



Addressing the Needs of People with Disabilities in Public Health Emergencies

Cindy Hinton, PhD, MS, MPH

Health Scientist, Disabilities and Health Branch

National Center on Birth Defects and Developmental Disabilities

Emergency Partners Information Connection (EPIC) Webinar Series
November 28, 2018

What is a disability?

What legislation addresses disability in preparedness and emergency response?



What is a Disability?

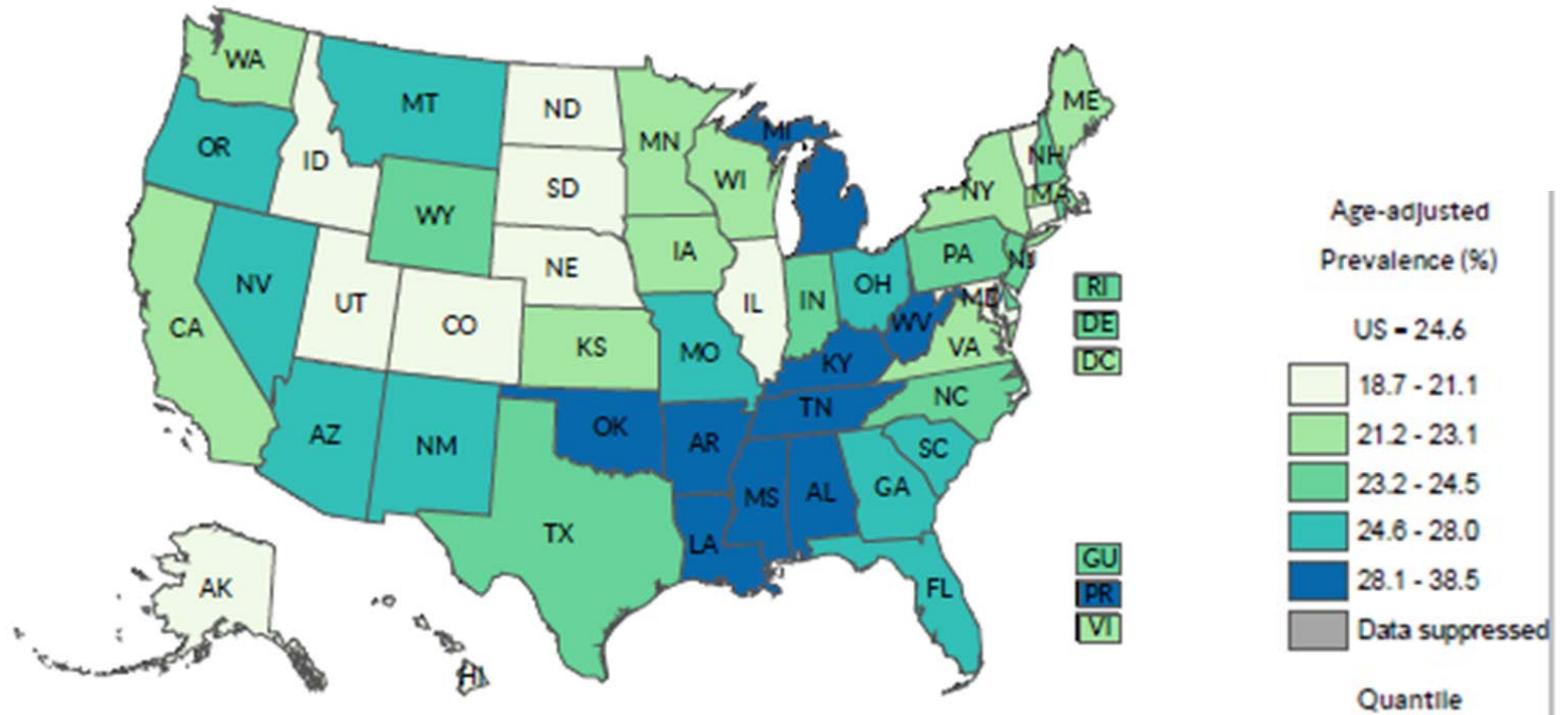
- Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions.
 - An impairment is a problem in body function or structure.
 - An activity limitation is a difficulty encountered by an individual in executing a task or action.
 - A participation restriction pertains to normal daily activities, such as working, engaging in social and recreational activities, and obtaining health-care and preventive services.
- For public health surveillance, disability is categorized by level of difficulty with mobility, vision, hearing, cognition, self-care, and independent living.

Disability Status Among U.S. Adults

Disability Type	Age-adjusted Prevalence (%)
Any Disability	24.6
Cognitive	10.8
Hearing	5.3
Mobility	12.6
Vision	4.5
Self-Care	3.5
Independent Living	6.5
No Disability	75.4

Data source: Behavioral Risk Factor Surveillance System, 2016 <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>

U.S. Distribution of Disability, 2016



Data Source: Behavioral Risk Factor Surveillance System <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>

Types of Disabilities and Impact in Emergency

- Mobility impairments
 - Ability to leave home, evacuate, get to shelter, function in shelter
- Deaf or hard of hearing
 - Hearing emergency communications or instructions
- Blind or low vision
 - Seeing communications, transportation
- Intellectual/cognitive disabilities
 - Comprehension of situation
- Mental health/Post-traumatic stress disorder
 - Comprehension, ability to follow instructions



Hurricane Katrina Exposed Disparities

- 155,000 people with disabilities over the age of 5 lived in the three cities hardest hit by the hurricane: Biloxi, Mississippi; Mobile, Alabama; and New Orleans, Louisiana.
- 73% of Hurricane Katrina-related deaths in New Orleans area were among persons age 60 and over, although they comprised only 15% of the population in New Orleans.
- At least 50% of people with disabilities in New Orleans who are of working age are not employed, making disaster recovery more difficult.
- Many rely on a variety of government programs such as Supplemental Security Income and Medicaid to help them meet their daily service and support needs.

References, National Council on Disability:

<https://www.ncd.gov/publications/2006/Aug072006#population>

<https://ncd.gov/publications/2005/09022005>

Disability and Legal Requirements

- Americans with Disability Act (ADA) of 1990 (P.L. 101-336)
- Executive Order 13347: Individuals with Disabilities in Emergency Preparedness (2004)
- Safe, Accountable, Flexible, Efficient Transportation Equity Act: A Legacy for Users, 2005 (SAFETEA-LU) (P.L. 109-59)
- Pet Evacuation Transportation Standards Act of 2006 (P. L. 109–308, 2006) (PETS Act)
- HHS, Pandemic and All-Hazards Preparedness Act (P.L. 109-417, 2006) (PAHPA)
- **NEW!** Disaster Recovery and Reform Act of 2018 (DRRA)



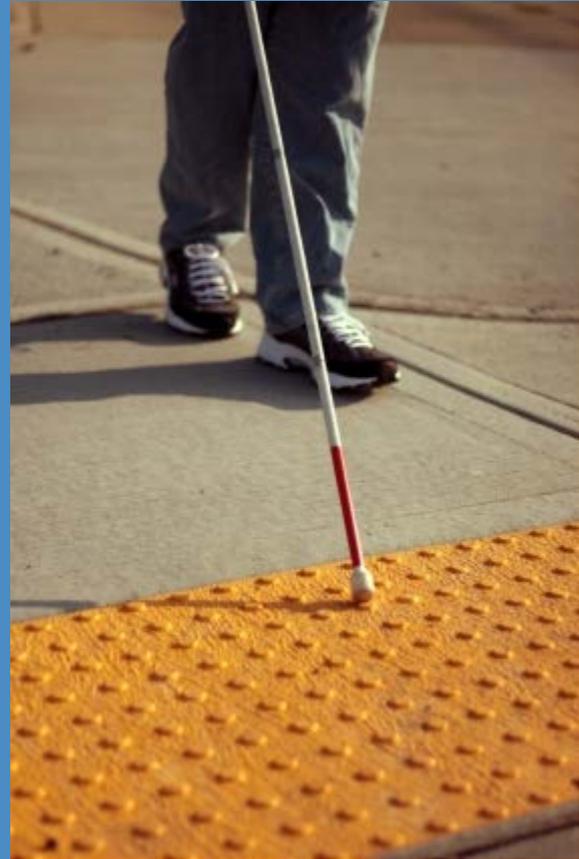
Americans with Disabilities Act (ADA) 1990

- Title II prohibits discrimination against people with disabilities and mandates that accommodations be provided.
- The ADA does not specifically address emergency preparedness.
- Emergency planning has developed through litigation against governments and schools.

Sandy Impacted Disabled NYC Residents

- Brooklyn Center for Independence of the Disabled v. Bloomberg (NYC), 11/7/13
 - “New York City has violated the rights of about 900,000 of its residents with disabilities by failing to accommodate for their needs during emergencies, a federal judge ruled.”
- Cited as a violation of the Americans with Disabilities Act
 - No evacuation plans from high-rises.
 - Lack of water, heat, and power.
 - Inadequate shelters.
 - Lack of information about availability and location of emergency services.

How should people with disabilities or their caregivers prepare for and handle emergencies?



Prepared Individuals Make for a Stronger Community Response

- What types of disasters might occur locally?
- What are my abilities at this time and where do I need help?
- What medications, equipment, other supplies will I need to stockpile?
- Whom do I need to inform of my plans?



Preparedness Tools



“Get a Kit. Make a Plan. Be Informed.”



New Hampshire Disability & Public Health Project The C-MIST Personal Planning Tool

The C-MIST personal planning tool assists you to consider what specialized items to add to a Stay Kit and Go Bag, and guides you through the creation of a personalized Emergency Plan. The planning tool consists of three steps:

Step 1: Assess

Use the space provided in the left column of each page to answer the prompting questions for the five C-MIST categories. Think about and write down what strengths and abilities the individual has, rather than writing needs or deficits. Focusing on strengths and abilities will help you to think constructively about planning in the following steps. For example:

Instead of:

*Person can't go anywhere alone
Person doesn't talk at all*

You write:

*Person's caregiver accompanies on all outings
Person responds to simple drawings*

Step 2: Brainstorm

After compiling a list of the person's strengths and abilities with the personal assessment in Step 1, brainstorm what the individual may need in order to maintain abilities and continue functioning in an emergency situation. Write your thoughts in the space provided. Consider answers to the following questions:

- *What might this ability look like in an emergency?*
- *What tools and strategies could help the person to stay safe and continue functioning?*
- *What information would be useful to a first responder?*

Step 3: Plan

Transform the information and strategies you came up with in Step 2 (anything you wrote in the right column) into action steps and concrete plans.

	Emergency Plan Date: _____ Time: _____
C	
M	
I	
S	
T	

READY NOW!

Emergency Preparedness Tool Kit For People with Disabilities

Oregon Office on Disability & Health (OODH)
Oregon Institute of Disability & Development (OIDD)
Center on Community Accessibility (CCA)
Oregon Health & Science University (OHSU)

Grant funded by the Centers for Disease Control and Prevention
Grant # GCDRC0164

For Example, Pages from READY NOW!

7 Steps

to personal emergency preparedness

- 1 Know the types of emergencies that could happen and what to do.
- 2 Complete a personal assessment.
- 3 Develop a personal support network.
- 4 Gather emergency papers and medical information.
- 5 Keep a 3-7 day supply of medications and supplies on hand.
- 6 Make an emergency supply kit.
- 7 Make your home, school, and work safer.

Preparing for an emergency or disaster can seem overwhelming, but not everything needs to be done at once. You may want to begin with the tasks that will be most important to you for any emergency.

Some plan is better than no plan

You can do it!

Step 1

KNOW THE TYPES OF EMERGENCIES THAT COULD HAPPEN AND WHAT TO DO



Emergency/Disaster	What to Do
Fire	Smoke detector on every floor and outside bedrooms. Change batteries every 6 months. Check to see if you can hear the alarm. In case of fire, remain calm, drop to the floor and crawl to get the cleanest air. Identify and practice evacuation routes in your home. Know the meeting place.
Tornadoes	Stay informed. Know the safe place in your home like under a sturdy table in the basement. If no basement, go to a small interior room or a room on the opposite side from a tornado. Stay away from windows. Practice to be sure you can get there and stay there, or identify if help is needed.
Flash Floods	Know your risk and stay informed. If you are told to leave, don't wait. Have a transportation plan. Identify higher ground that you can evacuate to. Stay away from floodwater. Even a shallow depth of fast-moving floodwater produces dangerous force.
Extreme Heat	Stay informed. Drink plenty of fluids. If your home does not have air conditioning, find schools, libraries, theaters and other community facilities near your house that you can go to during the hottest part of the day. Think about what you will do if power is lost, especially with health or communication devices.
Severe Winter Storms	Listen to your television or radio for emergency messages. Travel only if needed. Be ready to shelter at home with emergency supplies for 3 days. Plan for no services coming to your home. Plan for loss of power.
Biological Threat (example: an influenza epidemic)	Watch TV, listen to the radio, or check the Internet for official news. Find out (1) if you are in the group or area that have been exposed, (2) if you show any signs of the disease, and (3) who is distributing medications or vaccines and how to get them.
Hazardous Materials Incidents	Public health officials will provide the information based on the specific incident. In the meantime, use your personal emergency support network and emergency kit as necessary.
Bomb/Nuclear Threats	Listen for public officials to provide safety information based on specific incident. You may be asked to "shelter-in-place" in which case you will stay inside your home until further notice. Use your emergency supply kit if needed.

ACTION STEPS I NEED TO TAKE:

Extra considerations for people with special needs

These items in your "Take and Go" bag would be specific to your needs.

- Medicines, kept either in emergency kit or a location that makes them easy to add to "Take and Go"
- Medical supplies: catheters, oxygen tubing, wound care, or DM testing
- Extra eyeglasses/contact lenses and magnifier
- Contact lens supplies
- Hearing aid batteries
- Communication device batteries
- Picture communication board, dry erase board
- Any assistive technology for Activities of Daily Living
- Wheelchair repair kit: duct tape, super glue, can of tire inflator, tools
- White cane
- Ear plugs or muffs to reduce noise stimulation
- Plastic sheeting or garbage bags and tape to create visual isolation area
- Alternative activities for stimulation, diversion, or calming
- Other _____

Service Animal or Pet Emergency Supply Kit

Label items with pet and owner information, including:

- Food (you may need food for taking shelter elsewhere) and water for 3 days
- Pet-related emergency papers, medical information, and vaccination information
- "Take and Go" Bag
- Medicines
- Water and food container
- Collar/leash
- Service harness, pack, or cape
- Sanitation: Kitty litter and box for cat, plastic bags to collect animal waste, large paper bag/ties, and hand sanitizer
- Newspapers
- Towel
- Disinfectant towelettes
- Rug
- Entertainment (like a chew toy)
- Travel crate

ACTION STEPS I NEED TO TAKE:

CDC Disability Emergency Preparedness for Emergency Managers, Individuals, Caregivers

The screenshot shows the 'Disability & Health Home' website. The left sidebar contains a navigation menu with items like 'Disability Overview', 'Disability Inclusion', 'Healthy Living', 'Emergency Preparedness' (which is expanded), 'Monitoring', 'Tools and Resources', 'Assessment', 'Data & Statistics', 'Articles & Key Findings', 'Resources & Materials', 'Grantee Information', and 'Information for Specific'. The main content area is titled 'Emergency Preparedness: Including People with Disabilities' and includes social media icons for Facebook, Twitter, and a plus sign. A language dropdown menu is set to 'English'. The main text states: 'Emergencies and disasters can strike quickly and without warning, forcing people to quickly leave or be confined in their home unexpectedly. For the millions of Americans who have disabilities, emergencies, such as fires, floods and acts of terrorism, present a real challenge.' Below this is a section titled 'Resources from State Disability and Health Programs' with a sub-header 'Monitoring' and a description: 'The following resources were developed by CDC funded [State Disability and Health Programs](#). Public health professionals, emergency personnel and communities can use them to create emergency preparedness and response plans that are inclusive of people with disabilities.' At the bottom, there are three columns: 'Monitoring' (Learn how State Disability and Health Programs identify the...), 'Tools and Resources' (Find tools and resources developed by State Disability...), and 'Assessment' (See how State Disability and Health Programs have worked...).

Disability & Health Home

[Disability & Health Home](#)

Emergency Preparedness: Including People with Disabilities

Language: English

Emergency Preparedness

Emergencies and disasters can strike quickly and without warning, forcing people to quickly leave or be confined in their home unexpectedly. For the millions of Americans who have disabilities, emergencies, such as fires, floods and acts of terrorism, present a real challenge.

Resources from State Disability and Health Programs

The following resources were developed by CDC funded [State Disability and Health Programs](#). Public health professionals, emergency personnel and communities can use them to create emergency preparedness and response plans that are inclusive of people with disabilities.

Monitoring	Tools and Resources	Assessment
Learn how State Disability and Health Programs identify the	Find tools and resources developed by State Disability	See how State Disability and Health Programs have worked

Source: <https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html>

**What is caregiver stress
and how can people
minimize it?**



Everyone Reacts Differently to Stressful Situations.

Typical Reactions to Emergency Sheltering:

- Anxiety about the situation
- Worry that family members will be separated from caregivers
- Guilt about not being able to perform regular caregiving activities
- Feeling lonely, isolated, sad, or bored
- Fear and worry about loss of income



Self-Care for Caregivers

- Stay informed from reliable sources.
- Avoid excessive media coverage.
- Connect with others.
- Call SAMHSA's free 24-hour Disaster Distress Helpline at 1-800-985-5990, if you feel lonely or need support.
- Overwhelmed with thoughts of hurting self or others? Call 911 or the National Suicide Prevention Lifeline at 1-800-273-TALK (1-800-273-8255).

Substance Abuse and Mental Health Services Administration (SAMHSA)

- SAMHSA Website:
<https://www.samhsa.gov/disaster-preparedness>
- Materials on resilience and stress management
- Disaster Distress Hotline: 1-800-985-5990
- Disaster Technical Assistance Center supports state and local governments
- Behavioral Health Disaster Response Mobile App



What should response organizations and their employees do to be ready to help people with disabilities during emergencies?



Suggestions for First Responders and Emergency/Shelter Workers

- Don't assume. Ask people at shelters if they require any assistance or resources.
- Look for any type of special health instructions (bracelets, other information posted).
- Maintain the connection of people with disabilities to essential equipment and supplies:
 - Wheelchair, walker
 - Oxygen
 - Batteries
 - Communication devices (head pointers, alphabet/picture boards/speech synthesizers, etc.)
- Consider use of service animals.

Special Word on Service Animals

- A service animal means any animal that is individually trained to do work or perform tasks for the benefit of an individual with a disability.
- Service animals might perform different tasks.
 - pulling a wheelchair, retrieving dropped items, alerting a person to a sound, reminding a person to take medication, or pressing an elevator button
- They are not pets.
- Do not separate individuals from their service animals.
- Ask owners for permission to touch their service animals.

Tools for First Responders and Shelter Workers



“Order Show Me“ from www.mass.gov/dph/showme Apps via App Store or Google play

“Tips” available from <http://cdd.unm.edu/dhpd/tips/tipsenglish.html> in either a downloadable PDF, or order form for laminated, color-coded, ring-bound booklet. Also available in Spanish.

**What can
communities do to
be inclusive of people
with disabilities?**



Building Partnerships for a Resilient Community



Source <https://www.fema.gov/media-library/assets/images/69344>

Mitigation Core Capabilities



Source: https://www.fema.gov/media-library-data/1466014166147-11a14dee807e1ebc67cd9b74c6c64bb3/National_Mitigation_Framework2nd.pdf

Effective Partnerships Include Diverse Groups

- Government agencies, all levels
- Independent living councils
- Developmental disabilities councils
- Nonprofit organizations
- Academia
- Businesses and business organizations
- Faith-based organizations
- Advocacy groups
- Neighbors



Puerto Rico Disability Community Relief Network (PRDCRN)

- Hurricane Maria hit PR on September 20, 2017.
 - Category 4 hurricane with sustained winds of 155 mph
- Network partners
 - Movimiento para el Alcance de Vida Independiente (MAVI)
 - Protection and Advocacy System of Puerto Rico
 - Puerto Rico Assistive Technology Program
 - Puerto Rico Developmental Disabilities Council
 - University Center for Education on Development
 - National Association of Voluntary Organizations Active in Disaster (National VOAD)
- View presentation about PRDCRN
 - <http://www.adapresentations.org/webinar.php?id=143>



Resources: CDC

- CDC Emergency Preparedness and Response
 - <https://www.emergency.cdc.gov/protect.asp>
 - Reaching At-Risk Populations <https://emergency.cdc.gov/workbook/index.asp>
- CDC National Center on Birth Defects and Developmental Disabilities Online Catalog
 - <https://www.cdc.gov/ncbddd/disabilityandhealth/index.html>
- CDC's Social Vulnerability Index
 - <https://svi.cdc.gov/>
- Public Health Emergency Preparedness (PHEP) Cooperative Agreement
 - <https://www.cdc.gov/cpr/readiness/phep.htm>

Resources: Other Federal/National

- Assistant Secretary for Preparedness and Response
 - <https://www.phe.gov/Preparedness/planning/abc/Pages/atrisk.aspx>
- Administration for Community Living
 - <https://acl.gov/programs/emergency-preparedness>
- FEMA Office of Disability Integration and Coordination
 - <https://www.fema.gov/office-disability-integration-and-coordination>
- ADA National Network Learning Sessions
 - <http://www.adapresentations.org/archive.php>
- National Association of Voluntary Organizations Active in Disaster
 - <http://www.nvoad.org>

Resources: State Partnerships

- Association of University Centers on Disabilities
 - University Centers of Excellence on Developmental Disabilities
<https://www.aucd.org/directory/directory.cfm?program=UCEDD>
 - Emergency Preparedness resources: <https://www.aucd.org/template/page.cfm?id=544>
- State Councils of Developmental Disabilities
 - <https://nacdd.org/>
- Centers for Independent Living
 - <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>
- State Departments of Public Health
 - Emergency Managers
 - Disability and Health Program
- Portlight Strategies, Inc. “Getting It Right”
 - <http://www.portlight.org>

Thank You



For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov



The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.