Individuals with Disabilities & Families of Children with Special Health Care Needs, Pre/Post Disaster

May 16, 2018

Sponsored by Family Voices’ NCFPP and Family Liaisons to the Friends of NCBDDD in Support of the National Center on Birth Defects and Developmental Disabilities

Welcome! We will begin shortly. Phone lines are muted, and will be opened for Q&A near the end of the webinar.
Moderator
Artila “Tila” Mims
NCBDDD Family Liaison & Family Leader
Arc of Illinois/Family-to-Family
Agenda

1. Welcome and Objectives

2. Presentations
   - Dr. Cynthia Hinton, Centers for Disease Control and Prevention (CDC)
   - Ms. Jessica Franks, National Center for Birth Defects and Developmental Disabilities
   - Ms. Nicole Pratt, SPAN Parent Advocacy Network

3. Q & A
Disability and Disasters: Preparedness, Response, Recovery

Cynthia F. Hinton, PhD, MS, MPH
Health Scientist, Disability & Health Branch

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National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability
CDC’s National Center on Birth Defects and Developmental Disabilities (NCBDDD)
C-MIST framework

- Provides a flexible, cross-cutting approach to defining vulnerable populations to address a broad set of common access and functional needs
- Irrespective of specific diagnoses, statutes, or labels
- The functional approach defines the type of services needed but they do not specify how responders might locate vulnerable populations who have those needs
Persons with Disabilities

- Includes persons with physical, medical, sensory or cognitive impairments
- 57 million Americans have a disability, and anyone can be at risk for developing one in their lifetime through illness, injury or aging
- Persons with disabilities are at risk during an emergency
  - Confined to home
  - Separation from caregiver
  - Lack of access to medications or medical supplies
  - Lack of access to care
  - Lack of access to basic services- water, gas, electricity, telephone
CDC Preparedness: Incorporating Disability into Preparedness and Response

- Public Health Preparedness Program (PHEP) awards
  - Funded since 2002
  - Supports 62 state, local and territorial public health departments
  - Building resilience, effective communication, medical countermeasures, coordinating responses, surge management
  - Must indicate how they are including vulnerable populations

- Vulnerable populations are at the table in planning, exercises and drills, and response
  - Disability, maternal and child health
  - At-Risk Task Force
Emergency Preparedness: Including People with Disabilities

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.

https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html
“Get a Kit. Make a Plan. Be Informed.”
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 plan.
7. Make your home safe.

Step 1

Preparing for an emergency—everything needs to be done that will be most important.

Some plan is better than none!

You can do it!

Step 6

BUILD AN EMERGENCY SUPPLY KIT

Everyone should make plans and have supplies to take care of themselves for at least 3 days at home. Remember during a disaster or emergency you may not have power, electricity, or water supplied to your home. Part of your home may be destroyed or you may have to take shelter in only part of your home.

Depending on your home situation, your abilities and needs, your emergency supply kit could be stored in:

- a plastic tub or crate with wheels
- an under-bed storage device
- extra-large sealable

You will already have non-duplicate items that you check some each month until it is time for your support network to leave your home quickly.

Service Animal or Pet Emergency Supply Kit

- Medications
- Water and food container
- Collar/leash
- Service harness, pack, or cage
- Sanitation: kitty litter and box for cat, plastic bags to collect animal waste, large paper baggies, and hand sanitizer
- Newspapers
- Towel
- Disinfectant wipes
- Rug
- Entertainment (like a chew toy)
- Travel crate

Extra considerations for people with special needs

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

- Medications 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/prescription and magnifier
- Contact lens supplies
- Hearing aid batteries
- Communication device batteries
- Picture communication board, dry erase board
- Assistive technology: Activities of Daily Living
- Wheelchair repair kit: duct tape, super glue, can of fire extinguisher, tools
- White cane
- Ear plugs or muffins to reduce noise stimulation
- Plastic sheath or garbage bags and tape to create visual isolation area
- Alternative activities for amnesia, disorientation, or calming

Other...
Americans with Disabilities Act (ADA) 1990

- Title II and its implementing regulations prohibit discrimination against people with disabilities and mandates accommodations be provided.
- However, nothing specifically addresses emergency preparedness.
- Planning has developed through litigation against state and local governments, against schools.
- Federal agencies have developed guidance and resources
  - Notification, evacuation, transportation, sheltering, access to medical supplies and power, access to mobility devices and service animals, access to information.

Building Partnerships

https://www.fema.gov/media-library/assets/images/69344
Recovery and Mitigation

https://www.fema.gov/media-library/assets/images/128968
Resources

- Online Emergency Preparedness Catalog: Including People with Disabilities
  https://www.cdc.gov/ncbddd/disabilityandhealth/emergencypreparedness.html

- CDC State and Local Readiness PHEP Program
  https://www.cdc.gov/phpr/readiness/index.htm

- CDC Emergency Preparedness and Response
  https://emergency.cdc.gov/

- ASPR Access and Functional Needs
  https://www.phe.gov/Preparedness/planning/abc/Pages/afn-guidance.aspx

- FEMA Disability https://www.fema.gov/disability

- “The Development of Emergency Planning for People with Disabilities Through ADA Litigation.”
Thank you!
CHinton@cdc.gov

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov   Web: http://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.
Family Voices: Individuals with Disabilities & Families of Children with Special Health Care Needs, Pre/Post Disaster

Planning and Caring for Children with Special Healthcare Needs in Emergencies

Jessica Franks, MPH, CHES
Health Communicator, Children’s Preparedness Unit
Overview

- Background: Children’s Preparedness Unit
- Children with Special Healthcare Needs in Emergencies
  - Planning
  - Response
  - Recovery
Children’s Preparedness Unit
To champion the needs of children in emergency preparedness and response

Build an evidence base of best practices

Increase awareness of children in preparedness planning

Offer technical assistance as subject matter experts

Develop partnerships with leaders in preparedness planning
2009 H1N1 Outbreak
2014 Unaccompanied Minors
2014-15 Ebola Outbreak
2015-17 Zika Outbreak
2016 Water Contamination, Flint, MI *
2016 Hurricane Matthew
2017 Hurricanes Harvey, Irma, Maria

* Response led by U.S. Dept. of Homeland Security
Because they *breathe in more air for their size* than adults, children *absorb harmful materials from the air* more readily.

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**Children are more vulnerable in emergencies**

Because they need vaccines, medicines, and specially designed equipment for emergency situations that are different from adults.

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Because they spend more time outside, are lower to the ground, and they put their hands in their mouths more often than do adults.

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Because they may not be able to communicate their symptoms or feelings.
Children with Special Healthcare Needs (CSHCN) in Emergencies
Children and Youth with Special Healthcare Needs in Emergencies

Nearly 1 out of every 5 children in the United States has a special healthcare need. Children and youth with special healthcare needs (CYSHCN), also known as children with special healthcare needs (CSHCN), require more care for their physical, developmental, behavioral, or emotional differences than their typically developing peers. A special healthcare need can include physical, intellectual, and developmental disabilities, as well as long-standing medical conditions, such as asthma, diabetes, or a muscular dystrophy.

All children have unique needs in emergencies, but care for children with special healthcare needs is often more complex because of their various health conditions and extra care requirements. They may have a hard time moving from one place to another, urgent or constant medical needs, difficulty communicating or have trouble with transitioning to different situations. A disaster can present all these difficulties at once. Knowing what to do can help maintain calm and keep your family safe. Read more about the real stories of children with special healthcare needs preparing for and responding to emergencies.

CSHCN: Planning
EASY AS ABC

THREE STEPS TO PROTECT YOUR CHILD DURING EMERGENCIES IN THE SCHOOL DAY

A. ASK how you would be reunited with your child in an emergency or evacuation

B. BRING extra medications, special food, or supplies your child would need if you were separated overnight

C. COMPLETE a backpack card and tuck one in your child’s backpack and your wallet

https://www.cdc.gov/childrenindisasters/infographics/easyasabc.html
✓ Do you have all of your child’s medical information and general supplies?
✓ Do you have back-up power and supplies?
✓ Do you know how to get emergency medical supplies and medicines for your child?
✓ Do you have all the medical supplies and medicines for your child?

https://www.cdc.gov/childrenindisasters/checklists/special-healthcare-needs.html
CSHCN: Response
Response Activities: Public Outreach

https://www.youtube.com/watch?v=seNoCbxFuY&feature=youtu.be

https://www.cdc.gov/childrenindisasters/videos.html

https://www.youtube.com/watch?v=seNoCbxFuY&feature=youtu.be
CSHCN: Recovery
Coping After a Disaster

Caring for Children in a Disaster

Helping Children Cope with Emergencies

Regardless of your child's age, he or she may feel upset or have other strong emotions after an emergency. Some children react right away, while others may show signs of difficulty much later. How a child reacts and the common signs of distress can vary according to the child's age, previous experiences, and how the child typically copes with stress.

Children react, in part, on what they see from the adults around them. When parents and caregivers deal with a disaster calmly and confidently, they can provide the best support for their children. Parents can be more reassuring to others around them, especially children, if they are better prepared.

People can become more distressed if they see repeated images of a disaster in the media. Early on, consider limiting the amount of exposure you and your loved ones get to media coverage.
- Transporting Children with Special Healthcare Needs (AAP): [http://pediatrics.aappublications.org/content/104/4/988](http://pediatrics.aappublications.org/content/104/4/988)
- Emergency Preparedness for Children with Special Healthcare Needs (AAP): [http://pediatrics.aappublications.org/content/104/4/e53](http://pediatrics.aappublications.org/content/104/4/e53)
Thank You!

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For more information, contact CDC
1-800-CDC-INFO (232-4636)

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Nicole Pratt
PTI Senior Parent Professional Staff Trainer, FASD Project Coordinator/Trainer, SEVA Family Engagement Facilitator, Statewide Parent Advocacy Network
The Jersey Shore Hurricane Sandy
Jersey Shore Hurricane Sandy
Jersey City, NJ Hurricane Sandy
Jersey City, NJ, Hurricane Sandy
Jersey City, NJ, Hurricane Sandy
Nicole Pratt: My Family Story
DISABILITY RIGHTS CENTER OF THE VIRGIN ISLANDS
Advancing Justice through Protection and Advocacy

“Each one of us has lived through some devastation, some loneliness, some weather super storm or spiritual super storm, when we look at each other we must say, I understand. I understand how you feel because I have been there myself. We must support each other and empathize with each other because each of us is more alike than we are unlike.”

~ Maya Angelou ~

DRCVI MISSION STATEMENT
Advance the legal rights of people with disabilities, support and empower families and provide training and information that promotes the overall health and educational development of children and youth.
Resources

Knowledge is Power! Spreading Awareness of the Zika Virus

Happy and Healthy from 0-3

Trauma and Developmental Disabilities

Emergency Preparedness for People with Disabilities
Thank You!