

**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*



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## Learning Objectives

- Understand effect of ADA noncompliance on individuals with disabilities before, during and after 2017-2018 disasters.
- Understand complex circumstances contributing to disproportionate impact of disasters on people with disabilities.
- Be aware of recommendations for improving preparedness and disaster resilience established by a broad coalition of disability inclusive emergency management stakeholders.



## Partnership for Inclusive Disaster Strategies

- Provides advocacy, community engagement, training, technical assistance and disaster services in support of disability community leaders,
- Promotes universally designed and inclusive emergency planning, disaster response, relief, recovery and mitigation for disaster survivors with access and functional needs,
- Guided by core values of equal access, inclusion and independence and a future where community resilience is achieved and sustained for all - throughout planning, alerts, evacuation, shelter, health maintenance and individual and community recovery
  - accessible to all,
  - led by active involvement of people with disabilities and fully informed by community as a whole.



## Partnership For Inclusive Disaster Strategies

- Disaster Hotline
- Disability organization-led stakeholder teleconferences
- Coordination of immediate lifesaving rescue assistance
- Collaboration to provide health maintenance and replace lost, damaged and destroyed supplies and assistive devices
- Deployment of disability experts to meet immediate needs and support local disability organization leadership
- Getting It Right conferences and legislation
- Digital Workshop Series



## National Preparedness Goal

“Care must be taken to identify and eradicate social and institutional barriers that hinder or preclude individuals with disabilities and others in the community historically subjected to unequal treatment from full and equal enjoyment of the programs, goods, services, activities, facilities, privileges, advantages and accommodations provided.”

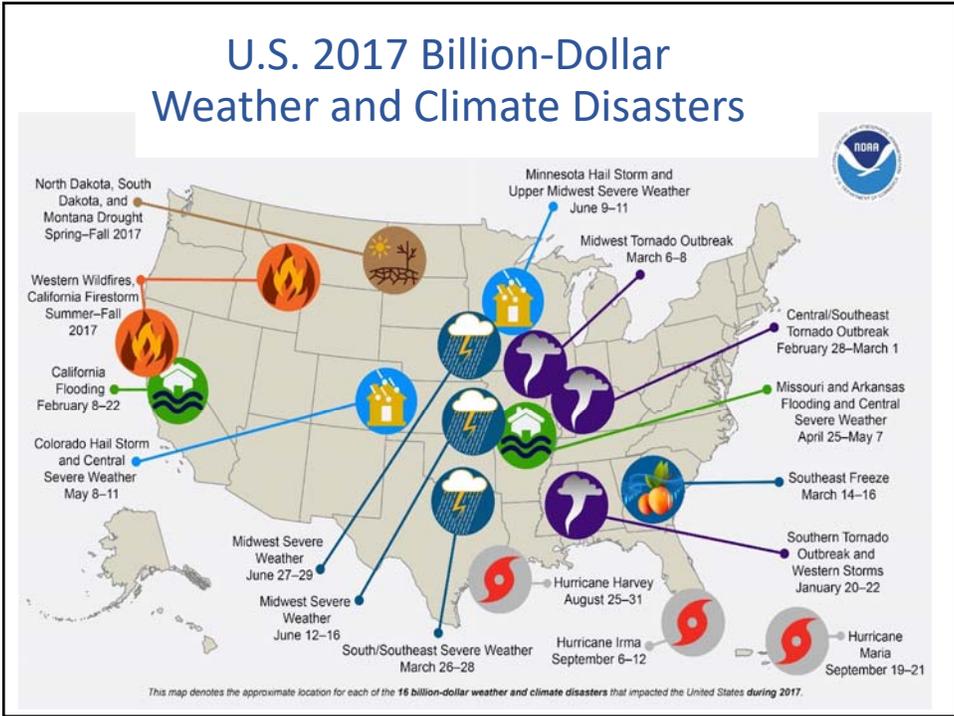


## National Preparedness Frameworks

“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...”





### Puerto Rico Disability Community Relief Network

**PRDCRN**  
DISABILITY COMMUNITY RELIEF NETWORK

Partner organizations include: cedd, PRATP, MAVI, and PORTLIGHT.



**Puerto Rico Disability  
Community Relief Network**

- Advocacy for the rights of people with disabilities.
- Capacity building for individuals, public and private organizations and communities.
- Dissemination of evidence based approaches.
- Research and Evaluation.
- Emergency Preparedness: Planning, Response, Recovery and Mitigation.

## After Action Report

### Background

- What is an After-Action Report
- Intent
- Authors
- Key Informants
- Funder



## After Action Report

Interviews with key informants with disabilities and allies with disability expertise in the disaster impacted areas

Review of –

- Data from 3,200 Disaster Hotline calls
- Information from daily stakeholder teleconferences
- Transcript of Department of Homeland Security listening session
- Congressional correspondence and testimony
- Media reports



## Findings

Decades of data and information from previous disasters have not been applied.



## Findings

Lack of equal access was compounded for individuals with disabilities who are also people of color, older adults, LGBTQ people, children, women, have limited English proficiency and immigrants, especially those without documentation.



## Findings

Continual reliance on disability organizations to act as “provider of first resort”, usually without compensation

Constant use of volunteers and donations by government to meet disability civil rights obligations



## Findings

Disability organizations filled gaps to meet needs

- Locating people
- Disability accommodations
- Distributing food and water, durable medical equipment and disability related supplies
- Preventing and curtailing unnecessary institutionalization



## Legal Obligations

Federal, state and local governments have significant and non waiverable obligations to children and adults with disabilities.

The After-Action 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.



## Some Federal Legal Obligations to Individuals with Disabilities

- Rehabilitation Act of 1973, as amended
- Americans with Disabilities Act (ADA) of 1990, as amended 2008
- Individuals with Disabilities Education Act (IDEA) of 1975, as amended



## Disproportionate Health Impact

New England Journal of Medicine (May 2018) Harvard study, “Mortality in Puerto Rico after Hurricane Maria,” documented what we already knew:

- Interruption of health care and disability services were primary cause of high mortality rates in months after hurricane
- Most frequently reported problems:
  - Inability to access medications (14.4% of households)
  - Need for respiratory equipment requiring electricity (9.5%)



## Examples from Maintaining Health Content

### Emergency Support Function #8 - Public Health & Medical Services shortfalls:

- Primary focus hospital & medical facility operations
- Lack of community health maintenance assistance outside of medical facilities
- Lack of support for people evacuated for health reasons

### Recommended fixes:

- Temporary deployment of qualified professionals
- Expand community focus and resources
- Expedite replacement of durable medical equipment, disability supplies and assistive devices



## Health Plan Roles – What Worked:

- Call Center protocols
- Community partnerships
- Member emergency plans
- Posting/disseminating emergency preparedness information
- Life-safety checks
- Health information exchange
- Preventing and diverting inappropriate admissions
- Expediting replacement of equipment and supplies
- Messaging
- Member tracking



## Health Plan Roles – Recommended Fixes:

- States should incorporate emergency roles & responsibilities into health plans contracts.
- Create health plan industry-wide emergency service, guidance, training, technical support, and regulatory standards such as the CMS Emergency Preparedness Rule for facilities and suppliers.
- Integrate specific emergency performance clauses into vendor and contractor agreements.
- Establish & test agreements for emergency supply delivery and evacuation services.
- Connect with community partnerships for planning, exercises, drills, response, and recovery activities.



## Registry After Action Report Content – Another Example

- 50 minutes workshop from Getting It Right Conference
- **Search for:**
  - **The Inconvenient Truth About Registries, Power, Alerts and Evacuation**
- or
- Go to: <https://www.youtube.com/watch?v=y1SpBhpUUbk>



## Failure to Provide Equally Effective Communication

Lack of equally effective communication in shelter for people who are Deaf

**Example:** Individual walking around George R. Brown Convention Center with a sign with the word “Deaf” on it

### Recommendations

- Department of Justice and other Federal civil rights offices must enforce compliance with effective communication obligations.
- Training and technical assistance must be provided to local emergency management.



## FEMA registration process inadequate to provide equal access and reasonable accommodations

Inability to indicate that you have a disability when registering for FEMA

**Example:** Disaster survivor with a spinal cord injury institutionalized due to pressure sores because he was forced to share a TSA bed because he could not identify his need for accommodation on application

### Recommendations

- Redesign and publish FEMA disaster assistance application
- Engage knowledgeable disability community leaders



## Education

Students with disabilities are denied a Free and Appropriate Public Education

**Example:** Student with autism had no transportation to new school and no transition support

### Recommendations

- IEPs and 504 plans must be 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.
- IEPs and 504 Plans must include emergency contingencies



## Additional Equal Access Failures

- Notification
- Evacuation
- Sheltering
- Disaster Recovery Centers
- Food and Water Distribution
- Distribution of Goods
- Home Inspection
- Housing
- Appealing Denials



## Disaster Response Hurricane **Harvey**



## Disaster Response - Hurricane **Irma** Partnership, National Guard, Trach Mamas



## Disaster Response - Hurricane Maria



<https://www.facebook.com/rootedinrights/videos/1530404470381837/>



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Danger      Opportunity

**JOHN F. KENNEDY**

“When written in Chinese, the word “CRISIS” is composed of two characters – one represents DANGER, the other represents OPPORTUNITY.”





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