and disseminate these practices. Without dissemination, communities that have not experienced disasters and those that have not optimized their community partnerships after previous disasters are not benefiting from these newly established or refined promising practices. Thus, robust stakeholder engagement, whole community resilience practices and the opportunity to customize practices to meet the specific needs of their community are not informed by the experiences of other communities.

## ***Community Partnership Competencies***

The intended process of these cooperative partnerships is a blending of competencies and skill sets that included:

- applying sophisticated disability rights competencies, values and expertise,
- helping people with often complex and urgent disability-related needs,
- preventing and diverting inappropriate admissions to medical facilities and institutionalization
- Key core emergency response competencies from the disability service community staff are critical and included, but are not limited to:
  - Understanding the lived experience, details, diversity, nuances and complexity of living with disability cannot be duplicated and/ or always thoroughly understood by those

without a disability

- Integrating the practice of asking, listening, learning, respecting, and incorporating information learned from people with disabilities and others with access and functional needs
- Understanding and working with the complexities of what it takes for someone with a disability to maintain one's health and safety and survive emergencies
  - Working knowledge of multiple and cross-disability access issues (be it hearing, vision, mobility, speech and / or memory and understanding)
  - Applying independent living values which includes honoring people's right to self-determination
- Self-determination, which means the right to make choices and decisions, take risks, self-direct and exercise control over services and supports that are offered to them. A core value reflected here is that independent living does not mean doing everything without assistance, rather it is being in control of how, when, and what things are done, regardless of whether one uses the services and assistance of others.[ref: Kailes, J.I. (2017) [Defining Functional Needs - Updating CMIST](#) (2017)]
  - Applying the social model, versus a medical model, of disability which entails identifying, remedying, and retooling interventions that reflect old, but still common, stigmatizing biases, stereotypes and beliefs about people with disabilities, such as: the belief that people with disabilities are sick, need medical care, need protection, need supervision, need to be cared for and need special shelters.
- What may look "acute, vulnerable and fragile" to the untrained eye is just living with disability to non-governmental disability service community providers and advocates.
- Indiscriminately applying the medical service model denies that health and disability co-exist. People who live with chronic conditions (not illness) can also be healthy. In addition, the false belief that most people with disabilities need medical services and medical care, unnecessarily overburdens scarce emergency medical resources. Replacing medications, essential equipment, mobility aids and /or supplies often maintains health and related needs.<sup>4</sup> Thus, unless individuals require acute medical care, typically provided in a hospital; maintaining health, stabilization, treatment and a dependable power source, all of which can be provided in a community setting, leaving the limited resources of medical care available to those with real acute medical needs.

## Recommendation Part II – Section 1.1

### Charge the Center of Excellence in Disability Inclusive Emergency Management to:

- Identify, acquire, evaluate, disseminate and continually update promising community partnership strategies

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<sup>4</sup> Kailes, J.I. (2017) [Defining Functional Needs - Updating CMIST](#)

- Package promising practices in new or updated tools, checklists, and field operation guides for quick activation in future disasters
- Create content for just-in-time training regarding how to use tools, checklist, and field operation guides<sup>5</sup>
- Create evaluation tools that measure the effectiveness of delivery, performance, impact, and outcomes
- Create tools for identifying, achieving and measuring inclusive planning.

## Recommendation Part II – Section 1.2

**Disability service community providers should take appropriate steps to allow for supplemental funds to be awarded in future disasters.**

The Texas Department of Vocational Rehabilitation counselors checked on their clients, and received some supplemental federal funds to assist with items like equipment replacement for current and former clients; the area Agencies of Aging received supplemental funds to assist the people they support with individual recovery; but independent living centers were not able to get supplemental funds because there was nothing in their existing legislative language which allowed for that, despite that in Katrina, they were given supplemental funds to assist with individual recovery.

**Disability organizations should review their authorizing legislation and take the appropriate steps to allow for supplemental funds to be awarded in future disasters.**

### ***Functional Assessment Service Teams***

Functional Assessment Service Teams (FAST) were an early attempt to operationalize community partnerships for disaster response. The biggest difference between these teams and the Community Partnerships model is that FAST was primarily shelter-focused.

During the recent disasters FASTs, for the most part, did not appear to be deployed, except in California where individuals were deployed under the auspices of the State and several counties.

#### **History**

In the 1970s and 80s, decades before Katrina, a handful of California advocates documented the deep and dramatic lack of equal and inclusionary emergency services for people with disabilities. Examples of this discrimination included: people with disabilities being turned away from general population shelters (wheelchair users, service animal users, people who were deaf, blind, etc.) and people with disabilities who were sometimes separated from families and significant others, and asked to go to or sent to medical shelters, or other facilities and institutions (hospitals and long-term care facilities). In addition, community-based disability services staff who volunteered to help at shelters were turned away because of “lack of proper credentials.”

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<sup>5</sup> Kailes, J.I. (2017) [Training: Maximizing Your ROI](#)



For decades disability community leaders advocated to close these service gaps and stop civil rights violations by integrating the expertise of the disability service community and advocates into emergency services.

In 2007 the California Department of Social Services enlisted the expertise of June Kailes, to develop the FAST concept, plans, and a training course. The training was approved by FEMA in 2010.

## **Vision**

- The vision entailed “doing better and working smarter together” through building partnerships with disability service organizations, community based organizations (CBOs) (sometimes also referred to non-governmental organizations (NGOs), government: local (towns, cities, counties and states) and Voluntary Organizations Active in Disasters (VOAD), such as the American Red Cross.
- FASTs were to be inclusive of community disability services NGOs, not just those that are “for and about”, but most importantly those who are “of, by and with” people with disabilities, including but not limited to, people who are blind, deaf, hard of hearing, have speech and language disabilities, mental health conditions, learning, intellectual and developmental disabilities, and chemical sensitivities, etc.
- A blending of skills sets, and competencies detailed under Partnership Competencies.

## **Current Status**

FAST has been created and customized in different versions around the county.<sup>6</sup> The names and focus vary but in general, common characteristics are:

- the vision and the intended FAST partnerships have weakened in translation and execution over time
- FAST is a heavy lift for many jurisdictions who are challenged by lean and mean budgets which contribute to a significant strain on sustaining partnerships and replenishing teams.

Many FASTs are government-centric. Expense reimbursement, insurance and liability issues allowing for real NGO disability services participation has not been adequately addressed. NGO disability services staff often must volunteer with no reimbursement, insurance or opportunities to continue earning their salaries. Government FASTs may involve some people with disabilities who happen to be government employees, but this is no assurance that they bring to their FAST role identifying as having a disability, or skills at applying independent living values, a social model to service delivery and civil rights protections.

Weakened community participation partnerships contributed to:

- lack of commitment and know how regarding recruiting NGO disability services staff. For government-centric FAST it is easier and takes much less effort to recruit government workers.

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<sup>6</sup> ADA National Network Learning Session Webinar 10/12/17: [How Functional Assessment Service Teams \(FAST\) are being implemented in 3 states](#)

- FAST practices exhibit “medical model” creep (see “Vision” under FAST) with team membership being more “for and about” rather than “with, by and of” people with disabilities,
- lack of NGO involvement in updating of FAST models, reach, processes, procedures, protocols, policies and training.

Given the weakened translation and execution of the original intent of FAST, it is recommended that it is either discontinued as a practice or the following recommendations be incorporated into a revitalized iteration of it.

### **Recommendation Part II – Section 1.3**

#### **Government units supporting FAST shall:**

- Establish, revive and sustain partnerships with disability service community providers and advocates including aging, independent living, developmental disability, deaf, hard of hearing, low vision, blind, speech and language disabilities, and behavioral health, health care coalitions, health plans and mental health provider networks.
- Fund their recruitment, training and reimbursement
- Fund their participation in updating and revising FAST training

### **Recommendation Part II – Section 1.4**

**Establish Regional FAST teams which allow small counties to pool resources.**

### **Recommendation Part II – Section 1.5**

**Issue guidance for local jurisdictions about requesting state FAST including process and cost.**

### **Recommendation Part II – Section 1.6**

#### **Broaden the FAST focus**

The sheltering focus is too narrow. An expanded focus should include:

- Provide home visits for life safety checks
- Provide access navigators at disaster recovery and assistance centers and Points of Commodity Distribution Sites (PODS) i.e. water, food, etc.
- Change the name from Functional Assessment Service Team to Functional Assistance Service Team. Assessment is not enough, without the critical assistance that needs to follow.

### **Recommendation Part II – Section 1.7**

**Create content for Just-In-Time Training regarding how to use tools, checklist, and field operation guides.**

## **Recommendation Part II – Section 1.8**

### **Create Effectiveness and Quality Improvement Plans.**

There is a need to use evaluation methods that measure the effectiveness of delivery, performance, impact, and outcomes rather than just counting how many attended a training, how many answered the designated number of post-test questions correctly, and the learners' documenting reactions to and satisfaction with the training and presenters.

The gold standard metrics of performance should answer whether the targeted outcomes were achieved. In addition to self-reports, use of independent evaluators to observe performance, analyze targeted outcomes and raw uncensored hot wash content.

Use metrics such as:

Teams and numbers of active members:

- How is a team defined?
- How many teams are available for deployment?
- How many people are on the active list for deployment (means individual's information has been updated when the last 12 months)?
  - How many people on the active deployable list are disability service community providers and advocates? [Centers for Independent Living, Area Agencies on Aging, Regional Centers, etc.]?
  - How many identify as a person with a disability?

Training:

- How many on the active deployable list have taken a current FAST Course?
- How many on the active deployable list have taken a current FAST Refresher Course?
- How many on the active deployable list have taken current FAST Leaders Training?

Deployments:

- How many teams have deployed and to which events?
- How many individuals have deployed and to which events?
- How many survivors were served at each event?

Evaluation:

How are outcomes, impact, performance and successes measured?

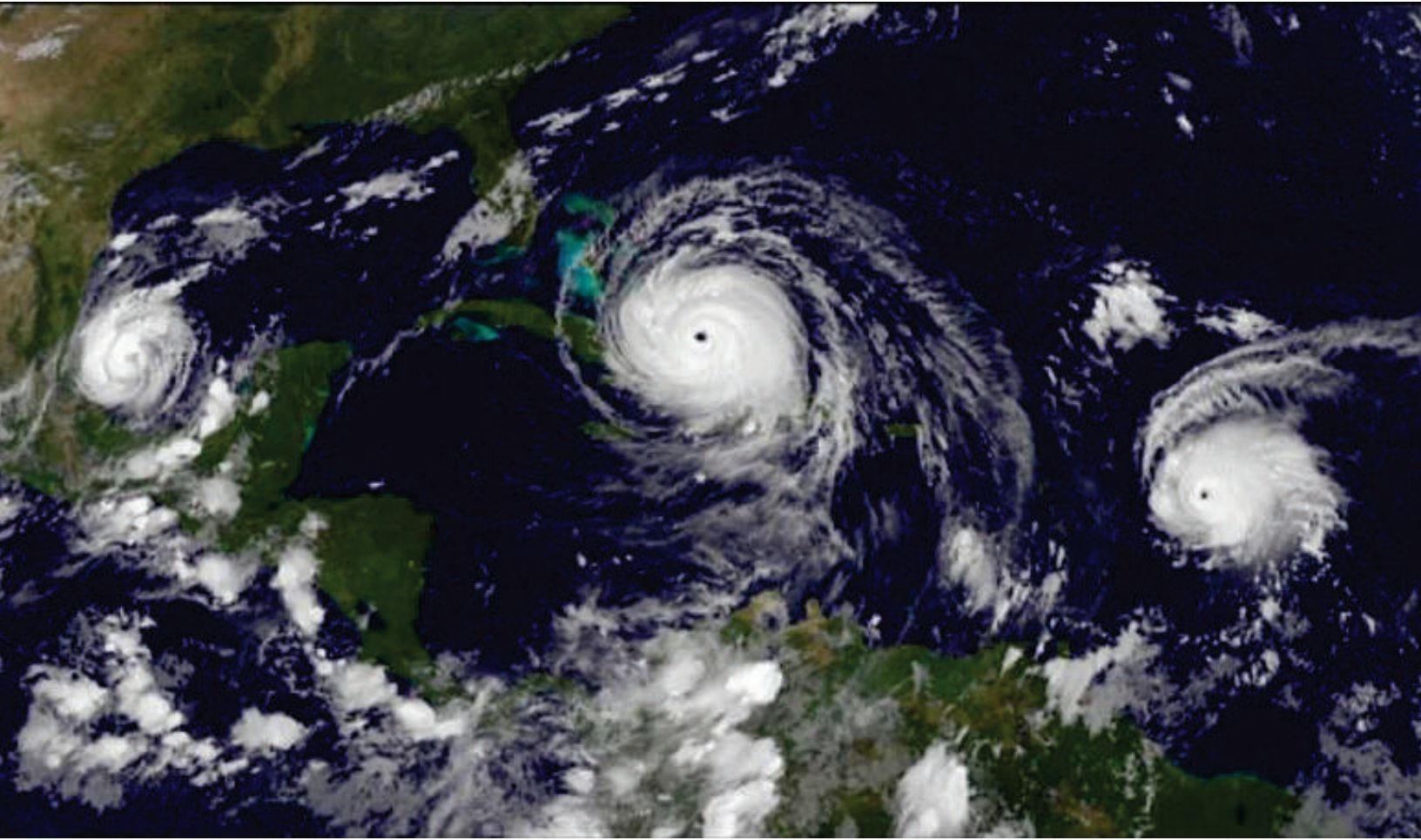
## **Recommendation Part II – Section 1.9**

**Study other models that have similar focus, as well as their processes, procedures, protocols, policies and training, and effectiveness.**

## Recommendation Part II – Section 1.10

**Develop additional resilient models in which disability service community providers and advocates are equal partners. FAST is important, but not the only tool in the response tool chest.**

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*Figure 4: A photo taken from space shows Hurricanes Irma, Katia and Jose all in the Atlantic Ocean (NASA).*

### **Part III: Federal Legal Protections of People with Disabilities Before, During, and After Disasters**

In response to a history of segregation and exclusion, a body of law has been established to codify and protect the rights of individuals with disabilities. People with disabilities have substantial protections under federal law that range from the right to an equal opportunity in education to the right not to be unnecessarily institutionalized. There is substantial state/territory legal protection as well. Accordingly, federal, state and local governments have significant and non waivable obligations to children and adults with disabilities. This report describes federal obligations and the role of these laws when providing emergency programs and services to children and adults with disabilities before, during and after disasters.

Relevant Statutory and Executive Order Obligations May Include:

- § *Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act)*, as amended;
- § *Post-Katrina Emergency Management Reform Act*;
- § *Rehabilitation Act of 1973*, as amended;
- § *Americans with Disabilities Act (ADA)*, as amended 2008;
- § *Fair Housing Act of 1968*, as amended;
- § *Architectural Barriers Act of 1968*;
- § *Communications Act of 1934*, as amended;
- § *Individuals with Disabilities Education Act (IDEA) of 1975*, as amended;
- § Executive Order 13347 (July 22, 2004), – *Individuals with Disabilities in Emergency Preparedness*.

Failing to comply with legal obligations can have long-term negative consequences on entire communities. “Statutory and Executive order obligations include accessibility in architecture, transportation, housing, effective communications, employment, social services and public benefits, education, and policies and programs including those receiving Federal funding.”<sup>7</sup>

Further, these obligations are not waivable. “Given the scope and magnitude of a catastrophic incident, waivers, exceptions, and exemptions to policy, regulations, and laws may be available in order to save and sustain life, and to protect property and the environment. However, any such waivers, exceptions, and exemptions must be consistent with laws that preserve human and civil rights and protect individuals with disabilities and others with access and functional needs...”<sup>8</sup>

In other words, the civil rights of children and adults with disabilities are never suspended during a disaster.

Below is a brief summary of key laws that protect people with disabilities before during and after disasters. Failing to provide individuals with disabilities equal access to federal state and local government disaster services is not simply a failure of policy. It can be a violation of federal law.

## Summary of Key Laws

### Law: Fair Housing Act of 1968 and Fair Housing Act as Amended in 1988

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<sup>7</sup> [FEMA National Preparedness Goal](#)

<sup>8</sup> Ibid



Overview: The Fair Housing Act of 1968 prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, or national origin. The provisions cover all types of housing (regardless of type of funding) intended as a short- or long-term residence, including the following types that are often used to house persons displaced by disasters:

- Shelters that house persons temporarily
- Transitional housing facilities
- Short- and long-term rentals
- Manufactured housing

### **Law: Architectural Barriers Act of 1968**

Overview: The Architectural Barriers Act requires that facilities designed, built, altered, or leased with funds supplied by the Federal Government be accessible to the public. The law helps ensure that certain federally funded buildings and facilities are designed and constructed to include accessibility for people with disabilities. Facilities constructed prior to the law's enactment generally are not covered, but alterations or leases undertaken after the law took effect are usually included.

### **Law: Robert T. Stafford Disaster Relief and Emergency Assistance Act (as amended)**

Overview: The Robert T. Stafford Disaster Relief and Emergency Assistance Act of 1988 (as amended) is the law that authorizes Federal assistance when the President declares a State to be a disaster area. The Stafford Act prohibits discrimination during disaster relief and assistance activities. Section 308 of the Stafford Act was amended by the Post-Katrina Emergency Management Reform Act of 2006 (discussed later) to extend those protections to include race, color, religion, nationality, sex, age, disability, English proficiency, and economic status.

The Stafford Act applies to:

- FEMA services and operations.
- Personnel carrying out Federal assistance functions.
- Other bodies participating in relief operations, including all private relief organizations, contractors, and volunteers.

### **Law: Rehabilitation Act of 1973**

Overview: The Rehabilitation Act of 1973 prohibits discrimination against persons with disabilities. Section 504 of the act requires all entities that receive Federal financial assistance to:

- Effectively communicate with people who have communication disabilities including hearing, vision, or cognitive disabilities.
- Meet accessibility standards in new construction and altered facilities.
- Make changes to policies, practices, procedures, and structures as a reasonable accommodation for individuals with disabilities unless doing so would require a fundamental alteration of the program or constitute an undue financial and administrative burden.



Section 504 of the Rehabilitation Act applies to all types of entities that receive Federal financial assistance, regardless of whether they are a governmental agency, a private organization, or a religious entity. It also applies to organizations and entities that receive Federal monies distributed through State or local agencies (subrecipients).

Federal financial assistance is defined very broadly. For example, a private nonprofit organization that receives a Federal contract to provide services is covered by Section 504, as is an organization that receives free or subsidized use of Federal property, or is provided staff paid by a Federal agency.

Section 508 requires Federal electronic and information technology to be accessible to people with disabilities.

An accessible information technology system is one that can be operated in a variety of ways and does not rely on a single sense or ability of the user.

### **Law: Individuals with Disabilities Education Act (IDEA) of 1975**

Overview: The Individuals with Disabilities Education Act (IDEA) was enacted in 1968 and has been amended several times to clarify its intent.

The law requires that qualifying students be provided a free and appropriate education that prepares them for further education, employment, and independent living.

The law as amended in 2004 also specifies that:

- “Special education and related services should be designed to meet the unique learning needs of eligible children with disabilities, preschool through age 21.”
- In order to qualify for IDEA, the student’s disability must “result in the student needing additional or different services to participate in school”.

IDEA applies to children affected by disasters, by requiring their return to school along with their peers with the continuation of their Individual Education Plan in place.

### **Law: Americans with Disabilities Act (ADA) of 1990 and ADA Amendments Act of 2008**

Overview: The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered.

Title II of the Americans with Disabilities Act (ADA) of 1990 requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities.

Requirements include meeting specified architectural standards and ensuring effective communication with people who have hearing, vision, or speech disabilities.

Title II also applies to public transportation services, such as city buses and public rail transit (e.g., subways, commuter rails, Amtrak). Public transportation authorities may not discriminate against people with disabilities in the provision of their services. They must comply with requirements for accessibility in newly purchased vehicles, make good faith efforts to purchase or lease accessible used buses, remanufacture buses in an accessible manner, and, unless it would result in an undue burden, provide paratransit where they operate fixed-route bus or rail systems. Paratransit is a service where individuals who are unable to use the regular transit system independently (because of a physical or mental impairment) are picked up and dropped off at their destinations.

Title III covers businesses and nonprofit service providers that are public accommodations, privately operated entities offering certain types of courses and examinations, privately operated transportation, and commercial facilities. Public accommodations are private entities who own, lease, lease to, or operate facilities such as restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, daycare centers, and recreation facilities including sports stadiums and fitness clubs. Transportation services provided by private entities are also covered by title III.

Public accommodations must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment. They also must comply with specific requirements related to architectural standards for new and altered buildings; reasonable modifications to policies, practices, and procedures; effective communication with people with hearing, vision, or speech disabilities; and other access requirements. Additionally, public accommodations must remove barriers in existing buildings where it is easy to do so without much difficulty or expense, given the public accommodations resources.

Title IV addresses telephone and television access for people with hearing and speech disabilities. It requires common carriers (telephone companies) to establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week. TRS enables callers with hearing and speech disabilities who use TTYs (also known as TDDs) and callers who use voice telephones to communicate with each other through a third-party communications assistant. The Federal Communications Commission (FCC) has set minimum standards for TRS services. Title IV also requires closed captioning of federally funded public service announcements.

The ADA Amendments Act of 2008 broadened the definition of disabilities.

Title IV of the ADA requires that Telecommunications Relay Services (TRS) be made available to individuals with speech and hearing impairments to the fullest extent possible and in the most efficient manner.

Any television public announcement that is produced or funded in whole or in part by the Federal Government must be closed captioned.

Individual with a Disability: An individual with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activities that an average

person can perform with little or no difficulty, or has a record of such impairment, or is regarded as having such impairment.

The law defines specific terms as follows:

- **Physical impairment:** Includes disorders of the sense organs (talking, hearing, etc.), motor functions, and body systems such as respiratory, cardiovascular, musculoskeletal, reproductive, digestive, genitourinary, hemic, lymphatic, skin, neurological, and endocrine systems.
- **Mental impairment:** Includes most psychological disorders and disorders such as organic brain syndrome, learning disabilities, and emotional or mental illness. It specifically excludes various sexual behavior disorders, compulsive gambling, pyromania, and disorders due to current use of illegal drugs.
- **Major life activities:** Include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, breathing, learning, reading, concentrating, thinking, communicating, and working. Major life activities also include the operation of major bodily functions, such as the immune system and normal cell growth, which covers persons with HIV or cancer.
- **Substantial limits:** The severity and duration of an impairment determines whether it substantially limits a major life activity. Impairment must last for several months and significantly restrict a major life activity, but an impairment that is episodic or in remission is still a disability if it would substantially limit a major life activity when active. Similarly, an impairment is still regarded as a disability even if the individual uses medication, equipment, learned adaptive behaviors, or other mitigating measures to lessen the effects of the impairment.

The Equal Employment Opportunity Commission (EEOC) has adopted the provisions of the ADA as guiding principles of the Rehabilitation Act.

### **Law: Telecommunications Act of 1996**

Overview: The Communications Act of 1934 was amended by the Telecommunications Act of 1996. Among its provisions, the 1996 law required that people with disabilities have access to products and services such as telephones, cell phones, pagers, call-waiting, and operator services that were previously not accessible for many people with disabilities.

### **Law: Post-Katrina Emergency Management Reform Act of 2006**

Overview: The Post-Katrina Emergency Management Reform Act of 2006 included provisions that amended the Stafford Act to better integrate consideration of all populations and needs into general emergency management planning, response, recovery, and mitigation. As such, those provisions amended Section 308 of the Stafford Act to extend protection of the rights of all populations, including individuals with disabilities, persons with limited English proficiency, children, and the elderly.

### **Law: 21st Century Communications and Video Accessibility Act of 2010**

Overview: The 21st Century Communications and Video Accessibility Act requires captioned television programs to be captioned when delivered over the Internet, requires video description on television for people with vision loss, allocates \$10 million per year for communications equipment used by people who are deaf-blind, ensures emergency information is accessible to individuals who are blind or have low vision, and provides for accessibility of advanced communications such as text messaging, email, and Web browsing on mobile devices, among several other provisions.<sup>9</sup>

## **How federal legal protections apply during disasters**

As stated in the National Preparedness Goal, civil rights of people with disabilities are not waived before during or after disasters. As such, people with disabilities always have the complete protection of all disability rights laws. Below we discuss how several of these laws - the Rehabilitation Act, the ADA and IDEA - may be of particular relevance in times of disasters.

### **The Rehabilitation Act of 1973**

This Act provides people with disabilities broad protection from discrimination. It protects the civil rights of persons with disabilities by prohibiting discrimination on the basis of disability by the federal government, federal contractors, and by recipients of federal financial assistance. Any recipient or subrecipient of federal funds is required to make their programs accessible to individuals with disabilities. Its protections apply to ALL programs and businesses that receive ANY federal funds. This applies to all elements of physical/architectural, programmatic and effective communication accessibility in all services and activities conducted by or funded by the federal government.

### **Compliance with the Rehabilitation Act during disasters**

The Rehabilitation Act prohibits the federal government and recipients of federal funds from discrimination against people with disabilities. People with disabilities must be provided equal access to disaster programs and services. This includes: alerts, notification, evacuation, sheltering, medical care, temporary housing, health maintenance and all federally funded emergency programs and services throughout response and recovery. Physical access, equally effective communication and modifications to policies and practice are required.

### **Compliance with the Rehabilitation Act after disasters**

All federal dollars expended during and after disasters must be spent in compliance with the Act. This includes programs and services conducted by the federal government as well as programs and services funded with federal dollars in assisting with the provision of programs and services. This means that structures built, substantially repaired or replaced using federal dollars must comply with all applicable laws.

### **Compliance with the Americans with Disabilities Act during and after disasters**

State, territory and local governments and public accommodations have obligations to people with disabilities under the ADA independent of the expenditure of federal funds. These obligations mirror obligations under Section 504 of the Rehabilitation Act.

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<sup>9</sup> [FEMA Including People With Disabilities and Others With Access and Functional Needs in Disaster Operations](#)

The underlying values of the ADA, like the Rehabilitation Act are integration, equal opportunity and full participation of people with disabilities. The Supreme Court, through *Olmstead v. L.C.*, 527 U.S. 581 (1999) held that people with disabilities must be given services in the most integrated setting appropriate to the needs of that person. This means that people with disabilities including older adults cannot be unnecessarily institutionalized under the ADA. Despite this, people with disabilities are commonly institutionalized shortly before, during and after disasters, as a consequence of inadequate planning.

### **Compliance with the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act for children from birth through 21, during and after disasters**

Under IDEA children with disabilities who receive special education and related services have specific protections. Like the ADA and the Rehabilitation Act, these protections are non-waiverable in a disaster. Children with disabilities have the right to return to school at the same time as their peers and to receive services as delineated in their Individualized Education Plan or Rehabilitation Act Section 504 plans without interruption.

This report will convey information from stakeholders, key informants, participants in an HHS listening session in Houston and Hotline callers and examine instances where people with disabilities may not have had the equal access to programs and services guaranteed in the laws summarized above. The authors collected information from August 25, 2017 until the publication of this report.

### **The Pattern: Lack of Equal Opportunity in Disasters Despite Civil Rights Protections**

Disturbingly, through engagement of stakeholders, the result of poor planning revealed a pattern of equal access failures across disasters. After Action review findings documented this pattern of failure to anticipate, identify and address equal access shortfalls with devastating outcomes.

*The pattern of dismissing and ignoring civil rights laws protecting children and adults with disabilities means that the people with the highest level of legal protection in disasters, people with disabilities, are denied or receive inadequate emergency and disaster services.*

As this inequity was discovered by stakeholders, the Partnership amplified these circumstances via social media and the press, resulting in individual, but not systemic, resolution. There were situations where solutions came too late, such as for the individuals who lost their lives in a nursing home in Hollywood, Florida; the individuals who were unable to obtain dialysis, oxygen and other life-saving measures in Puerto Rico; and the individuals who were unable to evacuate from the path of wildfires in CA.

Other examples include failure of high rise evacuation of children and adults with disabilities, and failure of basic supplies, such as food and water not delivered to residents with mobility disabilities sheltering-in place in multi-story buildings.

Residents of nursing homes and other institutions were frequently not evacuated. This was highlighted through a viral photograph of residents of a TX assisted Living facility in chest deep water. The team, in collaboration with Cajun Navy, arranged for the rescue of these individuals and hundreds of others who were in need of rescue from similar circumstances.

Other elements of the pattern will be examined below, including false reliance on existing plans, registries, and non-existent response systems.

While each disaster is unique in nature, all harm caused in the disasters examined in this report was foreseeable. It was foreseeable that a large hurricane could decimate the power grid and infrastructure of island territories. It was foreseeable that people with disabilities would get trapped in high rise buildings funded with HUD Section 211 money, occupied by people with disabilities. It was foreseeable that people with disabilities would require accessible transportation to evacuate fast-moving fires and it was foreseeable that people who are deaf and hard of hearing would need actionable information in accessible formats to take personal protective measures in all of the disasters.

Thus, government entities and non-governmental organizations can no longer default to the cliché that disasters are unique to justify the inability to plan for and respond to predictable outcomes. While the disasters were not avoidable, many of their disproportionate impacts were preventable or could have been mitigated.



*Figure 5: A hurricane seen from space.*

## **Part IV: Findings**



Overarching themes about what was effective and what did not work emerged from information collected through the hotline, stakeholder calls, Congressional Correspondence, a DHS listening session in Houston, interviews with key informants and other sources delineated in the Methodology section above. Immediately below, themes about what was effective and what wasn't are discussed broadly. This is followed by a detailed discussion of equal access for adults and children with disabilities in ten areas critical to disaster survival and resilience.

A major finding that emerged from the research indicated that the federal government failed in meeting its legal obligation to provide equal access to programs and services for people with disabilities. This failure occurred across all disasters to people with all types of disabilities throughout the disaster cycle.

The legal obligation is shared by federal agencies and Offices including the Department of Homeland Security, FEMA and the Office of Civil Rights and Civil Liberties and the Department of Health and Human Services including the Office of the Assistant Secretary for Preparedness and Response (ASPR), Administration for Children and Families (ACF) and Administration for Community Living (ACL). The failures as well as successes of these agencies are reviewed throughout this report.

Another theme about what was effective in providing equal access to adults and children with disabilities in disasters also became apparent through the research. There appeared to be consensus among key informants that national disability led organizations and other disability services and advocacy organizations and allies provided the most effective assistance to adults and children with disabilities. While the specific organization providing primary assistance varied with localities, the consistent factor was that they were run by organizations whose values put a priority on the civil rights of people with disabilities.

Local and national disability groups who valued equal access for children and adults with disabilities and were led and staffed by people with disabilities and family members saved lives of people with disabilities and, in many cases, helped to ensure that their right to equal access to services in disasters were protected.

Organizations that had the expertise and credibility that comes with placing a priority on civil rights of people with disabilities and being run by people with disabilities and family members, ended up being the payer of first resort for programs, services and goods for adults and children with disabilities. The non-governmental organizations often have a deeper understanding of the needs of people with disabilities because they are managed and staffed by people with disabilities and they have the capacity to respond quickly and because they have the nimbleness that comes with being a small organization. The result was that in order to save and sustain lives and to prevent people with disabilities from being unnecessarily institutionalized, disability non-governmental organizations paid for and delivered an enormous amount of durable medical equipment; consumable medical equipment, including adult and older child diapers; and other necessary supplies.

The non-governmental organizations had a better sense of where their constituencies were located. FEMA, 211 and the Red Cross very frequently referred survivors with disabilities to Portlight and the Partnership for Inclusive Disaster Strategies, Centers for Independent Living and other disability organizations to get equipment and services. These organizations also played a critical role in food and water distribution. In Puerto Rico and the US Virgin Islands this included delivering food and potable water to remote areas. In Florida this included ensuring that food was distributed so that people with disabilities had equal access to public food and water distribution without paying transportation costs to reach points of distribution.

## Part IV - Section 1: Overarching Themes

### Deficiencies in equal access in areas critical to disaster survival and community resilience

Disaster survival, recovery and resilience for children and adults with disabilities and their communities rely on equal access throughout all aspects of the emergency management cycle, including the period long before the disaster and long after the disaster strikes.

Barriers to equal access to disaster related programs and services encountered by people with disabilities is described below. Instances where people with disabilities were disproportionately impacted by circumstances that occurred before, during or after disasters are included. Strategies utilized that had a positive or somewhat positive effect, as well as good and promising practices are delineated. Recommendations to facilitate protection of civil rights, health and lives of children and adults with disabilities before, during and after disasters are included.

The gaps in equal access to food, water and other life-sustaining government assistance are addressed. Repeated instances of these gaps, forcing non-governmental organizations to fill the void by default, are noted, this is because not only is this unacceptable, it is not permissible. The civil rights of a legally protected class cannot be relegated to nonprofit organizations, volunteers and charities. People with disabilities have the highest degree of legal protection and the government's responsibility to provide equal access is never waived. Federal, tribal, state, territorial and local government cannot shirk their obligation to uphold civil rights law. Even when government entities do rely on non-governmental organizations and charities to meet their obligations, the obligations remain with the government entity.

A government entity cannot grant, outsource or subcontract its obligation to provide equal access to individuals with disabilities.

A government entity cannot grant, outsource or subcontract its obligation to provide equal access to individuals with disabilities.

Among the gaps in process repeatedly observed was a startling reliance on disability organizations to serve as payers and providers of first resort, whether the need was food, water, disability related equipment and other life-saving and life-sustaining necessities. This reliance by the government on poorly resourced and non-reimbursement eligible sources highlighted the imbalance in government priorities. Government entities must examine these priorities and ensure that public resources are appropriately assigned to meet the civil rights obligations associated with those federal funds. Reliance on charity, volunteerism and donation systems, while always a wonderful symbol of whole community commitment, must not be the government's substitute for meeting its obligations.

Once the balance in role assignment is more appropriately established, it is imperative that information sharing and reimbursement barriers are resolved so that the appropriate role of non-government partners are utilized to optimize limited human and financial resources.

The responsibility for preventing unnecessary institutionalization is held by the government, it is also shared among government and non-government entities, including the American Red Cross and other emergency and disaster relief organizations.

The National Council on Independent Living NCIL published the following on March 22, 2018:

*Statement of Concern from the National Council on Independent Living Regarding the American Red Cross:*

*“The American Red Cross exists to: ‘provide compassionate care to those in need. Their network of generous donors, volunteers and employees share a mission of preventing and relieving suffering, here at home and around the world, through five key service areas: Disaster Relief; Supporting America’s Service Families; Life Saving Blood; Health and Safety Services; and; International Relief.’*

*The National Council on Independent Living advances independent living and the rights of people with disabilities. NCIL envisions a world in which people with disabilities are valued equally and participate fully. NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: individuals with disabilities, Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.*

*The purpose of the NCIL Emergency Preparedness Subcommittee: is to address the need for people with disabilities to be involved in the development, assessment, and implementation of emergency preparedness in all stages of a disaster. This includes advocating for the rights of individuals to receive equal access to any services offered by any governmental or non-governmental agency before, during and after a disaster or emergency.*

*NCIL Leadership and the Emergency Preparedness Subcommittee have made every effort to work closely with the American Red Cross and ensure that their relief efforts provide equal access and are fully accessible to individuals with disabilities. Our work with them has been substantial and o non-governmental organizations since 2012. A Memorandum of Understanding was negotiated over the course of two years and signed by both parties in July 2014. The MOU was allowed to expire without renewal in July 2016. NCIL leadership and the sub-committee members were pleased with their hiring of a full time Disability Integration Advisor in August 2016 and indeed have seen improvements in disaster affected areas in which she has deployed. However, the vast systemic and cultural changes needed within the Red Cross organization have not been made. Both NCIL, through the development of the MOU, and Portlight Strategies through a contract with Red Cross, provided numerous suggestions and recommendations and much advice and guidance to Red Cross leadership regarding their treatment of and services to individuals with disabilities affected by disaster.*

*The 2017 Hurricane Season was devastating and impacted millions of individuals in our coastal states and the territories of Puerto Rico and the US Virgin Islands. Despite years of strong advocacy, detailed discussions and numerous suggestions, people with disabilities affected by Hurricanes Harvey, Irma and Maria were disenfranchised, discriminated against and suffered undue hardship at Red Cross operated shelters and through Red Cross operated relief programs. Laws in place to protect the rights of people with disabilities were broken by Red Cross. There is no excuse for this 28 years after passage of the Americans with Disabilities Act.*

*NCIL leadership has recently met with Red Cross Humanitarian Services and Disaster Services leadership to discuss our grave concerns. That meeting yielded nothing to assuage our fears that people with disabilities will not continue to suffer discrimination from Red Cross volunteers and staff. The platitudes received have been given numerous times before with little result. NCIL has been invited to participate in an After Action Review of the 2017 Hurricane Season sponsored by the Red Cross on March 26. We will attend this meeting in the hopes that we hear something different and more satisfying from their staff. Our expectations are low and if we don't see a plan for tangible improvements at that meeting, then NCIL's focus going forward will be on holding the Red Cross accountable for their failures to the disability community and countless disaster survivors with disabilities who are now experiencing serious degrading of their independence and their health".*

### **Recommendation Part IV – Section 1.1**

**Develop policies reflective of an analysis of the failure to protect the rights of people with disabilities in recent disasters.** These policies must ensure that federal, state and local governments do not abdicate their responsibility to protect the rights of people with disabilities to have equal access to programs and services or their responsibility to monitor and enforce civil rights protections.

### **Recommendation Part IV – Section 1.2**

**Develop and disseminate a template for government and non-government Memoranda of Agreements to include Centers for Independent Living and other disability-led organizations to identify partnerships, responsibilities, information sharing and resources for addressing and meeting disaster-related individual and community needs.**

### **Recommendation Part IV – Section 1.3**

**Contracts and reimbursement protocols should be developed with local and national disability led non-governmental organizations to plan for and provide life-saving and life-sustaining necessities, technical assistance, and subject matter expertise for meeting the disaster-related access and functional needs of children and adults with disabilities in the most integrated setting appropriate to meet their needs.**

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## ***Part IV - Section 2: Equal Access to Federal Programs and Services***

There are at least 25 Federal agencies responsible for the administration of dozens of disaster related programs, most of which rely heavily on active participation by state and local governments for implementation.

The United States Department of Homeland Security (DHS) is the third largest Cabinet department, leading the nation's efforts to secure our country from terrorism and natural disasters.

The United States Department of Health and Human Services has 11 operating divisions, including eight agencies in the U.S. Public Health Service and three human services agencies. These divisions administer a wide variety of health and human services and conduct life-saving research for the nation, protecting and serving all Americans.

The Department of Health and Human Services (HHS) has the medical responsibility for Federal preparedness and disaster response efforts.<sup>10</sup>

The programs and services of the Department of Homeland Security (DHS) and The Department of Health and Human Services (HHS) are the primary federal programs reviewed in this report.

The primary agency within the Department of Homeland Security that provide services to and protect the rights of people with disabilities in disasters is the Federal Emergency Management Agency (FEMA).

[Robert T. Stafford Disaster Relief and Emergency Assistance Act](#), Public Law 100-707, signed into law November 23, 1988; amended the Disaster Relief Act of 1974, Public Law 93-288. It created the system in place today by which a presidential disaster declaration of an emergency triggers financial and physical assistance through the Federal Emergency Management Agency (FEMA).

The Act gives FEMA the responsibility for coordinating government-wide relief efforts.

## **2.1 Equal Access to Department of Homeland Security (DHS) Programs and Services**

The [Office for Civil Rights and Civil Liberties](#) (CRCL) supports the Department's mission to secure the nation while preserving individual liberty, fairness, and equality under the law.

DHS integrates civil rights and civil liberties into all agency activities by:

- Promoting respect for civil rights and civil liberties in policy creation and implementation;
- Communicating with individuals and communities whose civil rights and civil liberties may be affected by Department activities, and informing them of policies and avenues of redress;
- Investigating and resolving civil rights and civil liberties complaints filed by the public regarding Department policies or activities; and
- Leading the Department's equal employment opportunity programs and promoting workforce diversity<sup>11</sup>

**Equal access to and civil rights protection by offices within the Department of Homeland Security will be discussed in detail below.**

On October 23rd 2017, members of the House Committee on Homeland Security sent the Acting Secretary of DHS and the Administrator of FEMA a five-page letter delineating concerns that they had

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<sup>10</sup> [U.S. Response to Disasters & Public Health Emergencies - Section 2: U.S. Response Organizations](#)

<sup>11</sup> [DHS - Civil Rights and Civil Liberties](#)

about people with disabilities being denied equal access to programs and services required under federal law (see Appendix A). They asked ten questions, paraphrased here, that queried: the process by which they ensured that federal funds were spent in compliance with the Rehabilitation Act; processes that CRCL and FEMA utilize to investigate, resolve and coordinate complaints; the number and resolution of CRCL complaints; the number and resolution of complaints received by FEMA; who is responsible for assisting families who self-evacuated due to disability issues; why the USNS Comfort was being underutilized; how FEMA is coordinating medical evacuations with HHS; what the deployment numbers are for each of the disasters; why the Disability Coordinator position at ODIC was vacant for such a long period; and what training Surge Capacity Force receives in the government's obligations to people with disabilities.

They requested a written response to these questions by October 27, 2018 as authorized pursuant to Rule X and Rule XI of the U.S. House of Representatives. As of publication of this report there has been no response.

## **2.1.1 Equal Access to Federal Emergency Management Agency (FEMA) Programs and Services**

### **The Agency and Its Obligations**

The Federal Emergency Management Agency coordinates the federal government's role in preparing for, preventing, mitigating the effects of, responding to, and recovering from all domestic disasters, whether natural or man-made, including acts of terror.

Federal civil rights laws require accessibility and prohibit discrimination against people with disabilities in all aspects of emergency mitigation, planning, response, and recovery. To comply with these laws, people responsible for notification protocols, evacuation and emergency operation plans, shelter identification and operations, emergency medical care facilities and operations, human services, and other emergency response and recovery programs must:

- (1) have sound working knowledge of the accessibility and non-discrimination requirements applicable under Federal disability rights laws;
- (2) be familiar with the demographics of the population of people with disabilities who live in their community;
- (3) involve people with different types of disabilities in identifying the communication and transportation needs, accommodations, support systems, equipment, services, and supplies that residents and visitors with disabilities will need during an emergency; and
- (4) identify existing and develop new resources within the community that meet the needs of residents and visitors with disabilities during emergencies.

*The Department of Homeland Security (DHS), Federal Emergency Management Agency (FEMA), is committed to serving all individuals equally. This commitment extends to individuals with disabilities. FEMA must provide access to Agency programs and activities equal to the access provided to non-disabled persons.*

*It is FEMA's policy, in accordance with Sections 501 and 504 of the Rehabilitation Act of 1973, as amended, that no qualified individual with a disability shall be denied participation in, or benefit of, any program conducted by FEMA, including employment (see Title 44, Code of Federal Regulations, Part 16).*

*It is FEMA's policy in accordance with Section 508 of the Rehabilitation Act of 1973, as amended, to provide comparable access to employees and the general public through the procurement, development, maintenance and use of electronic information technology that conforms to Section 508 Standards issued by the Architectural and Transportation Barriers Compliance Board (i.e., the "Access Board"). This minimum accessibility requirement became effective June 21, 2001. (Emphasis ours)*

It is FEMA's policy in accordance with Federal law to ensure that the Civil Rights of all persons receiving services or benefits from agency programs and activities are protected. No person shall, on the grounds of race, color, national origin, sex, religion, nationality, age, disability (emphasis ours), limited English proficiency, or economic status, be denied the benefits of, be deprived of participation in, or be discriminated against in any program or activity conducted by or receiving financial assistance from FEMA. In particular, all personnel carrying out Federal major disaster or emergency assistance functions, including the distribution of supplies, the processing of applications, and other relief and assistance activities, shall perform their work in an equitable and impartial manner without discrimination. In accordance with Federal law, FEMA prohibits such discrimination in any programmatic guidelines, procedures, or other directives. All valid complaints of Civil Rights violations will be investigated promptly, and any settlement will be enforced, if necessary, by administrative, legal, or judicial means.

These prohibitions extend to all entities receiving Federal financial assistance from FEMA, including state and local governments, educational institutions, and any organization of any type obtaining benefits through the Infrastructure or Mitigation Programs.<sup>12</sup>

Because of its pervasiveness, and because of its central role in enabling survivors with disabilities equal access guaranteed under federal law, equal access of survivors with disabilities to FEMA services is discussed first.

Virtually every key informant volunteered information about their interactions with FEMA. Generally most, but not all, of these respondents reported less than favorable experiences with FEMA. It is understood by the authors that FEMA is often scapegoated by stakeholders and the general public for all shortfalls throughout disaster response without regard for who was responsible. Regardless, the reports painted a credible and disturbing picture.

A key informant in Texas was of the opinion that FEMA was not staffed with personnel with adequate disability expertise that some were "unhelpful almost to the point of being unprofessional on daily conference calls" and that Disability Integration Advisors at times resisted giving contact information both on calls and to individual survivors.

Disability leaders who deployed to Puerto Rico reported that they never saw FEMA staff in the field and that they "refused to leave the air-conditioned headquarters." According to this leader when they asked disaster survivors if they had met with FEMA staff, most said that they had not yet seen them, this persisted at least into February 2018.

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<sup>12</sup> [FEMA Accommodating Individuals with Disabilities in the Provision of Disaster Mass Care, Housing, and Human Services](#)



Others had different opinions and reported that FEMA was helpful. For example, it was reported that in the USVI there were some FEMA workers who consistently went “out into the trenches” to locate and assist people who could not leave their homes. Some FEMA staff were very active in engaging local disability leaders as valued partners, while others consistently avoided opportunities to collaborate.

## **2.1.2 Equal Access to FEMA Eligibility Process**

### **Obtaining FEMA Assistance**

Lack of equal access to FEMA services was raised by hotline callers, DHS listening session participants, key informants, and on stakeholder teleconferences. They enumerated barriers for people with disabilities which consistently prevented them from accessing or utilizing FEMA programs and services.

#### **2.1.2.1 Barriers to Equal Access in the FEMA Application Process**

To most effectively communicate the input from key informants, stakeholders and hotline callers, this discussion has been divided into two categories; barriers to equal access in applying for FEMA specific to the territories; and barriers to equal access encountered by disaster survivors with disabilities generally.

##### **2.1.2.1.1 Barriers to the application process specific to Puerto Rico and the US Virgin Islands**

Areas impacted by the disasters lost power, internet access and phone connectivity. Six months after the storm large portions of Puerto Rico and the US Virgin Island still do not have power, internet access or phone connectivity. Survivors were told, if they received any information at all, that they must apply for FEMA online. If they did not have internet some key informants wanted the option of completing a paper application forms, citing previous experience after hurricane Hugo and other disasters.

More than one key informant in the territories reported that they did not understand that people with disabilities had to apply for FEMA assistance before they could be eligible for FEMA services and they were never told that this was the case. It seemed counterintuitive to them that individuals would be required to apply for FEMA assistance when it was often impossible to do so.

#### **What worked:**

As was the case in previous disasters, what worked was utilizing disability leaders from Centers for Independent Living, Protection and Advocacy systems and University Centers for Excellence in Developmental Disabilities as well as people with disabilities who were deployed from Portlight and the Partnership who deployed to areas where people with disabilities were located. If they were unable to get to Disaster Recovery Centers they were provided internet access, where there was connectivity, so that survivors could apply for FEMA assistance online with their support.

### **2.1.2.1.2 Barriers to the application process that occurred primarily in the territories**

Disaster survivors with disabilities did not have equal access to the FEMA application process. Some people with disabilities could not leave their homes to get to sites where they could apply for FEMA. The reasons ranged from the fact that they were power dependent and needed life-saving equipment in order to leave; roads were blocked and they were unable to traverse them in wheelchairs or they lacked conventional or accessible transportation to get to the site. Those who were able to get to the site to apply for FEMA encountered additional barriers to equal access.

Survivors with and without disabilities were required to wait in long lines to register for FEMA services. This was often a significant barrier for people with disabilities. Unlike many barriers to equal access encountered by children and adults with disabilities, lines are a relatively simple problem with a relatively simple solution, that being line management. Long unmanaged lines had a disproportionate impact on people with a wide array of disabilities. This included people whose disability impacted their ability to stand as well as people who because of anxiety and other psychiatric disabilities, autism and ADHD could not tolerate standing for hours. Long lines had a disproportionate impact on families with children with disabilities. This was because their parents and caregivers could not leave them unattended while they waited in line and because they were subsequently denied access to programs and services that were only available at the end of those long lines.

In areas where individuals could apply by phone there were sometimes day-long hold times which is particularly problematic when survivors do not have access to power to charge phones or when they are deaf or hard of hearing and others who could not multitask while waiting on hold. Once again, the long hold disproportionately impacted children and adults with disabilities including individuals who are deaf or hard of hearing and people with mental health disabilities, autism, ADHD, chronic health conditions and mobility disabilities.

#### **What worked:**

In Texas Man II Man, a group of fathers of children with autism coordinated respite so that parents could wait in line to register for FEMA, goods and other services while their children were cared for.

Some key informants reported that there was informal line management by disaster survivors.

As was the case in the territories, some disability organizations brought laptops to register survivors with disabilities into the field. A Center for Independent Living in Florida that was destroyed by the storm deployed all staff into the field.

### **Recommendation Part IV – Section 2.4**

**Deploy FEMA laptop-equipped staff in the field in numbers in proportion to the impact of the disaster. Their responsibility should include locating disaster survivors with disabilities, performing wellness checks and registering disaster survivors for FEMA.**

### **Recommendation Part IV – Section 2.5**

**Develop comprehensive plans with implementation components that are regularly drilled for disasters where the entire power grid will not be functional.** These plans should assume that some survivors with disabilities will not be able to access shelters and Disaster Recovery Centers.

[Jump to List of Recommendations by Section \(Page 11\)](#)

### **Recommendation Part IV – Section 2.6**

**Develop and execute an actionable plan to with organizations and groups that are most likely to know the whereabouts of disaster survivors with disabilities.** These groups and organizations should include Centers for Independent Living, senior centers, local paratransit, psychosocial clubs, deaf clubs, disability specific groups the people with disabilities participate in regularly.

### **Recommendation Part IV – Section 2.7**

**Develop and execute an actionable plan whereby people who cannot wait in line due to their disabilities have access to FEMA services.**

### **Recommendation Part IV – Section 2.8**

**Increase phone and on the ground staff capacity in proportion to the disaster to respond to disaster survivors with disabilities.**

## **2.1.2.2 Equal access to the FEMA application process**

When disaster survivors with disabilities navigated the barriers to equal access described above, they discovered that the FEMA application form itself posed a barrier to equal access to FEMA programs and services.

Key informants, participants in the HHS listening session and hotline callers reported that people who were deaf or blind and people who had cognitive disabilities including learning disabilities, intellectual disabilities, autism, and dementia mental health disabilities were confused by the form. Barriers in the form led to incomplete and inadequate applications which resulted in delayed or denied services. Based on comments made by hotline callers it was likely that some applications were never filed at all.

### **Examples of Barriers to the Deaf Community**

Key informants reported that members of the Deaf Community repeatedly informed FEMA that the language used in the application form was not understandable to native American Sign Language (ASL) users. Note that ASL is a language with unique grammar, syntax and idiom. Native ASL users who read English may miss nuances of language. This complication is magnified given that native English speakers often found the form difficult to understand.

It was reported by key informants that FEMA instructed members of the deaf community to go to disaster recovery centers to get assistance from interpreters in completing the application form. It was

also reported that interpreters were often not present, and in Florida often not certified - the state of Florida does not require certification - and sometimes volunteers. It was reported that the Deaf Community was emphatic that the Disaster Recovery Centers did not work as a means of applying for FEMA or for obtaining other services.

### **Example of barriers to people who are blind and have low vision**

A participant in the DHS listening session reported not being able to navigate the application form.

### **Examples of barriers to people with cognitive, mental health and intellectual disabilities**

Numerous Hotline callers with cognitive, mental health and intellectual disabilities reported that they were unable to complete the application form. They found it confusing to the point of being unusable.

While an improved form would alleviate barriers for many people with disabilities, the reality is that there are people who do not have the ability to utilize a computer because of their disability. Hotline callers and participants in the HHS listening session expressed the need for an alternative method of completing the application form when one does not have an access to a computer and/or lacks computer skills as did key informants in Puerto Rico who recalled paper applications after hurricane Hugo.

### **Barriers to identifying that an individual or household member has a disability**

Critically, it was difficult for anyone to identify on the form that the applicant or a member of their household has a disability. The disability-related questions are unclear. If an individual does not answer the question correctly the first time it is almost impossible to rectify the situation. This problem is not new. Given that this barrier has been identified for years it is unapparent why it has not been remedied.

A key informant was of the opinion that the fact that it is not specified what, if any, benefits applicants with disabilities may receive, could prohibit some survivors from disclosing that they had a disability.

People with disabilities did not have equal access to the FEMA registration process AND once they applied they had no consistent means of identifying themselves as a person with a disability and/or their accommodation requirements. This problem has been identified for years without resolution.

People with disabilities did not have equal access to the FEMA registration process AND once they applied they had no consistent means of identifying themselves as a person with a disability and/or their accommodation requirements. This problem has been identified for years without resolution.

### **What worked:**

Disability organizations including Centers for Independent Living and Protection and Advocacy systems were able to assist some survivors with disabilities in completing the form. Often the Hotline referred callers to their local organizations.

### **Caveat**

To the degree that this was a solution, it was only viable for survivors with disabilities who had the information, connectivity and ability to contact these organizations. Even with assistance, the forms and process remain flawed, making it difficult for anyone to identify that an individual had a disability.

## **Recommendation Part IV – Section 2.9**

**Redesign and publish the FEMA disaster assistance application, engaging knowledgeable disability community leaders as subject matter experts throughout the revision and implementation of the updated registration process.**

The application form must allow applicants to revise and update their response to disability related questions when necessary. It must also describe specific benefits in the instructions for identifying applicant and household member disabilities and the accommodations they may need in multiple formats including pictograms, plain language and in compliance with all Rehabilitation Act Section 508 accessibility mandates.

## **Recommendation Part IV – Section 2.10**

**Publish the FEMA disaster assistance process for applicants with disabilities who require accommodations for equally accessing the registration process in multiple formats including pictograms, plain language and in compliance with all Rehabilitation Act Section 504 and 508 accessibility mandates.**

### **2.1.3 Equal access throughout the FEMA Appeals Process**

Often FEMA denials were found to be a result of clerical errors or incorrectly reported information. Many people were ultimately approved for FEMA assistance after multiple appeals. Key informants reported that applicants with disabilities were frequently denied, leading to questions about the role of accessibility throughout the application process.

The same barriers in the application form that prevented equal access to disaster survivors with disabilities also seemed to inhibit equal access to the appeals process. Once again, disaster survivors with disabilities struggled with a prohibitively complex and inaccessible form; inability to access or use a computer due to their disability; long telephone hold time; long waits in on-site lines, and other barriers to access. Additionally, key informants, hotline callers and stakeholders on teleconferences reported that they were given conflicting and often erroneous information about the appeals process.

Key informants, hotline callers and DHS listening session participants reported that often adult children and grandchildren filed initial applications for family members with disabilities but did not share passwords, adding complication to the appeal process.

Survivors were told that they must get bids from three contractors and fax quote when filing an appeal. This disproportionately impacted survivors with cognitive and communication disabilities who because of their disability had more difficulty communicating with contractors. Hotline callers also reported not understanding inspector's instructions or the appeals process.

Stakeholders on teleconferences and participants in the HHS listening session reported that organizations and people with disabilities are running up against roadblocks to appeals. People with disabilities are being denied eligibility because they lack documentation and that they cannot stop the appeals clock while trying to obtain it. This situation has a disproportionate impact on people with disabilities who lack transportation or the ability to understand steps that are presented to them in ways that they have reported to be too complex, hard to understand and frequently contradictory. This is especially problematic for disaster survivors from the territories who evacuated from the island because of their disability and are unable to monitor the situation at their home.

*When disaster survivors in shelters signed up with FEMA, they were informed that they had “started the clock”. This was described as having 21 days to provide the documentation needed to process the claim. This was often difficult to achieve because many people were not home and also didn’t have access to the internet. Once they were notified of their denial and subsequently able to access the disaster assistance website, they were given the option to appeal. Once they selected the appeal button, they triggered a new clock with a 60 day duration and no further options. There was no option offered to request disability accommodations to make the process accessible. [Paraphrased from the DHS Texas listening session]*

Key informants also raised concerns about the impact of denials on eligibility for other non-disaster or supplemental disaster programs. Triggering the appeals process did not help these individuals to avoid interruption of other critical services and supports required to enable them or their family to continue with their recovery process

#### **What worked:**

Disability organizations including Centers for Independent Living and Protection and Advocacy systems were able to assist some people with disabilities in filing an appeal or multiple appeals. Often this connection was made by referrals from the Partnership hotline.

In some instances hotline operators were able to contact FEMA staff and apprise them of the immediate situations of specific survivors with disabilities. On some occasions FEMA was able to assist in resolving immediate needs.

#### **Caveat**

***This did not help people with disabilities who did not know about or have access to these organizations, or to the hotline.***

### **Recommendation Part IV – Section 2.11**

**Increase applicant services capacity to provide disability accommodation experts to applicants and appellants with disabilities.** This increase must be in proportion to the projected impact on disaster survivors with disabilities, i.e. if there are 1000 applicants, it is expected that over 200 will require disability accommodations. Additionally, it is anticipated that there will be many other applicants who have access and functional needs and who will also benefit.

### **Recommendation Part IV – Section 2.12**

**Conduct an analysis of the number of, and reason for denials that are overturned.**

### **Recommendation Part IV – Section 2.13**

Use these data to correct the application process, eliminating the underlying causes of erroneous denials.

### **Recommendation Part IV – Section 2.14**

In the revision and publication of the FEMA application form, correct all identified barriers to eligibility all in multiple formats including pictograms, plain language and in compliance with all Rehabilitation Act Section 504 and 508 accessibility mandates with the goal of mitigating user errors, providing equal access and optimizing results.

### **Recommendation Part IV – Section 2.15**

Provide accommodations to appellants with disabilities throughout the appeals process to facilitate all of the requirements without penalty. For example, the process by which appellants locate and provide documents may need to be extended.

### **Recommendation Part IV – Section 2.16**

Publicize the appeals process and instructions for appeal in a plain language document in multiple formats, widely disseminated to the public, internally to all FEMA applicant services providers and other federal, state, territorial and local government and non-government application services providers.

### **Recommendation Part IV – Section 2.17**

Review current notification processes for denials and appeal rights with community partners who have knowledge of local language, culture and FEMA applicant services experience.

#### **2.1.3.1 Inspection**

There were frequent reports of inadequate communication with applicants by inspectors and other FEMA staff resulting in disproportionate impact for survivors with disabilities. Hotline callers with disabilities reported not knowing when inspectors were coming, not having transportation in time to meet the inspector, not having a sign language interpreter provided despite requesting one, not understanding inspector's instructions and not being able to comply with instructions as they understood them.

##### **What worked:**

Once again, Centers for Independent Living and other disability organization often referred by the hotline were able to assist survivors in understanding the results of the inspection and taking further action.

### **Recommendation Part IV – Section 2.18**



**Publicize the inspection process and instructions for preparing for a home inspection in existing plain language documents in multiple formats, widely disseminated to the public, internally to all FEMA and contract inspectors and other federal, state, territorial and local government and non-government application services providers to assist disaster survivors to understand the inspection process.**

### **Recommendation Part IV – Section 2.19**

**Review current inspection process with community partners who have knowledge of local language, culture and FEMA home inspection experience, as well as knowledge of disability accessibility features, equipment and devices that may have been damaged or destroyed.**

### **Recommendation Part IV – Section 2.20**

**Increase applicant services capacity to provide disability accommodation experts throughout the inspection process .This increase must be in proportion to the projected impact on disaster survivors with disabilities.**

#### **2.1.3.2 Habitability**

Hotline callers reported to that uninhabitable housing had been deemed habitable. Housing impacted by mold was not deemed uninhabitable. This poses an additional burden on people with disabilities like COPD.

On stakeholder calls the life-sustaining needs of disaster survivors who require uninterrupted power was a recurrent topic. When disaster survivors with disabilities questioned why their eligibility for Transitional Sheltering Assistance had ended, they were informed that their home had been deemed “habitable”. For some, the discontinuance of Transitional Housing Assistance was complicated by their location. For disaster survivors from the US Virgin Islands and Puerto Rico who had evacuated to mainland hotels, assessing habitability was often impossible. For individuals who require uninterrupted power for respiratory, feeding and other life support devices, habitability was contingent upon the availability of uninterrupted power.

Transitional Sheltering Assistance (TSA) is funded by FEMA but only provided at the request of the state or territory. This program is provided to eligible applicants until their home is deemed “habitable” (among other criteria). Once the decision to discontinue TSA is made by the state or territory, whether or not the home is habitable no longer seems to be a TSA eligibility criteria. For disaster survivors with disabilities who require uninterrupted power, the determination of habitability may have been considered for their community, and not for their individual needs. When TSA was discontinued, these individuals had no alternatives. They cannot remain in the TSA hotel and they cannot return home to their damaged dwelling, without assurance of uninterrupted power.

#### **What worked:**

Identifying specific examples on Stakeholder teleconferences, persistently raising concerns about life safety for disaster survivors, and seeking solutions for their individual circumstances.

### **Recommendation Part IV – Section 2.21**

**Implement policies requiring provision of uninterrupted power as a condition of habitability for individuals who are power dependent, including a policy for TSA continuation.**

## **2.1.4 Transitional Sheltering Assistance**

In order to qualify for Transitional Sheltering Assistance (TSA) one has to have successfully completed a FEMA application and be deemed eligible. For the reasons described above, disaster survivors with disabilities did not have equal access to this process. In addition, there was considerable confusion about who qualified for TSA and how they would be notified. Many hotline callers, particularly those with cognitive disabilities, reported that they thought that the TSA application process was different from the overarching FEMA application process.

Even when people with disabilities were approved for TSA, they still did not have equal access. A key informant (RP) reported that members of the deaf community sometimes left TSA hotels early, because it was not made clear to them how long they were permitted to stay in hotels under TSA. It appears that there were deaf people to who did not receive equally effective communication regarding TSA and TSA extensions.

Some of the barriers to equal access stem from ambiguity about identifying that an applicant or household member had a disability and what their accommodation needs were. For instance, survivors were unable to communicate that they or a member if their household needed accessible bathrooms or were not able to safely share a bed.

A young man with paraplegia was told that he must share a bed in a TSA hotel room. He had nighttime urinary incontinence necessitating that he transfer onto the floor to change his clothes during the night. He developed pressure sores from transferring in the floor. He was placed in a rehabilitation/nursing facility because of injuries he sustained because FEMA required him to share a bed.

***FEMA requiring this individual to share a bed resulted in him being unnecessarily institutionalized.***

**When the hotline contacted FEMA, the hotline operator was told that people in TSA hotel rooms must share a bed. In this case, there were four people in a room with two beds. When questioned, the FEMA representative responded that had the individual with a disability notified FEMA that he had a mobility disability, he would not have been required to share a bed.**

***There was no reliable way for him to do this.***

A leader of a father's group for children with autism reported that families with members with autism told him they often felt unwelcome in TSA hotels.

A young man with paraplegia was told that he must share a bed in a TSA hotel room. He had nighttime urinary incontinence necessitating that he transfer onto the floor to change his clothes during the night. He developed pressure sores from transferring in the floor. He was placed in a rehabilitation/nursing facility because of injuries he sustained because FEMA required him to share a bed.

The manner in which TSA is administered imposed burdens on all disaster survivors. But the burdens had a disproportionate impact on survivors with disabilities. For example, people are granted TSA vouchers for a relatively short amount of time. Typically this period was extended at the last minute. It has been reported that this is done to encourage disaster survivors to find permanent housing. This strategy comes at a high cost to all disaster survivors, but it comes at a disproportionate cost to adults and children with disabilities who have even fewer options for accessible and affordable housing in proximity to the disability related services they require.

While the burden of uncertainty about temporary housing doubtlessly caused anxiety for all recipients of FEMA services, it imposed additional anxiety for adults and children with anxiety related disabilities including mental health disabilities, autism, and dementia.

#### **What worked:**

Hotline operators, when apprised of situations where people with disabilities did not have equal access, called local FEMA staff who were sometimes able to resolve TSA related issues.

### **Recommendation Part IV – Section 2.22**

**Set TSA discontinuation dates utilizing a realistic timeline for acquiring accessible and affordable housing in their community taking into account the impact of the disaster on available housing stock and the functionality of the power grid and community resources such as accessible transportation, groceries and disability and community services.**

### **Recommendation Part IV – Section 2.23**

**In the revision of the FEMA application, individuals and households must be able to document their disability related housing needs and requirements.**

### **Recommendation Part IV – Section 2.24**

**Clarify civil rights compliance requirements for TSA hotel contracts for accommodating adults and children with disabilities, including people with mental health disabilities and autism.**

## **3.1.5 Equal Access to the Programs and Services of the Office of Civil Rights and Civil Liberties**

### **The Agency and Its Obligations**

The Office for Civil Rights and Civil Liberties (CRCL) supports the Department [of Homeland Security's] mission to secure the nation while preserving individual liberty, fairness, and equality under the law. CRCL integrates civil rights and civil liberties into all of the Department activities:

- Promoting respect for civil rights and civil liberties in policy creation and implementation by advising Department leadership and personnel, and state and local partners.

- Communicating with individuals and communities whose civil rights and civil liberties may be affected by Department activities, informing them about policies and avenues of redress, and promoting appropriate attention within the Department to their experiences and concerns.
- Investigating and resolving civil rights and civil liberties complaints filed by the public regarding Department policies or activities, or actions taken by Department personnel.
- Leading the Department's equal employment opportunity programs and promoting workforce diversity and merit system principles.<sup>13</sup>

### **Barriers to receiving civil rights protection**

In its letter of October 23, 2017, the House Committee on Homeland Security states that “we understand that CRCL has failed to take meaningful action in response to complaints of civil rights violations from individuals with disabilities...” (see Appendix A). The Committee requested that DHS provide complaints received by CRCL and their resolution as well as the processes that it uses to investigate and resolve complaints. **As of the publication of this After Action Report, there has been no response to this request made pursuant to Rule X and Rule XI of the House of Representatives.**

The Officer of the Office of Civil Rights and Civil Liberties held two national calls to hear from stakeholders about their disaster related civil rights and civil liberties concerns. Stakeholders expressed frustration with the logistics of the first call. On the first call there were delays and problems with spoken language interpreters. Stakeholders reported having little if any opportunity to provide input during these calls.

#### **What worked:**

Staff members from the Office of Civil Rights and Civil Liberties were the only federal representatives who consistently attended and participated on stakeholder calls.

The CRCL Officer held a well-attended listening session in Houston where people with disabilities, service providers and family members were able to offer considerable feedback about both what did and did not work during hurricane Harvey.

Additional listening sessions were held in California, and more are scheduled for Florida, the US Virgin Islands and Puerto Rico.

### **Recommendation Part IV – Section 2.25**

The Secretary of the Department of Homeland Security should provide a full response to the House Homeland Security Committee questions relevant to CRCL in response to the October 27, 2017 deadline.

## **2.2 Equal Access to Programs and Services of the Department of Health and Human Services (HHS)**

<sup>13</sup> [Office for Civil Rights and Civil Liberties](#)

Within the Department of Health and Human Services (HHS) the Office of Civil Rights (OCR), Office of the Assistant Secretary for Preparedness and Response (ASPR), Administration for Children and Families (ACF), Centers for Disease Control and Protection (CDC) and the Administration for Community Living (ACL) share most of the HHS preparedness, response and recovery functions.

## **2.2.1 Equal Access to Programs and Services of the Office of the Assistant Secretary for Preparedness and Response (ASPR)**

### **The Agency and Its Obligations**

The mission of the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR) is to save lives and protect Americans from 21st century health security threats.

ASPR leads the nation’s medical and public health preparedness for, response to, and recovery from disasters and public health emergencies. ASPR collaborates with hospitals, healthcare coalitions, biotech firms, community members, state, tribal, territorial and local governments, and other partners across the country to improve readiness and response capabilities.

The Office of the Assistant Secretary for Preparedness and Response (ASPR) has a very clearly defined obligation to provide equal access throughout all aspects of their work in carrying out Emergency Support Function #8. The requirements of the Rehabilitation Act, the Americans with Disabilities Act, and other civil rights laws are not waivable. Despite this, some of the most significant gaps in services to disaster survivors with disabilities occur under the umbrella of public health and medical services. For the 59 million Americans with disabilities, acute medical care is often not needed, however the need for health maintenance is of paramount importance throughout disaster response and recovery for both individuals and for the overall resilience of the whole community.

## **2.2.2 Access to Programs and Services from the Administration for Community Living (ACL)**

### **The Agency and Its Obligations**

“All Americans—including people with disabilities and older adults—should be able to live at home with the supports they need, participating in communities that value their contributions. To help meet these needs, the U.S. Department of Health and Human Services (HHS) created the Administration for Community Living (ACL) in 2012. its mission is to Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

ACL brings together the efforts and achievements of the Administration on Aging (AoA), the Administration on Intellectual and Developmental Disabilities (AIDD), and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan”.<sup>14</sup>

### **Barriers**

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<sup>14</sup> [About ACL](#)

In a call between members of the National Council on Independent Living and the Administration for Community Living, the Florida Centers for Independent Living were informed that they could not use federal funds for providing food and water to disaster survivors. The Centers were also informed of a number of other restrictions on their life-saving and life-sustaining efforts to assist disaster survivors with disabilities.

#### **What worked:**

Continued advocacy finally led to a subsequent meeting in April, 2018, with a promise of further written guidance on the use of federal funds to serve the immediate needs of disaster survivors with disabilities. As of the publication of this After Action Report, this guidance has not yet been issued and food and water distribution has not been resolved.

### **Recommendation Part IV – Section 3.1**

**The Administration for Community Living must issue clear guidance to Centers for Independent Living and State independent living Councils regarding the use of federal funds to provide life-saving and life-sustaining services and resources to people with disabilities in disasters.**

## **2.2.3 Equal Access to Programs and Services from the Administration for Children and Families**

### **The Agency and Its Obligations**

The HHS Administration for Children and Families' mission is to foster health and well-being by providing federal leadership, partnership and resources for the compassionate and effective delivery of human services.<sup>15</sup>

The ACF includes "The Office of Human Services Emergency Preparedness and Response (OHSEPR) promotes the resilience of vulnerable individuals, children, families and communities impacted by disasters and public health emergencies, and provides expertise in human services preparedness, response and recovery through policy, planning, operations and partnerships".<sup>16</sup>

Among other responsibilities, ACF leads the federal Disaster Case Management program. Competence in disability culture and accessibility is required throughout disaster case management. However, historically and repeatedly, disaster case management services are contracted to social services organizations without the expertise required to comply with their civil rights obligations to disaster survivors with disabilities.

### **Recommendation Part IV – Section 3.2**

**Local disability led organizations must be considered as the provider of first resort and given the resources to provide the comprehensive and locally sourced programs and services needed by disaster survivors with disabilities in their community.**

<sup>15</sup> [ACF Vision, Mission, & Values](#)

<sup>16</sup> [ACF Fact Sheet \(PDF\)](#)

Disability led local organizations are always the most knowledgeable and skilled providers of disaster case management services for the residents of their communities. They do need additional resources to add unanticipated disaster related services without diminishing their existing programs and services.

**The U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) enforces federal civil rights laws, protect fundamental rights of nondiscrimination, conscience, religious freedom, and health information privacy.**

## **2.2.4 Equal Access to Programs and Services of the Office for Civil Rights**

### **The Agency and Its Obligations**

The Office for “Civil Rights for Individuals and Advocates...enforce[s] laws against discrimination based on race, color, national origin, disability, age, sex, and religion by certain health care and human services.

Covered entities must:

- Provide services and programs in the most integrated setting appropriate to the needs of the qualified individual with a disability
- Ensure that programs, services, activities, and facilities are accessible
- Make reasonable modifications in their policies, practices, and procedures to avoid discrimination on the basis of disability, unless it would result in a fundamental alteration of the program
- Provide auxiliary aids to persons with disabilities, at no additional cost, where necessary to afford an equal opportunity to participate in or benefit from a program or activity

### **Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead**

The U.S. Supreme Court’s 1999 landmark decision in *Olmstead v. L.C.* (*Olmstead*) found the unjustified segregation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). The U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) plays a pivotal role in supporting the *Olmstead* decision and promoting community living through our vigorous enforcement of the ADA and other key civil rights laws.

OCR investigates complaints alleging a violation of the ADA's "integration mandate," which requires that individuals with disabilities receive services in the most integrated setting appropriate to their needs. This principle is central to the Supreme Court's *Olmstead* decision. The Court held that states are required to provide community-based services for people with disabilities who would otherwise be entitled to institutional services when: (a) such placement is appropriate; (b) the affected person does not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other individuals with disabilities.



During disasters, key informants, Hotline callers and the observations of Stakeholders all confirmed the disproportionate use of hospitals, nursing homes and other facilities as shelters. This has correlated with the failure to plan adequately for accommodating children and adults with disabilities in community/general population shelters.

In the document *Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning*, the US Department of Health and Human Services states that disaster survivors, “should not be institutionalized inadvertently. All people should be able to live in the least restrictive setting.” If survivors are inadvertently placed, discharge planning is an imperative. “Planning must focus on appropriate settings, but it may take time because necessary home and community supports need to fully recover in order to support independent living” .These individuals “must be connected to those resources and follow up must occur to ensure that acceptable services and supports are arranged. This can help confirm that the patients encounter the least restrictive environment.”<sup>17</sup>

### Recommendation Part IV – Section 3.3

**The US Department of Health and Human Services Office for Civil Rights must immediately identify all individuals evacuated from their homes and admitted to a medical or custodial facility beginning on August 25, 2017 and continuing until all disaster survivors with disabilities have obtained permanent housing.** All individuals who were placed in a more restrictive setting than their home must be provided with discharge planning and necessary services and supports for returning to the least restrictive environment in order to adhere to HHS policies and obligations.

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## Part IV - Section 3: Maintaining Health

**“Traditional definitions describe health and disability at opposite ends of a single health continuum. Such definitions lead far too many people to view health and disability as mutually exclusive of each other; an either/or proposition.”<sup>18</sup>**

Health includes a dynamic balance of physical, social, emotional, spiritual and intellectual factors. When this definition is used, disability poses no obstacle to maximizing health and one’s potential.<sup>19</sup>

Health providers, like society at large have the same, if not stronger misunderstandings about the health of people with disabilities. People working in medical settings and emergency responders constantly have these stereotypes reinforced, often because they are only exposed to people with disabilities and chronic conditions who are sick. When medical and emergency personnel do not understand the health maintenance needs of people with disabilities, this translates into decisions that affect the health maintenance resources provided to people with disabilities throughout evacuation, sheltering and recovery. While disability and long-term health conditions can involve illness and pain, disability and health can and do coexist. Most people with disabilities are not sick.

<sup>17</sup> [Working with Older Adults and People with Disabilities: Tips for Treatment and Discharge Planning](#)

<sup>18</sup> Kailes, J. (2000). [Can Disability, Chronic Conditions, Health and Wellness Coexist?](#) KAILES - Publications, [jik@pacbell.net](mailto:jik@pacbell.net).

<sup>19</sup> Lanig, I.S., Theresa M. Chase, Lester M. Butt & Kathy L. Hulse., *A Practical Guide to Health Promotion after Spinal Cord Injury*. Aspen Publishers, Inc., Gaithersburg, MD., 1966. p.13.

They are healthy, when health is defined as the absence of illness and disease beyond disability. People with disabilities are disproportionately more susceptible to certain health and secondary conditions in emergencies. For example, some people with spinal cord injuries are more likely to have to deal with pressure sores, urinary tract infections and kidney conditions during evacuation and sheltering. People with respiratory conditions are more susceptible to respiratory infections in disaster environments.<sup>20</sup>

### 3.1 Emergency Support Function (ESF) #8

Among the fourteen Emergency Support Functions defined in the National Preparedness System, Emergency Support Function (ESF) #8 Public Health and Medical Services provides the mechanism for Federal assistance to supplement local, state, tribal, territorial, and insular area resources in response to a disaster, emergency, or incident that may lead to a public health, medical, behavioral, or human service emergency, including those that have international implications.

“ESF #8 provides planning and coordination of Federal public health, healthcare delivery, and emergency response systems to minimize and/or prevent health emergencies from occurring; detect and characterize health incidents; provide medical care and human services to those affected; reduce the public health and human service effects on the community; and enhance community resiliency to respond to a disaster. These actions are informed through integrated biosurveillance capability, assessment of health and human service needs, and maintenance of the safety and security of medical products, as well as the safety and defense of food and agricultural products under the Food and Drug Administration’s (FDA) regulatory authority.

Public health and medical services (e.g., patient movement, patient care, and behavioral healthcare) and deliver support to human services (e.g., **addressing individuals with disabilities and others with access and functional needs**) (emphasis ours) through surge capabilities that augment public health, medical, behavioral, and veterinary functions with health professionals and pharmaceuticals. These services include distribution and delivery of medical countermeasures, equipment and supplies, and technical assistance. These services are provided to mitigate the effects of acute and longer-term threats to the health of the population and maintain the health and safety of responders. ESF #8 disseminates public health information on protective actions related to exposure to health threats or environmental threats (e.g., to potable water and food safety).

ESF #8 may continue providing services and ensure a smooth transition to recovery while the community rebuilds their capability and assumes administrative and operational responsibility for services. ESF #8 provides supplemental assistance to local, state, tribal, territorial, and insular area governments in the following core functional areas:

- Assessment of public health/medical needs
  - Health surveillance
  - Medical surge
  - Health/medical/veterinary equipment and supplies
  - Patient movement
  - Patient care
  - Safety and security of drugs, biologics, and medical devices
  - Blood and tissues

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<sup>20</sup> Ibid Kailes, J. 2000

- Food safety and defense
- Agriculture safety and security
- All-hazards public health and medical consultation, technical assistance, and support
- Behavioral healthcare
- Public health and medical information
- Vector control
- Guidance on potable water/wastewater and solid waste disposal
- Mass fatality management, victim identification, and mitigating health hazards from contaminated remains
- Veterinary medical support<sup>21</sup>

## **Barriers to equal access to health maintenance under the Office of the Assistant Secretary for Preparedness and Response**

Barriers to equal opportunity to receive health care and ESF 8 services from the Department of Health and Human Services (HHS) were among the most devastating gaps repeatedly reported by stakeholders, key informants and hotline callers. These gaps were also consistently reported in traditional and social media.

For example, one of the gaps that was repeatedly raised but never resolved was the provision of oxygen to disaster survivors in Puerto Rico who were not in acute medical settings. Reportedly, there are over 50,000 individuals living in the community across Puerto Rico who use oxygen for maintaining their health and independence. Oxygen was previously manufactured and supplied on the island and provided to residents. When the manufacturing capability was indefinitely disrupted, there was no plan for providing an alternative source of oxygen. This critical life-saving and life-sustaining need seemed to fall squarely within the responsibility of ESF 8, however the focus of all of ASPR's efforts were on establishing hospital and medical facility operation, leaving no clear lead for meeting the health maintenance needs of thousands of disaster survivors who depend on receiving oxygen outside of medical facilities.

When the US Naval Ship Comfort arrived, it was assumed that their oxygen manufacturing capability would be utilized to meet these unmet needs, however it quickly became apparent that the hospital ship was only providing oxygen for facility-based care, further eliminating any immediate resources for non-institutional provision to disaster survivors with disabilities. While it is unclear what the outcome was for these individuals, it has to be assumed that the absence of oxygen was not compatible with survival.

Another striking gap in ESF 8 was the incomplete process of serving the dialysis and related needs of disaster impacted individuals from the US Virgin Islands. Approximately 200 people requiring dialysis and a companion were evacuated from the US Virgin Islands to San Juan during hurricane Irma. Then, these individuals were further evacuated to Atlanta in anticipation of hurricane Maria's landfall on Puerto Rico. These individuals were provided with hotel rooms and dialysis services but it quickly became apparent that their other needs and the needs of their companions had not been considered. It required intervention from government and non-government resources to begin to address basic needs such as food, transportation for non-dialysis needs, such as trips to the grocery store, and disability related medical equipment and supplies. The resources of the Partnership, Portlight, Pass It On Center, Trach Mommas and others were looked to as payers of first resort, rather than as a fundamental element of the ESF 8 function for maintaining health. As of publication there is no

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<sup>21</sup> [Emergency Support Function #8 – Public Health and Medical Services Annex \(PDF\)](#)

definitive timeline for restoration of dialysis services in the US Virgin Islands. These disaster survivors remain in hotels without a plan for them to return home or for permanent relocation. Despite repeated inquiries from stakeholders, the US Department of Health and Human Services has remained silent.

Disaster case management was not provided to these individuals until April, 2018.

#### **Recommendation Part IV – Section 3.4**

**Designate a position within HHS that is accountable for overseeing that the ESF 8 responsibilities are equally provided for all disaster survivors with disabilities.** This includes providing life-saving and life-sustaining health maintenance services, support and supplies such as oxygen, durable medical equipment, medication and accommodating dietary needs in non-medical settings in the community, i.e. in their home, community shelters or temporary housing.

#### **Recommendation Part IV – Section 3.5**

ASPR must provide a knowledgeable representative to regularly participate with stakeholders convened by the Partnership to report the status of ESF 8 response for maintaining the health of people with disabilities impacted by disasters.

#### **Recommendation Part IV – Section 3.6**

**ASPR must identify a process that can be replicated in future disasters when the health maintenance needs of disaster survivors cannot be met in their home state or territory.** This is required so that future evacuees do not languish under similar circumstances as the hundreds of disaster survivors from the US Virgin Islands, who were evacuated to Atlanta to continue dialysis treatments.

### **3.2 Service Delivery Interruption**

The disasters caused services delivered to people with disabilities to maintain their health to be interrupted, delayed and in some instances, discontinued. Interruption of services was particularly significant in Puerto Rico and the US Virgin Islands, where service providers have evacuated and are permanently relocating. Key informants from the territories have reported that the number of health professionals and caregivers who have evacuated from the island is disproportionately impacting children and adults with disabilities who require physical, occupational, speech, psychological and other therapy and for personal assistance with activities of daily living.

#### **Recommendation Part IV – Section 3.7**

**Establish contracts for deploying federally funded qualified temporary staffing to maintain disability and health maintenance services throughout disaster and evacuation related service interruptions.**

#### **Recommendation Part IV – Section 3.8**

**Contract with disability led organizations to recruit and train personal assistance service providers utilizing self-determination principles. Utilize these service providers to assist disaster survivors with disabilities to maintain their health, safety and independence in their home and community, preventing unnecessary placement in nursing homes and hospitals.**

## **Recommendation Part IV – Section 3.9**

**Conduct a study to identify promising practices for supporting service providers to maintain continuity of service delivery throughout disaster response and recovery. This may include incentives, considerations for meeting family needs and other alternatives to permanent relocation after evacuation.**

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### **3.3 Meeting the Durable Medical Equipment Needs of People with Disabilities**

The Pass It On Center (PIOC), the National Assistive Technology Device Reutilization Coordination and Technical Assistance Center, collaborates with the Partnership and Portlight to respond to the assistive technology (AT) needs, including durable medical equipment, of people affected by disasters. The availability of AT is often a significant factor in the ability of individuals affected by disaster to cope with the ensuing recovery process. The need for interim AT devices is caused by the potential loss of existing AT used by people with functional needs (e.g., the AT in use prior to the event), by new needs arising from injuries caused by a disaster, and by the disruption in normal services and supplies that support individuals with functional needs in their everyday lives. Reutilized assistive technology, especially durable medical equipment, plays an important role in providing temporary devices to people with disabilities when the normal replacement process is disrupted. For some affected persons without insurance or financial resources, the reused device becomes a permanent solution.

#### ***The Role of Pass It On Center and AT Act Programs in Disaster Response***

Formed in 2006 to improve and expand the safe, effective, and appropriate reutilization of assistive technology for people with disabilities, PIOC provides technical assistance to the 56 state and territorial AT Act Programs ([Assistive Technology Act of 2004, 108th Congress Public Law 364](#)) and their nonprofit partners, including Centers for Independent Living, University Centers on Disabilities, Area Agencies on Aging, and disability advocacy organizations. PIOC partners with other organizations that serve individuals with disabilities to respond to disasters by facilitating the matching of identified needs by responding organizations with resources from AT Act Programs and their partners. Assistive Technology (AT) reuse became a mandated activity for the Tech Act Programs in 2004. Although some reuse programs participated in disaster response, no formal, coordinated role was proposed until Pass It On Center hosted the first National Leadership Summit on Emergency Management and Assistive Technology Reutilization in February 2010 in Washington, DC. Summit participants from a wide range of responding organizations identified key issues affecting outcomes for people with disabilities and mapped a three-year action plan to address those issues. Pass It On Center became a unifying point for providing education and training, and for the coordination of emergency response with both the Assistive Technology (AT) Act Programs and volunteer organizations in support of people with disabilities. In any disaster, a call to PIOC for assistance triggers the resources of the informal network.

Managed by Tools for Life, Georgia's Assistive Technology Act Program, and hosted by AMAC Accessibility Solutions and Research Center within the College of Design at the Georgia Institute of Technology, PIOC is based in Atlanta. This unique position provides the PIOC with access to innovative resources and research initiatives. A few partnering programs within Georgia Tech have already begun the process of analyzing notes, recordings, processes, and protocols over the past few months to identify needs and specific trends related to the individuals with disabilities during emergencies. It is the hope of PIOC, along with the support of the Partnership and Portlight, that these research initiatives, coupled with the real-time response within the affected communities, can provide solutions to the response and execution of services supporting the unique needs of individuals with disabilities in times of disasters.

### **Pass It On Center's Collaboration with the Partnership**

Over the years Pass It On Center (PIOC) had worked frequently with Portlight in disaster response, but in 2017, beginning with Hurricane Harvey, PIOC worked with the Partnership for Inclusive Disaster Strategies and Portlight to coordinate response to overwhelming needs precipitated by Harvey and subsequent disasters. Those efforts resulted in a massive expansion and coordination of volunteer efforts and in the joint development of an [online software portal for the reporting and tracking of needs and donations of Assistive Technology \(AT\)](#).

During the hurricanes and wildfires in the months following, PIOC hosted daily conference calls to address reported needs and to identify resources. Even now, those calls continue weekly. The PIOC and Partnership collaboration ensures that these weekly calls remain a success, providing a platform for key disaster relief and emergency response stakeholders in the assistive technology and disability communities to come together to coordinate and provide resources for collecting, shipping, storing, and appropriately matching assistive technology and durable medical equipment to those in need. Those joint efforts resulted in the donation of more than 24,000 [TR1] devices to individuals affected by hurricanes, flooding, and wildfires in the period spanning September 2017 through March 2018.

### **Barriers to Meeting Assistive Technology/Durable Medical Equipment Needs**

Although extensive resources were made available by donor organizations, the scope and severity of the disasters highlighted vital gaps in response infrastructure:

1. The need for an enhanced technology-based resource to capture and report on the reported needs, the available resources, and the matching of needs and resources.
2. The need for expedited procedures for replacement of Assistive Technology/Durable Medical Equipment provided by the largest purchasers in the nation, i.e., Medicare and Medicaid.
3. The need for greatly improved planning for channels of delivery and distribution of donated equipment and supplies to disaster-affected areas.
4. The need for caches of the most commonly needed durable medical equipment devices at strategic locations, and a uniform process to attempt to recover equipment into donor inventories when it is no longer needed.
5. Despite the long advocacy for the inclusion of people with disabilities into the community and state disaster planning process, this has not happened to a degree sufficient to ensure seamless interfaces among the existing agencies and resources.



### Recommendation Part IV – Section 3.10

**Increased automation for information sharing.** Although in the middle of the Hurricane Harvey crisis the Partnership and Portlight created an online portal to capture information about needs and donations, this tool could be enhanced to minimize some of the intensive commitment of time required to match donations to need and to provide a more detailed reporting infrastructure to document needs.

### Recommendation Part IV – Section 3.11

**An improved process for replacement of CMS-purchased durable medical equipment.** As the largest payers for durable medical equipment, Medicaid and Medicare hold the keys for immediate and dramatic improvement in the replacement of durable medical equipment lost or damaged in disasters. This could expedite the delivery of permanent solutions for a large number of affected individuals. Pass It On Center is working with the Centers for Medicare and Medicaid Services (CMS) and FEMA to create a webinar to educate responders about the replace of CMS-purchased durable medical equipment. However, PIOC recommends that the process itself change. The current procedure requires the beneficiary to obtain a copy of the original prescription from the prescribing physician and contact the original device provider for replacement. These conditions may be impossible to meet due to the dislocation of both beneficiaries and providers in the aftermath of disasters. However, information about the provider of the device and the device itself are contained in the request for reimbursement submitted by the durable medical equipment provider. That provider is required to have on file the Detailed Written Order (DWO) from the physician with prescription specifics about the type of device required, and when applicable, the settings for that device. If CMS required durable medical equipment providers to submit the DWO with the request for reimbursement, it would become part of the electronic record. Then, presumably, arrangements could be made to provide access to retrieve those key pieces of information from any location to facilitate replacement of durable medical equipment.

### Recommendation Part IV – Section 3.12

**The need for drastically improved channels for delivery of equipment is addressed in other sections of this report.** Delivery solutions would minimize delays in providing critical durable medical equipment devices.

### Recommendation Part IV – Section 3.13

**Recovery of lightly used durable medical equipment. In most current instances, the donation of AT is permanent.** However, it is desirable to recover the temporary devices when a permanent replacement is found to replenish the stores for the next disaster. It would be helpful to **implement a uniform national system to encourage the return or donation of devices that are no longer needed to partners of the AT Act Programs for future use.** These would not need to be returned to the donor, but instead to the nearest reuse program for future use. This could be facilitated by labeling devices.

### Recommendation Part IV – Section 3.14



**Research to identify community-based solutions.** PIOC proposes to work with the Partnership and other responders in participatory research to inform improved solutions for response within the affected communities. Funding for this research is being sought now.

The Pass It On Center, the Partnership for Inclusive Disaster Strategies, and Portlight, along with a number of national organizations share objectives in improving and maintaining the quality of life of people with disabilities, and in securing equal assistance in disaster response. Pass It On Center stands ready to assist in the improvement and expansion of the scope and quality of disaster response for people with disabilities.

The Pass It On Center and the Partnership collaborated with Trach Mommas. Trach Mommas brought their wealth of personal disaster experience and played a pivotal role in connecting the Hotline and the national network of Assistive Technology organizations. They refined their ability to acquire, match and transport the critical supplies and equipment that enable children and adults with disabilities to maintain their health and independence in the aftermath of disasters. Examples of their success included getting the first shipment of medical supplies to Puerto Rico when disability leaders were told it couldn't be done. They partnered with their Governor and the National Guard by shipping directly to a local organization in San Juan, bypassing delays at the Port that extended for months. They partnered with Protect TX Fragile Kids to deliver ostomy supplies to an older woman in a flooded area of Houston within an hour of her grandson's call to the Hotline. The lived experience of the Trach Mommas was further demonstrated when a caller to the Hotline needed guidance on how to evacuate with her child from Texas to Louisiana while managing her child's various life support equipment.

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### 3.4 Health Plans

Many of the key informants for this section represent Medicaid Managed Care Health Plans. Most of the content pertains to all health insurance carriers as well as organizations that focus on supporting the health and health care of people with disabilities and others with access and functional needs. This includes non-governmental organizations and government agencies such as the Veterans Administration, local disability service providers, disability-specific organizations (muscular dystrophy, cerebral palsy, multiple sclerosis, blind, deaf, hard of hearing, autism, mental health, developmental disability, etc.), Easter Seals, community clinics, Federally Qualified Health Centers, equipment vendors, and home health agencies.

Health plans in this report refer to health insurance plans across all lines of business: employer-sponsored coverage, individual insurance market, and public programs (Medicare and Medicaid). Health plans can serve a critical role in life-saving and life-sustaining interventions and mitigating these disruptions and disproportional impacts.

Health plans such as Anthem Blue Cross Blue Shield, Amerigroup, Superior Health Plan in Texas and Sunshine Health® in Florida (Superior and Sunshine are wholly-owned subsidiaries of Centene Corporation) are examples of plans that quickly activated their emergency response plans. This operationalizing included, but was not limited to: messaging, life-safety checks, member tracking, quickly sharing critical

Like the disability service community providers, health plans should be on the front lines of protecting, addressing and maintaining the critical health needs of members, before, during and after an emergency.

health information, preventing and diverting inappropriate admissions to medical facilities and institutionalization, and commitment to the continuous strengthening of their emergency plans during and after their response.

Examples of some of these health plans' promising practices are described throughout this section as well as reflected in the recommendations that follow. A common thread emerged. These health plans, and probably others we lacked time to identify, had a strong "perception of threat." These plans operate from the "not if, but when" risk of real and reoccurring disasters. These health plans acknowledged that their members live in high hazard threat and disaster probability areas. Because of this, these health plans have robust policies, training, processes, procedures and protocols.

All health plans should be proactive in addressing the inevitable degrading or failure of critical member personal support systems during disasters, which include equipment, supplies, technologies and customized environments that typically work in non-emergency times. These support interventions have direct and substantial impact on the health of their members, and their degradation and failure has a devastating impact on the health, safety and independence of their members.

Rapid health plan response can also mitigate the disturbing trend in disasters of transfer of people with disabilities who lived in the community to institutional settings because of planning failures including lack of health care options, post-shelter housing options and difficulties these individuals have in accessing and navigating the complex maze of disaster recovery assistance.

**Like the disability service community providers, health plans should be on the front lines of protecting, addressing and maintaining the critical health needs of members, before, during and after an emergency.**

The speed at which health plans activate their emergency response plans has a direct correlation to life-sustaining outcomes for many who can be disproportionately impacted. Rapid health plan response can also mitigate the disturbing trend in disasters of transfer of people with disabilities who lived in the community to institutional settings because of planning failures including lack of health care options, post-shelter housing options and difficulties these individuals have in accessing and navigating the complex maze of disaster recovery assistance.

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## Recommendation Part IV – Section 3.15

**Emergency Preparedness Should Include Member Needs.**

### Health Plan Roles

Health plans emergency preparedness must go beyond the implementation of business continuity plans to also include member needs.

## Planning

### Call Centers

Establishing call center emergency protocols including just-in-time training, developing and use of scripts, and processes for escalating callers through warm internal hand-off connections for members needing immediate critical assistance, especially when local first response and government's 911, 211, and 311 call centers are not functioning (power, connectivity, staffing) or not functioning well (overwhelmed and long wait times).

### Community Partnerships

Establish and maintain active connections with community partners in planning, exercises, drills, response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

Anthem quickly contracted with Portlight and the Partnership for Inclusive Disaster Strategies to increase the effectiveness of member outreach services. This partnership was built on trust resulting from an existing relationship of several years. This agreement collaboration pairing Anthem's health care expertise with Portlight's: disaster response competencies, deep understanding of the complexities and nuances of the lived disability experience, and strong and current connectedness to other local and self-organized responders (such as the Cajun Navy) helped us respond more quickly and support people in their communities. "Rapidly augmenting Anthem's response with Portlight and the Partnership's expertise just made good sense, enlisting experienced responders and local community engagement experts with the know-how, creativity, nimbleness, and flexibility to help our members get immediate critical needs met," explained Merrill A. Friedman, Senior Director, Disability Policy Engagement, Federal Affairs, Anthem, Inc.

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### Member Emergency Plans

Health plan care coordinators and case managers should be required to assist members to develop and sustain personal emergency plans. All three health plans interviewed for this After Action Report

incorporated personal emergency plans into their members' care plans. This included planning for power outages, an extra supply of medication, evacuation, sheltering-in-place, and identification of support systems. For example, Florida's contract with Medicaid health plans requires that a well-documented emergency plan is in place for members. Sunshine Health® reviews these plans with members every 90 days.

## Posting and Disseminating Emergency Preparedness Information

Posting and disseminating emergency preparedness information for members, family members, personal assistance and caregivers is also important. Information disseminated must be tailored to the needs of members; general emergency preparedness information is relevant for everyone. Emergency preparedness information for the general population, however, is not always sufficient for people with disabilities. Materials can be more inclusive when they contain information that focuses on specific functional needs, in addition to health (hearing, vision, mobility, speech) and cognition (thinking, understanding, learning, remembering) and also on no-cost and low-cost preparedness strategies in addition to costly activities. These no-cost preparedness activities include: identifying support teams and evacuation plans, collecting emergency health information and emergency documents and discussing these plans with personal attendants/ family and significant others, and exercising and updating plans to align with current health and functional needs.<sup>22 23 24 25</sup>

A critical focus of such plans should include member power backup planning and improving the resilience of people living independently who depend on power and battery- dependent life-sustaining equipment and mobility equipment. Examples include breathing machines (respirators, ventilators, CPAP and nebulizers), power wheelchairs and scooters, and oxygen, suction, nutrition or home dialysis equipment.)<sup>26 27</sup> Users need clear instructions regarding backup power options for batteries as well as supplying and charging extra batteries, where indicated.

### Recommendation Part IV – Section 3.16

**Health plans should require their contracted vendors and providers to thoroughly and often instruct users regarding emergency procedures for their equipment.** Their instructions and training protocols should be regularly assessed for accuracy and effectiveness.

#### Life-safety Checks

Superior Health Plan made 14,000 outbound calls to their members receiving long term services and supports four to five days before hurricane Irene made landfall to help members activate their emergency plans. For example, these calls prompted people when needed to complete such tasks as filling prescriptions early and have their grab and go bags and evacuation plans ready.

Sunshine Health® care coordinators helped members pre-hurricane to board up windows and post-hurricane they delivered food, water, oxygen, medications, equipment, and supplies via face-to-face visits. They shipped meals, tracked where the power grid was down and made in-person visits to those areas a priority. Because emergency information is often changing, Sunshine Health® created

<sup>22</sup> Kailes, J. I. (Edition 1.0, 2016) [Be Real, Specific, and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs \(PDF\)](#)

<sup>23</sup> Kailes, J.I. (Edition 2.0, 2016) [Emergency Preparedness for Personal Assistant Services \(PAS\) Users \(PDF\)](#)

<sup>24</sup> Kailes, J.I. (Edition 2.0, 2016) [Emergency Supplies Kits for People with Disabilities and Activity Limitations \(PDF\)](#)

<sup>25</sup> The American Journal of Managed Care > January 2015 – Published on: January 16, 2015 State of Emergency Preparedness for US Health Insurance Plans Raina M. Merchant, MD, MSHP; Kristen Finne, BA; Barbara Lardy, MPH; German Veselovskiy, MPP; Casey Korba, MS; Gregg S. Margolis, NREMT-P, PhD; and Nicole Lurie, MD, MSPH

<sup>26</sup> Kailes, J.I. (2013). Emergency power planning for people who use electricity and battery dependent assistive technology and medical devices. Pacific ADA Center.

<sup>27</sup> Kailes, J.I (2009). [Emergency Safety Tips for People Who Use Electricity and Battery-Dependent Devices](#)

an internal centralized point, called “Response Central”, for staff to get current and reliable updates to frequently changing information.

**Members with pre-identified serious gaps in their emergency plans and those with complex health needs were prioritized by all three health plans into a tiered system which enabled first contacting members projected to be the most disproportionately impacted.**

This first contact group included members with complex health care needs, who may not be able to get or understand emergency alerts, need dialysis, chemo and temperature regulated medication (insulin and biologics, for example), who are dependent on power to operate essential life-sustaining equipment and motorized mobility devices, who lack emergency support from family, friends or others, who are in need of food, water, oxygen, medications, power, equipment, and supplies and who are unable, or least able, to get to commodity distribution points.

These three health plans dispatched service coordinators to conduct in-person life safety checks when members could not be reached. Anthem distributed cell phone solar chargers and bottled water, when needed, to members during these visits. These health plans also instituted member tracking when evacuations resulted in transport to another county or state.

### **Health Information Exchange**

Planning for methods to quickly share health information that is critical to a member’s life and essential continuity of care. Training staff regarding when and how to apply the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule in emergencies.

Members with pre-identified serious gaps in their emergency plans and those with complex health needs were prioritized by all three health plans into a tiered system which enabled first contacting members projected to be the most disproportionately impacted.

### **Transitions**

Preventing and diverting inappropriate admissions to medical facilities and institutionalization.

Assisting members who get caught in the institutional net to move back **into the homes and communities of their choice.**

- Problem-solving and marshalling resources to meet urgent needs and anticipate surmounting geographical and logistical challenges to provide notification, actionable instructions, evacuation, rescue, accessible transportation, sheltering and health care.
- Organizing matches of critical needs with delivery of needed items damaged, destroyed, lost, or left behind: delivery of food, water, generators, fuel, equipment, supplies, medication, mobility devices (wheelchairs, canes, crutches, walkers, shower chairs, raised toilet seats) and technology.
- Helping with transitions back home, or to temporary and new homes through exercising flexibility in funding of nontraditional services like emergency evacuation, disaster case management to navigate disaster programs, air conditioners and air filters, mold removal, reconstruction of ramps, accessible showers, debris removal, loaned and expedited replacement of disability equipment, transportation for food and repair shopping, etc.

### **Messaging**

Communicating with members using multiple dissemination channels: email, text, website and social media, public service announcements, outbound calls.

Creating prewritten messages (pre-tested for clarity) ready to be customized and finalized per the event.

Messages include details regarding:

### **Pre-emergency**

Proactive reminders to members to review and have ready emergency plans for sheltering-in-place and evacuation and how to refill prescriptions early

### **During and post emergency**

- How to reach the health plan, care coordinators, nurse hotline, telehealth services.
- How and where to go when primary pharmacy, dialysis centers or chemo and other infusion therapy sites are not available.
- Relaxing benefit restrictions such as: priority medical authorizations, out-of-network care, medication refills, durable medical equipment loans and replacement, getting an emergency supply of medications, and medical record access.
- Where to get behavioral health or mental health services, i.e., counseling.
- Guidance for addressing disruptions to in-home support for children and adults with autism, mental health and similar support needs to prevent acute hospitalization or institutional placement.
- Reliable, tailored situation updates compiled from public and private sources
- Portals for members during emergencies can be very helpful:
- Medications:
  - [Healthcare Ready](#) activated it's free, interactive RxOpen map to show open and closed pharmacies in the region affected by Hurricane Harvey. Citizens and first responders were encouraged to use this map as an initial resource, and to call their pharmacy to ensure their specific medication was in stock.
  - [Payer hotlines and assistance information](#) (PDF)
- Pharmacy Resources
  - Many laws for prescription refills are modified during emergencies such as during Hurricane Harvey. Contact numbers for insurance companies that may be able to help with prescription coverage were provided even if the individual did not have



their insurance card.

- Kidney Dialysis
  - [Kidney Community Emergency Response \(KCER\) Coalition](#)
  - KCER Hotline: 866.901.3773
- Health Plans (sample)
  - Anthem Blue Cross Blue Shield: [Help for Members Impacted by Hurricane Harvey in Texas and Louisiana](#)
- Superior Health Plan –Texas: [SUPPORT FOR SUPERIOR MEMBERS AFFECTED BY RECENT STORMS](#)

Anthem provided members and non-members with a free 24-hour nurse hotline and online access to a doctor for assistance with a specific medical, mental health and behavioral health issues at [www.livehealthonline.com](http://www.livehealthonline.com). Kiosks at various locations also offered this service via Telehealth (video connection with doctors) and included blood pressure measurement. The Anthem wheelchair accessible mobile health clinic in Houston, donated by American Well, had one of these kiosks.

Sunshine Health® is working to strengthen partnership with Centers for Independent Living. They are piloting this approach with the Miami Center for Independent Living serving the same Medicaid population to optimize shared capacity to co-manage information during disasters and provide updated information via automated outbound calls. Sunshine Health® is also partnering with Florida's Association of Centers for Independent Living to determine each Center's capacity to provide emergency preparedness and disaster response services.

### Quality Improvements

Having in place a system to evaluate response outcomes, successes, as well as mechanisms that incorporate new learning into future emergency response protocols.

## Recommendation Part IV – Section 3.17

### States Should Incorporate Emergency Roles and Responsibilities into Health Plans Contracts.

Detailing the emergency roles and responsibilities of health plans, detailed above, into state contracts will have to foster a stronger health plan emergency response.

## Recommendation Part IV – Section 3.18

### Industry-Wide Guidance, Training and Technical Support

The rapid stand up of member emergency services could use industry-wide guidance, training, technical support, and regulatory standards such as the CMS Emergency Preparedness Rule.

## Recommendation Part IV – Section 3.19



## **Integrate Specific Emergency Performance Clauses into Vendor and Contractor Agreements.**

Health plans should integrate specific emergency performance clauses into their vendor and contractor agreements which includes compliance with the CMS Emergency Preparedness Rule. Health plans should also audit vendors and contractors for compliance. These audits should be conducted by individuals who are qualified to thoroughly review emergency plans for realistic, actionable and tested elements.

### **Recommendation Part IV – Section 3.20**

**Connect with Community Partnerships for Planning, Exercises, Drills, Response, and Recovery Activities.** Health plans should actively connect with and support disability inclusive community partnerships, with emphasis on including disability-led groups, throughout planning, exercises, drills and response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

### **Recommendation Part IV – Section 3.21**

#### **Establish and Test Agreements for Emergency Supply Delivery and Evacuation Services.**

Establish and test agreements with emergency supply delivery and evacuation services, for example, utilizing existing military and non-government public safety capability to deliver medications, life-sustaining supplies and equipment. These agreements can prevent a slow or failed response which has been shown to result in a preventable cascading exacerbation of what are typically well controlled chronic health conditions. This failure led to many unreported and under-reported deaths.

### **Recommendation Part IV – Section 3.22**

#### **Need for Evidence Based Emergency Plan Research (See Long Term Care Facilities Emergency Plans)**

### **Recommendation Part IV – Section 3.23**

Internal Emergency Procedures are Inclusive of Staff and Visitors Who Have Access and Functional Needs

Health plans should ensure that their internal emergency procedures are inclusive of staff and visitors with access and functional needs. For example:

Health plans should have inclusive procedures in place regarding evacuation of staff and visitors who will need evacuation or other assistance (those who have a have a variety of disabilities - mobility, breathing, allergies, hearing, seeing, reading, understanding) or chronic conditions and may have difficulty or be unable to:

- use stairwells
- hear alarms
- see or read exit signs

- understand written or verbal instructions
- take personal protective measures
- move to safety

## Agreements

Health plans should integrate specific emergency performance clauses into their vendor and contractor agreements which includes compliance with the CMS Emergency Preparedness Rule. Health plans should also audit vendors and contractors for compliance. These audits should be conducted by individuals who are qualified to thoroughly review emergency plans for realistic, actionable and tested elements.

### Recommendation Part IV – Section 3.24

#### **Connect with Community Partnerships for Planning, Exercises, Drills, Response, and Recovery Activities.**

Health plans should actively connect with and support disability inclusive community partnerships, with emphasis on including disability-led groups, throughout planning, exercises, drills and response, and recovery activities that go beyond regulatory agencies like departments of health services and health care coalitions.

### Recommendation Part IV – Section 3.25

Establish and test agreements with emergency supply delivery and evacuation services, for example, utilizing existing military and non-government public safety capability to deliver medications, life-sustaining supplies and equipment. These agreements can prevent a slow or failed response which has been shown to result in a preventable cascading exacerbation of what are typically well-controlled chronic health conditions. This failure led to many unreported and under-reported deaths.

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## Emergency Plans for Long Term Care Facilities

Long term care facilities are a diverse group of licensed care facilities, congregate care, residential facilities, nursing homes, assisted living, group homes, intermediate care, senior housing, etc. Many of these facilities have insufficient emergency plans, and many more have no emergency plans at all.

The federal government’s Centers for Medicare & Medicaid Services (CMS) Emergency Preparedness Rule provides regulations and guidelines for many of these and other facilities, as do the states. Enforcement is up to the states. Failure to comply may affect the facility’s Medicare or Medicaid reimbursement. For nursing homes, states are required to perform unannounced inspections of every facility. The state’s review of each nursing home is subject to CMS approval.

Reference: [What You Need to Know About Nursing Homes New regulations, growing competition and frailer residents mean the industry must evolve](#), by Kenneth Terrell, AARP Bulletin, November 2017.

“Some nursing homes had and deployed emergency plans that worked. ...managers at Genesis HealthCare pulled out its emergency response plan. Following the playbook, they evacuated 67 residents at Oak Crest Center in Rockport before Harvey hit, and 103 residents from its Clairmont facility in Beaumont immediately after the storm.” Err on the side of caution,” says Genesis HealthCare CEO George Hager. “If there’s a chance for patients at risk, you evacuate to safer areas, even if it’s disruptive to patients who are sick and frail, and even if it may be difficult.” “Genesis executives from regions outside the storms served as drivers, shuttling residents from evacuated facilities to safe locations. Extra buses and U-Haul trucks were rented where needed. Genesis also provided evacuated Texas residents with backpacks filled with several days of their medications, copies of medical charts and a change of clothing. Dozens of staffers left their homes and families to accompany evacuated residents.”

## **New Medicare and Medicaid Guidelines**

New Medicare and Medicaid guidelines were driven by the deaths of over 200 hospital and nursing home residents during Hurricane Katrina. New plans must include procedures to deal with everything from storms to cyberattacks. These regulations are inadequate unless paired with equally strong enforcement provisions that include actionable processes, procedures, protocols, policies and non-governmental organizations training and frequent live drills.

The CMS Emergency Preparedness Rule, which went into effect in November 2016, details “**Four Core Elements of Emergency Preparedness.**”

- Risk Assessment and Emergency Planning (Include but not limited to):
  - Hazards likely in geographic area
  - Care-related emergencies
  - Equipment and Power failures
  - Interruption in Communications, including cyber attacks
  - Loss of all/portion of facility
  - Loss of all/portion of supplies
  - Plan is to be reviewed and updated at least annually
- Communication Plan
  - Complies with Federal and State laws
  - System to Contact Staff, including patients’ physicians, other necessary persons
  - Well-coordinated within the facility, across health care providers, and with state and local public health departments and emergency management agencies.
  - Policies and Procedures
  - Complies with Federal and State laws
- Training and Testing
  - Complies with Federal and State laws
  - Maintain and at a minimum update annually

“A recent review of federal records found that nursing home inspectors issued 2,300 violations of emergency-planning regulations over the past four years nationwide. Nearly 1,400 nursing facilities were cited for neglecting upkeep on emergency power generators.”<sup>28</sup>

### **Recommendation Part IV – Section 3.26**

#### **Develop Strong Qualifications for Emergency Plan Reviewers and Guidelines for Emergency Plans**

To prevent minimalistic or cursory plan reviews, State departments responsible for long term care facilities licensing should develop essential and robust qualifications for emergency plan reviewers, and establish minimum guidelines for emergency plans that include clear performance measures and benchmarks for preparedness and corrective action plans.

### **Recommendation Part IV – Section 3.27**

Conduct Meaningful Audits. State departments responsible for long term care facility licensing should conduct meaningful audits that examine to specifics of every facility’s emergency plans related to, but not limited to:

- Compliance with the CMS Emergency Preparedness Rule
- Evaluating the ability to accept and appropriately serve additional admissions during emergencies;
- Developing and regularly updating memoranda of understanding with multiple “like” facilities of variable distances away (within 10 miles, 20 miles, neighboring city, and states) who have the space for (often using unconventional spaces like common areas and dining rooms) and agree to accept their residents in an emergency.
- Assessing realistically the numbers of staff who will remain and or return to work after a disaster;
- Assessing the adequacy of plans for supplementing staffing to meet the needs of residents and emergency admissions if needed; and
- Transportation provider agreements for evacuations.

### **Recommendation Part IV – Section 3.28**

#### **Provide Guidance, Training and Technical Assistance Regarding Long Term Care Facility Emergency Planning.**

States and local governments responsible for long term care facility licensing should provide emergency planning guidance, training and technical assistance to ensure.

### **Recommendation Part IV – Section 3.29**

<sup>28</sup> [Are Nursing Homes Ready for the Next Natural Disaster? Recent storms have put the spotlight on emergency planning for patients](#), by Gary Strauss, AARP Bulletin, November 2017

## Identify Discrepancies Between State and Federal Requirements

State departments responsible for licensing long term care facilities need to identify any discrepancies between state and federal requirements and work to reconcile them for consistent interpretations. For example, the federal and state requirements regarding the numbers and types of drills can be different.

### Recommendation Part IV – Section 3.30

#### Need for Evidence Based Emergency Plan Research

Centers for Medicare & Medicaid Services

How can the Centers for Medicare & Medicaid Services (CMS) strengthen incentives and enforcement of emergency procedures?

Has CMS guidance been developed and disseminated regarding how to meet the needs of people displaced to other states in emergencies, including guidance for addressing Medicaid portability?

If yes, is it disseminated? If no, how will it be developed and when will it be disseminated?

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#### Emergency Plan Reviews

Most long term care providers have requirements for developing and maintaining emergency plans. Sometimes these plans lack the specificity, robustness and interconnectedness with local emergency systems that make for real versus symbolic plans (see section on symbolic planning under registries). A plan quickly reviewed by remote individuals working for licensing, certifying or accrediting organizations often lacks the capability to determine the fidelity of an emergency plan. Reviews by local emergency, public health and community services personnel who know their local resources can offer critical reality filters. Such a review can identify inadequate or inaccurate elements of the plans, sometimes based on false assumptions, that need attention. Without these filters, plans will continue to be subject to failure, with catastrophic results.

The imperative for a reliable process must be built into already over stretched workloads. Effective and comprehensive planning isn't optional. Penalties for failure are not enough to ensure the safety of the individuals served. Incentives for compliance need to be created and excellence needs to be rewarded.

## ***Part IV - Section 4: Unnecessary Institutionalization***

In each of the disasters, survivors with disabilities were unnecessarily institutionalized. Others were underserved in poorly prepared general population shelter settings. Unnecessary institutionalization has been characterized as a potential or known outcome of unequal access to disaster services. Factors that can lead to unnecessary institutionalization include not having access to power and medical necessities including medical treatment and supplemental oxygen, medication, consumable

supplies and medical equipment. It also includes not having equal access to food that meets dietary needs, potable water and services offered by federal, municipal, county and state/territory government. Survivors with disabilities, including older adults are at risk of unnecessary institutionalization at all points of the emergency response and recovery, including transitioning from temporary settings to more permanent solutions, i.e.: from a shelter to temporary housing. Institutionalization is also more likely when returning home is delayed or impossible, due to extended disruption in services or the extent of damage to the home or community.

“There was a disturbing trend of people with disabilities who had lived in the community being transferred to institutional settings, either due to lack of post-shelter housing options or due to the difficulties of navigating disaster recovery.”- NCIL report on Hurricane Harvey

The Red Cross describes one of the barriers to shelter transition as:

“Medicalization of Disability – The tendency to view individuals with disabilities as patients in need of medical intervention, even though they are living independently in the community prior to the disaster. This can result in placement of an individual into a “special needs” shelter or skilled nursing facility which removes their right to make decisions for themselves, often with grave consequences”.<sup>29</sup>

Not only is unnecessary institutionalization a breach of the autonomy of disaster survivors with disabilities, it is prohibited under Title II of the Americans with Disabilities Act (ADA) as interpreted in the Olmstead Supreme Court decision. Although any denial of equal access to programs and services is prohibited under the ADA and the Rehabilitation Act, unnecessary institutionalization constitutes the greatest deprivation of liberty and the highest impact on the quality of life of disaster survivors with disabilities. In addition to being denied liberty or perhaps as a result of it, the health of people who are institutionalized often deteriorates and their life expectancy decreases.

“There was a disturbing trend of people with disabilities who had lived in the community being transferred to institutional settings, either due to lack of post-shelter housing options or due to the difficulties of navigating disaster recovery.”

Once a survivor is unnecessarily institutionalized it is difficult for them to return to the community. Sometimes survivors who have been institutionalized cannot be located by loved ones; allies and advocates do not know where they are. Additionally, the accompanying health deterioration that is inherent in institutional placement leads to the need for a more complex array of services at the same time that community resources have been depleted and previous support systems remain disrupted.

Unnecessary institutionalization is not a phenomenon only witnessed in 2017 and 2018, It has repeatedly occurred in previous disasters. There is no indication that this will be remedied in future disasters without sweeping changes. These changes must occur through planning, implementation, monitoring and enforcement of federal obligations to provide equal access. This must include physical, program and effective communication access and modifications to policies, practices and procedures when necessary to avoid discrimination before, during and after disasters.

In its report, NCIL also references unnecessary institutionalization of homeless Floridians with disabilities in the context of threats of commitment under the Baker Act (Florida Statute 394.451-

<sup>29</sup> [Multi-Agency Sheltering/Sheltering Support Plan Template](#): Tab A to Appendix F Transition to Alternate Sheltering and Housing Solutions Considerations, updated March 2017

394.47891 2009 rev.) In a letter to Florida division of Emergency management DHS Office for Civil Rights and Civil Liberties, FEMA Offices of Disability Integration and Coordination and Equal Rights expressed “concern related to homeless individuals refusing shelter being threatened with involuntary commitment” (see Appendix B).

Key informants, Hotline callers and stakeholders shared the following examples of unnecessary institutionalization:

- A Hotline caller from Texas reporting that she was in the George R Brown Convention Center Shelter and was told she was being sent to a nursing home with a group of other shelter residents. She refused and left the area. When she returned, the others were gone. She doesn't know where they went.
- Key informants in Puerto Rico reported that the local hospitals became de facto shelters for people with disabilities.
- Key informants in Florida expressed concerns that survivors were going into assisted living or nursing facilities upon discharge from special needs shelters. They reported that they were unable to track the whereabouts of these survivors.
- Key informants in Puerto Rico and the US Virgin Islands reported that the loved ones of people with disabilities who evacuated from the territories still could not account for them.
- A woman in Texas with a mental health disability was institutionalized ostensibly due to trauma from the disaster. She was discharged from the hospital with prescriptions for which she could not afford the copay. By the time that the Hotline operator persuaded the pharmacy to accept a credit card and for her to get to the pharmacy she was re-institutionalized. During her last contact with the Hotline she had been discharged but was returning to the hospital for a medication check. While she was in the hospital the operator heard her being reprimanded for stealing food from the hospital. She had just reported that she had no money for food.
- A disaster survivor in Texas called the Hotline and reported that she had been placed in a nursing home against her will. The nursing home staff had just informed her that she would be required to relinquish her FEMA and Social Security checks to the facility for payment.
- A Hotline caller requested assistance for several individuals who had been evacuated several hundred miles from home to a nursing home. Their home was not damaged, but there were no accessible transportation resources being provided for the return trip. The individuals were unable to leave the nursing home until funding for their transportation could be identified.

### **What worked:**

Disability leaders in local communities, FEMA disability integration advisors, and the Hotline team attempted to keep track of the whereabouts of survivors with disabilities when it became obvious that no one else was.



Continued advocacy on stakeholder calls, through Portlight testimony, and a National Council on Independent Living statement elevated the issue of unnecessary institutionalization in disasters. This led the National Council on Disability to identify it as a priority in 2018/2019.

***Caveat***

The government maintains a non-waiverable obligation to provide services to disaster survivors with disabilities in the most integrated setting appropriate to meet their needs. The health and liberty of disaster survivors with disabilities must never be contingent upon the largess of under resourced non-governmental organizations.

**Recommendation Part IV – Section 4.1**

**Conduct a study of the disaster evacuation and sheltering related placement of individuals with disabilities and older adults in hospitals and nursing homes due to planning failures and medical model assumptions.** Objectives of the study should include identifying the extent of the problem and subsequent costs and outcomes, including violations of disability equal access and non-discrimination obligations and courses of action.

**Recommendation Part IV – Section 4.2**

**Update the National Response Plan, Federal Emergency Support Functions and Federal Interagency Operations Plans, Public Health Emergency and all other applicable federal directives and plans to specifically address responsibility for meeting the equal access, health maintenance, safety and independence needs of children and adults with disabilities to prevent unnecessary institutionalization.**

**Recommendation Part IV – Section 4.3**

**Establish a process for Medicaid portability between states and territories during disasters to ensure uninterrupted health maintenance and medical care in the least restrictive environment for Medicaid eligible children and adults.**

**Recommendation Part IV – Section 4.4**

**Establish a process for ESF 6 and ESF 8 to prioritize health maintenance for children and adults with disabilities and seamlessly deliver services and supports to individuals in the most integrated setting throughout evacuation, temporary housing and disaster recovery.**

**Recommendation Part IV – Section 4.5**

**Establish a process for states and territories to provide for loaning and replacing durable medical equipment, consumable medical supplies, assistive technology, disability services and supports, and disaster case management to disaster survivors with disabilities in order to provide equal access and non-discrimination throughout emergency response to meet their immediate health, safety and independence needs.**

**Recommendation Part IV – Section 4.6**

**Amend the Stafford Act and the Post Katrina Emergency Management Reform Act to specify actions for the federal government, states and territories to meet their obligations to prevent unnecessary institutionalization in compliance with disability civil rights laws.**

#### **Recommendation Part IV – Section 4.7**

**The Department of Justice, the Department of Homeland Security, the Department of Health and Human Services and the Department of Housing and Urban Development shall monitor the use of all disaster funds and their enforcement arm shall ensure compliance with the civil rights requirements of the Rehabilitation Act of 1973, as amended and the Americans with Disabilities Act of 1990, as amended and other applicable civil rights laws for equal access and non-discrimination before, during and after disasters.**

#### **Recommendation Part IV – Section 4.8**

The Department of Justice, the Department of Homeland Security, the Department of Health and Human Services and the Department of Housing and Urban Development shall provide guidance and technical assistance to all recipients of federal financial assistance and other stakeholders to ensure all responsible actors have been trained on the obligation to serve individuals with disabilities in the most integrated setting and the non-waiverability of civil rights obligations throughout disasters.

#### **Recommendation Part IV – Section 4.9**

The Department of Justice, the Department of Homeland Security, the Department of Health and Human Services and the Department of Housing and Urban Development shall provide guidance and technical assistance to all recipients of federal financial assistance and other stakeholders to prevent, minimize, and rectify the segregation, discrimination, institutionalization and/or loss of critical home and community-based services for children, adults and older persons before, during and after disasters.

#### **Recommendation Part IV – Section 4.10**

The Department of Justice shall assess the equal access and non-discrimination civil rights compliance performance of the American Red Cross and other shelter and mass care providers in relation to their actions resulting in institutionalization of disaster survivors.

#### **Recommendation Part IV – Section 4.11**

Provide Homeland Security and Administration for Community Living grant funds to support Independent Living Centers in supporting disaster impacted individuals with disabilities in their community. This incorporates all five of their core services, including their obligations for preventing and diverting institutionalization of disaster impacted individuals throughout disaster response and recovery.

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## **Part IV - Section 5: Equal Access to Effective Communication**

COMMUNICATION IMPACTS EVERYTHING. INFORMATION HAS TO BE ACCESSIBLE TO BE ACTIONABLE.

The National Preparedness Goal<sup>30</sup> describes capabilities necessary to save lives, protect property and the environment, and meet basic human needs, before, during and after an incident has occurred. It is focused on ensuring that the Nation is able to effectively respond to any threat or hazard, including those with cascading effects. Response emphasizes saving and sustaining lives, stabilizing the incident, rapidly meeting basic human needs, restoring basic services and technologies, restoring community functionality, providing universal accessibility, establishing a safe and secure environment, and supporting the transition to recovery.

Among the Core Capabilities identified in the National Preparedness Plan is “Deliver coordinated, prompt, reliable, and actionable information to the whole community through the use of clear, consistent, accessible, and culturally and linguistically appropriate methods to effectively relay information regarding any threat or hazard and, as appropriate, the actions being taken and the assistance being made available.”<sup>31</sup>

This was not the case. In fact, communication failures where people with disabilities did not have equal access to communication or where they were disproportionately impacted by overall communication failures were among the first issues brought up on stakeholders calls and by interviewees.

### **5.1 Federal, state and local government entities, relief organizations and media often did not provide equally effective communication to people with disabilities as required under the Rehabilitation Act and the Americans with Disabilities Act.**

Communication failure affected people with a wide variety of disabilities in all of the disasters and occurred during all stages of the disaster. Below are some examples of these failures.

**People who are deaf or hard of hearing were not provided equally effective communication.** Some instances of this included:

- the absence of qualified sign language interpreters on news broadcasts, at evacuation sites, in shelters and in other vital information dissemination points (see Appendix B);
- Instances where interpreters that were not qualified were used and in one highly publicized instance in Florida, a grossly unqualified interpreter was used (see Appendix B);
- information on broadcast was often not captioned and instances were reported where captioning was blocked by other streaming media;

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<sup>30</sup> National Preparedness Goal: [https://www.fema.gov/media-library-data/1443799615171-2aae90be55041740f97e8532fc680d40/National\\_Preparedness\\_Goal\\_2nd\\_Edition.pdf](https://www.fema.gov/media-library-data/1443799615171-2aae90be55041740f97e8532fc680d40/National_Preparedness_Goal_2nd_Edition.pdf)

<sup>31</sup> Id

- the fact that actionable information from the media was solely available through one radio station in Puerto Rico and the US Virgin Islands which obviously excluded people who were deaf and hard of hearing;
- reports during the HHS listening session in Texas that first responders would yell outside buildings urging people inside to urge evacuation posing a barrier to equal access for people that were deaf and hard of hearing; and
- Text 911 and video relay often failed.

A participant in the DHS listening session stated that communications with deaf people and hard of hearing people is complex. Video relay, video remote interpreting services, video interpreter for first responders, FEMA and at a DRC using an iPad or computer [had many barriers to equally effective communication]. User error that occurred when a hearing person is not familiar with the importance of placement, location, and other critical factors. In addition, regional linguistic nuances that got lost when an interpreter is not local. (paraphrased from HHS listening session).

In addition it was reported that long wait times for Public Safety and other Special Community Service Numbers (911, 211 and 311) had a disproportionate impact on Deaf and Hard of Hearing Community. Unlike hearing people who can multitask by listening to their phones while they prepare to evacuate, Deaf and Hard of Hearing people must be in sight of their screens so they can read them. This decreased time that they were able to spend doing life-saving preparations significantly.

**People with vision disabilities were not provided equally effective communication.** An instance of this included:

- Lack of accessible computers in a very busy and understaffed Texas Disaster Recovery Center (DRC) left a disaster survivor unable to apply for disaster services..

Communication issues were not limited to people with communication disabilities. A participant in the DHS listening session reported that message content posed a barrier for people with mobility disabilities when people were instructed to go to their attic with an ax and wait to be rescued.

### **What worked:**

In listening sessions and on stakeholder calls it was reported that the Houston office for people with Disabilities sent out daily emails with warnings and resources. This was highly effective, but only for people with computer or smartphone access.

Houston Center for Independent Living (HCIL) established a Facebook page for deaf hurricane survivors that became a resource for deaf people that didn't have communication with 911 and became a source of news and information for the Deaf Community. It attracted approximately 2,000 followers.

FEMA broadcasted a town hall meeting so it was accessible for all of Houston area and people in other states who were watching to learn how Houston was responding.

Being “open to the idea of coming from our local resource specialists and trying any innovative way that we can to make things work.”

## **Caveat**

**Disability leaders and their organizations being in a position to locate and provide information is not a substitute for the government meeting its obligation to provide equally effective communication to people with speech, visual, cognitive and hearing disabilities.**

### **Recommendation Part IV – Section 5.1**

**Deploy disability organizations and groups to locate people with disabilities and provide them with information in formats that are accessible to them.**

### **Recommendation Part IV – Section 5.2**

**Train any staff or volunteers that will communicate with the public that internet and social media is the preferred form of communication for most Deaf and Hard of Hearing people and provide information accordingly.**

### **Recommendation Part IV – Section 5.3**

**Deploy disability organizations and groups to locate qualified sign language interpreters.**

### **Recommendation Part IV – Section 5.4**

**Post ASL interpreted emergency announcement videos produced by an ASL native signer who is a specialist in ASL. All of these emergency announcements should be posted on the county, city, office of Emergency management websites and Facebook, and other social media pages**

### **Recommendation Part IV – Section 5.5**

**Ensure that interpreters are visible on television and other screens.**

### **Recommendation Part IV – Section 5.6**

**Ensure that visible open captioning is present and not blocked by streaming video on all disaster-related broadcasts.**

### **Recommendation Part IV – Section 5.7**

**Widely publicize the number of video phones to the Deaf Community and to the public at large and provide an adequate number of trained interpreter operators in proportion to the impact of the disaster.**

### **Recommendation Part IV – Section 5.8**

**Utilize local interpreters who capture regional language nuance and who are qualified for disaster communications (including usage of terms, protocols and instructions for camera visibility).**

## **Recommendation Part IV – Section 5.9**

**Consistently provide materials in alternative formats; screen reader technology that was compliant with section 508 of the Rehabilitation Act; and actionable information provided in news and public official instructions.**

## **Recommendation Part IV – Section 5.10**

Craft messages that include feasible alternatives for people with mobility disabilities who cannot access an attic or upper floor.

**Recommendations for people with disabilities would also support communication access for people with low literacy, limited English proficiency and a need for information in plain language.**

Other communication barriers arose and are noted throughout this report.

## **5.2 Communication by and with Federal Government Entities**

Key informants and stakeholder teleconference participants continually raised deep concerns with government communication failures and their disproportionate impact on disaster survivors with disabilities.

### **5.2.1 Communication failures with stakeholders and disability leaders**

Stakeholder teleconferences, initially held seven days per week, were an effective strategy utilized to share information throughout the disasters of 2017 and 2018. However, the inconsistent attendance by representatives of the various governmental entities and their frequent inability to provide critical, accurate, actionable, and timely information perpetuated continual gaps. These and other communication failures had a disproportionate impact on children and adults with disabilities.

A prime example was the inability of the US Department of Health and Human Services leadership to identify the individual, office or function that was ultimately responsible for assisting the territorial government in providing oxygen to individuals who lived in communities across Puerto Rico. This was especially disturbing since it was reported that there were approximately 50,000 individuals who rely on supplemental oxygen at home and in the community.

Stakeholders found that despite consistent participation and contributions from deployed FEMA disability integration advisors and the DHS Office for Civil Rights and Civil Liberties, government representatives were rarely able to obtain requested information.

Another example reported by key informants on the ground in Puerto Rico and US Virgin Islands was that many service providers and disaster survivors with disabilities did not know they must register with FEMA in order to receive FEMA assistance. This absence of knowledge should have been anticipated given that it was nearly impossible for people with disabilities or anyone else to register for FEMA due to the connectivity failure and the massive destruction of communication infrastructure.

## What worked:

When government entities participated, stakeholder teleconferences provided a one-stop venue for government and non-government agencies to communicate with each other, brainstorm and solve problems.

## Recommendation Part IV – Section 5.11

**Local disability organizations and other community entities that will be expected to assist disaster survivors with disabilities must be provided with training and funding for preparedness.** This must include just-in-time training and technical assistance.

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### 5.2.2 Communication failure amongst and between government entities

The siloing and unilateral operations of government agency functions posed an insurmountable obstacle to actionable communications throughout disaster response and recovery. Inevitably, the gaps between various disaster programs and services had a disproportionate impact on children and adults with disabilities. These were often of such a serious magnitude that the health, safety and independence of disaster- impacted individuals with disabilities was repeatedly endangered.

For instance, key informants in the territories reported that there was a communication disconnect between territory government and the federal government. A key informant who visited the affected areas described this as reluctance of territorial government representatives to admit that their planning efforts were inadequate or that they needed help. It was also widely reported that funds for cost-share were unavailable and many resources were denied or expected to be denied due to the lack of available funds.

However, when the territorial government did ask for help, communication about resources was inadequately provided. One of the most troubling failures was a lack of information and instructions for accessing medical resources that were deployed to Puerto Rico.

At a hearing on September 26, 2017, Chairman of the Joint Chiefs Gen. Joseph Dunford said “the priority is making sure airfields can operate. All the other support they need can't come in until we get the ports and airfields open.”<sup>32</sup>

Dunford said he expects more military aircraft will be used particularly for "generators, water, food, those kind of immediate needs... The responsibility is primarily DHS, but at this point we're not trapped in bureaucratic niceties, what we're trying to do is make sure that we get the people of Puerto Rico the support they need when they need it.”<sup>33</sup>

In response to a specific request, the Navy also announced that they were deploying the US Naval Ship Comfort. The Comfort is a seagoing medical treatment facility "capable of providing resuscitation and stabilization care; initial wound and basic surgery; and postoperative treatment," according to the US Navy. This shining example of the nation's most sophisticated mobile medical technology was

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<sup>32</sup> [CNN - US military sends ships, aircraft to Puerto Rico](#)

<sup>33</sup> Ibid



anticipated to be a vital resource for meeting the urgent medical and health maintenance needs of disaster survivors unable to access the decimated health care infrastructure.

The Comfort arrived early in the first week of October. However, two weeks later CNN reported that no one knew how to get assistance from the hospital ship, telling the story of a disaster survivor with cerebral palsy and other acute medical conditions in need<sup>34</sup> of critical medical care, including oxygen.<sup>35</sup>

CNN also reported that Medical “Clinics that are overwhelmed with patients and staff say they don't even know how to begin sending cases to the ship. Doctors say there's a rumor that patients have to be admitted to a central hospital before they can be transferred to the Comfort”... and that “only 33 of the 250 beds on the Comfort -- 13% -- are being used”.

This is despite correspondence from Coast Guard Lt. David Connor reporting that "Only patients with critical needs requiring specialized care will be transferred to USNS Comfort,"

Concurrently, the Hotline was assisting with another disaster survivor with critical care needs and multiple disabilities. This individual was located in a very remote part of the island, and the lack of power, potable water and nutrition exacerbated his health conditions, resulting in a need for urgent care. After a series of failed transfers from his home to locations that may have been able to provide acute care, he was finally referred to the USNS Comfort by a medical doctor at a shelter. The referral came after determining that he required critical care. He and his father were then brought to the USNS Comfort for treatment of massive and possibly gangrenous pressure sores. For reasons that are unclear, he was denied admission to the vessel. He was referred to a MASH unit that was closed and was instructed to wait outside overnight in its dark parking lot. He chose not to be treated and returned to his home. Subsequently the Hotline team was devastated to learn that he died without the critical care he sought.

No one seemed to understand the complex protocol for getting a patient admitted to USNS Comfort for treatment. It appeared that some individuals were too sick to be admitted and others not sick enough. Many doctors and hospitals gave up referring patients because they did not understand criteria for admission and the complex referral process. The ship was grossly under capacity the entire time it was in the various ports. Failure to communicate both the location and process for admission disproportionately impacted people with disabilities.

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<sup>34</sup> CNN - [There's a hospital ship waiting for sick Puerto Ricans -- but no one knows how to get on it](#)

<sup>35</sup> Ibid

Another example of the lack of communication between federal agencies included a very disturbing disconnect among federal agencies including the US Department of Health and Human Services, the Department of Homeland Security and the Department of Defense regarding availability and distribution of oxygen to disaster survivors in immediate need, outside medical facilities.

Members of Congress had difficulty receiving communication from FEMA and the DHS Office of Civil Rights and Civil Liberties. The House Committee on Homeland Security issued a letter to DHS and FEMA posing ten questions which were summarized above. Despite the request for a written response due by October 27, 2017 as authorized pursuant to Rule X and Rule XI of the U.S. House of Representatives (see Appendix A), no response was provided as of the publication of this report.

## ***Part IV - Section 6: Equal Access throughout Planning and Execution***

Following hurricane Katrina, there have been huge investments of time and treasure in emergency and disaster planning at the local, state, territorial and national levels. This was supposed to be explicitly inclusive of the access and functional needs of children and adults with disabilities in accordance with the National Preparedness System.<sup>36</sup>

Despite this, people with disabilities were frequently denied equal access to disaster programs and services due to inadequate community engagement and poorly exercised plans. Many key informants and stakeholders reported that there was little evidence of planning or that plans were often either not communicated or abandoned. One key informant in Puerto Rico did feel that there was ample planning but it was not implemented.

Examples of inadequate planning included providing sign language interpreters without mastery of regional idiom; plans to establish quiet areas in shelters without cognizance of the noise level in adjacent areas (such as next to a basketball court) and failing to adequately plan for accommodating tens of thousands of people with disabilities in community shelters by directing them to “special needs” shelters and without providing adequate assistance in either type of shelter, jeopardizing the health and safety of people with and without disabilities.

### **What worked:**

Numerous disability leaders reported that local and national stakeholder teleconferences allowed them to identify barriers to equal opportunity for people with disabilities to participate in implementation and real-time revision of the plan. Problems and solutions were identified with input from disability community and government stakeholders. Many key informants specifically referenced the local Texas calls facilitated by the Houston Mayor’s Office for People with Disabilities and local and national calls facilitated by the Partnership for Inclusive Disaster Strategies as being conducive to identifying issues and collectively solving problems.

### **Caveat**

**The time to plan for disasters is before the event occurs. Although it was good that stakeholders had the opportunity to identify barriers, discuss solutions and sometimes implement them, the fact these barriers were identified on calls indicated that people**

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<sup>36</sup> [FEMA National Preparedness System](#)

with disabilities had encountered barriers. While planning for removal of barriers to equal opportunity for people with disabilities after the fact is better than not removing the barriers at all, however it is not an adequate solution, nor is it a good practice. Every disaster is unique, however the consequences are foreseeable and can often be mitigated.

### **Recommendation Part IV – Section 6.1**

Establish emergency preparedness funding for Independent Living Centers, state Independent Living Councils, State Developmental Disability Councils and national Disability Inclusive Emergency Management and Disaster Risk Reduction organizations and other consumer-controlled disability and aging organizations to develop and deliver disability inclusive planning, preparedness, readiness and resilience training and technical assistance for individuals and communities.

### **Recommendation Part IV – Section 6.2**

Establish an American Independence Corps, similar to FEMA Corps made up of at least 5,000 citizen members with and without disabilities to carry out planning and preparation activities in each State, DC and Territory year-round.

### **Recommendation Part IV – Section 6.3**

Direct FEMA and the Administration on Community Living to lead a coordinated effort across federal government agencies, the States, CBOs, foundations, and other sectors, with individuals who are aging and individuals with disabilities in leadership roles, aimed at achieving on-going planning, preparation, and implementation of these recommendations.

### **Recommendation Part IV – Section 6.4**

Conduct a study of the disaster evacuation and sheltering-related placement of individuals with disabilities and older adults in hospitals and nursing homes due to **planning failures and medical model assumptions**. Objectives of the study should include identifying the extent of the problem and subsequent costs and outcomes, including violations of disability equal access and non-discrimination obligations.

### **Recommendation Part IV – Section 6.5**

Update the National Response Plan, Federal Emergency Support Functions and Federal Interagency Operations Plans, Public Health Emergency and all other applicable federal directives and plans to specifically address responsibility for meeting the equal access, health maintenance, safety and independence needs of children and adults with disabilities.

Notification is discussed in Communication, Evacuation and Registries Sections.

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## Part IV - Section 7: Emergency Registries

Key informants discussed the use of emergency registries in Texas and Florida. If the State of Texas Emergency Assistance Registry (STEAR) was used in the Hurricane Harvey response, finding anyone able to report the result was elusive. Florida's Special Needs Registry is tied to its Special Needs Shelter Program and was used in Hurricane Irma.

In this report, emergency registries refer primarily to government plans to collect information about people with disabilities. See Appendix E for an expanded discussion of Emergency Registries. This information typically consists of a database of individuals who voluntarily sign up and meet a variety of eligibility requirements for receiving emergency response services based on a need. Registries vary in form. In theory they collect the names, locations, and contact information of people in a given area or jurisdiction who are likely to need emergency help.

They intend to provide a priority warning when possible regarding pending emergencies, including the shut off of power or water service, evacuating people from a danger area, providing sheltering, checking on individuals' health and safety, and connecting people with other viable and available supports and resources.

Many registries are developed using outdated technology and collect information using medical model biases about people with disabilities. Applying the social model versus a medical model of disability entails identifying, remedying, and retooling interventions that reflect common stereotypes and beliefs about people with disabilities. Manifestations of medical model stereotypes include assuming that people with disabilities are sick or are "homebound" and need medical care, protection, supervision, and separate shelters.

Most people with disabilities are not "homebound" and may not be home at the time of an emergency or situation for which they initially registered. Potential registrants object to the inherent registry bias that most people with disabilities are easy to locate because they are "homebound." That is, registries do not account for the reality that this diverse population, just like everyone else, works, volunteers, plays, prays, shops, eats and travels. Fixed location registries can mean wasted trips and wasted time for overstretched first responders.<sup>37</sup>

Most, if not all, access and functional needs registries have systemic problems. A registry plan may sound feasible, but it may not be able to achieve its well-intentioned objectives for two reasons. First, the response capacity is not considered or calculated based on the size of potential events, and second, knowing where people live doesn't tell responders where individuals are located at the time of the event. The former presumes that there are enough responders available for mid-to-large scale events when there are not. The latter wastes critical resources and time as the limited number of responders look for people in the wrong places, which helps neither the responder nor the evacuee.

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<sup>37</sup> Kailles, J. and Enders, A. (2014) [Access and Functional Needs Emergency Registries: Research Needed](#)

## Registry Disclaimers

Registries use disclaimers to address situations where a mismatch between registrant expectation/need and responder resources/timeframe may occur. But that leaves the individual not knowing what they can and cannot expect in any given emergency. Will the responders, the transportation, the assistance, be there? And if so, when?

Registries give people a false sense of security, even when they come with clear disclaimers . Despite the disclaimers and instructions that most registries contain, the expectation of the registrants is that registering means they will receive a priority response for being rescued or evacuated and not left behind.

The State of Texas Emergency Assistance Registry (STEAR) focuses on practices, procedures, updates and recommendations for a free state registry to provide local emergency planners and responders with additional information on the needs of individuals in their community.”<sup>38</sup>

STEAR’s disclaimer states:

“Does registration with STEAR guarantee I will be evacuated during an emergency event such as a hurricane? No, your information will be provided to participating local governments for their use in developing emergency management plans and to assist them in preparedness and response activities. Each local government uses the information in different ways and registering in the system does NOT guarantee that you will receive additional assistance during an event. Contact your local Emergency Management Coordinator to determine their level of participation in this program.”<sup>39</sup>

## Effectiveness and Outcome Information

Comments from the City of Houston to Federal Communication Commission regarding response efforts related to the 2017 hurricane season provides some effectiveness and outcome information. These comments reflect the input of the Houston Emergency Center, the Houston Police Department, the Houston Fire Department, the Houston Information Technology Department and the Mayor’s Office for People with Disabilities.

Texas uses the State of Texas Emergency Assistance Registry (STEAR). In theory, people with disabilities can register with STEAR so that they can receive assistance evacuating during a disaster. Many people with disabilities registered with STEAR and expected that they would receive assistance from emergency responders when their homes started flooding. They repeatedly called 911 and 211 and received no assistance. The State of Texas makes it clear that registering with STEAR does not guarantee assistance with evacuation, however, for Harvey, because broad evacuations were not ordered, only six individuals were actively contacted through the STEAR database. Many power-dependent people with disabilities received water in their homes and needed to be evacuated, despite the lack of an official evacuation order. States and localities are increasingly using databases/registries like this. The FCC should issue guidance on best communications practices for entities using a disaster response assistance registry for people with disabilities. Such guidance could assist in getting

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<sup>38</sup> [DPS Texas Committees and Councils – STEAR](#)

<sup>39</sup> [DPS Texas STEAR FAQs](#)



more people with disabilities more consistent, responsive interactions with emergency workers.<sup>40</sup>

“The Florida Division of Emergency Management, in coordination with each local emergency management agency in the state, developed a registry to allow residents with special needs to register with their local emergency management agency to receive assistance during a disaster. The statewide registry provides first responders with valuable information to prepare for disasters or other emergencies”.<sup>41</sup>

Concerns about this system were frequently raised by key informants, stakeholders, Hotline callers, traditional and social media. Key informants voiced many serious concerns about the registry, especially as it related to sheltering. Concerns included lack of capacity to accept registrants into their special needs shelters, registrants who were turned away because of lack of space, refusal to admit registrants who were unable to bring a personal assistant with them, and no capacity to admit people in need who did not pre-register.

### Registry Use as a Planning Tool

Local governments often use registries as a planning tool. However, a registry is not effective as a planning tool. There is little likelihood that everyone, or even most individuals that need to be included in the planning process will ever register, making analysis inaccurate.

“A registry will not be effective if it is used as the primary planning tool for populations with access and functional needs. Believe it or not, many emergency planners look at registries, spreadsheets, lists, tables, and matrices as a sort of planning panacea. Neat columns and rows replete with filled-in data fields are de-facto substitutes for substantive information. All too often, tabular data is accepted without any real analysis on the part of plan reviewers. So long as the key words appear in the heading boxes and some degree of descriptive ‘stuff’ is visible in the appropriate columns/rows, the ‘plan’ passes muster.”

- Philmont M. Taylor, commander of the Emergency Services Division of Los Alamos, New Mexico

There are more efficient and effective ways to collect data about the demographic and geographic distribution patterns in a jurisdiction. Information used solely for planning purposes could more easily be collected through optimizing readily available existing data. These information sources include Census data and program administrative data from government and community service agencies.

<sup>40</sup> Federal Communications Commission PS Docket No. 17-344

<sup>41</sup> [Florida Special Needs Registry](#)

“A registry will not be effective if it is used as the primary planning tool for populations with access and functional needs. Believe it or not, many emergency planners look at registries, spreadsheets, lists, tables, and matrices as a sort of planning panacea. Neat columns and rows replete with filled-in data fields are de-facto substitutes for substantive information. All too often, tabular data is accepted without any real analysis on the part of plan reviewers. So long as the key words appear in the heading boxes and some degree of descriptive ‘stuff’ is visible in the appropriate columns/rows, the ‘plan’ passes muster.”

The focus should be on how to capture the power of accelerating technology capabilities which can effectively and efficiently perform some of the many life-saving and life-sustaining tasks (search and rescue, evacuation, transportation, delivery of emergency supplies, restoration of communication arteries) that overwhelm first responders in catastrophic events.

## Efficient and Effective Use of Technology as an Alternative to Voluntary Registries

The emergency sector's performance depends on resilience and flexibility to evolve as economic, learning, technology, legal and social landscapes change. In this world of shrinking budgets, scarce first responder resources must be used wisely. This includes prioritizing efficiencies that modernize how people signal for and receive help in real time, and harnessing technology through potential viable applications like social media, mobile devices, sensors and supply delivery via drones and services such as Uber, Lyft, Amazon, UPS and FEDEX. Technology can broaden and replace the traditional registry concept.

The focus should be on how to capture the power of accelerating technology capabilities which can effectively and efficiently perform some of the many life-saving and life-sustaining tasks (search and rescue, evacuation, transportation, delivery of emergency supplies, restoration of communication arteries) that overwhelm first responders in catastrophic events.

During Hurricanes Irma and Maria the paratransit agency on St. Thomas proactively and independently contacted all of their riders to check on their safety and their needs, and to offer any assistance they could. Their rider list is current, and they know well all of their customers.

### Recommendation Part IV – Section 7.1

**Government should not mandate or endorse emergency registries.**

### Recommendation Part IV – Section 7.2

**Use existing planning tools to collect information, such as program administrative data from government sources including the US Census, US Department of Health and Human Services emPOWER Tool, the Social Security Administration and community service agencies.**

### Recommendation Part IV – Section 7.3

**Emergency services should strengthen connections and planning with organizations who maintain current lists of the individuals they serve, such as accessible transportation providers, paratransit providers, Aging and Disability Resource Centers, Area Agencies on Aging, equipment vendors, assistive technology centers, developmental disability services, health plans, home health agencies, Meals on Wheels, mail order pharmacy services, personal assistance services (public and private), utility discount lists (power and water), Independent Living Centers, early childhood, in-home, and school-based special education services and many other existing sources of information that can guide whole community planning.** Successful partnerships with the resources of government, community organizations and businesses are far more likely to yield favorable outcomes for disaster-impacted communities than separate voluntary collection of perishable and inexact information.

During Hurricanes Irma and Maria the paratransit agency on St. Thomas proactively and independently contacted all of their riders to check on their safety and their needs, and to offer any assistance they could. Their rider list is current, and they know well all of their customers.



## Recommendation Part IV – Section 7.4

Use technology-incorporating universal design standards to improve how people signal for and get help.

## Recommendation Part IV – Section 7.5

Conduct Evidence-Based emergency registries research.

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## ***Part IV - Section 8: Equal Access to Evacuation services***

People with disabilities encountered significant barriers to equal access throughout evacuation. This was repeatedly observed in multi-story building evacuation as well as local and long distance evacuation. This was especially onerous for individuals with disabilities when evacuating from island territories.

### **Barriers for people with mobility disabilities**

In addition to specific barriers, the DHS Office for Civil Rights and Civil Liberties and the FEMA Office of Equal Rights expressed concern about lack of equal access to evacuation in a letter to the Florida Division of Emergency Management referencing concern relating to planning for evacuation of elderly/individuals with disabilities living in high rise buildings (see Appendix B). This concern arose numerous times on stakeholder calls as well.

### **Barriers for people who are deaf and hard of hearing**

First responders used loud voices and bullhorns as a sole means of instructing people to evacuate in Texas. Repeated reports of the absence of captioning and sign language interpreters provided during notification and actionable evacuation instructions.

### **Barriers for people with autism and challenging behavior**

Participants in the DHS Texas listening session reported that evacuation was a major concern for individuals with intellectual disabilities and individuals with autism. For example, difficulties were described when persuading a large man with an intellectual disability to get on a boat to evacuate. They also described a lack of strategies for coaxing children and individuals with challenging behavior to safety.

### **Barriers for people who are power dependent**

It was brought up in the DHS listening session that first responders did not understand what constitutes a potential emergency for people with disabilities, i.e., a few inches of water could be life-threatening to people who use a ventilator, communication device or power wheelchair.

Frequent reports from all disasters included instances where first responders assumed that people with disabilities who were power dependent required hospitalization even though they simply needed an uninterrupted power source.

### **Recommendation Part IV – Section 8.1**

**Implement policies for delivering actionable evacuation instructions in multiple formats.**

### **Recommendation Part IV – Section 8.2**

Engage individuals with behavior support needs and sensory sensitivities and their allies in reviewing and updating policies and procedures utilized by first responders, public safety officials and others throughout evacuation.

### **Recommendation Part IV – Section 8.3**

Engage individuals with behavior support needs and sensory sensitivities and their allies in developing, delivering and implementing training and exercise protocols to test and improve readiness for evacuees and responders.

### **Recommendation Part IV – Section 8.4**

Engage individuals who rely on uninterrupted power and their allies in reviewing and updating policies and procedures utilized by first responders, public safety officials and others throughout evacuation to address requirements of people who require uninterrupted power.

### **Recommendation Part IV – Section 8.5**

Engage individuals who rely on uninterrupted power and their allies in developing, delivering and implementing training and exercise protocols to test and improve readiness for evacuees and responders.

### **Recommendation Part IV – Section 8.6**

**Conduct a study (or initiate a competition) to identify new approaches and solutions to address the challenges of high rise building evacuation and transporting individuals with disabilities and their needed assistive devices throughout evacuation and return home.**

[Jump to List of Recommendations by Section \(Page 11\)](#)

## **8.1 Evacuation from Territories**

Several hundred people requiring dialysis were evacuated from the US Virgin Islands to San Juan and then to Atlanta for treatment. Many others who also had immediate health maintenance or treatment needs were also evacuated long distances. This was discussed in more detail in the section on Maintaining Health.

Many individuals and families were forced to make difficult decisions about evacuation. The complexities of these decisions were highlighted by a group of families in Puerto Rico whose children are on life support and require uninterrupted power. Many of these children were not hospitalized before the hurricane, but when the power was interrupted they evacuated to local medical facilities. When these facilities were unable to provide adequate power, the children were evacuated to the Children's Hospital in San Juan. When it became clear that this hospital was also having difficulties with power, doctors reached out to colleagues on the mainland who made arrangements to evacuate the children to Florida and other destinations.

Once the children arrived in Florida, many issues emerged. Some of the children did not need a hospital level of care, and were not eligible for admission. Others were admitted, but without portability of Medicaid, issues with payment immediately arose. In addition to the immediate needs of the children, family members who had evacuated with their child had no place to go, no funds and often were in settings where their first language of Spanish was not understood.

In one especially difficult discussion about one of the children, an infant who used a ventilator and had a feeding tube, FEMA informed advocates that since the family had "self-evacuated" without the assistance of the government, they were ineligible for FEMA assistance. The child and her mother had no food, no place to stay and they reported to the Partnership that they were being threatened with intervention by Child Protective Services due to the mother's status as "homeless."

Collaborative advocacy, led by the Partnership, Portlight and Florida disability leaders, was ultimately successful in navigating some resources for the child and her family.

### **Eligibility for Medicaid**

Residents of Puerto Rico and the US Virgin Islands had to apply for Medicaid in the state they evacuated to, even if they had Medicaid already. This caused delay in medical services for people with disabilities in many instances and ignited a political firestorm over the financial responsibility for evacuees.

### **Eligibility for Transitional Sheltering Assistance (TSA)**

While individuals from Puerto Rico and the US Virgin Islands may have been granted TSA in the mainland, its limitations were exacerbated. For instance, TSA provides temporary hotel accommodations, however, food, transportation and other needs are not included. Without employment, public assistance and family resources nearby, people with disabilities were disproportionately impacted by these shortfalls.

## ***Part IV - Section 9: Sheltering***

During the period from August 25, 2017 until the closure of the last shelters, hundreds of thousands of disaster survivors utilized these community resources as a refuge from disasters and their destruction.

Shelters are established and operated by a tapestry of public and private entities. While there are many variations, each of these places of public accommodation falls under the same legal obligations

to provide equal physical and program access, as well as equally effective communication throughout their operation.

The obligation to provide equal access is always retained by the government entity responsible for providing services. Simply put, a government entity can't avoid its legal obligations under the Rehabilitation Act or the Americans with Disabilities Act by contracting them to private organizations. When a shelter fails to provide equal access, it is irrelevant that a non-governmental organization was the contractor. Non-governmental organizations have obligations under the Rehabilitation Act if they receive any federal funds. In any case, they also have obligations under the Americans with Disabilities Act due to their status as a place of public accommodation.

It is important to note that the highest level of legal obligation always rests with the government. When a contractor fails to provide equal access, this means the government is failing to provide equal access to disaster survivors with disabilities.

The sections below are divided into "general" and "special needs shelters." These are sometimes called "medical shelters," however they are utilized for individuals who do not require hospital-level care, in the absence of providing equal access in the general population or community shelter.

Key informants, stakeholders, Hotline callers and media all reported that many people with disabilities did not have equal access to any shelter. People with disabilities were turned away from both general and special needs shelters. Reasons reported included power dependence, personal assistance services requirements, service animals, need for bariatric equipment, mental health conditions, chemical sensitivities, autism and need for support due to cognitive or intellectual disabilities. It is reported that many of these individuals were diverted to hospitals or long-term care facilities when they did not need a more restrictive environment but simply needed equal access. Key informants in Puerto Rico reported that hospitals had become de facto shelters for people with disabilities who did not require hospitalization.

## **9.1 General/Community Shelters**

### **Barriers to equal access**

Key informants, stakeholders, Hotline callers and participants in listening sessions identified numerous barriers to equal access for children and adults with a variety of disabilities in general to community shelters.

The House Committee on Homeland Security brought up in its letter that it had received reports that "people with disabilities were turned away from shelters and that shelters do not have trained personnel or medical supplies", and "were denied accessible toilets and showers" (see Appendix A).

In their letter to Florida Department of Emergency Management, the DHS Office of Civil Rights and Civil Liberties and the FEMA Offices of Disability Integration and Coordination and Equal Rights raised "concerns related to service animals in emergency response and sheltering", and "concerns related to lack of discharge planning for people leaving emergency shelters" (see Appendix B).

A key informant in Texas reported that Americans with Disabilities Act specialists and advocates and Applied Behavior Analysis therapists were turned away from shelters because they were not registered with the Red Cross. Other advocates reported difficulty in offering services to shelter

residents in other disaster impacted states and territories despite years of effort to eliminate these barriers.

### **Barriers that impacted disaster survivors with all disabilities**

In some shelters, survivors with disabilities had no way to request disability accommodations.

For example, during a DHS listening session, the following illustrative anecdote was shared:

“Deaf people were walking in a sea of 5,000 people [at the G.R. Brown Center shelter in Houston]. They can't hear the announcements. They have no access to information and no direction. I walked around for three hours with a sign that said 'DEAF' on it looking for deaf people.” There was no other obvious way to connect deaf survivors with sign language interpreters and other communication accommodations.

Other listening session participants and Hotline callers reported frustration at not having a way to indicate their disability-related needs and request accommodations when arriving at shelters and throughout their stay.

As has been the case historically, there were many reports of individuals with service animals being denied access to shelters, or being requested to produce certification of the animal's status as a qualified service animal, despite the fact that this is prohibited under the Americans with Disabilities Act.

### **Barriers to people with chronic health conditions**

Key informants and Hotline callers reported that some people undergoing chemotherapy, or having chronic health conditions affecting their immunity, need to be accommodated in an environment that meets their hygiene and health maintenance needs to have equal access to programs and services.

### **Barriers to disaster survivors with mobility and stamina disabilities**

The following barriers were described:

#### **Toilet rooms and showers**

Key informants and stakeholders on teleconferences reported the lack of physical access to bathrooms and showers in Florida, Texas and the territories. Disaster survivors with mobility disabilities did not have accessible showers in some shelters in Texas for weeks and in the US Virgin Islands for over a month.

#### **Sleeping area configuration and accessible cots**

Key informants reported that cots in some shelters were not configured to provide accessibility for people with mobility disabilities. There were widespread reports that accessible cots were not provided.

“Deaf people were walking in a sea of 5,000 people [at the G.R. Brown Center shelter in Houston]. They can't hear the announcements. They have no access to information and no direction. I walked around for three hours with a sign that said 'DEAF' on it looking for deaf people.” There was no other obvious way to connect deaf survivors with sign language interpreters and other communication accommodations.

## Equal access to medication in shelters

Equal access to medication was not provided in some shelters. A participant in the DHS listening session shared the following anecdote:

A woman who went to the medical area of the facility received a prescription for the insulin she needed. She then stood in a second line at the shelter pharmacy. Once she reached the front of the line, the pharmacist told her the prescription was not appropriate, and he would not fill it. He directed her to wait again in the first line for a new prescription. Several days later, she reported that she still hadn't received insulin because she didn't have the stamina to stand in the lines.

## Barriers to people who are deaf or hard of hearing

Key informants and participants in the DHS listening session reported that sign language interpreters in shelters were sometimes absent and others were not qualified.

## Barriers to people requiring low stimulation areas

Shelters often did not have designated quiet areas or they were not placed appropriately. For example, a shelter quiet area in Texas was located adjacent to frequently used indoor basketball court.

## Lack of disability equipment in shelters

It was expressed in the DHS listening session and on Hotline calls that there was a need for bariatric equipment and other durable medical equipment in shelters to replace lost or destroyed equipment. Others, particularly older adults with disabilities who did not use equipment at home, required equipment to maintain health, safety and independence in large shelter environments.

### What worked:

Planning had previously addressed shelter accessibility requirements and those plans were implemented. This included shelters that complied with physical access and effective communication obligations.

In Houston, disaster survivors requiring dialysis were provided with assistance to locate dialysis treatment and transportation in proximity to their shelter location.

A woman who went to the medical area of the facility received a prescription for the insulin she needed. She then stood in a second line at the shelter pharmacy. Once she reached the front of the line, the pharmacist told her the prescription was not appropriate, and he would not fill it. He directed her to wait again in the first line for a new prescription. Several days later, she reported that she still hadn't received insulin because she didn't have the stamina to stand in the lines.

## Recommendation Part IV – Section 9.1

**All shelters must comply with the obligations clearly described in the 2007 US Department of Justice *Americans with Disabilities Shelter Checklist*.**<sup>42</sup> This checklist and other tools for compliance were also published in 2010 in the *FEMA Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters*.

<sup>42</sup> [FEMA Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters \(PDF\)](#)

Both of these guidance documents are being updated and it is further recommended that the updated versions of these tools and resources are released immediately.

### **Recommendation Part IV – Section 9.2**

**Access surveys must be conducted at all potential shelter sites by individuals who have extensive training in conducting access audits.** It should never be presumed that because a shelter is in a government operated building, such as a school, that it meets accessibility requirements.

### **Recommendation Part IV – Section 9.3**

**Direct the Department of Justice to review the status of all Project Civic Access settlements to assess compliance with all emergency and disaster-related agreements.**

### **Recommendation Part IV – Section 9.4**

**Direct the relevant federal civil rights offices to assess the equal access and non-discrimination civil rights compliance performance of the American Red Cross and other shelter and mass care providers within 90 days.**

### **Recommendation Part IV – Section 9.5**

**Charge the newly constituted National Advisory Council on Disabilities and Disasters with developing recommendations for immediate actions.**

## **9.2 Special Needs Shelters**

Over the past ten years, there has been a national discussion about sheltering and accommodating the medical and health maintenance needs of disaster survivors.

Guidance from the US Department of Justice, FEMA and legal decisions have all established the requirement for children and adults with disabilities to have equal access to emergency services and programs throughout disasters. This includes the services and supports required to provide accommodation in the most integrated shelter setting appropriate to the individual.

‘One of government’s primary responsibilities is to protect residents and visitors. Providing emergency shelter during disasters and emergencies is a basic way of carrying out this duty. Shelters are sometimes operated by government entities themselves. More commonly though, shelters are operated for the state or local government by a third party – often the American Red Cross. Regardless of who operates a shelter, the Americans with Disabilities Act (ADA) generally requires shelters to provide equal access to the many benefits that shelters provide, including safety, food, services, comfort, information, a place to sleep until it is safe to return home, and the support and assistance of family, friends, and neighbors.’<sup>43</sup>

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<sup>43</sup> [The ADA and Emergency Shelters - Access for All in Emergencies and Disasters](#)



The state of Florida is required to have designated “special needs” shelters for disaster survivors with disabilities under Florida Statute Section 381.0303. The Department of Homeland Security (DHS) and FEMA noted that there had been concerns about the “use of and services provided in special needs shelters” in their letter to the Florida Division of Emergency Management (see Appendix B). The House Homeland Security Committee correspondence with FEMA and DHS (see appendix A), refers to a situation where a man with quadriplegia was separated from his fiancé and sent to a special needs shelter. He was later discharged from that shelter with nowhere to go in dangerously high heat. The Committee reported that the individual subsequently had a heat stroke.

On stakeholder and Hotline calls there was confusion about the requirements for registering for these special needs shelters in advance, which survivors were not “qualified” to go to special needs shelters, and whether going to a special needs shelter was required for people with certain disabilities even if they wanted to receive services in the general community shelter. It was unclear which services were provided in special needs and general needs shelters to accommodate people with disabilities, if they did attempt to exercise their right to be served in the general community shelter.

For example, Hotline callers who use oxygen or ventilators reported conflicting information about eligibility for special needs shelters, with the prevailing directive indicating that neither general, community shelters nor special needs shelters were available to accommodate these individuals.

In other disaster-impacted states and territories there were frequent reports that individuals with disabilities were diverted to “medical shelters” despite the fact that they were not in need of acute medical care that would otherwise be provided in a hospital. Often these individuals were in need of personal assistance, medication, power or disability equipment to maintain health, safety and independence, but they were denied access in the most integrated setting, and presumed to be appropriately in need of “medical” sheltering.

## Recommendation Part IV – Section 9.6

States and territories, including Florida and others with similar legislation, must revise their statutes regarding special needs and medical sheltering. This must include meeting state and territory obligations to provide programs and services in the most integrated setting appropriate to the needs of each individual.

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## ***Part IV - Section 10: Disaster Recovery Centers (DRCs) and Remote Registration for FEMA Assistance***

### **Barriers**

Much like barriers to equal access in shelters, key informants, Hotline callers, and stakeholders on teleconferences reported that Disaster Recovery Centers posed barriers to equal opportunity to participate in and benefit from disaster programs and services.

Some examples reported by key informants and Hotline callers included the absence of remote or on-site sign language and interpreters, and sign language interpreters who were not qualified.

The following quote is from the DHS listening session in Texas:

“We were told that to get interpreters, find a way to get yourself to a DRC when your car has been flooded and walk in and ask for an interpreter and sit and wait for hours and see if they can get one there. If they can't, use the VRI (video remote interpreting) which is not effective and then maybe come back tomorrow.”

It was also reported that print and electronic information were not always accessible to people with vision disabilities or low literacy.

Another significant barrier was the inability to reach Disaster Recovery Centers. This was particularly true in Puerto Rico and the US Virgin Islands who could not get to DRCs due to impassable roads or lack of conventional and accessible transportation. This was also true in the Houston area due to the placement of DRCs in locations far from the locations of known concentrations of disaster survivors.

For disaster survivors with disabilities, additional barriers were experienced as these applicants faced long lines, hours long wait times for assistance and physical accessibility barriers in the DRC.

#### **What worked:**

Disability organizations and volunteers joined with FEMA Disaster Survivor Assistance Teams, and their imbedded Disability Integration Advisors and qualified sign language interpreters to reach and register disaster survivors in remote areas. Disability organizations including Centers for Independent Living and protection and advocacy systems were also able to assist some survivors with disabilities with addressing their immediate needs.

The deployment of FEMA Disability Integration Advisors and Sign Language Interpreters, as well as the assistive communication devices provided in some DRCs.

“We were told that to get interpreters, find a way to get yourself to a DRC when your car has been flooded and walk in and ask for an interpreter and sit and wait for hours and see if they can get one there. If they can't, use the VRI (video remote interpreting) which is not effective and then maybe come back tomorrow.”

It was also reported that print and electronic information were not always accessible to people with vision disabilities or low literacy.

### **Recommendation Part IV – Section 10.1**

**DRCs must be accessible at all times.** Despite the fact that access surveys are conducted at all DRCs, many were found to be noncompliant. DRC accessibility must be verified prior to opening and monitored throughout operation.

### **Recommendation Part IV – Section 10.2**

**Local deaf leaders must be included in all decisions about optimizing the deployment of qualified sign language interpreters with regional language expertise.**

### **Recommendation Part IV – Section 10.3**

**FEMA must publicize the availability and location of on-site sign language interpreters and assistive communication devices. FEMA must also provide a local resource for**

questions about requesting, accessing and utilizing accommodations throughout the registration process.

## **Recommendation Part IV – Section 10.4**

**FEMA must deploy Disability Integration Advisors and qualified sign language interpreters to remote areas when DRCs are inaccessible due to destroyed or damaged infrastructure and access barriers.**

## **Recommendation Part IV – Section 10.5**

**FEMA must ensure that accessible transportation to DRCs is provided.**

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## ***Part IV - Section 11: Food and Water Distribution***

Food and potable water distribution shortfalls became a crisis in all of the disasters. Access to sufficient food and potable water disproportionately impacted children and adults with disabilities due to the failure of planning and implementation strategies absent of access considerations. The October 23, 2017 letter from the House Committee on Homeland Security cites reports that, “Since Maria struck Puerto Rico, people with disabilities have been denied clean water or provided dirty water, [and have] been provided expired canned foods...” (see Appendix B).

### **Lack of access to food and clean water**

Just as long lines disproportionately impacted some people with disabilities registering for FEMA services, food and water lines and distribution schemes also disproportionately impacted people with disabilities. Again, this is the result of inadequate planning and execution to eliminate a predictable barrier. People with mobility disabilities, disabilities that impacted stamina, chronic health conditions as well as people with mental health disabilities, autism and ADHD were often unable to tolerate waiting in long lines to obtain food and clean water.

Disability leaders reported that disaster survivors in Puerto Rico were required to wait in separate lines in different parts of a locality for food and water. At times in Puerto Rico, disaster survivors were charged for potable water. These factors disproportionately impacted disaster survivors with disabilities because they are more likely to be poor, and susceptible to the health effects of dehydration and impurities in the water.

### **Unequal access to food drops**

Key informants in Puerto Rico described privately donated food and medical supplies being airdropped or brought in by truck to remote areas. People with disabilities who were not able to travel through disaster damaged terrain did not have equal access to food and medical supplies distributed in this manner.

### **Unequal access to food distribution systems**

On Florida stakeholder calls there were continual discussions about the urgent and unmet nutrition and hydration needs of disaster survivors with disabilities. There were disturbing reports of denial of equal access to food and water in distribution schemes. For instance, survivors with disabilities were trapped in high-rise Department of Housing and Urban Development (HUD) section 211 buildings. In one case the elevator was functional but blocked by debris which prevented residents with disabilities from reaching food and water distribution. In another situation, it was reported that ice and food had been dropped off in the first floor lobby of a HUD Section 211 building without power, rendering the elevators inoperable.

A person with a mental health disability called the Hotline to express her panic while waiting in a line to apply for DSNAP. She reported that the line circled a large shopping mall twice. She was unable to complete her call to the Hotline because her phone did not have an ample charge.

Daily stakeholder calls included debates among disability leaders, Red Cross and government representatives about how to meet the immediate hydration and nutrition needs of disaster survivors with disabilities. Some government officials argued that there were ample accessible feeding stations. Disability leaders including staff and members of State Independent Living Council and Centers for independent living staff pointed out that many people could not leave their homes, and for others paratransit to these areas was costly. Grocery “gift cards” were provided through Portlight and other donors. While these were a solution for some disaster survivors in proximity to operational grocery stores, gift cards were not a viable solution for people with disabilities without the means to reach grocery stores.

One strategy frequently discussed was for the American Red Cross and other voluntary organizations to provide food directly to the Independent Living Centers and to assist them in delivering it to disaster survivors who could not reach any local points of distribution.

Once a few solutions were identified, it still took daily discussion for these solutions to be deployed. Unfortunately, even when they were deployed, there were reports that the amounts and types of foods contained in individual packages was inadequate or inappropriate (ie: pasta that required cooking despite power outages and a single serving carton of milk to feed a family.)

### **Disaster Supplemental Nutrition Assistance**

Disaster Supplemental Nutrition Assistance (DSNAP) was one of the programs the state of Texas chose to offer to eligible disaster survivors. This program was implemented over a time period that made DSNAP available in some locations weeks before it became available in other locations. Disaster survivors in Houston were among the last to have DSNAP provided, even though Houston was known to be the most significantly disaster affected area of the state. The disproportionate impact of nutrition shortfalls on children and adults with disabilities in the Houston area was further exacerbated by this delay.

In Florida, DSNAP was also activated. For individuals already participating in the state’s Supplemental Nutrition Assistance Program, an increase of 40% of their monthly allocation was announced. While this was portrayed as a significant benefit for disaster survivors, in reality many SNAP recipients were typically receiving amounts as low as \$15 per month, meaning the replacement of their damaged food would be supplemented by an increase of \$6.00.

A person with a mental health disability called the Hotline to express her panic while waiting in a line to apply for DSNAP. She reported that the line circled a large shopping mall twice. She was unable to complete her call to the Hotline because her phone did not have an ample charge.

## What worked:

Stakeholder calls provided disability leaders a forum to share up-to-date information and strategize solutions to enable people with disabilities to access food and potable water..

Staff from Protection and Advocacy systems, University Centers for Excellence in Developmental Disabilities, Centers for Independent Living, Deaf organizations and other disability organizations delivered food and water to disaster survivors with disabilities in all of the disaster-impacted areas. Portlight provided funds and deployed disability leaders to support local disability organizations to meet these and other life-saving and life-sustaining immediate needs.

## Recommendation Part IV – Section 11.1

**Disaster planning in every state and territory must identify and implement policies and standard operating procedures for providing equal access to food and water distribution to disaster survivors with disabilities throughout disaster response.** This must include funding the participation of local disability leaders throughout planning and implementation for distributing food and water to people with disabilities who may not be able to access points of distribution. This must also include strategies for equal access throughout the point of distribution process, including mitigation of predictable barriers including line management.

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## ***Part IV - Section 12: Distribution of goods***

### **Barriers: Distribution of goods in the territories**

Distribution of equipment, including durable medical equipment, medical supplies, food, fuel, generators, oxygen, and other life-saving and life-sustaining necessities posed some of the most complex challenges in Puerto Rico and the US Virgin Islands. People with disabilities were disproportionately impacted by distribution failures because of their reliance on goods such as medication, medical supplies, and medical equipment to maintain their health, safety and independence throughout the disaster.

Shipment and distribution of these goods once they arrived in port constituted an enormous barrier to equal access for survivors with disabilities. Shipping protocols were ambiguous, and they frequently failed. It often took months to get disability-related goods into the hands of people with disabilities who required them for survival and recovery.

When power was interrupted, many people who routinely used ventilators and other life-sustaining equipment requiring uninterrupted power were forced to rely on gas or diesel powered generators. Inadequate availability and distribution of fuel compounded by the high cost for constant generator operation made matters worse. Additionally, constant operation of generators led to mechanical failures which further jeopardized the health, safety and independence of disaster survivors with disabilities.

It has been widely speculated that there is has been a significant loss of life reported as a result of the barriers to goods and services experienced by these disaster survivors.

In October the Mayor's Office for People with Disabilities coordinated a large shipment of disability supplies and durable medical equipment for disaster survivors in Puerto Rico whose equipment and supplies had been lost, damaged or destroyed. The shipment arrived in port on October 27, 2017. In March 2018, these 20 pallets of goods were finally located after months of effort. Initially release was refused, however a strong advocacy effort led by local disability advocates and supported by Portlight and the Partnership finally succeeded in the release of these critically needed goods. Unfortunately, despite their release, there was an unexpected \$13,000 storage fee. Again, strong advocacy was needed, and ultimately successful, with the shipping company waiving the fee once they learned what the shipment contained. In April, the items were finally delivered to disaster survivors who remained in great need of these goods to continue their recovery.

#### **What worked:**

**Portlight, Trach Mommas, Pass It On Center and others tested alternative shipping methods when it became evident that disability supplies were not getting to the survivors who needed them.**

**Continued advocacy with government and non-governmental entities leading disaster response, without prioritizing the access and functional needs of disaster survivors with and without disabilities.**

**Utilizing the generosity of government partners such as National Guard, to add medical supplies and equipment to their shipments.**

### **Recommendation Part IV – Section 12.1**

**The government must establish a process for providing for the movement and distribution of goods to meet the equal access requirements of children and adults with disabilities to participate in emergency programs and services.**

### **Recommendation Part IV – Section 12.2**

**The government must have a defined process for moving and distributing volatile life-saving good, such as oxygen, beyond fixed medical facilities to meet the needs of disaster survivors outside of acute medical care settings.**

### **Recommendation Part IV – Section 12.3**

**FEMA must update policies for transporting life-saving and life-sustaining goods, including donated goods provided by non-government whole community partners. Current policies are inconsistent and are not in alignment with the needs of disaster survivors to maintain health, safety and independence outside of acute medical facilities.**

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## **Part IV - Section 13: Housing**

The goal of disaster recovery is always to reestablish the full function of every community impacted by disasters. Permanent housing is a fundamental element of recovery. For individuals with disabilities and their family, accessible, affordable housing located in proximity to the goods, systems, services and networks is vital to their community participation, inclusion and independence.

It is widely known that there is scarcity of these housing resources in every community across the country before disaster strikes. This chronic failure is exacerbated when housing is damaged or destroyed. This causes disproportionate upheaval, relocation and service disruption for children and adults with disabilities. And yet, programs and services to address these foreseeable consequences of disasters are routinely overlooked in planning followed by continually failing to prioritize the requirements for providing equal access to housing for disaster survivors with disabilities.

**As far back as September, a national coalition of organizations was forming to address the housing crisis they foresaw. In a letter to both Houses of Congress, a large group of national organizations and local governments expressed their expectations that the “federal government would ensure federal housing recovery and rebuilding efforts are complete and equitable for all individuals and communities impacted by the devastation caused by Hurricanes Harvey, Irma and Maria”.**

**The Partnership has become an active member of the Disaster Recovery Housing Coalition, led by the [National Low Income Housing Coalition](#). The Coalition called on Congress to “make certain that federal disaster recovery resources reach all impacted households, including those with the lowest incomes who are often the hardest-hit by disasters and have the fewest resources to recover afterwards.**

### **Barriers**

Survivors with and without disabilities in affected areas still do not have access to affordable, accessible and in many cases even habitable housing. As of late February 2018, 27,000 people in Texas were without permanent housing solutions. Two months later the numbers had not diminished markedly. As of publication, the Hotline continues to receive daily calls from panicked survivors who are desperate for housing, and often report that they are within hours of homelessness.

A DHS listening session participant shared the following anecdote:

A family of six was living in HUD housing that was deemed substandard and condemned by HUD. They stayed in the home because they had nowhere else to go. In December when it was cold the home burned down. The family, composed of a single mother with five children, three of whom have disabilities were living in their car as of February 2018.

### **Recommendation Part IV – Section 13.1**

**Conduct a study (or initiate a competition) to identify new approaches and solutions to address the housing and wrap-around services needs of disaster survivors with disabilities.**

### **Recommendation Part IV – Section 13.2**



Establish metrics and measure availability of the ready supply of accessible, adaptable, affordable, and disaster resistant permanent and temporary housing nationwide.

### **Recommendation Part IV – Section 13.3**

**Exempt the cost of disability related repairs and replacement from the FEMA Individuals and Households maximum Grant ceiling (currently \$34,000). Disability related repairs and replacement of durable medical equipment and other disability items includes replacing wheelchairs, customized vehicles, medical devices, entrance ramps, elevator installation to meet home elevation requirements, and other items that provide equal access for people with disabilities in recovering from a disaster.**

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## ***Part IV - Section 14: Intersectionality and equal access to disaster programs and services***

It is no surprise that key informants reported that marginalization and barriers to equal access to programs and services were even greater for individuals with disabilities who are people of color, live in poverty, experience homelessness, women, people who are lesbian, gay, bisexual, transgender, queer or questioning, intersex, and asexual or allied, and immigrants with disabilities, especially individuals who are “undocumented.”

A key informant noted that these individuals frequently live with a lack of access to health care, transportation, adequate housing and jobs in pre-disaster conditions. The disasters exponentially worsened the situations of these individuals.

### **Barriers**

It was reported that bias stemming from race, class, ethnicity, gender and especially immigration status frequently impeded access to disability-related and other disaster programs and services. A key informant reported that xenophobic rhetoric from elected Federal and State officials, anti-immigrant legislation and repression by immigration and law enforcement agencies created a well-founded climate of fear among immigrant and refugee communities. In many cases it led them to avoid seeking shelter and other life-saving assistance and continues making access to disaster recovery resources difficult.

it was also noted that loss of medical equipment and supplies, as well as personal vehicles and accessible public transportation, represent a great challenge for U.S. citizens with disabilities, but it is even worse for those who are denied access to FEMA and other government-funded resources. The key informant’s organization provided medical equipment, supplies and small amounts of financial help to people with disabilities affected by disasters. He reported that many of those who were denied help by FEMA are low income African American, Latinos or immigrant families with U.S.-born children.

### **Recommendation Part IV – Section 14.1**

Every government entity that provides disaster services must address and eliminate all structural barriers that prevent or impede equal access to disaster assistance for all disaster survivors with disabilities.

### **Recommendation Part IV – Section 14.2**

FEMA must clearly document demographic information of those who apply for assistance.

### **Recommendation Part IV – Section 14.3**

Non-governmental, disability rights and immigrant rights organizations must continue to collaborate to develop better and more inclusive disaster responses.

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## ***Part IV - Section 15: Equal Access to Education for Students with Disabilities***

Since the disasters, students with disabilities have been repeatedly denied their right to a Free and Appropriate Public education guaranteed under the Individuals with Disabilities Education Act (IDEA), as well as the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.

Hotline callers reported that students, in some cases, were required to wait longer to return to school than their non-disabled peers. This was because new schools and schools systems were not “ready” to receive them. In some cases there was no accessible or conventional transportation available to take students with disabilities to school.

Hotline callers reported instances where students with disabilities such as autism had difficulty transitioning to a new school and this had not been planned for.

Key informants from Puerto Rico and the US Virgin Islands reported that because schools were only in session for half days- because schools had been destroyed or still do not have power- students were not receiving services delineated in the IEP or 504 Plans.

Qualified educators and other educational services professionals have frequently relocated and their required services are not available to students guaranteed their services.

Even though students with disabilities are the only students guaranteed the right to a free and appropriate public education they were the ones who received it last in many cases.

Parents were forced to stay home from work impacting their job security, their family’s financial stability and the local economy.

#### **What worked:**

Parents who banded together to support each other was reported as successful by Hotline callers.

Special Education group in Texas and other localities made progress toward the goal of attaining a Free and Appropriate Public Education that students with disabilities are guaranteed under federal law.

Bringing the issue of students not receiving a Free and Appropriate Public Education was continually brought up on stakeholder calls. This provided a forum to ensure that education for students with disabilities who had survived disasters remained a priority.

### **Recommendation Part IV – Section 15.1**

**IEPs and 504 Plans must be digitized and stored in the cloud for availability during and after disasters.**

Parents should be given digitized versions of IEPs or 504 Plans on flash drives each time the IEP or 504 Plan is updated.

### **Recommendation Part IV – Section 15.2**

IEPs and 504 Plans must contain emergency contingencies regarding transportation in the event of a disaster, support that will be put in place should a student have to relocate to a new school in the event of a disaster.

### **Recommendation Part IV – Section 15.3**

**The Department of Education must issue strong guidance regarding compliance with obligations throughout emergency planning and response and recovery.**

### **Recommendation Part IV – Section 15.4**

Students with disabilities must be given a full day of services even when school is operating on a part day basis when necessary to provide a free and appropriate public education (FAPE), and must be provided with compensatory services for all gaps in IEP delivery.

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# **Appendix A: Letter to Acting Secretary U.S. Department of Homeland Security and Administrator Federal Emergency Management Agency from members of the U.S. House of Representatives Committee on Homeland Security**

Note: Format has been modified for accessibility.

MICHAEL T. McCAUL, TEXAS  
CHAIRMAN

BENNIE G. THOMPSON, MISSISSIPPI  
RANKING MEMBER

Image: One Hundred Fifteenth Congress / U.S. House of Representatives / Committee on Homeland Security / Washington, DC 20515

October 25, 2017

The Honorable Elaine C. Duke  
Acting Secretary  
U.S. Department of Homeland Security  
245 Murray Lane SW Washington, DC 20528

The Honorable Brock Long  
Administrator  
Federal Emergency Management Agency  
U.S. Department of Homeland Security  
500 C Street SW Washington, DC 20472

Dear Acting Secretary Duke and Administrator Long:

We write to express our profound concern about reports that the Federal government is not integrating individuals with access and functional needs into ongoing response and recovery efforts in Puerto Rico and the U.S. Virgin Islands. By failing to ensure access to disaster relief services, the Federal government is violating rights guaranteed to individuals with disabilities under Federal law (Footnote 1) and jeopardizing the lives and safety of disaster survivors. We call on both of you to take swift action to include individuals with disabilities in disaster response and recovery efforts.

The Rehabilitation Act of 1973, as amended, provides: "No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service." (Footnote 2) Nevertheless, we have learned individuals with disabilities have either been excluded from or denied the benefit of Federal disaster response activities because neither the Department of Homeland Security (DHS) nor the Federal Emergency Management Agency (FEMA) have taken the requisite actions to integrate special needs populations into their disaster relief plans and policies.

Despite well-established protections for individuals with disabilities, challenges related to integrating those with access and functional needs into disaster response and recovery activities are nothing new. After the abominable Federal response to Hurricane Katrina, Congress passed the Post Katrina Emergency Management Reform Act (PKEMRA), which, among other things, authorized the position of Disability Coordinator within FEMA. (Footnote 3) PKEMRA charged the Disability Coordinators with reviewing disaster response plans, including evacuation routes and transportation options, to make certain they accommodate and are made known to individuals with disabilities. (Footnote 4) PKEMRA also directed FEMA to work with state and local governments to identify critical gaps in regional capabilities to respond to populations with special needs. In December 2009, former Administrator Craig Fugate established the Office of Disability Integration and Coordination (ODIC), overseen by the disability coordinator, to help carry out the FEMA's responsibilities under PKEMRA. As we understand it, FEMA was without a permanent Disability Coordinator for the better part of the year and ODIC has never had the funding necessary to fully execute its mission.

Meanwhile, DHS's Office of Civil Rights and Civil Liberties (CRCL) is charged with reviewing and assessing reports of civil rights abuses, assisting the Department and its components with developing and implementing policies to ensure civil rights and civil liberties protections are integrated into agency programs and activities, and overseeing "compliance with constitutional, statutory, regulatory, policy, and other requirements relating to the civil rights and civil liberties of individuals affected by the programs and activities of the Department" (Footnote 5)

Unfortunately, we understand that CRCL has failed to take meaningful action in response to complaints of civil rights violations from individuals with disabilities. We have learned that the Department and FEMA have, in large part, punted complaints about Federal civil rights violations to territory and municipal leadership, thereby absolving themselves of any obligation to ensure that the billions of dollars in Federal disaster relief funds are spent in compliance with Federal law. However, neither DHS nor FEMA has the authority to shirk their responsibilities to enforce Federal laws prohibiting discrimination. (Footnote 6)

As DHS and FEMA play "hot potato" with their responsibilities to protect the civil rights of disaster survivors, people with disabilities are paying the price. Since Hurricane Maria struck Puerto Rico, people with disabilities have been denied clean water or provided dirty water, provided expired canned foods, excluded from FEMA applicant services, excluded from access to medical care, and denied accessible toilets and showers. We have heard reports that people with disabilities have been turned away from shelters and that shelters do not have trained personnel or medical supplies. (Footnote 7) Moreover, the Federal government has failed to communicate information about alerts, warnings, evacuations, medical care, sheltering, and the provision of commodities in a manner accessible to individuals with hearing impairments or other disabilities. Finally, the Federal government is failing to provide assistance to homebound people who need fuel for generators to power oxygen tanks and refrigerate medicine. This is unacceptable.

We also note that while we have focused primarily on challenges the disability community is experiencing in Puerto Rico and the U.S. Virgin Islands, we understand that disaster response activities following Hurricanes Harvey and Irma and the California wildfires were similarly not inclusive of people with disabilities. For example, following Hurricane Harvey, we understand a quadriplegic man was separated from his fiance to be placed in a special needs shelter and ultimately released even though he had nowhere to go. (Footnote 8) He slept outside and suffered heatstroke before FEMA helped him find an accessible hotel room. (Footnote 9)

We hoped that the reforms Congress enacted after Hurricane Katrina would ensure that people with disabilities are integrated into disaster response and recovery plans, but that does not seem to be the

case. Accordingly, pursuant to Rule X and Rule XI of the U.S. House of Representatives, we ask that you provide a written response to the following information, and whatever supplementary information you deem responsive, by October 27, 2017:

- Who is responsible at both DHS and FEMA for ensuring that all recipients of Federal assistance comply with Federal laws and regulations prohibiting discrimination against individuals with disabilities in the States and territories impacted by Hurricanes Harvey, Irma, and Maria as well as the California wildfires?
- What is the process DHS CRCL utilizes to investigate and resolve complaints of civil rights violations raised by individuals with disabilities related to access to disaster relief services? What is the process FEMA utilizes to investigate and resolve complaints of civil rights violations raised by individuals with disabilities related to access to disaster relief services? How do DHS CRCL and FEMA coordinate activities related to investigation and redress of complaints of civil rights violations raised by individuals with disabilities related to access to disaster relief services?
- How many complaints of civil rights violations raised by individuals with disabilities related to access to disaster relief services has DHS CRCL received? How has DHS CRCL resolved each complaint?
- How many complaints of civil rights violations raised by individuals with disabilities related to access to disaster relief services has FEMA received? How has FEMA resolved each complaint?
- We understand that families of sick children self-evacuated to states, such as Florida, when generators at medical facilities proved unreliable and the Federal government was unable to facilitate timely evacuations. We also have learned that families of these children have been denied housing assistance since evacuating to Florida, leaving them with nowhere to go even when their child is discharged from the medical facility. Are families who had to self-evacuate from Puerto Rico to access reliable healthcare eligible for Individual Assistance? If not, who is responsible for assisting these families?
- We understand that the USNS Comfort is underutilized. As of last week, just 23 out of the 250 beds on board had been filled." (Footnote 10) We have learned that part of the reason the USNS Comfort is underutilized is that individuals with disabilities are unable to get there or are unable to get referrals for treatment. How is FEMA working with its interagency partners to eliminate barriers affecting access to medical services provided by the USNS Comfort?
- Under the National Response Framework, DHS-FEMA is the Emergency Support Function (ESF) coordinator for Mass Care, Emergency Assistance, Temporary Housing and Human Services. The Department of Health and Human Services (HHS) is the ESF coordinator for Public Health and Medical Services. From what we know about circumstances on the ground in Puerto Rico and the U.S. Virgin Islands, there appears to be a lack of coordination among the agencies responsible for carrying out these distinct but related functions. How is DHS-FEMA coordinating with HHS to ensure individuals with access and functional needs can obtain the support and medical services they need? How is DHS-FEMA coordinating with HHS to facilitate medical evacuations of individuals with access and functional needs?

- With respect to FEMA's disaster workforce, how many individuals deployed to respond to Hurricanes Harvey, Irma, and Maria and the California wildfires are from the Disability Integration Cadre? Please provide specific deployment numbers for each State and territory.
- We understand that there has not been a permanent Disability Coordinator in place for over six months and that ODIC suffers from budget challenges. Please explain why the Disability Coordinator position was vacant for so long. Please also provide the current funding level for ODI C and the current Full Time Equivalents. Finally, please also describe any contractor support ODIC receives, including the number of contract employees who support the Office, the entity with which ODIC has the contract, and the scope of contracted services.
- Please describe any training that the Surge Capacity Force receives related to the rights of individuals with disabilities and the Federal government's obligations to them as it engages in disaster relief efforts.

Thank you for your attention to this matter. If you have questions or require additional information, please contact Alison Northrop, Chief Director for Oversight, at (202) 226-2616.

Sincerely,

BENNIE G. THOMPSON I  
 Ranking Member  
 House Committee on Homeland Security

Donald M. Payne, Jr.  
 Ranking Member  
 Subcommittee on Emergency Preparedness, Response, & Communications

James R. Langevin  
 Member

BONNIE WATSON COLEMAN  
 Member

Appendix A Footnotes:

1. The Rehabilitation Act of 1973, as amended, codified at 29 U.S.C. §794(a).
2. *Id.*
3. The Post Katrina Emergency Management Reform Act, Pub. L. No. 109-295.
4. Section 513 of P.L. 109-295 (6 U.S.C. 321 b) describes the position and responsibilities of the Disability Coordinator.
5. The Homeland Security Act of 2002, §705, codified at 6 U.S.C. §345
6. The Stafford Act, codified at 42 U.S.C. §5151 (b) ("As a condition of participation in the distribution of assistance or supplies under this chapter or of receiving assistance under this chapter, governmental bodies and other organizations shall be required to comply with regulations relating to nondiscrimination promulgated by the President, and such other regulations applicable to activities within an area affected by a major disaster or emergency as he deems necessary for the effective coordination of relief efforts.").
7. Erin Cohan, et. al, Center for American Progress, "[Recovering From Hurricane Maria Requires Extensive Federal Response](#)," (Oct. 12, 2017).



8. Erin Vogel-Fox, "[Hurricane Nursing Home Deaths Cause a Bipartisan Gut-Check in Congress](#)," WJLA (Sept. 21, 2017).
9. *Id.*
10. MarEx, "[Hospital Ship Waits Off San Juan, But Sees Few Patients](#)," The Maritime Executive (Oct. 17, 2017).

# Appendix B: Letter from FEMA to Director of Florida Division of Emergency Management

Note: Format has been modified for accessibility.

Office for Civil Rights and Civil Liberties U.S.  
Department of Homeland Security  
Washington, DC 20528

Image: Logo – U.S. Department of Homeland Security

November 1, 2017

Wes Maul  
Director  
Florida Division of Emergency Management  
2555 Shumard Oak Blvd. Tallahassee, FL 32399-2100  
Wes.Maul@em.myflorida.com

Dear Mr. Maul:

In light of the devastating damage caused by Hurricane Irma, the U.S. Department of Homeland Security (DHS), Federal Emergency Management Agency (FEMA) recently approved the State of Florida to receive federal financial assistance in connection with Major Disaster Declaration DR-4337 for Hurricane Irma. Related to this declaration and FEMA-State Agreement (FEMA-4337-DR-FL), the DHS Office for Civil Rights and Civil Liberties (CRCL), FEMA Office of Disability Integration and Coordination (FEMA ODIC) and the FEMA Office of Equal Rights (FEMA OER) would like to remind the State of Florida of its obligations to carry out its federally assisted activities in a manner that is consistent with Section 504 of the Rehabilitation Act of 1973, as amended (Section 504) and Section 308 of the Robert T. Stafford Disaster Relief and Emergency Assistance Act, as amended (the Stafford Act). As you may know, Section 504 prohibits discrimination based on disability, and the Stafford Act prohibits discrimination on the grounds of race, color, religion, nationality, sex, age, disability, English proficiency, and economic status in disaster relief and assistance activities. The State of Florida is also responsible for ensuring compliance with these requirements on the part of any sub-recipients of the federal funds.

DHS continues to engage with community stakeholders on challenges related to accessibility for persons with disabilities during disaster response and recovery efforts. Through this engagement, CRCL, FEMA ODIC and FEMA OER are aware of reports and ongoing concerns related to lack of effective communication, program access, and physical access for persons with disabilities in programs and activities related to Hurricane Irma. (Footnote 1)

Recognizing that many are still working hard dealing with ongoing issues subsequent to the hurricane, we would ask that in the short term you consider how to prevent additional concerns that are likely to emerge now that the affected communities are starting on the arduous road to long-term recovery. In particular, the State of Florida, and any sub-recipients, should take steps to ensure that individuals with disabilities and their families:

- have physical access to and receive effective communication regarding registration for recovery programs and activities;
- receive assistance in re-constituting the community supports that enable them to live as independently as possible;
- benefit equally with other state residents from the construction of new affordable and accessible housing within their pre-disaster community of residence;
- benefit from re-established public transportation services that enable them to access health care, education, and employment opportunities; and
- are afforded a meaningful opportunity to participate in the town hall meetings and various input processes used by localities to engage community members regarding recovery plans.

CRCL, FEMA ODIC and FEMA OER are available to provide technical assistance to the State of Florida, as needed or desired, to ensure nondiscrimination in its emergency programs and activities now, as well as to participate in any after-action activities to revise planning for future disasters. Absent any such specific requests, or any request to jointly participate in resident feedback, CRCL, FEMA ODIC and FEMA OER are likely to make arrangements in coming months to get feedback from residents regarding challenges faced by those with access and functional needs during the recent hurricane and will share with you any systemic issues and concerns brought to our attention.

There are several resources to assist federal aid recipients, such as your office, and any sub-recipients, in implementing your civil rights obligations to which we would like to draw your attention. These include:

- [Tips for Effectively Communicating with the Whole Community in Disasters](#)
- [Accommodating Individuals with Disabilities in the Provision of Disaster Mass Care, Housing, and Human Services](#)
- [Notice for Recipients on Nondiscrimination During Disasters](#)
- [Guide to Interacting with People Who Have Disabilities](#)

We stand ready to assist your State as it carries out its important mission to respond to individuals and communities affected by Hurricane Irma and to lead recovery efforts. Please do not hesitate to reach out to this office directly at 202-401-1474 or toll free at 1-866-644-8360, or by email at [crcl@dhs.gov](mailto:crcl@dhs.gov).

Sincerely,

Cameron Quinn  
Officer for Civil Rights and Civil Liberties  
U.S. Department of Homeland Security

Regis Phelan  
Acting Director, Office of Equal Rights Federal Emergency Management Agency U.S. Department of Homeland Security

Linda Mastandrea  
Director, Office of Disability Integration and Coordination  
Federal Emergency Management Agency  
U.S. Department of Homeland Security

cc: Governor Richard L. Scott

Appendix B Footnotes:

1. Examples of concerns brought to the attention of DHS staff include:
  - Concerns related to the evacuation of persons with disabilities and others with access and functional needs;
  - Concerns about the use of and the supports provided within special needs shelters;
  - Concerns related to the provision of effective communication to persons with disabilities, including the use of unqualified sign language interpreters;
  - Concerns related to service animals in emergency response and sheltering;
  - Concerns related to planning for evacuation of elderly/individuals with disabilities living in high rise buildings;
  - Concerns related to lack of discharge planning for people leaving emergency shelters; and
  - Concerns related to homeless individuals refusing shelter being threatened with involuntary institutionalization.

# Appendix C: NCIL Report on Texas

## Emergency Management Challenges and Failures for People with Disabilities in Texas During Hurricane Harvey

Prepared by Sarah Blahovec  
National Council on Independent Living  
November 7th, 2017

### Executive Summary

The year 2017 brought devastation across the United States and its territories through multiple hurricanes. Hurricanes Harvey, Irma, and Maria swept across the South, The U.S. Virgin Islands, and Puerto Rico, and as of November 2017, there are still months of recovery ahead. This devastation had a particular impact on people with disabilities, as emergency management has always had, and still does have, challenges in meeting their needs, although they make up nearly one fifth of the American population. This report dives into these problems from the point of view of Americans with disabilities who were impacted by Hurricane Harvey in Texas. After reviewing changes to emergency management through litigation in recent years, this report lays out the narratives of people with disabilities who experienced problems with emergency management during and after Hurricane Harvey and analyzes what could be done to reduce or eliminate these problems in future emergency situations.

Among the most significant findings:

- Among the experiences submitted for this report, people with disabilities encountered the most barriers and problems during application for assistance from the Federal Emergency Management Agency (FEMA).
- There was a disturbing trend of people with disabilities who had lived in the community being transferred to institutional settings, either due to lack of post-shelter housing options or due to the difficulties of navigating disaster recovery.
- Among nearly all the submitted reports, there were significant problems with communication between emergency services and people with disabilities, which show that emergency services may need to become better educated on how to interact with people with disabilities and learn about making information accessible.
- Although there are many different routes that could be taken to fix the problems detailed in this report, there is an overarching necessity for emergency management and response organizations and disability advocacy organizations to proactively work together before crises occur to anticipate and meet the needs of people with disabilities in emergency situations.

### Background

Emergency planning for people with disabilities is a critical but often overlooked aspect of emergency management. Emergency stakeholders must intentionally anticipate and plan for the needs of people with disabilities in disaster situations and understand that these needs are neither unusual nor infrequent—especially when people with disabilities make up nearly 20 percent of the population of the United States (Footnote 1). Furthermore, people with disabilities and elderly adults are two to four times more likely to die or be seriously injured in a disaster (Footnote 2).

Unfortunately, the civil rights of people with disabilities have been significantly and negatively impacted by poor emergency planning. Following the devastation of Hurricane Katrina in 2005, some people with disabilities were "temporarily relocated" to institutional settings such as nursing homes (Footnote 3). These individuals, seemingly forgotten once their needs were met, were not tracked and not provided the appropriate support to assist them with transitioning back into their communities.

Disability advocacy organizations have spent years working on local and national levels to build relationships with emergency management and response organizations to improve responsiveness to and the ability to meet the needs of people with disabilities in emergencies. In many cases, the resistance of governments toward making comprehensive and proactive emergency plans for people with disabilities has only been solved by painstaking, complex litigation. In 2011, a court ruled that the City of Los Angeles violated the Americans with Disabilities Act (ADA) by "failing to meet the needs of its residents with mobility, vision, hearing, mental, and cognitive disabilities in planning for disasters," in *Communities Actively Living Independent and Free v. City of Los Angeles*. The city, which experiences frequent emergencies from earthquakes, fires, and landslides, was ordered to revise their emergency planning to include people with disabilities (Footnote 4). The ruling outlined nine essential components of effective emergency planning: "comprehensive emergency plans", "assessments of the efficacy of emergency plans," "identification of the needs that will arise and resources available to meet those needs," "public notification and communication," "policies and procedures concerning the concept of sheltering in place," "plans to provide shelter and care for individuals forced to evacuate their homes," "assistance with evacuation and transportation," "plans for provision of temporary housing when evacuees cannot return to their homes," and "plans for...recovery and remediation efforts after an emergency or disaster (Footnote 5)."

Another example of this litigation was *Brooklyn Center for Independence of the Disabled (BCID) v. Mayor Bloomberg*. Filed more than a decade after September 11th, 2001 and during the time of disasters such as Hurricanes Irene and Sandy, the Court found that New York City had discriminated against people with disabilities by failing to plan for their needs in large-scale disaster situations. This ruling led to a settlement between parties that required the city to make improvements to their emergency management planning for people with disabilities in all major affected programs and services, including transportation, evacuation from high rises, and sheltering (Footnote 6).

In "The Right to be Rescued: Disability Justice in an Age of Disaster," attorney and Yale Law School graduate Adrien A. Weibgen found that *BCID v. Bloomberg* established several principles surrounding emergency planning for people with disabilities: first, that government entities must have detailed plans that understand and anticipate the needs of people with disabilities and plan strategies in advance of disasters to meet those needs; next, that cities must communicate clearly and effectively with people with disabilities before, during, and after emergencies and disasters; third, that cities should include experts from outside their own organizations to provide input on emergency plans; and fourth, that people with disabilities "must be allowed to meaningfully participate in emergency planning processes." Weibgen points to centers for independent living (CILs) in particular, because as cross-disability, community-based organizations that are required to be majority run by people with disabilities, CILs are entities both with access to the local disability community and with significant experience through their advocacy and individual experiences as people with disabilities (Footnote 7).

Although these lawsuits have made significant headway in getting cities to incorporate people with disabilities comprehensively into their emergency planning, it is clear that we still have so far to go. The 2017 hurricane season, with the devastating impacts of Hurricanes Harvey, Irma, and Maria, proved challenging to emergency management for people with disabilities before, during, and after the storms.

Shortly before Hurricane Harvey made landfall in Texas in September 2017, Judge Jeff Branick of Jefferson County announced that "1000 people with 'special needs' will be ferried ... to other parts of the state for short term care..." This announcement sparked concern throughout the disability community and echoed actions taken after Hurricane Katrina more than 10 years earlier.

Because of the potential for more people with disabilities to be stripped of their civil rights and placed in institutional settings during and after Hurricane Harvey, the disability community jumped into action during the 2017 hurricane season to attempt to track any reports of institutionalization, as well as any other problems experienced by people with disabilities interacting with emergency services. Although the lawsuits discussed above have led to improvement of cities' emergency plans for people with disabilities, governments nationwide still have significant deficiencies in addressing the needs of people with disabilities in large-scale emergency situations.

Quite a few incidents relating to the treatment of people with disabilities in emergency planning unfortunately made national news during the 2017 hurricane season. 14 patients in a Florida nursing home during Hurricane Irma perished from a loss of electricity and subsequent extreme temperatures, and investigation is still determining what failures led to this tragedy (Footnote 8). In Manatee County, Florida, the county "borrowed" an employee from a neighboring county to interpret into American Sign Language (ASL) critical information on evacuation and emergency preparedness for Hurricane Irma, but the man was not proficient in ASL and was not able to communicate this extremely important information (Footnote 9). In Texas during Hurricane Irma, people with disabilities experienced problems ranging from lack of access to transportation to and from shelters, to mistreatment, to transition to institutional settings instead of back to their communities following the storms.

This report intends to examine the individual narratives of people with disabilities in Texas and the challenges they faced in shelters and in recovery during Hurricane Harvey, analyze what problems they experienced, and recommend possible policies and practices so that these problems can be properly addressed and eliminated in future disasters.

## **Methodology**

The National Council on Independent Living (NCIL) set out to collect stories of people with disabilities and the challenges they faced before, during, and after Hurricane Harvey. To collect these stories, NCIL engaged in stakeholder phone calls on the national and state level, and conducted outreach throughout late September and October 2017 to Texas CILs to ask them to collect narratives from CIL staff and consumers on these challenges. CILs were asked to cast a wide net for information on how people with disabilities were affected before, during, and after the storm, collecting information on any incidents in shelters and in interactions with emergency services. In some cases, narratives were written by staff members of CILs to whom the details were dictated, while others came directly from those who experienced the problems. All stories were examined, summarized, and scrubbed of as many identifying details as possible.

This report will share these narratives, which provide comprehensive details of some of the challenges and barriers people with disabilities encountered throughout the storm. The stories requested for this report include but are not limited to the following areas: sheltering, transportation, evacuation, post-storm housing, applying for benefits, obtaining necessities, communications, and interacting with emergency management entities. From these details, we can draw recommendations on what can be improved to reduce or eliminate these problems in future emergency situations.



## Narratives

### Sheltering:

- A male wheelchair user bussed to a shelter on 30 August, was checked in, and then was transported to another shelter upon check in. The next day, he was told to relocate again to another shelter but there was no accessible bus available, so he was transferred by a hospital van. He stayed at this Red Cross shelter for the duration of the storm starting 31 August. This shelter provided daily trips to Walmart and the laundromat, but the bus for these trips was not accessible to him or the other wheelchair users in the shelter, making these services completely inaccessible to them. On 6 September, the mandatory evacuation was lifted for the man's hometown, but the buses provided were not accessible. Two other wheelchair users were told to load their luggage on the inaccessible buses and that they would be transported by ambulance the next day, separately from their belongings. The man and two other wheelchair users were transported back home on 11 September, five days after the mandatory evacuation was lifted.
- A person with Multiple Sclerosis is living on the streets because they are afraid of what will happen to them and their property in a shelter.
- A family submitted a story about evacuation and sheltering in Texas. They have a son with Autism Spectrum Disorder and who struggles with change. They lived in a community that hadn't experienced flooding in previous storms, so they decided they were going to shelter in place so that their children would be more comfortable. Their neighborhood flooded and they decided to evacuate. The parents carried their two children through around three feet of water in their back yard and over a fence to a boat that they flagged down. Upon evacuation, shelters were offered, but due to the loudness and the crowding of the shelters, they decided not to enter a shelter and stayed with family members. In future disasters, they recommend that shelters have calm-down or sensory zones for people with anxiety or autism, people who do not do well in bright, loud environments.
- A woman and her child who has autism and a medical condition stayed only one night at the George R. Brown Convention Center Shelter, because that's all they were able to endure due to being scared and feeling unsafe. There was no room or place for people with disabilities or autism, and the mom was able to convince officials to allow her and her daughter in the medical room. According to the mom, people were having their possessions stolen, including blankets and cots, when they went to use the bathroom. She stayed awake all night guarding her daughter and their backpack, which contained her daughter's communication device and medication. Some people split open cardboard boxes to sleep on and officials suspended shower privileges after thefts occurred.

### Evacuation:

- Family of four evacuated from their home as flood water rose. The father carried their youngest daughter, and their eight-year-old son with autism was chest-deep in flood water walking beside his mother to get to the dump trucks that transported them. From there, they took a military convoy to the shelter. However, the National Guard driving the convoys didn't know the way. The mother ended up jumping in the front of the convoy to help direct and the convoy made it to the shelter in two to three hours. On both the dump truck and the convoy, the residents sat in the back exposed to the elements. The family decided to check into a hotel

instead of staying at the shelter because the shelter was not a sensory-friendly environment for their son. The family recommended that a police escort could have helped keep the convoy from getting lost.

### **Medical:**

- A person with a psychiatric disability had an episode right after the storm and was discharged with prescriptions but was unable to pay the copay. A Portlight volunteer assisting with the case spent many hours on the phone with the person's local pharmacy and the volunteer's local pharmacy trying to resolve the situation. By the time the case was resolved and medication was restocked, the person with the disability had a seizure and had to be briefly hospitalized.
- A man with a spinal cord injury was in the hospital and rehabilitation for wound healing. At rehab, he was told that he could not leave rehab until he could show that he had a place to stay. His equipment was destroyed because the hospital would not allow him to bring it with him when he went to the hospital for surgery.

### **Federal Emergency Management Agency (FEMA):**

- A person with a spinal cord injury in a transitional shelter assistance (TSA) hotel had to share a bed. He had to transfer from wheelchair to floor to change undergarments after incontinence incidents during the night. He is now in a rehab facility with a pressure sore from the transfers. FEMA told someone familiar with the man's case that had this person identified their need on an application, they would not have been required to share a bed, but this was apparently not made clear to the person who filled out the application.
- A person with significant psychiatric disabilities could not manage to live in a tent shelter so they are living in an unlivable housing situation. FEMA said there was inadequate damage and they are revisiting the person's living situation.
- A hearing relative of a Deaf person called because FEMA told them that there was no way to identify the need for an interpreter and text notifications of inspections through the FEMA application form.
- A CIL purchased an electric Hoyer Lift for a wheelchair user who could not get in or out of her bed on her own. She received the lift on 24 August, and Hurricane Harvey struck on 26 August. The lift was still in the box. The woman experienced flooding and the Hoyer Lift experienced water damage. The lift was assessed and the electrical components of the lift need to be replaced. The woman made a claim to FEMA regarding her house and contents, and FEMA denied her. She appealed the denial and was denied again. She continues to live without her Hoyer Lift and has to rely on others for assistance, and this has decreased her independence. FEMA continues to deny her assistance.
- A woman with medical issues and who needs assistance with her medication and CPAP machine was displaced due to Hurricane Harvey and continues to live at a shelter or with friends. Her medication and CPAP were at her family's residence, which was flooded during the storm. She made a FEMA claim and was denied, and has attempted to dispute the denial, but FEMA can no longer find her original claim. She continues to go without all her medications and her CPAP machines, which is having a negative toll on her body. She is trying to receive

SSI or SSDI and has an upcoming hearing. This hearing is more than two months after the hurricane, and she is unable to receive the assistance she needs to replace her medications and CPAP machine.

### **Institutionalization:**

- A person with a disability was being taken care of by their adult child. The child could no longer provide care for the parent after the storm, and the parent had to be placed in an institutional setting.
- A person with a disability was told, with a group of people, that she had to go to a nursing home from a shelter. The person refused and walked away. When they came back, the other people with disabilities who were told to go to the nursing homes were gone, and the person did not know to what nursing home they may have been taken.
- An independent elderly woman from Rockport, Texas lost the RV she owned during the storm. She was staying in a Red Cross shelter in Corpus Christi until she was relocated to a nursing facility. When an IL specialist followed up with her, she explained that she was placed there because the Red Cross shelter was closing and she had no place to go. She is in the nursing facility because she was "tired of moving from place to place and not getting any help."
- A man from Rockport, Texas was placed in a nursing home due to the Red Cross shelter closure. Accessible hotels were not readily available and because he was an amputee, a room at a nursing facility was offered to him. He expressed that he would like to leave and find housing, but would accept this as a temporary option.
- A CIL is assisting an individual in the local Red Cross shelter. Staff was there on a Friday and no information was provided to them that day about the shelter possibly closing. On Saturday, the CIL staff got a call that the shelter was closing. If CIL staff had not intervened, this person would most likely be in a nursing home, according to the staff.
- A 67-year-old person with a disability is currently residing in an assisted living facility in Nueces County after being displaced from her home after Hurricane Harvey. She was referred to a CIL's transportation program by a FEMA worker to help her get linked with transportation to her hometown to meet with the FEMA inspector assessing the damage and work being done to her residence, as she was not able to make the drive independently. The hurricane caused substantial damage to her home, making it uninhabitable due to the damage sustained and the mold that destroyed most of her belongings. She and her terminally ill husband, who has since passed away in September, were forced to seek residence at an assisted living facility in Corpus Christi. She was required to sign a minimum of a three-month contract at the facility she is currently residing at and will not be able to move until the end of November. The monthly cost for the facility for her and her husband at the facility was \$2,600. Although this amount has decreased some since her husband passed away, the cost is not affordable due to a decrease in benefits subsequent to her husband's death. She is struggling to find a more affordable place to live in her hometown at the end of November while her home is still being repaired. She stated that the repairs being done on her home are through a volunteer group. She is unsure how long she will be displaced and has not received any housing assistance from FEMA. The CIL is attempting to assist with disaster funds for Tenant-Based Rental Assistance through the Texas Department of Housing and Community Affairs.

## Implications

Several trends stood out in the narratives that were submitted to this report. First, there is a disturbing trend of institutionalization, both forced and elective, particularly for elderly people with disabilities who were impacted by Hurricane Harvey. In one case, this choice was made because the person affected was tired of navigating resources for recovery and wanted to move to somewhere secure. That decision reflects the fact that emergency services post-hurricane were not easy to navigate for people with disabilities and elderly people. In many cases, people had no other choice due shelter closures, ongoing repairs to damaged homes, and lack of alternative and accessible housing options.

Institutionalization is a problem for people with disabilities because it strips them of their independence and effectively robs them of their civil rights. Although institutional settings following a disaster such as nursing homes do often provide a dry bed and the ability to manage individual medical or support needs, it comes at a high cost of putting people with disabilities in settings where their choices are severely limited and controlled. They are placed in segregated settings with others dictating when they get to eat, to leave the property (sometimes requiring supervision or attached to a curfew), and perform other daily living activities. Also, as shown in one of the stories above, some people are required to sign lengthy and costly contracts that require them to live there for a certain amount of time.

Just like people without disabilities, people with disabilities and elderly individuals should not have to sacrifice their civil rights and independence to have a dry place to sleep post-storm. Unfortunately, this is a complex issue on many fronts. Affordable and accessible housing becomes even more in demand by both disabled and non-disabled people displaced by storms, and prices increase. Furthermore, without robust planning by emergency organizations before a disaster hits to ensure that people with disabilities are not institutionalized, there is a good chance that some people with disabilities will end up in institutions because it is seen by non-disabled individuals as a convenient way to meet the "special needs" of disabled people and to give them shelter and necessities.

Furthermore, people with disabilities who are placed in institutional settings need support to transition back to their community, something that is not considered a priority post-disaster by those who see nursing homes as a solution. Once people with disabilities are effectively "out of the way" of the recovery efforts, they can be forgotten and those who put them there may not follow up and provide appropriate support, or even refer these people to the appropriate services and supports, to transition back into their communities. Due to privacy laws, it is difficult for outside organizations to track when someone is institutionalized and provide support to help them transition back to their community if they so desire. That said, some CILs did track their consumers closely to ensure that they can continue to provide support and assist in transition back to the community if it's wanted.

Still, not all CILs are able to provide this level of support, and the burden should not be solely on them to provide it. Those entities that placed people with disabilities in institutional settings need to commit to following up with these people to help them transition back to their homes and communities and to ensure that the institutionalization is not permanent. Additionally, emergency planning should take into account that people with disabilities may need affordable and accessible housing options post-storm so that there are options for those who do not want to be transferred to nursing homes but who cannot go back to their property due to damage and recovery efforts. All stakeholders involved with emergency planning need to proactively address the challenge of assisting people with disabilities to find housing in ways that do not sacrifice their independence, and in cases where they are institutionalized, emergency services need to have comprehensive plans to track and follow up on the people they placed into those settings.

Another major trend in the narratives sent to us was regarding the Federal Emergency Management Agency (FEMA). This trend could be broken down into two main problems: difficulties with the application and application denials. With regard to the former, there seems to be room for improvement on the FEMA application to take into account the needs of people with disabilities. In one situation, there was no place on the form that allowed for a Deaf person to notify FEMA that they needed text notifications and an interpreter to assist with interacting with a FEMA inspector. In another case, it was not clear to an applicant that they could put down the accommodations they needed to avoid making him share a bed with another person. When it comes to recognizing the needs of people with disabilities, it seems like there is still room for improvement on FEMA's application. FEMA needs to clarify where and how applicants can request disability-specific needs on their application.

Another substantial problem was application denials by FEMA. As shown in the narratives, many people with disabilities experienced denials of their FEMA application. In some cases, FEMA refused to cover disability-specific property and supplies, leaving people with disabilities without the supports they require although they were damaged in the storm. In another case, someone has become homeless because the damage to their property was considered inadequate and they were denied support. Both of these issues are barriers, especially when supports and medical supplies are involved. These supports, such as the Electric Hoyer Lift are integral to independent living, and damaging it is a blow to the person's independence and quality of life. In other cases, the supplies damaged are medically necessary, such as the damaged CPAP, and can lead to physical suffering for people with disabilities. Often, these supports and devices are very costly and people with disabilities may not be able to afford fixing or replacing them on their own.

There is great room for improvement on how FEMA interacts with people with disabilities. A good starting point would be to evaluate how the FEMA aid application reads to people with various disabilities and to identify where there are inadequacies in allowing people to identify their disability-specific needs. The application needs to be clear and straightforward for people with disabilities, with a specific area to identify the needs of a person with a disability who is applying for assistance. Furthermore, the application needs to have uncomplicated language so that people with cognitive disabilities do not have trouble filling it out.

It is also clear that FEMA may have different perceptions on supplies and supports necessary to quality of life and independence for people with disabilities. By increasing their interaction with the disability community prior to a disaster, they can gain more knowledge on challenges specific to people with disabilities and what unique support they may need in a disaster situation. FEMA needs to understand that some supports that may be damaged in a hurricane may be intrinsic to a person's independence, and that very often, people with disabilities may not have the financial ability to replace costly devices or supports destroyed in a disaster.

Another trend in the narratives submitted was that people experienced problems while sheltering. These problems involved issues of safety and comfort for people with disabilities, as well as equal accommodations and access. In one case, services provided in the shelter were not accessible, and therefore, not available to residents with disabilities. This inaccessibility significantly impacts the quality of life inside the shelter for people with disabilities, which is already strained by the nature of the environment. Shelters should work towards ensuring that their services and supports are accessible to people with disabilities. Additionally, transportation to and from the shelter, if provided, needs to be accessible so that people with disabilities don't have to take segregated transportation at a later date, or have to separate from their belongings when people without disabilities do not have to do the same.

Some issues that were submitted impact people with and without disabilities, such as looting within the shelter and the impact of the noisy and bright shelter environment. However, these issues are deterrents for people in the future who may need to evacuate but may be afraid of the risks to their property, especially medically necessary property, or who may not be able to function within the shelter environment due to its chaotic nature. When possible, shelters should work to ensure that medically and disability specific equipment is safe from damage or theft. If shelters have the capacity to do so, they should also consider trying to create a separate space that is calmer and quieter for people with anxiety, autism, or intellectual disabilities.

A final underlying trend is problems with communication. Communication is a challenge in itself in emergency situations due to the immediacy of the problem. However, poor communication can be a significant challenge for people with certain disabilities, especially cognitive disabilities. Emergency organizations should make an effort to understand the need for clear and simple communication with people with disabilities to ensure that they understand what they may need to do before, during, and after an emergency. Applications for assistance or benefits should be clear and simple as well, with a possibility to include information on disability-specific needs or requests. People who are providing information and referral services should be trained on how to interact with people with disabilities and how to direct them to the correct resources or provide clear instructions. Disability etiquette training can help to reduce miscommunication and help emergency organizations and their staff interact effectively with people with disabilities and meet their needs.

## Conclusion

As evidenced by the narratives included in this report, there is still great room for improvement on meeting the needs of people with disabilities in emergency situations. By analyzing these stories and figuring out what went wrong, we can prescribe some potential solutions to mitigate these issues in the future. However, implementing any solutions depends on emergency organizations and the disability community proactively forming relationships and working with each other to understand the other's needs and challenges. These organizations need to interact with each other consistently before a disaster strikes to try to improve disaster response for people with disabilities.

It is unlikely that every single one of the stories included in this report could have been solved by greater cooperation between the disability community and the emergency management community. Disasters and emergencies are chaotic and difficult to predict, and so it is not always possible to keep things from going wrong. However, if disability organizations and emergency organizations interact more consistently on the local level, that will be a good starting point for fixing the problems that resulted from a lack of understanding of the needs of people with disabilities in emergency situations. By comprehensively working together, disability organizations and the emergency management community can work to address the problems explored in this report, and anticipate and meet the needs of people with disabilities in the next emergency.

## Appendix C Footnotes:

1. US Census Bureau Public Information Office. "Newsroom Archive." [Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports](#) - Miscellaneous - Newsroom - U.S. Census Bureau. May 19, 2016. Accessed October 30, 2017.
2. *Disaster Preparedness and Response: The Special Needs of Older Americans* (2017) (testimony of Paul Timmons, Portlight Inclusive Disaster Strategies, Inc.).
3. Malloy, Robin P. *Law and Recovery from Disaster: Hurricane Katrina*. Routledge, 2016. Accessed October 30, 2017.

4. "[Communities Actively Living Independent and Free \(CALIF\), et al. v. City of Los Angeles.](#)" Disability Rights Advocates. Accessed November 06, 2017.
5. Weibgen, Adrien A. "[The Right To Be Rescued: Disability Justice in an Age of Disaster.](#)" *Yale Law Journal* 124, no. 7 (May 2015): 2202-679.
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9. Christina Caron, "[Sign Language Interpreter Warned of 'Pizza' and 'Bear Monster' at Irma Briefing.](#)" *New York Times*, September 17, 2017, accessed October 31, 2017.



# Appendix D: NCIL Report on Florida

## Emergency Management Challenges and Failures for People with Disabilities in Florida During Hurricane Irma

Prepared by Sarah Blahovec  
National Council on Independent Living  
November 7th, 2017

### Executive Summary

The year 2017 brought devastation across the United States and its territories through multiple hurricanes. Hurricanes Harvey, Irma, and Maria swept across the South, The U.S. Virgin Islands, and Puerto Rico, and as of November 2017, there are still months of recovery ahead. This devastation had a particular impact on people with disabilities, as emergency management has always had, and still does have, challenges in meeting their needs, although they make up nearly one fifth of the American population. This report dives into these problems from the point of view of Americans with disabilities who were impacted by Hurricane Irma in Florida. After reviewing changes to emergency management through litigation in the past 10 years, this report lays out the narratives of people with disabilities who experienced problems with emergency management during and after Hurricane Irma and analyzes what could be done to reduce or eliminate these problems in future emergency situations.

Among the most significant findings:

- Among the experiences submitted for this report, people with disabilities encountered the most barriers and problems during sheltering, including problems with the shelter environment, shortages in necessities and supplies, and lack of understanding of their needs from shelter staff and volunteers.
- Among nearly all the submitted reports, there were significant problems with communication between emergency services and people with disabilities, which show that emergency services may need to become better educated on how to interact with people with disabilities and learn about making information accessible through plain language.
- Post-storm access to affordable and accessible housing, which is already a problem in for people with disabilities, is becoming more strained due to the number of people displaced from the storm who are in need of housing.
- Although there are many different routes that could be taken to fix the problems detailed in this report, there is an overarching necessity for emergency management and response organizations and disability advocacy organizations to proactively work together before crises occur to anticipate and meet the needs of people with disabilities in emergency situations.

### Background

Emergency planning for people with disabilities is a critical but often overlooked aspect of emergency management. Emergency stakeholders must intentionally anticipate and plan for the needs of people with disabilities in disaster situations and understand that these needs are neither unusual nor infrequent—especially when people with disabilities make up nearly 20 percent of the population of the United States (Footnote 1). Furthermore, people with disabilities and elderly adults "are two to four times more likely to die or be seriously injured in a disaster." (Footnote 2)

Unfortunately, the civil rights of people with disabilities have been significantly and negatively impacted by poor emergency planning. Following the devastation of Hurricane Katrina in 2005, many people with disabilities were "temporarily relocated" to institutional settings such as nursing homes (Footnote 3). These individuals, seemingly forgotten once their needs were met, were not tracked and not provided the appropriate support to assist them with transitioning back into their communities.

Disability organizations have spent years working on local and national levels to build relationships with emergency management and response organizations to improve responsiveness to and the ability to meet the needs of people with disabilities in emergencies. In many cases, the resistance of governments toward making comprehensive and proactive emergency plans for people with disabilities has only been solved by painstaking, complex litigation. In 2011, a court ruled that the City of Los Angeles violated the Americans with Disabilities Act (ADA) by "failing to meet the needs of its residents with mobility, vision, hearing, mental, and cognitive disabilities in planning for disasters," in *Communities Actively Living Independent and Free v. City of Los Angeles*. Los Angeles, which experiences frequent emergencies from earthquakes, fires, and landslides, was ordered to revise their emergency planning to include people with disabilities (Footnote 4). The ruling outlined nine essential components of effective emergency planning: "comprehensive emergency plans", "assessments of the efficacy of emergency plans," "identification of the needs that will arise and resources available to meet those needs," "public notification and communication," "policies and procedures concerning the concept of sheltering in place," "plans to provide shelter and care for individuals forced to evacuate their homes," "assistance with evacuation and transportation," "plans for provision of temporary housing when evacuees cannot return to their homes," and "plans for...recovery and remediation efforts after an emergency or disaster." (Footnote 5)

Another example of this litigation was *Brooklyn Center for Independence of the Disabled (BCID) v. Mayor Bloomberg*. Filed more than a decade after September 11th, 2001 and during the time of disasters such as Hurricanes Irene and Sandy, the Court found that New York City had discriminated against people with disabilities by failing to plan for their needs in large-scale disaster situations. This ruling led to a settlement between parties that required the city to make improvements to their emergency management planning for people with disabilities in all major affected programs and services, including transportation, evacuation from high rises, and sheltering (Footnote 6).

In "The Right to be Rescued: Disability Justice in an Age of Disaster," attorney and Yale Law School graduate Adrien A. Weibgen found that *BCID v. Bloomberg* established several principles surrounding emergency planning for people with disabilities: first, that government entities must have detailed plans that understand and anticipate the needs of people with disabilities and plan strategies in advance of disasters to meet those needs; next, that cities must communicate clearly and effectively with people with disabilities before, during, and after emergencies and disasters; third, that cities should include experts from outside their own organizations to provide input on emergency plans; and fourth, that people with disabilities "must be allowed to meaningfully participate in emergency planning processes." Weibgen points to centers for independent living (CILs) in particular, because as cross-disability, community-based organizations that are required to be majority run by people with disabilities, CILs are entities both with access to the local disability community and with significant experience through their work and individual experience as people with disabilities (Footnote 7).

Although these lawsuits have made significant headway in getting cities to incorporate people with disabilities comprehensively into their emergency planning, it is clear that we still have so far to go. The 2017 hurricane season, with the devastating impacts of Hurricanes Harvey, Irma, and Maria, again negatively impacted people with disabilities in many ways before, during, and after the storms.

Some high-profile events impacting people with disabilities before and after Hurricane Irma made national news due to their frustrating, misguided, and even tragic impacts. Shortly before Hurricane Irma made landfall in Florida, Miami-Dade County announced that it would potentially use the Baker Act to involuntarily admit to observation any homeless person (disabled and non-disabled) if they refused to relocate to a shelter (Footnote 8). In Manatee County, Florida, the county borrowed an employee from the neighboring county who had a deaf relative to interpret their emergency announcements instead of hiring an American Sign Language (ASL) interpreter. The man was not proficient in ASL and as a result, he failed to communicate critical information to the deaf and hard-of-hearing community in Manatee County (Footnote 9). While this news made national headlines due to the incorrect nature of what he signed, the impact on people who needed proper ASL communication was frustrating and potentially disastrous, as they were denied access to critical emergency preparedness information. And investigations are still being conducted on the Rehabilitation Center at Hollywood Hills, a nursing home that failed to evacuate 150 residents after losing power and climbing to extreme temperatures, leading to the deaths of 14 residents (Footnote 10).

Beyond these nationally recognized events, it is necessary to examine the challenges experienced by people with disabilities before, during, and after Hurricane Irma on an individual level, analyze what went wrong, and determine what can be done to address and eliminate the possibility of these challenges in future emergencies. This report intends to construct a picture of what happened to people with disabilities during the hurricane and what can be done to improve emergency response to millions of Americans with disabilities, both in Florida and nationwide, in future emergencies.

## **Methodology**

The National Council on Independent Living (NCIL) set out to collect stories of people with disabilities and the challenges they faced before, during, and after Hurricane Irma. To collect these stories, NCIL engaged in daily stakeholder phone calls on the national and state level, and conducted outreach throughout late September and October 2017 to Florida CILs to ask them to collect narratives from CIL staff and consumers on these challenges. CILs were asked to cast a wide net for information on how people with disabilities were affected before, during, and after the storm, collecting information on any incidents in shelters and in interactions with emergency services. In some cases, narratives were written by staff members of CILs to whom the details were dictated, while others came directly from those who experienced the problems. All stories were examined, summarized, and scrubbed of as many identifying details as possible.

Florida is unique in that Florida Statutes 252.355 and 381.0303 establish a special needs registry and "Special Needs Shelters," shelters segregated from general population shelters intended to meet the needs of people assessed to require assistance that exceed services provided at those general population shelters (Footnote 11). Because people with disabilities make up the population of the special needs shelters, CILs and other stakeholders involved in emergency management paid particular attention to the populations in these shelters; however, some people with disabilities sheltered in general population shelters and in Red Cross shelters, as well as abstained from entering shelters altogether and instead attempted to arrange homecare services during the storms.

Among the narratives that were submitted, there were also reports of situations in which there were incidents and situations in which problems encountered by people with disabilities were handled quickly and positively, or where CIL consumers reported no problems. In many of these cases, the CILs cited a pre-existing and robust relationship between the disability community and the local emergency management community. By working together regularly and learning about the needs of the disability community and the way various emergency management entities function, these two communities came together on local levels to proactively address the needs of people with disabilities

in emergency situations. In one instance, the emergency management community invited a panel of people with various types of disabilities to speak about what their specific needs would be in an emergency situation so they could understand these discrete disabilities and their individual differences.

In other incidents during and after the storm, people with disabilities brought up the challenges they encountered and asked emergency staff to address those challenges. In one general population shelter with a population of people with disabilities, people who brought their own transportation were allowed to leave the shelter at their own risk, while those who rode in on provided transportation were not allowed to be taken home unless they could provide reliable information proving that power had returned to their residences. Many people with disabilities were among the riders of the provided transportation. They brought up their concerns to their ADA Council Member after having to stay another night in the shelter instead of leaving to go home. The next day, the shelter staff changed the policy and allowed all people with disabilities, except those with disabilities that would prevent them from making a reasoned decision about their safety, to leave at their own risk if they so wished. The newly adopted policy was now in compliance with the local CIL's independent living philosophy, which holds that people with disabilities are the best determinants of their needs and should be the main people making decisions about their own lives.

The rest of this report will not be examining the scenarios where issues were properly addressed or mitigated through pre-existing relationships between people with disabilities and emergency management stakeholders, but instead delve into situations in which people with disabilities encountered problems that were not immediately or effectively solved. The stories requested for this report include but are not limited to the following areas: sheltering, transportation, evacuation, post-storm housing, applying for benefits, obtaining necessities, communications, and interacting with emergency management entities.

## **Narratives**

### **Communications and Evacuation:**

- Two people were on the special needs registry and were scheduled to be picked up and taken to a special needs shelter in Pasco County. They were not picked up at all and could not get through to anybody. One person called different services trying to get information and those who she contacted were very rude. The woman who called explained that she believed this rudeness was because the information operators did not know about disability and did not have training. She ended up having to sit through the storm in her home. The woman believed that the county emergency operations were to blame for this failure in Pasco County.

### **Sheltering:**

- A shelter resident submitted a detailed story of the challenges she faced in a special needs shelter in Palmetto. The resident had disabilities, as did her two children.
- Food: The family was told to bring three days' worth of food, while others were told to bring snacks or no food at all. The three food items they received daily from the shelter were brownies, small peanut butter and jelly sandwiches, and mini slider hamburgers that were allegedly served still frozen with ice all over them.

- Supplies: there was a shortage of mats and blankets, and some people had nothing upon which to sleep.
- Power: When the power went out, the first generator almost immediately failed, followed by the second. There was no power except to a few life support machines, but there was not enough power for all of the breathing machines.
- Illness: many shelter residents were suffering from vomiting and diarrhea due to the undercooked food
- Hygiene: the bathroom backed up due to the main valve breaking and lack of cleaning. There was diarrhea down the halls to the bathroom and on the bathroom floor. A day later, port-a-potties were brought in that were not wheelchair accessible and again there was feces outside of them. There were no showers available to the residents.
- Heat: due to the lack of electricity, the temperature was very high inside, around 90 to 95 degrees, and a cooling station was provided by way of a metro bus.
- Incidents witnessed: the woman witnessed several incidents of alleged mistreatment, including a man who got mad when his mother, for whom he was caring, had her bed confiscated. The woman's service dog was sent to the pound, the man was removed from the shelter, and the woman was placed in the hospital after the man complained. Another man was stuck in his wheelchair the entire time and developed sores all over his body to the point that he needed wound care, and diabetic patients could not eat because they were afraid that the food provided would put them in diabetic shock. Other residents suffered high blood pressure, with one being sent to the hospital and another being placed in front of a fan and then in the cooling station that was provided (the bus). A hospice patient allegedly passed away either due to heat or choking.
- At a shelter in LaBelle in Hendry County, a person who is diabetic had a blood sugar level of 400 or 500. She couldn't get it down because no special diet or food was given or offered to her, even upon her request.
- A wheelchair user who was homeless was first sent to two shelters which would not admit him, and then was transferred to a fairground "where they kept the animals and the homeless." Upon arrival, he was given a sleeping bag, but they lost his wheelchair and his blanket.
- A woman was an oxygen user who did not have her own oxygenator. She was transferred from shelter to shelter due to the fact that she (and the shelters) didn't have what she needed.

### **Communications and Sheltering:**

- A quadriplegic man called emergency services to make arrangements to evacuate during the storm, and was given contradictory information from people answering the phone. The man was assigned to go to a special needs shelter, but the man felt that he did not need a medical shelter, just that he needed to be able to plug in his wheelchair and get food. He ended up staying in the shelter at Atlantic High School. The operators told them they had supplies, such as cots and pillows, and when he arrived, he found that to be false, and since they had no adjustable cots or blankets, he had to sleep in his chair upright for four nights. The shelter had 1,000 people and ended up having a food shortage. The man reported that younger people

were stealing food from elderly and disabled shelter residents and that children were crying from not being fed. The man was able to hide his food, but witnessed people who had been homeless giving their food to children because the children had run out. The supplies were very rationed, and there was a lot of noise from the upset children. He reported a general lack of control of the environment.

- A 48-year-old man with mild intellectual disabilities lived with his parents until they passed away. He was told to bring food, water, a change of clothes, but not to bring his medicine, and he doesn't have the cognitive ability to remember to bring it. His local CIL luckily advised him to take his medication, so he was okay, but nervous about the shelter. He spent four days in the shelter with 100 people. There was a shortage of cots, so he slept on a blanket for four days. There were no pillows, although the shelter had told him before arriving that there would be pillows. The meals were small and there was no power for two days.
- A comprehensive report was submitted by a man who is a blind CIL staffer who entered the East High School Shelter in Lehigh with his blind wife and service dogs for a week. Both he and his wife were registered on the special needs list and received two sets of confirmation letters from their applications, telling them each to go to two different shelters. They only found out that they would be going to the East High shelter after the bus picked them up and informed them that the other shelter hadn't opened yet. Upon arrival at the shelter, they found that the crowd was large and the process was long because the number of registrants was over 1,000 people larger than planned for. The shelter experience went fairly well with the staff trying in earnest to meet the needs of residents with disabilities. The problems they experienced included the fact that there was no procedure or place set up during lockdown for the service dogs to relieve themselves, as the dogs were not trained to go inside. When power was switched to the generators during the storm, some fuel mixed into the water system and water was unsafe to drink. Unfortunately, there was no backup water supply for drinking for the 3,000 shelter residents. Although shelter residents shared their bottled water, residents suggested that a backup system be put in place for water in the future. Cafeteria staff and volunteers were confused about what their "special needs consumers" needed in terms of assistance, and volunteers assumed that all special needs consumers needed their food brought to them, when several wanted to independently go to the cafeteria. For those who needed help getting their trays, the staff seemed confused and offered minimal help. During the power outage, the bathrooms backed up and the bathrooms became nearly unusable except when absolutely necessary.

## **Medical Necessities**

- A woman with multiple disabilities and who required 24/7 access to an oxygen tank and charged medical equipment went for four to five days without oxygen, medication, and access to her CPAP and became ill. During that time, she called several shelters, which told her either they couldn't manage her medical needs or they were full. She called her local hospital asking for them to allow her to go there and charge her machines and get oxygen, but they would not allow her to come in and told her to go to a shelter. The woman then reached out to her brother who made phone calls and was able to get United Way and Red Cross to come to her neighborhood, and that she would be put up in a hotel after that. When they arrived, she had bad coloring and audible wheezing, and she also reported that there was blood in her CPAP. After they gave her oxygen, they transferred her to a hotel while power was restored so she could have access to air conditioning and electricity. They also provided her water and essentials that she hadn't had access to for two days.

- A single parent with a young son who is receiving chemo for sickle cell lost power and could not survive in an apartment that had no air conditioning. He was hospitalized four times in three weeks from dehydration from chemo and pain medication. Volunteers worked to get the insurance company involved, which advocated to get the power on. There was confusion about FEMA eligibility, perhaps because they had just moved from the northeast because the parent was told that her son could not survive any more harsh winters. The child needed Gatorade to survive but the insurance company could only get him Pedialyte, which is for younger children who weigh less. After talking to the parent many times, the volunteer realized that Gatorade was the biggest need so the volunteer bought them Gatorade at the local pharmacy, which the volunteer was able to persuade to take her credit card over the phone. Eventually, the power was restored and the parent was able to apply successfully for FEMA.

## **Housing:**

- Nearly all CILs have reported that housing post-storm has been a massive issue for their consumers, including those CILs that had no other problems to report. One example of this is in Monroe County, which has the highest cost of living in the state of Florida. A CIL staffer's husband met a person who had previously been paying \$1,400 a month for a one bed, one bath efficiency, but the landlord had increased the lease price to \$2,900 due to the housing shortage. People are frantically looking for housing across the state, and with waitlists already reaching a year before the storm in some cases for affordable housing, the situation has gotten significantly worse.

## **Implications**

As these narratives show, there are clear trends in problems experienced by people with disabilities during Hurricane Irma. One of the overarching trends is problems with communication. Clear communication is not just vital to all people regardless of disabilities, but it is particularly important for people with disabilities who have to take extra care or planning in an emergency situation. In several instances noted above, people with disabilities were given confusing, conflicting, or incorrect information on where to go and what to bring. In one situation, this confusion made it impossible for someone to evacuate at all, as the transportation to the shelter did not arrive and they were unable to get other information and arrange to evacuate. In another instance, the shelter forgot to tell someone with a cognitive disability to bring his medication, something he wouldn't have known to do on his own.

It is of critical importance to have clear communication in emergencies for people with disabilities. Because some disabilities may involve cognition difficulties, it is necessary to adopt clear, plain language that is free of jargon or contradictions and effectively conveys important information. People need clear guidance on where they need to go and what to bring, especially since some people with disabilities may not own transportation and may have to arrange for evacuation, and some may have specialized equipment or medical supplies that they must bring to the shelter.

There were significant issues involved with sheltering during Hurricane Irma. Although some of these issues impacted shelter attendees with and without disabilities, such as looting, supplies shortages, or miscommunication of what supplies the shelter has on hand, some challenges were unique to shelters with disabilities. In one scenario, shelter staff and volunteers did not know how to properly interact with people with disabilities, either providing too much or not enough support because they did not understand the needs of those they were helping. Shelter staff and volunteers could benefit from comprehensive disability etiquette training before disasters strike, especially training designed



by disability-led organizations such as CILs so that they obtain this knowledge directly from people with disabilities they may end up assisting in future disasters.

Other shelters had shortages of supplies including food, blankets, cots, and pillows. This clearly impacts all shelter residents regardless of disabilities, but in some cases, people with disabilities were disproportionately impacted due to special dietary needs or mobility issues that made laying on blankets on the floor impossible. In the future, shelters need to be prepared with food that can meet the dietary needs of people who have allergies, diabetes, or other common medical conditions. Although the shortage of supplies and bedding was not intentional, in many cases people were specifically told not to bring their own bedding. In future situations, staff and volunteers need to either provide these supplies, or if they anticipate a shortage, provide clear and consistent communication telling people to bring backup supplies. Shelters should also try to plan for possible contamination of the water supply in the future and have a backup plan, such as additional bottled water, to ensure that nobody experiences dehydration.

The chaotic nature of the shelter environment and the challenges faced during the storm made some of the issues that shelter residents experienced unavoidable, such as bathroom backups or failing generators. In future situations in which there are shelter-wide problems, shelter staff should be clear with residents about what is being done to fix the situation and should be attentive to any disability or medically-specific needs that arise from these situations, such as overheating or illness. If people are experiencing medical problems from the shelter environment, they need prompt medical care and staff need to clearly communicate what is being done to help the person experiencing the problem or illness. In some situations, residents felt like the shelter staff didn't understand or didn't care about the needs of people with disabilities, which means that staff or volunteers either need disability etiquette training or to communicate more clearly about what they are doing to fix the problems.

Evacuation also posed a few problems in the narratives above. In one situation, a homeless man with a disability was carted around to various shelters that did not allow him in, and he was forced to shelter at a fairground which lost his wheelchair. In another situation, a woman on oxygen was transported to several different shelters because of her needs. Due to the fact that Florida has special needs-specific shelters in place, the latter failure should not have happened, as special needs shelters should have been able to accommodate her needs. In the former example, the man was turned away from shelters and placed in a fairground seemingly due to his homelessness, a treatment that reduced his dignity and humanity, and on top of that, the fairground lost one of his most important possessions, his wheelchair. All people, regardless of disability or residency, should be treated equally, with dignity and respect, by emergency management organizations.

One final trend from above was clearly a problem across Florida: the lack of access to affordable and accessible housing following the storm. Many CILs, even those whose consumers faced no other issues or impacts from the storm, noted that it would become increasingly harder to find affordable and accessible housing options for people with disabilities following the storm. In some cases, there had already been a year-long waitlist to get such housing, and these waitlists will be further stretched by new people displaced by the storms. CILs would like to work with government and nonprofit groups involved with housing to address the burgeoning housing crisis for people with disabilities, who are already facing a shortage of affordable and accessible housing.

## **Conclusion**

As evidenced by the narratives included in this report, there is still great room for improvement on meeting the needs of people with disabilities in emergency situations. By analyzing these stories and figuring out what went wrong, we can prescribe some potential solutions to mitigate these issues in

the future. However, implementing any solutions depends on emergency organizations and the disability community proactively forming relationships and working with each other to understand the other's needs and challenges. These organizations need to interact with each other consistently before a disaster strikes to try to improve disaster response for people with disabilities.

It is unlikely that all of the stories included in this report could have been solved by greater cooperation between the disability community and the emergency management community. Disasters and emergencies are chaotic and difficult to predict, and so it is not always possible to keep things from going wrong. However, if disability organizations and emergency organizations interact more consistently on the local level, that will be a good starting point for fixing the problems that resulted from a lack of understanding of the needs of people with disabilities in emergency situations. A concerted effort between the disability community and the emergency management community to interact, understand each other, and proactively address problems affecting people with disabilities in emergency situations is vital to reducing or eliminating the scenarios explored in this report.

#### Appendix D Footnotes:

1. US Census Bureau Public Information Office. "Newsroom Archive." [Nearly 1 in 5 People Have a Disability in the U.S., Census Bureau Reports](#) - Miscellaneous - Newsroom - U.S. Census Bureau. May 19, 2016. Accessed October 30, 2017.
2. *Disaster Preparedness and Response: The Special Needs of Older Americans* (2017) (testimony of Paul Timmons, Portlight Inclusive Disaster Strategies, Inc.).
3. Malloy, Robin P. *Law and Recovery from Disaster: Hurricane Katrina*. Routledge, 2016. Accessed October 30, 2017.
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9. Christina Caron, "[Sign Language Interpreter Warned of 'Pizza' and 'Bear Monster' at Irma Briefing.](#)" *New York Times*, September 17, 2017, accessed October 31, 2017.
10. Pesantes, Erika. "[14th Person From Hollywood Nursing Home Dies, Police Say.](#)" *Sun Sentinel*, October 9, 2017. Accessed October 31, 2017.
11. "Emergency Preparedness & Response." [Special Needs Shelter Program | Florida Department of Health](#). Accessed November 06, 2017.

# Appendix E: Paul Timmons Testimony to the Senate Special Committee on Aging

[This testimony is also available online](#) (PDF).

United States Senate Special Committee on Aging

Hearing on:

“Disaster Preparedness and Response: The Special Needs of Older Americans”

Wednesday, September 20, 2017

9AM

562 Dirksen Senate Office Building

Statement for the Record

Paul Timmons, President Portlight Inclusive Disaster Strategies, Inc.

Portlight Inclusive Disaster Strategies, Inc. is a nonprofit, nonpartisan, disability inclusive disaster relief organization established in Charleston, SC, in 1997. Portlight Strategies does not receive federal funding.

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**“Disaster Preparedness and Response: The Special Needs of Older Americans” By Paul Timmons,**

President, Portlight Inclusive Disaster Strategies, Inc.

Chairman Collins and Ranking Member Casey: Thank you for the invitation to speak before the Committee on this important topic. My name is Paul Timmons, President of Portlight Inclusive Disaster Strategies. I have been working in the field of disaster preparation and response for people who are aging and those with disabilities for 15 years and have led Portlight since 1997. In my time I will share with you some of my observations related to our most recent disasters and make a number of recommendations for improving disaster preparedness.

As the news media began to cover the story of the horrific conditions at the Hollywood Hills Nursing Home in Hollywood FL and the deaths of eight of their residents on September 13, Portlight Strategies had begun our 18th straight day of round the clock disaster response efforts to address the disproportionate impact of hurricanes Harvey and Irma on older adults and people with disabilities. Given that people with disabilities and older adults are two to four times more likely to die or be seriously injured in a disaster, the urgency of our work cannot be understated. The disproportionate rate of injury and death is due to poor planning, inadequate accessibility, and the widely shared but incorrect assumption that people with disabilities and older adults are “vulnerable,” “special,” or “at-risk,” simply because of their diagnoses or stigmatizing beliefs about disability and aging. In fact, older adults and people with disabilities are extremely valuable experts on emergency problem

solving, with far more practice than younger people and people who don't navigate inaccessible environments and programs on a daily basis.

Since August 26, our work at Portlight has been spent, around the clock, organizing lifesaving rescues with our partners, organizing delivery of food, water, generators, wheelchairs, medical equipment and supplies, sign language resources, addressing civil rights violations, answering non-stop calls to our hotline, and pointing people to lifesaving and life sustaining emergency resources to meet the critical needs of older adults and people with disabilities.

We have organized daily national, state, and issue specific public-private coordination calls between governments, the Red Cross, disability organizations, and stakeholders to optimize limited resources and minimize duplication of effort.

For every heartwarming tale of heroism (and there are many), we are navigating the devastating stories from people who have not benefitted from the considerable tax payer investments in local, state, and national emergency preparedness initiatives. Local resources, the most knowledgeable daily lifeline for people with disabilities and older adults, are rarely funded before, during, and after disasters, with federal funds and donations going to organizations without a local foot print or experience in meeting the daily needs of older adults and people with disabilities in the impacted areas.

What has happened since the Post Katrina Emergency Management Reform Act was passed in 2007?

Great progress was made for many years, primarily by heavily investing in whole community inclusive initiatives, with true partnerships between FEMA and disability and older adult led organizations.

People with disabilities and those who are aging need to be at the table when planning for disasters. There is no more important time for the adage "nothing about us, without us" to be a reality. At the local, state, and federal levels, and in non-profit agencies dedicated to disaster preparation and response, those who are aging and disabled need to be both participants and leaders. Right now, most planning occurs "FOR" people with disabilities and older adults, not "WITH" us. Moving forward we need to ensure there is substantial leadership and participation during emergency planning.

To truly include older Americans and Americans with disabilities in the planning process, the following issues need to be addressed in order to reduce injuries, avoid deaths, and ensure response is as effective as possible:

- Ensure communication about emergency services are broadcast and distributed in American Sign Language and clear, plain language in all cases when communication about a disaster is made to the general public;
- Ensure that all emergency response communications, including 911, 311, and 211 emergency and information lines are accessible;
- Ensure all building evacuation procedures include procedures for those who need mobility support, have sensory disabilities, intellectual disability, and anxiety and other mental health concerns, and that personnel are trained to implement those plans;

- Ensure that all transportation to evacuate older persons and those with disabilities are fully accessible, have personnel who know how to operate the vehicles and the accessibility features, and are available during the emergencies;
- Ensure access to food, water, medicine, and power;
- Ensure all information about what to do, where to go, and how to get help is available in accessible formats, including video with captioning, audio, and plain language formats;
- Ensure all shelters, including both general population shelters and “special needs” or “special medical needs” shelters, are ready to support older adults and those with disabilities and that personnel staffing those sites are trained to support people with disabilities and those who are aging;
- Ensure all shelters are accessible and have trained personal assistants, accessible showers and toilets, flexibility in meals to meet dietary restrictions and requirements, and equal access to communication;
- Ensure admissions to medical facilities and nursing homes are not substituted for meeting civil rights obligations to provide equal access to emergency services and programs in their community;
- Ensure that all tracking information systems are up-to-date and personnel know how both to use the systems and maintain confidentiality;
- Ensure there is equal access to emergency registries operated by state, federal, and nonprofit emergency programs;
- Ensure voluntary registries are not only used in preparation for a disaster but are actually used as part of the response;
- Significant delays (up to 30 days, if the caller could even complete their call) in receiving “critical and immediate needs” assistance from FEMA and Red Cross, despite announcements to apply;
- Ensure individuals who use service animals are admitted to shelters and are able to stay with their animals while in shelters; and
- Ensure individuals who use mobility devices, sign language interpreters, personal assistants, communication devices, and health maintenance items are not separated from those devices and services.

Despite extensive planning, many of these items were not completed for the response to Harvey and Irma. We learned lessons from Katrina and Sandy but did not implement many of those lessons. Hopefully we will be able to implement more lessons from the most recent storms. The following are my priorities to improve responses to reduce injuries and save lives.

## **Recommendations**

1. Create an inclusive disaster relief fund for Independent Living Centers and other consumer controlled community disability and aging organizations to engage in emergency preparedness, response, recovery, and mitigation. Invest \$1 billion over five years to serve the people of their community before, during and after disasters. Those who are aging and those with disabilities are the experts on housing, access to health maintenance services, accessible transportation, getting people back to work, and keeping people out of nursing homes. Currently, Independent Living Centers and other consumer directed agencies receive no funding to do their emergency preparedness and disaster response, recovery and mitigation work. Funding for these efforts should not compete with first responders, public health, and state and local emergency managers. So it is essential to fund preparation and response work through separate sources.
2. Establish a National Center for Excellence in inclusive Disability and Aging Emergency Management. The initial focus of the Center should include community engagement, leadership, training and exercise development, evacuation, sheltering, housing, and universal accessibility. I suggest a budget of \$1 billion over five years to stand up the Center.
3. Direct the US Department of Justice, and provide the Department with resources, to monitor and enforce the use of all disaster funds to ensure compliance with the civil Paul Timmons September 20, 2017 Aging Committee Testimony rights requirements of the Rehabilitation Act of 1973, as amended and the Americans with Disabilities Act of 1990, as amended.
4. Provide Department of Homeland Security grant funds to specifically fund qualified and experienced statewide Access and Functional Needs Coordinators for all states and territories. These coordinators would serve as statewide subject matter experts across preparedness, response, recovery and mitigation to engage and coordinate whole community collaboration among disability leaders, community organizations, first responders, emergency managers, public health and safety, private sector and other stakeholders.
5. Conduct a study of the use of volunteers to determine efficacy in sheltering services to individuals with disabilities and older adults. Objectives of the study should include determining if the use of volunteers is adequate to comply with disability equal access and non-discrimination obligations.
6. Refresh the Post Katrina Emergency Management Reform Act to better define state and federal government obligations to plan for, respond to, recover from, and mitigate all hazards in compliance with disability civil rights laws.
7. Exempt the cost of disability related repairs and replacement from the FEMA Individuals and Households maximum Grant ceiling (currently \$33,300). Disability related repairs and replacement of durable medical equipment and other disability items includes replacing wheelchairs, customized vehicles, medical devices, entrance ramps, elevator installation to meet home elevation requirements, and other items that provide equal access for people with disabilities in recovering from a disaster.
8. Establish an American Independence Corps, similar to FEMA Corps made up of at least 5,000 citizen members with and without disabilities to carry out planning and preparation activities in each State, DC and Territory year round. 9. Direct FEMA and the Administration on Community Living to lead a coordinated effort across federal government agencies, the States, CBOs, foundations, and other sectors, with those who are aging and those with disabilities in leadership roles, aimed at achieving on-going planning, preparation, and implementation of these recommendations. Implementing these recommendations will:

- Prevent, minimize, and rectify the institutionalization and/or loss of critical home and community based services for children, adults and older persons in the lead up to, during or following a disaster; and
- Increase the ready supply of accessible, adaptable, affordable, and disaster resistant permanent and temporary housing nationwide.

## **Conclusion**

Let me be very clear, most of the failures and shortfalls we address are a direct result of the failure to plan at the local and state level and the failure to place subject matter experts in leadership roles at every level coupled with failure to include people with disabilities and older adults as key stakeholders in planning efforts. This has been coupled with blatant disregard for the unwaiverable civil rights obligations associated with the expenditure of every federal dollar spent by government, grantees and contractors without any monitoring and enforcement by the federal government over its civil rights obligations. To further emphasize this point, there are no civil rights loopholes releasing anyone from their legal obligations in emergencies and disasters. Period.

Despite years of planning, people with disabilities and older adults in Texas, Florida, and the U.S. Virgin Islands, and other hurricane impacted states have, once again, paid the price for our collective emergency planning shortfalls. Many thousands are still without the basic necessities to meet their independence, safety, and health maintenance needs. Most have been denied their basic right to equal access to federally funded emergency programs and services. We receive daily requests to assist people without food and water. Some of the people calling are in high rise buildings without power. Callers are unable to obtain prescription medications, return home from evacuation placement in nursing homes hundreds of miles away, having extreme difficulty in reaching FEMA and Red Cross to request assistance and being informed about wait times of up to 30 days for crisis and immediate assistance funds for food, water and medication.

Effective practices for whole community inclusion must be led by experts in disability and aging inclusive emergency management. The people most knowledgeable about the needs in their own community are best suited to lead disaster response and recovery. We must find a way for these organizations to have adequate resources to do the complex and long-term work that is needed for people with disabilities and older adults to participate with government and the disaster business giants to get grants, donations, and tax payer dollars to optimize whole community inclusive disaster recovery.

Portlight Strategies and our national Partnership for Inclusive Disaster Strategies stand ready to assist the American people to get this right.

Thank you for allowing me this opportunity to share my experience and recommendations with the Committee and I stand ready to answer any questions you might have.



# Appendix F: NCD Letter to FEMA Administrator Long

April 10, 2018

William B. "Brock" Long  
Administrator  
Federal Emergency Management Agency  
500 C Street SW.  
Washington DC 20024

Dear Administrator Long:

I write on behalf of the National Council on Disability - an independent, nonpartisan federal agency charged with providing advice to Congress, the President, and other federal agencies on matters affecting the lives of people with disabilities - to offer specific recommendations to improve the outcomes of people with disabilities before, during, and after a major disaster. Specifically, NCD recommends restructuring the Regional Disability Integration Specialist roles and responsibilities; supporting Congress in efforts to modify the Stafford Act to eliminate the inclusion of medical expenses for grant max totals, and implementing policies to improve data collection on the outcomes of people with disabilities in the aftermath of a major disaster.

The Post Katrina Emergency Management Reform Act (PKEMRA) required that NCD and FEMA work closely with each other to improve the outcomes of persons with disabilities before, during and after major disasters. NCD has served as a liaison within the disability community and FEMA in working to achieve that goal. Our recommendations are derived from meetings and discussions with the disability community in which they voiced concerns regarding these issues.

## **Restructuring of Regional Disability Integration Specialist Roles**

PKEMRA called for the creation of the Office of Disability Integration and Coordination (ODIC) and established the position of Regional Disability Integration Specialists (RDIS) charged with enforcing disability integration laws before, during, and after a major disaster. The hope was that the RDIS position would complement and assist ODIC in carrying out its mission. In its current form, RDISs are not systematically placed. Instead, regional offices determine the department the RDIS will be housed which may result in a lack of consistency in the specific roles and responsibilities of the position and differing expectations for that position. Additionally, RDIS' do not report to nor is that position held accountable at the federal level. This current structure creates a disconnect from the federal level as well as a lack of uniformity regarding its roles and responsibilities, which in turn may present as ineffective leadership in the field during a major disaster. NCD recommends the restructuring of the RDIS so that all are housed within the same department in each region, share the same roles and responsibilities, and complement and assist ODIC in fulfilling its mission.

## **Disaster Recovery Reform Act (HR 4460)**

The Stafford Act includes a provision which provides financial assistance to individuals and households who have been impacted as a direct result of a major disaster. These funds are used to supply temporary housing and/or to repair one's current residence. The provision also supplies funds for other needs such as medical, dental, childcare, and funeral expenses. The current maximum financial assistance an individual or household may receive from FEMA is \$33,000 per major disaster. On paper that seems like a lot of money for a person with a disability, that money can be

exhausted if a wheelchair must be replaced or due to new housing requirements the home requires costly modifications to ensure access. As was the issue post Hurricane Sandy, most of the destroyed homes were required to elevate their foundation in order to qualify for FEMA assistance which forced those with mobility restrictions to incur yet another monetary burden in the form of an elevator. As reference, a residential elevator starts at approximately \$25,000 and a complex power wheelchair starting price is approximately \$30,000. A person with a disability can easily exhaust FEMA funds on needed DME equipment or access needs, leaving zero grant money left to repair their home.

In order to level the playing field, NCD recommends FEMA support congressional efforts to amend the Stafford Act (The Disaster Recovery Reform Act (HR 4460)). The proposed amendment would ensure that funds provided to persons with disabilities used to purchase goods and services specifically required because of a person's disability would not be counted towards the maximum allowable FEMA grant money. By doing so, persons with disabilities would have access to the same monetary benefit to repair their home as everyone and would eliminate the need for a person with a disability to choose between much-needed medical equipment or a functional home to live in.

### **Data Collection and Data Usage**

Unacceptable outcomes for people with disabilities were revealed after 2017's hurricane season. In Texas, people with disabilities living in the community prior to the hurricane were transferred to institutional settings because of a shelter's inability to provide required services or lack of post shelter housing options. Additionally, many people with disabilities reported difficulties navigating disaster recovery registration and access to programs. These complaints and issues are recurring regardless of the disaster or the state in which it occurs.

The Office of Disability Integration and Coordination's (ODIC) mission is to achieve whole community emergency management, inclusive of individuals with disabilities and others with access and functional needs, by providing guidance, tools, methods and strategies to establish equal physical, program and effective communication access. As the above issues reveal, people with disabilities still do not have equal access to FEMA programs. This is due in part by the method in which FEMA collects and collates data.

Current data collection begins when a person applies for FEMA assistance – which means people with disabilities who have difficulty accessing FEMA assistance or are placed in institutions because of inaccessible shelters are not included in any FEMA data collection.

It is critical for FEMA to be able to access qualifying data to review and analyze so it can continue to improve the outcomes of persons with disabilities before, during, and after a major disaster. NCD recommends FEMA revisit its methodology for data collection by modifying the onset of data collection and the phrasing of questions to eliminate ambiguity; provide training to FEMA personnel to improve their ability during intake to identify hidden disabilities; shape follow-up questions to ensure that all persons with disabilities are provided accommodations required in order to access FEMA programs; provide public outreach to communities to stress the importance of accurate data collection pertaining to disability to ensure access to all FEMA programs; and retain collected data and analyze outcomes post disaster to improve the access to FEMA programs in subsequent major disasters for people with disabilities. Improved policies pertaining to data collection would give FEMA the ability to assess the specific outcomes of people with disabilities and proffer recommendations to mitigate the same or similar results in future disaster relief recovery efforts.

These recommendations are prudent and timely given the havoc wreaked by Hurricane Harvey, Irma, and Maria this past hurricane season and it is critical they be addressed before the next disaster

strikes so as not to place the well-being of people with disabilities in jeopardy again. NCD has enjoyed a long history of working with FEMA and ODIC to improve the outcomes of persons with disabilities in the wake of major disasters. The Council is headed to Texas in May to hear first-hand about the institutionalization of persons with disabilities following Harvey.

We look forward to discussing our recommendations with you further. Please have your staff contact my lead emergency preparedness staff, Amy Nicholas, at [anicholas@ncd.gov](mailto:anicholas@ncd.gov) to set up a time for us to meet.

Respectfully,

Neil Romano  
Chairman

# Appendix G: Emergency Registries

## Expanded Discussion of Getting it Wrong: An Indictment with a Blueprint for Getting It Right

June Isaacson Kailes, Disability Policy Consultant

04.11.18

This expanded discussion covers in greater detail some of emergency registry content and recommendations covered in **Getting it Wrong: An Indictment with a Blueprint for Getting It Right**.

Considered are the challenges and shortcomings of existing emergency registries with examples from recent hurricanes in Texas and Florida, as well as other disasters. Recommendations focus on the need to look beyond emergency registries to the new, ubiquitous technologies that more easily connect people with disabilities and others with access and functional needs to the supports and assistance they need in their communities before, during, and after a significant emergency.

As soon as Raymond Guzman, 35, learned Hurricane Harvey was headed toward the Texas Gulf Coast, he started calling for help.

The Victoria resident lived with his 63-year-old disabled mother in an aging trailer, where he worked as her full-time caretaker. Before the storm, Guzman registered with 211, a resource hotline, to be added to a list of Victoria residents who might need help evacuating.

But as the deadly storm barreled toward the coast, Guzman, who doesn't own a car, wasn't having luck getting help. He started frantically calling law enforcement and government officials to schedule a ride to safety - to no avail.

"Please send someone to come get us," Guzman recalled saying.

Help didn't come until more than a day after the storm passed, forcing Guzman and his elderly mother to hide in their mobile home as the hurricane ripped apart its walls and collapsed part of the ceiling.

But that isn't supposed to happen.

... Authorities say they usually start reaching out to vulnerable residents about 96 to 120 hours before a disaster strikes to ask whether they need help.

But Hurricane Harvey created unexpected logistical challenges for emergency officials as the forecast changed from a strong tropical storm to a Category 4 hurricane within two days.

"Obviously with Hurricane Harvey and the rapid intensification of it, that became a very unique situation for us," said Richard McBrayer, who oversees emergency operations for Victoria.

Usually, when emergency planners call residents before a storm hits, it gives officials time to arrange transportation. That could mean picking them up at their homes or directing them to a bus stop, McBrayer said.

But Hurricane Harvey's rapid intensification upset those plans. With little time left before the hurricane was expected to make landfall, emergency officials started a major "shelter-in-place" campaign, McBrayer said.

According to county data, the number of people registered in the emergency program plunged from 1,250 in 2016 to 270 this year. Officials attribute the decline to the fact that some people may have moved in with family, passed away or left the area (Footnote 1).

Victoria's county population is about 90,000 and, according to the 2012-2016 *American Community Survey 5-Year Estimates*, there are approximately 13,500 people with disabilities in the county. A key question for Victoria County emergency managers is whether they need to plan for 270 people, or 1,250 people or 13,500 people?

Raymond Guzman's story as well as other issues discussed in this section represent many of the inherent problems with registries. These shortfalls include: registrant expectations and responder capacity, integrity of the data, recognition of performance failures related scale of events and no-warning and short warning events and lack of evidence-based research regarding registry effectiveness,

### **Registry use in emergency management**

In this report registries refer primarily to government plans to collect information about people with disabilities. This information typically consists of a database of individuals who voluntarily sign up and meet a variety of eligibility requirements for receiving emergency response services based on a need. Registries vary in form. In theory they collect the names, locations, and contact information of people in a given area or jurisdiction who are likely to need emergency help. The intent of a registry is to provide a priority warning regarding pending emergencies, including the shut off of power or water service; evacuating people from a danger area; providing sheltering, checking on individuals' health and safety; and connecting people with other viable and available supports and resources.

This discussion provides additional information on the State of Texas Emergency Assistance Registry (STEAR) and its use in Hurricane Harvey and on Florida's Special Needs Shelter Program and its use in Hurricane Irma. STEAR focuses on practices, procedures, updates and recommendations for a free state registry to provide local emergency planners and responders with additional information on the needs of individuals in their communities. If STEAR was used in the 2017 Hurricane Harvey response, finding anyone able to report the result was elusive. The Florida's Special Needs Registry is tied to its Special Needs Shelter Program and was used in the 2017 Hurricane Irma.

From a voluntary registrant's perspective, any emergency registry is a tool for managing personal risk. From a responder's perspective, a registry is a tool for locating a person in danger and connecting them with needed resources. The fundamental dilemma in registry effectiveness is the relationship between registrant expectation and responder capacity. Timing, resources, scale, and type of warning all influence that relationship. The ambiguity of this catch-all "registry" term, can lead to oversimplification of complex concepts, encompassing and dependent on many elements, such as the nature and scale of the hazard, type of warning, promised assistance, prioritization, and methods of response.

It must always be assumed that a needs-oriented registry is incomplete and includes only a small percentage of the population. The University of Texas School of Public Health at Brownsville, for example, estimated that 350,000 people, about 1 in every 4 Rio Grande Valley residents require transportation assistance for evacuation, but only 11,000 have registered (Footnote 2).

In practice, needs-oriented registries have typically been unable to achieve well-intentioned objectives for two major reasons. First, the response capacity is not considered or calculated based on the size of potential events and presumes there are enough responders to act in the case of mid-to large-scale events when there are not. Second, the simple fact of knowing where people live doesn't tell you where they are at the time of the event, which wastes critical time and resources looking for people in the wrong places (Footnotes 3 and 4). Fixed location registries can mean wasted trips and wasted time for overstretched first responders. According to the *New York World*, 658 people in Suffolk County Long Island were on a registry maintained by the county's Office of Emergency Management. Before and after Hurricane Sandy hit, volunteers placed 4,000 calls to the people on the list and their emergency contacts. In all, responders only evacuated 130 people on the list from flood-prone areas (Footnote 5).

“Just Because You, Know Where I Live, Doesn't Mean You Know Where I Am!”

- June Kailes

Many people object to the inherent registry bias that most people with disabilities are easy to locate because they are "homebound." Registries negate the fact this diverse population, just like everyone else: works, volunteers, plays, prays, shops, eats and travels.

Many registries are developed using outdated technology and collect information using medical model biases about people with disabilities. Applying the social model, versus a medical model, of disability entails identifying, remedying, and retooling interventions that reflect common stereotypes and beliefs about people with disabilities. Manifestations of medical model stereotypes include: assuming that people with disabilities are sick, are “homebound” and need medical care, protection, supervision, and separate shelters.

The numbers indicate that in a large-scale emergency, despite planning, first responders and most communities do not have the capacity to respond to large events. For example, the 911, 211, 311 call centers and first responders are often overwhelmed and unable to handle to call volume. Although traditional emergency registries may work in small scale response events, e.g., a house fire, registry effectiveness is much more questionable in larger, catastrophic events.

In areas where large-scale emergencies seldom or rarely occur, significantly less time is typically spent on the details of emergency plans. The more often emergencies are experienced, the stronger the perception of risk and the more time is spent on planning. Recent memory is a great motivator for thinking through the effectiveness of registries and tends to counteract “magical thinking” that they are likely to be effective.

### **Clarifying Purpose and Expectations - Planning tool? Response tool?**

Planning will continue to miss the mark when people with disabilities and others with access and functional needs are considered separately, instead of recognized as people who are a part of every segment of the general population. These are, in plain terms, the people that in an emergency will have difficulty seeing, reading, hearing, understanding, talking, thinking, remembering, walking, using stairs, hiding, running, jumping, etc. In larger scale emergencies, functional needs significantly increase as people lose access to their devices, equipment, supplies, medications and to the supports and customizations they rely on in their environments. Counting others who acquire injuries resulting from the impact of the disaster, this group can represent well over 50% the population.

The numbers of registered people will never be the same as the number of people with access and functional needs in any community. This discrepancy leads planners to be ill-prepared for reality, especially in larger scale events. Many people with disabilities will not sign up for registries because they worry about their privacy and fear being tagged as vulnerable. Others are concerned about their legal status or that of their family members, and/or fear losing independence. Some will question what happens to the many who do not register. Developing voluntary registries as the basis of planning for people with access and functional needs is, at best, an exercise in symbolic planning or “magical thinking”, rather than realistic and practical planning.

## **Symbolic Planning**

Symbolic planning refers to guesses based on untried, undocumented, or unsuccessful practices. Symbolic plans lack specifics of who, what, where, when and how. A classic example is the April 20, 2010, gas leak and explosion on the Deepwater Horizon oil drilling rig in the Gulf of Mexico. Although not related to registry issues, eleven people died because of the accident, and others were injured. The fire burned for 36 hours before the rig sank, and hydrocarbons leaked into the Gulf of Mexico before the well was closed and sealed. Ultimately, the company’s emergency functions failed to seal the well after the initial explosions. As Lee Clark explained in his book *Mission Improbable*, there was a cleanup plan for spills in the sound, but this massive spill was unprecedented. The plan that had been developed and accepted as policy was based on little more than a patchwork of guesses, which is what typically happens with needs-based registries.

## **Planning with and for People with Access and Functional Needs**

Planners who recognize the actual composition and characteristics of their communities would be more productive identifying the community profile demographics using tools such as the Social Vulnerability Index, which can point to location of clusters of people, such as retirement communities, public housing and assisted living complexes.

Because of the multi-disciplinary nature of the people and agencies involved with emergency management, there are different expectations and sometimes competing priorities for using a registry. It is essential to agree on expected outcomes, the protocols for achieving these outcomes; and how the registry integrates with other parts of the emergency management and services system. (At a minimum, this includes emergency managers, planners, and responders for different types and scales of events; public health; potential registrants; resource organizations and services, e.g., transportation.) The most important issue to clarify is whether and why to establish/maintain an access and functional needs registry. What are developers/sponsors trying to accomplish with the tool? Whose perspective is driving the system? For example, a registry viewed from a public health and emergency management planning perspective may look quite different and have a different emphasis, then a registry viewed from the registrants’ and responders’ perspective.

Operationally, an emergency registry is a response tool that provides a response safety net for the people registered. Responders will be using it to improve their response effectiveness. A voluntary registry, however, is not an effective “stand-alone” planning tool because not everyone that needs to be included in the planning process will ever register. Thus, no voluntary registry can provide complete data about demographic and geographic distribution patterns so any subsequent analyses that might rely on registry data would be inaccurate.

The first registry questions from a registrant's perspective are: *What am I registering FOR? What will it do for me? What can I expect?* It is surprising to find that public health and emergency management professionals have a strong reaction to the concept that a registry is operationally a response tool,



and not a planning tool. They have difficulty addressing the question: *“Why would an individual register in a system that will be unable to provide assistance when emergency response is needed?”* (Footnote 6).

Personal emergency response systems (PERS) like LifeAlert and vehicle-based OnStar provide a useful comparison and benchmarks for other registries. These commercial systems provide “emergency response” to individuals who pay for the service and security provided by an on-call response system. They link an individual to the resources needed to respond to an individual emergency – e.g., falls in the home, car crashes. OnStar advertises that it will stay with you (by voice) until help arrives. The subscriber knows what to expect. They know that the PERS service personnel are not coming, but that someone will stay on the line with them until summoned help arrives. The subscriber is willing to pay a subscription fee to get assistance in contacting people who can help get responders to help them when assistance is needed. In a medium to large scale event, the call service would be able to tell them that assistance was not going to be available (e.g., the local jurisdiction’s call center was overloaded), and the subscriber would then know they were on their own. PERS systems are focused on response. They are not used for emergency planning.

## **Connecting Registrants and Responders**

How the connections are made between the registrant and the responder is essential to making the system work. What is the interface with responders? How is that handshake made and sustained? Private commercial PERS have a business model for operating the emergency response communication. Personnel in the service centers are neither registrants nor responders, but make connections between the two, on a fee for service basis. Most government registries do not have this active bridging element. This essential element appears to be missing in most registries.

## **Registry Disclaimers**

Registries use disclaimers to address situations where a mismatch between registrant expectation/need and responder resources/timeframe may occur. But that leaves the individual not knowing what they can and cannot expect in any given emergency. Will the responders, the transportation, the assistance be there? And if so, when?

Despite the disclaimers that most registries require, there will still be expectations about registering providing priority for being rescued or evacuated and not being left behind.

The STEAR disclaimer states:

“Does registration with STEAR guarantee I will be evacuated during an emergency event such as a hurricane? No, your information will be provided to participating local governments for their use in developing emergency management plans and to assist them in preparedness and response activities. Each local government uses the information in different ways and registering in the system does NOT guarantee that you will receive additional assistance during an event. Contact your local Emergency Management Coordinator to determine their level of participation in this program.” (Footnote 7)

Registries give people a false sense of security, even when they come with educational efforts and clear disclaimers. Registries can reinforce the phenomenon of “magical thinking.” This occurs because most people do not want to think about emergencies. Most people don’t pay attention to emergency details until they need to, just as people don’t pay attention to the details of health insurance, or using a fire extinguisher, or shutting off the water, or opening a power-dependent gate

or garage door during a power outage. Many people also find it disturbing to think about large-scale, Katrina-like events. It is much easier to believe that the government will automatically be there to help.

People persist in the magical belief that signing up for a registry guarantees assistance. This misguided belief can diminish or even divert the energy people should devote to developing and strengthening their personal preparedness plans that should include thinking through and taking appropriate steps to establish and keep current personal support systems.

## **Failures**

Disclaimers point to one of the major limitations of all registries. In a medium to large scale event, even the best commercial personal emergency response system is likely to fail. The person in need (or the PERS service center representative, or the staff at a human service agency) can make calls to the call center -- but if there are no response resources to deploy, there will be no response. The best the PERS service center can do, is stay on the phone with customers while they wait. Or if possible, help customers to activate another plan. Optimally, assistance in developing a personal emergency response plan would be included by default in the services any PERS systems offers.

## **Integrity and Accuracy of the Data**

A registry is not effective as a planning tool for populations with access and functional needs. There is little likelihood that everyone, or even most individuals, that need to be included in the planning process will ever register, making analysis inaccurate.

Reports from California detail serious problems in keeping registries current as well easily and quickly retrieving the data and responding when needed. Individuals in charge of registries were unable to access the list because of power outages and lack of access to work sites. Lists provided to local fire stations list were irretrievable because they were locked in cabinets, and all firefighters were out fighting the fires.

## **Costs**

Maintaining registries is expensive and is typically not economically viable. In 2004, the Los Angeles County Office of Emergency Management "...conducted research on the costs of developing and implementing a voluntary registry. According to this research, a registry program in LA would require 14 full-time staff, including 10 analysts, two employees to do [geographic information system](#) (GIS) mapping, and two administrative assistants. The total cost was estimated at just under \$1.4 million per year for the first three years of the program, with two-thirds of the funds going towards staff and the remaining one-third for technology."

## **State of Texas Emergency Assistance Registry (STEAR)**

Texas has invested significant dollars, time and effort in the establishment of the State of Texas Emergency Assistance Registry (STEAR). STEAR "focuses on practices, procedures, updates and recommendations for a free state registry to provide local emergency planners and responders with additional information on the needs of individuals in their community (Footnote 8).

Once the data is entered, STEAR information is the responsibility of a data custodian at the local level (for rural counties, usually the custodian is appointed at the county level). The county or city has discretion regarding how they use the data. There are significant questions about the rigor applied to

the critical effort of keeping data current and accurate given the short shelf-life and perishable nature of registry data. In STEAR, for example, there are several reported current vacant positions for the local data custodians (Footnote 9). Also, STEAR functions are decentralized. Emergency personnel at the county and city level do not have to use STEAR. There is no an overall reporting mechanism to evaluate the STEAR and there are no required procedures for using the information. There are reports that Harris County and the City of Corpus Christi used their STEAR data in response to Hurricane Harvey. In addition, there are unverified reports that STEAR information was used for search and rescue operations for Hurricane Ike and the 2016 Floods. However, searches for data regarding effectiveness and outcomes did not yield any publicly available information.

Comments from the City of Houston to Federal Communication Commission regarding response efforts related to the 2017 hurricane season provides some effectiveness and outcome information. These comments reflect the input of the Houston Emergency Center, the Houston Police Department, the Houston Fire Department, the Houston Information Technology Department, and the Mayor's Office for People with Disabilities.

Texas uses the State of Texas Emergency Assistance Registry (STEAR). In theory, people with disabilities can register with STEAR so that they can receive assistance evacuating during a disaster. Many people with disabilities registered with STEAR and expected that they would receive assistance that emergency responders when their homes started flooding. They repeatedly called 911 and 211 and received no assistance. The State of Texas makes it clear that registering with STEAR does not guarantee assistance with evacuation, however, for Harvey, because broad evacuations were not ordered, only six individuals were actively contacted through the STEAR database. Many power-dependent people with disabilities received water in their homes and needed to be evacuated, despite the lack of an official evacuation order. States and localities are increasingly using databases/registries like this. The FCC should issue guidance on best communications practices for entities using a disaster response assistance registry for people with disabilities. Such guidance could assist in getting more people with disabilities more consistent, responsive interactions with emergency workers (Footnote 10).

A review of 11/14/17 and 5/11/17 STEAR Advisory Council minutes yielded no insight into response outcomes. A major emphasis of the minutes was analyzing the statistics and demographic characteristics of STEAR registrants. The November 2017 minutes contained this statement regarding STEAR data used during Hurricane Harvey.

“Harris County Office of Emergency Management pulled information from B and C registrations and set up a call center to reach residence and inquire about emergency plans. They explained there was no evacuation order or transportation for residents; calls were for planning purposes only and conducted in a manner to avoid panic. Residence were glad to receive the calls. “Some roll over 9-1-1 calls were received. “ (meaning unclear)

### **Florida's Special Needs Shelter Program**

The Florida Division of Emergency Management, in coordination with each local emergency management agency in the state, developed a registry to allow residents with special needs to register with their local emergency management agency to receive assistance during a disaster (Footnote 11).

The Florida Division of Emergency Management, in coordination with each local emergency management agency in the state, developed a registry to allow residents with special needs to

register with their local emergency management agency to receive assistance during a disaster. The statewide registry provides first responders with valuable information to prepare for disasters or other emergencies (Footnote 12).

Concerns about this system were frequently raised by key informants, stakeholders, Hotline callers, traditional and social media. Key informants voiced many serious concerns about the registry, especially as it related to sheltering. Concerns included: lack of capacity to accept registrants into their special needs shelters, registrants who were turned away because of lack of space; refusal to admit registrants who were unable to bring a personal assistant with them and no capacity to admit people in need who did not pre-register.

## **Efficient and Effective Use of Technology as an Alternative to Voluntary Registries**

The emergency sector's performance depends on resilience and flexibility to evolve as economic, learning, technology, legal and social landscapes change. In this world of shrinking budgets, scarce first responder resources must be used wisely. This includes prioritizing efficiencies that modernize how people signal for and receive help in real time, and harnessing technology through potential viable applications like social media, mobile devices, sensors and supply delivery via drones and services such as Uber, Lyft, Amazon, UPS and FEDEX (Footnote 13).

Pew Research Center reports that cell phones ownership in 2018 to be 95% of the US population and 77% of those people own smartphones (Footnote 14). In many disasters, landlines and cell towers remain operational or come back up quickly in a significant portion or outages. Technology is also finding new solutions for prolonged cell tower and internet outages by using internet via drones and high-altitude balloons that deliver temporary communication and internet connectivity.

Rapidly advancing technology plus a more technologically savvy population change the public's expectations and emergency management's response capacity. Technology can broaden and replace the traditional registry concept. For example, proprietary systems exist which fully integrate data provided by individuals into a local call center's 911 database. Instead of a registry's focus on people who are viewed as different, special, at risk, at home, or vulnerable, there are software systems such as Smart 911 that allow any community member to build a safety profile which provides responders with immediate access to information about their access and functional needs, chronic conditions, medications, service animals, vehicles, pets, and emergency contacts. When someone in a household calls 911, their data is displayed for the 911 call taker and can be used to inform the response to the specific location. These systems are also not home dependent. The phone numbers are registered, not the location. Technology can efficiently build into the response infrastructure responder friendly mechanisms that enhance connections with all community members (Footnote 15).

## **Commercial Registries**

[Personal Emergency Response Systems](#) (PERS) (Footnote 16) are commercial registry systems that coordinate "emergency response" to individuals who pay for the service and security provided by an on-call response system. The vehicle-based systems like [OnStar SOS](#) (Footnote 17) and [Sync 911Assist](#) (Footnote 18) are also tied to mobile phone technology. Since 2010, the Personal emergency response systems (PERS) model has quickly evolved to a broad array of mobile-based platforms. People who "have fallen and can't get up" are no longer tethered to their homes.

## **Capturing the Power of Technology**

**The focus should be on how to capture the power of accelerating technology capabilities which can effectively and efficiently perform some of the many life-saving and life-sustaining tasks (search and rescue, evacuation, transportation, delivery of emergency supplies, restoration of communication arteries) that overwhelm first responders in catastrophic events.**

Mobile devices include smartphones, tablets, virtual assistants (Alexa, Cortana, Echo, etc.) wearables like Fit bits, Apple watches, etc. These mobile devices and their apps offer exciting new possibilities. The many peer to peer (P2P) apps available and in development take advantage of social media software that captures the strengths of spontaneous community response. Peer-to-peer (P2P) is a decentralized communications model in which each party has the same capabilities and either party can initiate a communication session. Existing products and newer prototypes of technologies to achieve an “anywhere anytime” communication and location identification systems for assistance already exists (Footnote 19).

The preciseness of location services is quickly evolving in their ability pinpoint exact locations. The wasted time, calls, and trips problem could be dramatically reduced by optimizing these location services. There are “Check In,” and “Find Me” apps,” and sensor technologies that detect falls and other dangers. Global positioning system (GPS) enabled apps like “Follow Me” features allow users to choose contacts who can track their location in real-time. An “I’m Safe” or “Need Help” signal can be activated to let ones’ designated lists of people know one is safe.

Some apps that activate a help signal that can be set to send a panic alert containing a link to one’s GPS location. The alerts go to one’s pre-selected emergency contacts via text message, and email, and if set up, posts to Facebook and Twitter. When “help” is activated, it automatically prompts the user to contact 911. Other apps offer one-button activation that calls everyone on a pre-designated list with a pre-programmed message.

People needing evacuation help could use the ride sharing economy’s Uber or Lyft-like transportation applications, when accessibility is a built-in feature, such as “need a wheelchair accessible vehicle” or “need driver able to lift/put my mobility device into the trunk.” Use of a signaling device could read the remaining battery power of a piece of life-sustaining requirement and signal designated organizations and responders with global positioning system coordinates of the device once it fell below a given battery charge threshold (Footnote 20). Airbnb-like sharing economy model could be adapted for use in providing temporary housing.

## **Recommendations**

Based on the documented experiences of the 2017/2018 disasters, as well as previous emergencies, this report concludes that most if not all, access and functional needs registries have common similar systemic problems. A registry plan may sound feasible, but it may not be able to achieve its well-intentioned objectives for two major reasons. First, the response capacity is not considered or calculated based on the size of potential events, and second, knowing where people live doesn’t tell you where they are at the time of the event. The former presumes that there are enough responders available for mid- to large-scale events when there are not. The latter wastes critical resources and time as responders look for people in the wrong places, which helps neither the responder nor the evacuee.

The following recommendations to national, state and local entities are offered to improve disaster response and outcomes for people with disabilities and others with access and functional needs.

1. Government should use existing planning tools to collect data about people with disabilities and others with access and functional needs.
2. Emergency services should strengthen connections and planning with organizations who maintain current lists of the individuals they serve, such as accessible transportation providers, paratransit providers, Aging and Disability Resource Centers, Area Agencies on Aging, equipment vendors, assistive technology centers, developmental disability services, health plans, home health agencies, Meals on Wheels, mail order pharmacy services, personal assistance services (public and private), utility discount lists (power and water), independent living centers, early childhood, in-home, and school based special education services and many other existing sources of information that can guide whole community planning.
3. Government should not mandate or endorse emergency registries.
4. Government should use technology to improve how people with disabilities and others with access and functional needs signal for and get help.
5. Conduct evidence-based registry research that includes outcomes, costs, and stakeholder satisfaction measures.

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**Recommendation 1: Government should use existing planning tools to collect data about people with disabilities and others with access and functional needs.**

Use effective planning tools to collect data regarding people with disabilities and others with access and functional need. Local governments often use registries as a planning tool. However, a registry is not effective as a planning tool. There is little likelihood that everyone, or even most individuals, that need to be included in the planning process will ever register, making analysis inaccurate.

“A registry will not be effective if it is used as the primary planning tool for populations with access and functional needs. Believe it or not, many emergency planners look at registries, spreadsheets, lists, tables, and matrices as a sort of planning panacea. Neat columns and rows replete with filled-in data fields are de-facto substitutes for substantive information. All too often, tabular data is accepted without any real analysis on the part of plan reviewers. So long as the key words appear in the heading boxes and some degree of descriptive “stuff” is visible in the appropriate columns/rows, the “plan” passes muster.” Philmont M. Taylor, commander of the Emergency Services Division of Los Alamos, New Mexico.

To collect data about the demographic and geographic distribution patterns in a jurisdiction for planning purposes, use readily available existing data. These information sources include program administrative data from government sources including the US Census, US Department of Health and Human Services emPOWER Tool, the Social Security Administration and community service agencies, and GIS (geographic information systems) tools.

**Recommendation 2: Emergency services should strengthen connections and planning with organizations who maintain current lists of the individuals they serve, such as accessible transportation providers, paratransit providers, Aging and Disability Resource Centers, Area Agencies on Aging, equipment vendors, assistive technology centers, developmental disability services, health plans, home health agencies, Meals on Wheels, mail order pharmacy services, personal assistance services (public and private), utility discount lists (power and water), independent living centers, early childhood, in-home, and school based special education services and many other existing sources of information that can guide whole community planning.**

Successful partnerships with the resources of government, community organizations and businesses are far more likely to yield favorable outcomes for disaster impacted communities than separate voluntary collection of perishable and inexact information.

California emergency responders commenting on the use of registries stated:  
“The act of creating a registry does not increase response capacity, but focusing on integrating community stakeholders in response does.”

It is important that government not limit its definition of community stakeholders and engagement only to those involved with Voluntary Agencies Active in Disasters (VOADs) or others who have as their mission emergency work. This leaves out many organizations that do not have emergency work as part of their primary mission but play a critical role in supporting people with disabilities and others with access and functional needs.

Emergency services should strengthen connections and planning with organizations who maintain current lists of the people they support who would be disproportionately Impacted in disasters. Successful partnerships with the resources of government, community organizations and businesses can result in far more positive outcomes for disaster impacted communities than separate voluntary collection of perishable and inexact information.

How effectively government can partner with, and leverage, the resources of community organizations and businesses will determine the success of the response. For example, these organizations can help during large emergencies by pre-developing a “priority emergency contact list” that can be used for life-safety check-in systems to reach out, to those who, through a pre-discussion process with the people they support, have self-identified as having the greatest need for assistance. This list can include people who are geographically isolated; lack viable support networks such as relatives, friends, and neighbors; cannot use or understand or be reached by existing alert and notification systems; are transportation-dependent and who are unable, or least able, to get to commodity distribution points. Leveraging community resources also entails recognizing the critical force multiplier value and efficiencies of working with self-organizing communities. It means partnering with the next Cajun Navy response effort and the many other examples in the 2017/2018 disaster seasons of self-organizing responders.

**During Hurricane Irma and Maria the paratransit agency on St. Thomas proactively and independently contacted all their riders to check on their safety and their needs of and offer any assistance they could. Their rider list is current, and they know well all their customers.**

Life-safety wellness checks by organizations also apply to people who are sheltering in place in their homes and do not need life-saving search and rescue. These checks provide people, when needed, with essential items, such as water, food, medications, supplies, evacuation, and transportation for

health care (such as dialysis), batteries, waste disposal, home health, and personal assistant services (Footnote 21).

An emerging government resource is the emPOWER tool maintained by Health and Human Services. This is a non-inclusive list of people who rely upon electricity-dependent medical equipment. This emPOWER provides information to local public health officials about the number of known Medicare beneficiaries in each impacted area who rely on 14 types of life-maintaining and assistive equipment. This equipment ranges from oxygen concentrators to electric wheelchairs, as well as data on the number of people who rely on dialysis, oxygen, and home health services (Footnote 22). (Note: it is imperative to recognize that there are many people on Medicare who won't be included, as the equipment they are using was not paid for by Medicare.)

**One critical caveat that must repeatedly be acknowledged is that these organizations will never reach all people with disabilities and others with access and functional needs. There are many who may need assistance who do not affiliate with, interact with or receive services from any of these organizations.**

**Recommendation 3: Government should not mandate or endorse emergency registries.**

State and local government emergency planners should not mandate or endorse the use of emergency registries unless and until registries effectiveness outcome data merits this endorsement. Government codifying registries confines and delays adopting newer technology approaches.

Texas, Florida, and North Carolina among other states and some local governments have regulatory language mandating the creation of registries. For example, the 2009 session of the North Carolina General Assembly authorized North Carolina Emergency Management to develop a voluntary special needs registry for use by counties and municipalities (Footnote 23).

These regulations are sometimes followed and sometimes ignored. Key informants explained that legislators are reluctant to remove these regulations or allow them to sunset (expire) because whether based on reality or not, they fear that at some point they may get blamed for some preventable disaster-related deaths. Ironically an even stronger argument can be made regarding the liability of allowing these statutes to remain in place.

**Recommendation 4: Government should use technology to improve how people with disabilities and others with access and functional needs signal for and get help.**

**Universal design specifications and features must be integrated into the device and app development process to insure ease of use of these emerging emergency innovations by diverse populations which include those with limited function related to: dexterity, seeing, hearing, speaking, reading, understanding or remembering. If access and functional needs issues are not consistently integrated into this rapidly evolving technology, it will mean continual catch-up and retrofit. It may also lead to wasted time and money in expensive litigation and settlements.**

**Recommendation 5: Conduct evidence-based registry research that includes outcomes, costs, and stakeholder satisfaction measures.**

The number of local jurisdictions (cities and counties) developing and using registries appears to be increasing. An online search for emergency management registries provides many links to registries focused primarily on "special needs populations." Yet little is known about their effectiveness, and



most of that is anecdotal. There has been little objective discussion about when and where a registry is a useful tool for emergency response, at what scale a registry becomes inoperable, and perhaps even more dangerous when it provides a false sense of security and diverts the registrants from developing emergency plans.

Registries have diverse and complex elements which include funding, administration, focus, recruitment of potential users, enrollment, disclaimers, education efforts, data management (information collected, privacy, refreshing-maintenance, storage and retrieval), and response capacity. Research does not exist that comprehensively examines registry elements such as costs; sustainability; effectiveness (successes and failures), geographic, event specific and scale of event specific issues; and the essentials of promising practices for these efforts.

## **Social Media**

How can stronger use of social media, Global Positioning Systems (GPS) and Google location services be strategically leveraged and integrated into response efforts?

Angela Wigglesworth has a form of muscular atrophy and uses an electric wheelchair. She and her fiancé had decided to get supplies and hunker down in their home near downtown Houston. “I’ve lived in Houston my entire life, so hurricanes weren’t foreign,” she says. “No one in our area was leaving. Even though we live in an area that floods, our house has never flooded.”

The couple woke up early Sunday morning, August 19, to a river of water in front of their house. “We turned on the news and saw people up on their roofs getting rescued not far from us. That’s when we knew we needed to go,” she says. They tried to call 911 but could not get through. Other emergency management services told Wigglesworth to get on her roof. Wigglesworth took to social media to ask for help when water started seeping into her house later that morning.

Her post went viral. A few hours later, a team of firefighters arrived, but they determined they could not transport her and her wheelchair safely. Later, three former Marines in a canoe paddled to her house, but there was too much risk that the canoe would tip over in the rushing water. “Being medically fragile, I was worried about being transported and transferred safely,” Wigglesworth explains. “There were these moments of relief because we thought we were being rescued, but then these letdowns when we realized it wouldn’t work.”

In all, it took six hours of trying before they were safely rescued. Two friends arrived with a snorkel Jeep that could drive into high waters and a 12-foot-long fishing boat that could accommodate her. Wigglesworth’s wheelchair was damaged from the rain and her home is still being repaired from flood damage, but she considers herself lucky to have had so many people try to help (Footnote 24).

## **Compare different models**

Compare different registry approaches and outcomes STEAR, PERS, SMART911 and the Florida Special Needs Registry.

How can the self-organizing community (s) be force multipliers and enhance efficiency for all?

## **Personal emergency response systems (PERS)**

What can government learn and apply from commercial PERS registry systems? (For example, PERS saw the value of mobile systems early on to accommodate the issues of “where I live, doesn’t tell you where I am.”

What were the PERS systems experiences in connecting to 911 or other response resources during 2017/2018 disasters?

What role does PERS play in assisting their customers in developing emergency plans?

## Closing Thoughts

To paraphrase a quote attributed to many people, “If you always do what you always did, you always get what you always got. Is that enough?” The answer is no. Thinking in the future tense means better decisions, strategies and policies for today and better outcomes for tomorrow. It means embracing and using technology. It means finding the resources to make the technology ubiquitous, affordable, and universal. This work will entail weaving together traditional emergency services and volunteer models with the emerging P2P models.

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