When Disaster Strikes: Caring for children with special health care needs and disabilities

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Zac and Julie’s story
Outline

- What is emergency preparedness?
- Special considerations for children
- Even more considerations for children and youth with special needs (CYSHCN)
- Special considerations for CYSHCN and influenza
- Steps to take to prepare for emergencies
What is Emergency Preparedness?

- Describes the steps that should be taken to be safe before, during, and after an emergency
- Occurs at all levels - individual, community and local, state, federal government
Types of Emergencies

- Preparedness for any type of emergency is known as an all-hazards approach. Some examples of hazards are:
  - **Natural Disasters**
    - Floods
    - Blizzards
    - Tornadoes
    - Earthquakes
    - Wildfires
  - **Man-made Disasters**
    - Explosions
    - Fires
    - Chemical attacks
    - Biological attacks
Natural Disasters Will Happen - in the past two weeks around the world...

April 29, 2014
- First major US tornado outbreak of 2014 kills 21 in Arkansas

April 24, 2014
- Flash floods claim 100 lives in northern Afghanistan

April 22, 2014
- Flooding in Romania kills 4, emergency declared in Serbia

April 19, 2014
- Deadliest avalanche at Mount Everest, kills 15

April 18, 2014
- Light earthquake shakes Oakham, Rutland region of England

April 17, 2014
- Landslide at Guinea goldmine claims 7

April 14, 2014
- Chile Forest Fires 2014: 16 dead, 2,000 homes destroyed, emergency declared
Atlanta snow storm
January 2014

- 1500 car accidents
- 2000 children spent the night in schools
- 12-25 hour commutes
- Baby delivered in the car by dad and police officer
- Schools, businesses, and government dismissed to go home at the same time
- Last snow storm (of any kind) in Metro Atlanta 2011
- 1-2 inches of snow and ice

What was missing that caused this to inconvenience and possibly harm so many?
Children will be affected by disasters.
Haiti Earthquake and Cholera Outbreak, 2010

Children may be disproportionately affected…
Oklahoma City Bombing, 1995
Beslan School Siege, 2004

...or even specifically targeted

Sandy Hook Elementary, 2012
Children are not “little adults”

- Difficulty communicating symptoms
- Underdeveloped sense of self-preservation
- More permeable skin
- Higher surface-to-mass ratio
- Higher metabolism
- Higher respiratory rate
- More active cell division
- More hand-to-mouth contacts
- Spend more time playing outside and on the ground
Children with special needs and emergency preparedness

- The Pandemic and All-Hazards Preparedness Act sets the requirements for public health preparedness and response for all of HHS
- Children with special needs cut across much of the “at-risk” definition

In addition to those individuals specifically recognized as at-risk in the statute, i.e., children, senior citizens, and pregnant women, individuals who may need additional response assistance should include those who: have disabilities; live in institutionalized settings; are from diverse cultures; have limited English proficiency or are non-English speaking; are transportation disadvantaged; have chronic medical disorders; and have pharmacological dependency.

Disability and Emergency Preparedness

- Americans with Disabilities Act of 1990
  - Requires local governments to make emergency preparedness and response programs accessible to people with a disability

- The needs that have the greatest impact of people with disabilities include:
  - Notification
  - Evacuation
  - Emergency transportation
  - Sheltering
  - Access to medication, refrigeration, and back up power
  - Access to mobility services or service animals in transit or at shelters
  - Access to information

http://www.ada.gov/emerprepguideprt.pdf
Children with special needs and emergency preparedness

- 1994 estimate: 18% of US children, or 12.6 million children nationally, had a chronic physical, developmental, behavioral, or emotional condition and required health and related services of a type or amount beyond that required by children generally.

- 2008 estimate: 15% of US children (~1 in 6) have a developmental disability, with increases in the number of children diagnosed with autism, attention deficit hyperactivity disorder, and other developmental delays.


Children with special needs and emergency preparedness

- Children and especially children with special needs and disabilities in public health emergencies
  - Children’s bodies are different from adults
  - Children will need help from adults in an emergency – level of dependency will vary
  - Mental stress from a disaster can be harder on children – certain disabilities will require specialized approaches
  - May depend on life saving medication or equipment
  - Mobility problems, developmental, hearing, learning, or seeing disabilities can add challenges

Planning ahead for the “whole community” is necessary to address these needs and challenges
Children with special needs and public health emergencies: natural disasters

- After Katrina, 34% of children living in FEMA-subsidized community settings had at least one diagnosed chronic medical condition
  - A rate one-third higher than that of the general pediatric population

- Katrina showed that children and adolescents with chronic conditions are at increased risk of adverse outcomes following a natural disaster.


Children with special needs and public health emergencies: seasonal and pandemic influenza

- Bhat et al. (2005) noted that children with neuromuscular conditions were at increased risk from death from influenza.
- 2009 pandemic (H1N1) – children with neuro- and neuro-developmental conditions were at higher risk.
  - MMWR Article: “Surveillance for Pediatric Deaths Associated with 2009 Pandemic Influenza A (H1N1) Virus Infection – United States, April-August 2009”
Influenza-Related Pediatric Deaths
MMWR—Sept. 3, 2009

- 36 deaths among children < 18 years of age
- 67% had at least one high-risk medical condition
  - Among children with high-risk medical conditions, >90% had neurodevelopmental disorders
    - developmental delay, cerebral palsy, epilepsy
  - 59% with neurodevelopmental disorders had more than one neurological diagnosis
  - 41% had a pulmonary diagnosis

- A study of 2003-04 seasonal influenza-associated child deaths also found a high proportion of children had a neurodevelopmental disorder.
Medically high risk children

- Children younger than 2 years old
- Children and adolescents with certain conditions:
  - Asthma
  - Neurological and neurodevelopmental conditions including disorders of the brain; spinal cord; peripheral nerve; and muscle such as cerebral palsy, epilepsy (seizure disorders), stroke, intellectual disability, moderate to severe developmental delay, muscular dystrophy, or spinal cord injury
Medically high risk children

- Chronic lung disease (such as cystic fibrosis)
- Heart disease (such as congenital heart disease and congestive heart failure)
- Blood disorders (such as sickle cell disease)
- Endocrine disorders (such as diabetes mellitus)
- Kidney disorders
- Liver disorders
- Metabolic disorders (such as inherited metabolic disorders and mitochondrial disorders)
- Weakened immune system due to disease or medication (such as people with HIV or AIDS, cancer, or those on chronic steroids)
- Receiving long-term aspirin
- Pregnancy
Continued concerns about children with neuro-and neuro-developmental conditions

- **2009 H1N1 influenza pandemic**
  - 343 pediatric deaths
    - 146 (43%) had at least one known underlying neurologic or neurodevelopmental disorder
      - Among these neurodevelopmental conditions
        - intellectual disability (111, 76%)
        - cerebral palsy (51, 35%)
        - epilepsy (74, 51%)

- **2004-2012 among children with documented medical histories occurred in children with neurologic disorders**
  - One third of pediatric deaths

Blanton et al.
Medically high risk children

- Survey and focus groups of caregivers and physicians who care for CYSHCN
- Low understanding of the severity of flu and the need for prevention/treatment
- 3 Key Messages
  - Vaccination
  - Early evaluation and empiric treatment
  - Have a plan
Preparedness and You

- For anyone, being prepared for an emergency means being able to provide for the health, both physical and mental, if a disaster were to limit access to care.
- Children with special needs may have unique considerations in caring for their physical health.
- Maintaining a sense of routine and familiarity is important in caring for their mental health.

...How do we prepare?
Preparedness and You

- **Get a kit**
  - Create an emergency kit for your home, office, school, and vehicle.
  - Your supply kit should include items that you might need in an emergency, including special items for children, special needs, and pets.

- **Make a plan**
  - Create a communication plan with important contacts for you and your family
  - Create a disaster plan for what to do in the event that a common disaster in your area hits

- **Be informed**
  - Know where to get information and how you will be informed of threats (e.g., text alerts, radio, TV, sirens, etc.)
GET A KIT
Emergency Kits

- Pack an emergency kit for your car, with a blanket, flashlight, food, and water that will last for 3 to 5 days
- Special needs considerations:
  - Medical supplies (e.g., extra supply of medicine, diabetic supplies, hearing aids w/extra batteries, glasses, syringes, canes)
  - Food for special diets, manual wheelchair, service animal’s supplies, a TTY
  - Baby supplies (e.g., bottles, baby food, diapers, breast pump w/extra batteries)
  - Games and activities for children
Why is an Emergency Kit Important?

“We first thought of a generator before her kidney transplant, but it took being without electricity to realize we really needed it.”

“...you can never have enough supplies on hand.”

“We now have a portion of her supplies packed and ready to go as well as a list of her essential equipment with it so we can grab that as well.”
Why is an Emergency Kit Important?

“I carried a one-day supply of seizure medication in my vehicle…”

“You don’t have time to pack when it happens.”

“…now I try to carry a one-week supply in case of an emergency.”
Disability and Emergency Preparedness

Bethel, Foreman, and Burke (2011)

- First national sample to study disaster preparedness in relation to disability and health status
- Findings showed that individuals who self-report having poor health, disability, or a chronic condition are less likely to:
  - Have the four recommended preparedness items (i.e., 3-day supply of food, 3-day supply of water, radio w/batteries, flashlight w/batteries)
  - Have an emergency evacuation plan
- And more likely to:
  - Have a 3-day supply of medication
- Individuals with physical limitations were more likely to have an evacuation plan than those without these limitations

MAKE A PLAN
Emergency Plans

- **Communications Plans can include:**
  - Names and phone numbers of your family members, doctors, and other emergency contacts
    - Out-of-town contacts who you can call to notify of your safety
  - Lists of medicine, dosages, and pharmacy information

- You should talk to your family about who to contact if you are separated during an emergency

- Download ready-made contact cards that are available online
  - [www.ready.gov](http://www.ready.gov)
Disaster planning includes:
- Identifying common types of disasters where you live
- Creating a plan for what to do in different situations
- Identifying where to shelter in place or evacuate
  - Practice evacuating and sheltering in place
- Locating shelters within your community
  - Identify if pets are allowed and make a plan for what to do with your pet, if not
- Getting a fire extinguisher for the home and learning how to use it
Why is it Important to Have a Plan?

“Evacuations began when both parents were at work, leaving our child with her nurse assistant stranded at home while we rushed home fighting traffic.”


“Have a set plan for transportation and a place that is safe and able to take care of your child.”
BE INFORMED
Being Informed

- The after effects of an emergency can be determined by how much you know before an emergency
  - Have an understanding of emergencies in your area
  - Know who to call that can respond to emergencies
  - Understand how to get information during an emergency (e.g., text alerts, emergency sirens, or other methods)
- Get a NOAA Weather Radio
- Understand the difference between a “watch” and a “warning”
What should you plan for in the recovery phase?

“Families should have a plan and backup plans in place and keep up with alerts and special needs shelters in case of an evacuation.”

“I had no resource other than radio, TV, and Facebook to help my daughter understand what had happened.”

“Those items were helpful, but not concrete enough for her.”

“We helped each other, whether food or a little money to purchase whatever we needed at that moment.”
How to be a Responder

PREPAREDNESS FOR AND BY THE WHOLE COMMUNITY
Preparedness at Your Organization

The same emergency preparedness tips can be applied at many levels.

- Individual
- Healthcare facilities and practices
- Communities
- Local, state and federal agencies

- Get a kit
- Be informed
- Have a plan
Healthcare Professionals

- Healthcare and allied health professionals can encourage families to:
  - Have a written disaster plan
  - Identify a meeting place
  - Be prepared to monitor and limit media coverage
  - Remember this is more than TV – children may see images on cell phones, iPads, Facebook and others

- Families are more likely to prepare if a trusted professional recommends it
What Tools Can Systems Use to Get Prepared?

"Using a patient registry to identify patients and employing care coordination were vital in working with children and youth with special health care needs during Hurricane Sandy."

"My role is to reach out to families, ensuring they get what they need. Working with these children and their families before a potential disaster was critical as opposed to following up after the event."
Preparing with the whole community

- **Prepare**
  - Form coalitions ahead of time that focus on the needs of children
- **Connect with groups providing initial response**
  - Red Cross, local charities, fire and rescue
- **Schools should have disaster plans that connect to community plans** (e.g., local police and fire dept.)
- **Special education/Individual Education Plan (IEP)** teams should discuss disaster planning with parents/child
- **Understand how your local public health agency will be involved**
Key Points

- Emergency preparedness starts with YOU
- Three easy steps to help you prepare for an emergency
  1. Get a kit
  2. Make a plan
  3. Be informed
- Organizations can follow similar steps to meet the needs of children with disabilities and special health care needs
- Remember to think about you or your family’s special needs in your emergency planning and find out your local government’s plans for the special needs of the whole community
What would you do differently now to prepare the children you care for?

Atlanta snow storm
January 2014

• 1500 car accidents
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• 12-25 hour commutes
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Resources

- **CDC**
  - emergency.cdc.gov/preparedness/
  - emergency.cdc.gov/children

- **FEMA**
  - www.ready.gov
  - www.ready.gov/kids
Summary

- Children and especially CYSHCN are at risk during emergencies.
- Preparing for emergencies and disasters is key to saving lives and preventing harm.
- Pandemic flu taught us about the need for heightened awareness of the needs of children with high risk conditions including those with developmental disabilities.
- As caregivers for CYSHCN we have the opportunity and responsibility to support preparedness, to minimize harm in emergencies and disasters.
Questions?
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For more information please contact Centers for Disease Control and Prevention

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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.

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities
Infectious Disease

- Children are easily exposed and can easily spread disease due to high personal contact rates.
- Children are difficult to diagnose due to unusual symptoms and difficulty communicating.

![Graph showing frequency of symptoms in first 10 Anthrax cases in 2001](image1.png)

![Graph showing frequency of symptoms in screened children ages 0-3 years](image2.png)
Many chemical agents are denser than air and settle at ground level.

Children are easily affected:
- Size
- Thin skin
- High surface area
- High respiratory rate

Mr Kerry said the dead included 426 children, and described the attack as an "inconceivable horror".

Syria chemical weapons attack killed 1,429, says John Kerry
Radiological and Nuclear

- Children will develop neutropenia from bone marrow suppression
- Children are susceptible to burns and mechanical injury and thus secondary infection
- Many radionuclides can potentially more severely affect children, such as I-131 which affects the thyroid
Mental Health Considerations

- Children may have difficulty coping with traumatic events
  - 35% percent of parents nationally reported children with at least 1 post-traumatic stress symptom 3-5 days after 9/11
  - 28.6% of NYC schoolchildren grades 4-12 had at least 1 anxiety/depressive disorder 6 months after 9/11
  - 14.9% of children from families in Hurricane Katrina’s path had a “serious emotional disturbance”, compared to 4-7% in communities nationally