

National Center for

Family Professional Partnerships

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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.**

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Moderator

Artila “Tila” Mims

NCBDDD Family Liaison & Family Leader

Arc of Illinois/Family-to-Family



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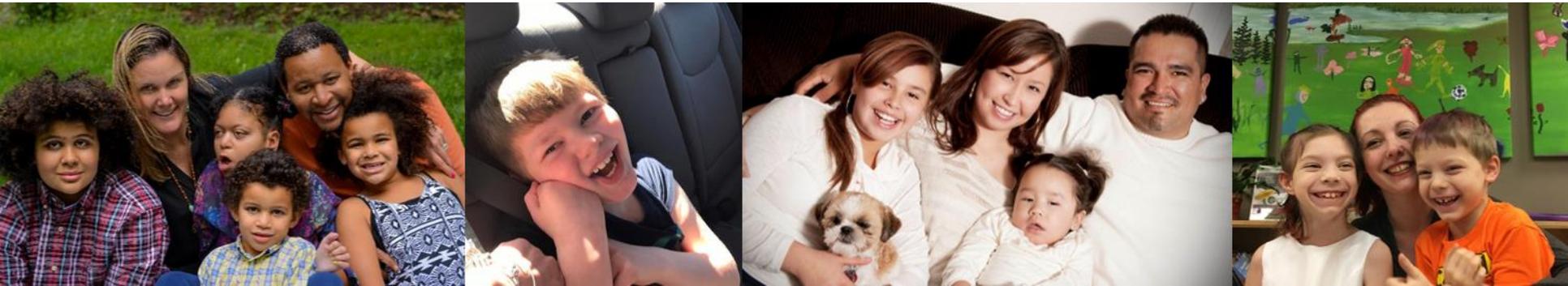
Agenda

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



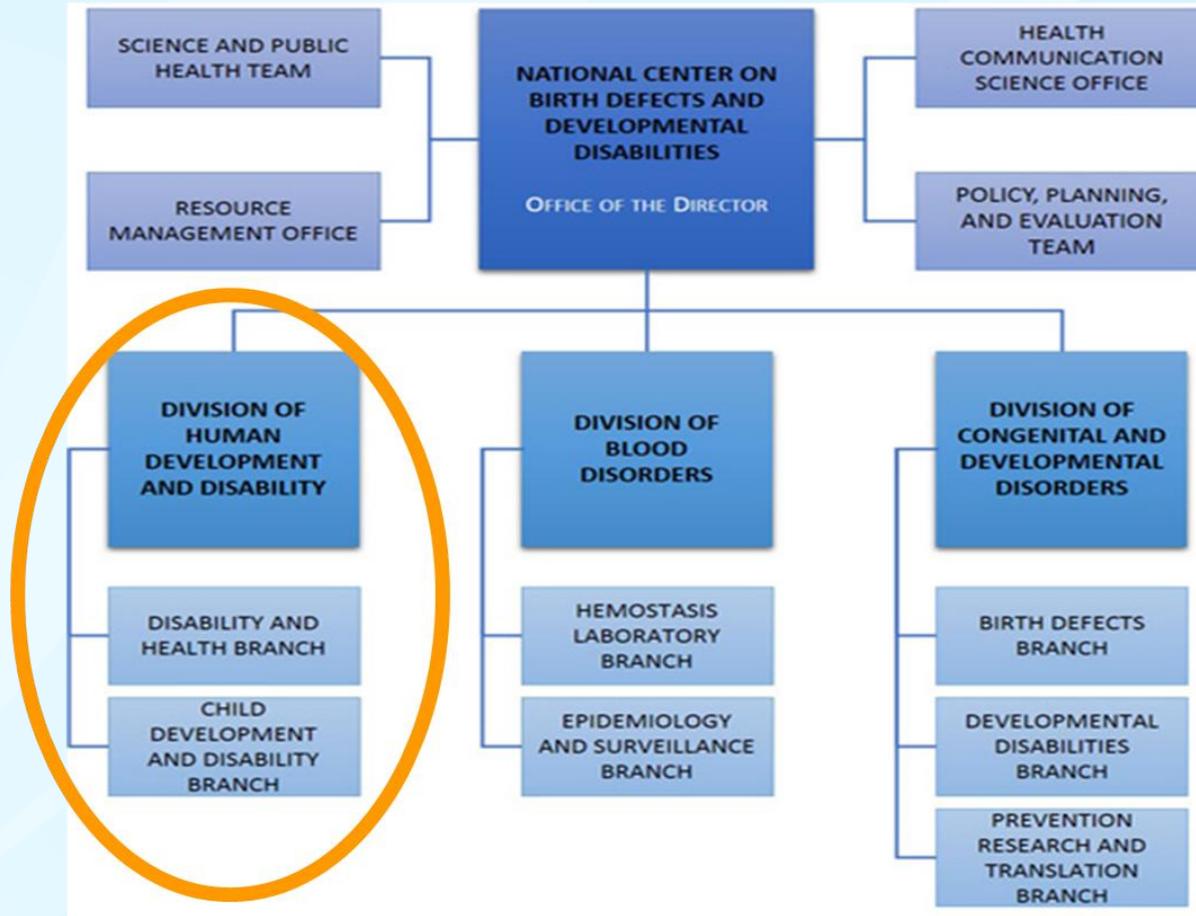
Disability and Disasters: Preparedness, Response, Recovery

Cynthia F. Hinton, PhD, MS, MPH

Health Scientist, Disability & Health Branch

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

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

VULNERABLE POPULATIONS MAY INCLUDE ANYONE WHO:



Has difficulty
communicating



Has difficulty accessing
medical care



May need help
maintaining
independence



Requires constant
supervision



May need help
accessing transportation

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

CDC Disability Emergency Preparedness Disability & Health Branch Funded Materials

| Disability & Health Home | Disability & Health Home | | | | | | |
|-------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|---------------------|------------|-------------------------------------------------------------|--------------------------------------------------------|----------------------------------------------------------|
| Disability Overview | <h2>Emergency Preparedness: Including People with Disabilities</h2> | | | | | | |
| Disability Inclusion + |    | | | | | | |
| Healthy Living + | Language: <input type="text" value="English"/> | | | | | | |
| Emergency Preparedness - | <p>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.</p> | | | | | | |
| Monitoring |  | | | | | | |
| Tools and Resources | <h3>Resources from State Disability and Health Programs</h3> | | | | | | |
| Assessment | <p>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.</p> | | | | | | |
| Data & Statistics + | | | | | | | |
| Articles & Key Findings + | | | | | | | |
| Resources & Materials + | | | | | | | |
| Grantee Information + | | | | | | | |
| Information for Specific Groups + | | | | | | | |
| | <table border="1"><tr><th>Monitoring</th><th>Tools and Resources</th><th>Assessment</th></tr><tr><td>Learn how State Disability and Health Programs identify the</td><td>Find tools and resources developed by State Disability</td><td>See how State Disability and Health Programs have worked</td></tr></table> | 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 |
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| 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 | | | | | |

“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 K 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 focusing on writing needs or deficits. Focusing on strengths and abilities will help you to think constructively at 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.

| | | |
|---|---|-------|
| C | : | _____ |
| M | : | _____ |
| I | : | _____ |
| S | : | _____ |
| T | : | _____ |

Get Ready! Alaska's emergency preparedness toolkit for people with disabilities

Sean Parsons
 Department of Health and Human Services
 William J. Streuter

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

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 safer.

Preparing for an emergency means to be do that will be most important

Some plan is better
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 every 6 months. Check to see if you can hear the alarm. In case remain calm, drop to the floor and crawl to get the cleanest air and practice evacuation routes in your home. Know the nearest exit. |
| Tornadoes | Stay informed. Know the safe place in your home like under a table in the basement. If no basement, go to a small interior 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 needed. |
| Flash Floods | Know your risk and stay informed. If you are told to leave, don't have a transportation plan. Identify higher ground that you can go to. Stay away from floodwater. Even a shallow depth of fast 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 health or communication devices. |
| Severe Winter Storms | Listen to your television or radio for emergency messages. If needed, be ready to shelter at home with emergency supplies. 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 out (1) if you are in the group or area that have been exposed, (2) show any signs of the disease, and (3) who is distributing medical vaccines and how to get them. |
| Hazardous Materials Incidents | Public health officials will provide the information based on the 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:

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 (electric/gas) 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, and 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 bags

You will already have many items. Duplicate items that you use often. Review it some each month until the items are stored in storage devices. Review it

You might have a sheet or map of parts of the house, for example

"Take and Go" Bag

You will want some items in your support net to leave your home quickly

Depending on your abilities and needs:

- suitcase with or without wheels
- plastic tub or crate
- backpack
- wheelchair bag
- a vest with many pockets

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/case/prescription 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:

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.”
<https://www.adapacific.org/assets/documents/emergency-preparedness-litigation-legal-brief-2-2018.pdf>

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

- 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.



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

Children are more vulnerable in emergencies



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

Because they **may not be able to communicate their symptoms or feelings**.





Children with Special Healthcare Needs (CSHCN) in Emergencies

Caring for Children in a Disaster

- Caring for Children in a Disaster
- How Children are Different
- Helping Children Cope
- Children with Special Healthcare Needs**
- Before, During, & After an Emergency +
- Specific Threats +
- Real Stories +
- Tools and Resources +
- Articles
- About Us

[CDC](#) > [Caring for Children in a Disaster](#) > [Children with Special Healthcare Needs](#)

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.



<https://www.cdc.gov/childrenindisasters/children-with-special-healthcare-needs.html>



CSHCN: Planning

EASY AS ABC

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



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



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



COMPLETE a backpack card and tuck one in your child's backpack and your wallet



<https://www.cdc.gov/childrenindisasters/infographics/easyasabc.html>



CSHCN: Response

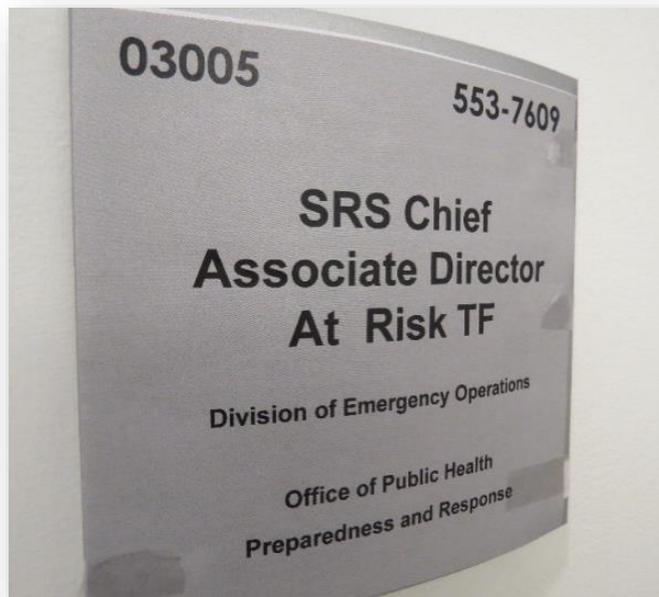


Photo used with permission from Natalia Toledo Melendez (CDC)



FEMA CDC Accessible: Shelters and Evacuations During a Disaster

FEMA
Subscribe 16K

<https://www.youtube.com/watch?v=seNoCbpxFuY&feature=youtu.be>



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



CSHCN: Recovery

Caring for Children in a Disaster

[CDC](#) > [Caring for Children in a Disaster](#) > [Helping Children Cope](#)

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.



COPING AFTER A DISASTER

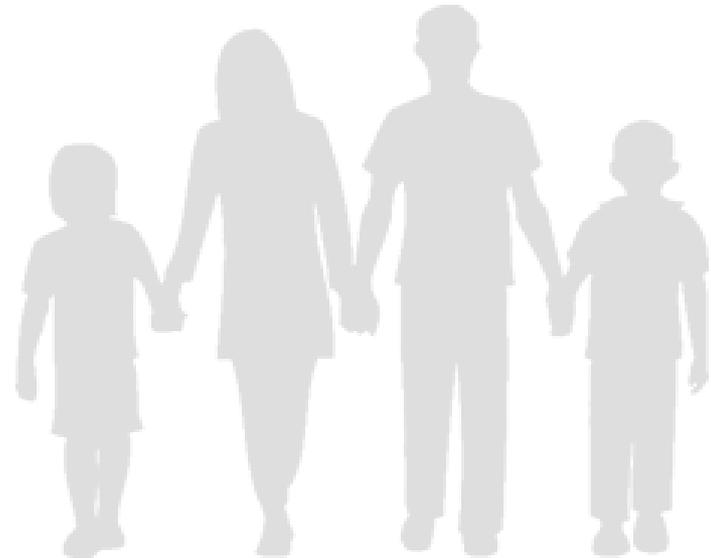




- Children and Youth with Special Healthcare Needs in Emergencies (CDC): <https://www.cdc.gov/childrenindisasters/children-with-special-healthcare-needs.html>
- Emergency Preparedness for Families with Special Needs (CDC): <https://blogs.cdc.gov/publichealthmatters/2013/07/emergency-preparedness-for-families-with-special-needs/>
- Children and Youth with Special Needs (AAP): <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Children-and-Disasters/Pages/CYWSN.aspx>
- Transporting Children with Special Healthcare Needs (AAP): <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>

Thank You!

Jessica Franks (luj8@cdc.gov)



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

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Nicole Pratt

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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 UNALIKE.”

~ 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](#)

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Q & A



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Thank You!

