



Ready Together: Emergency Preparedness for Families with Complex Needs



A presentation and family panel

Understanding Emergency Preparedness

Purpose

Equip families, providers, and community organizations with the resources needed to enhance emergency preparedness for families who have complex medical and/or social needs.

Agenda

- Why emergencies are especially risky for children who have complex medical and/or social needs
- Considerations for both families and providers on preparing for and responding to emergencies
- Q&A with family panel on ways to navigate emergencies

Why This Work Matters

You already know these families - here is the scale

1 in 5

Illinois children have a chronic or complex medical, social, behavioral, or educational need

~ 28,500

have medical complexity requiring intensive coordinated care

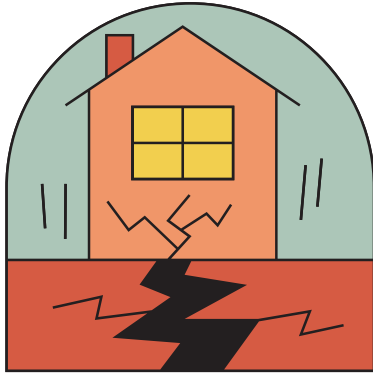
12%

receive care in a way that meets their families needs

Emergencies disrupt everything these children depend on - electricity for medical equipment, pharmacies, home nursing, schools, and specialty care. For a child with medical complexity a disruption can worsen their condition within hours. Families historically known facing the greatest everyday barriers including rural, experiencing financial or housing instability, lack of transportation or reliable internet, need language assistance, or disconnected from formal systems of care have the fewest options when an emergency hits.

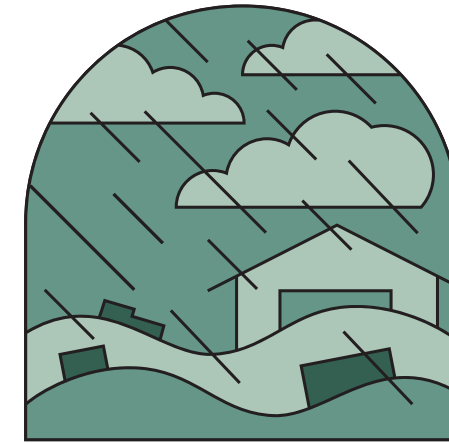


Types of Emergencies



Local Service Disruptions

water, natural gas, electricity, transportation, schools



Natural Disasters

floods, tornadoes, extreme weather



Human -Caused

mass violence or acts of terrorism



Infectious Disease Outbreaks

influenza, COVID-19, measles

Everyone Should Have an Emergency Plan

If you care for someone with complex medical needs, your emergency plan will be more detailed, involve more people, and may require additional or special equipment. Emergency plans are especially needed if someone:

- depends on electricity to breathe, be fed, stay comfortable
- cannot be moved easily because of a medical condition or equipment
- uses a wheelchair, walker, or other device to move
- cannot survive extreme weather temperatures (hot or cold)
- become afraid or agitated when sudden changes occur
- requires special foods or medications
- cannot get out of an emergency independently for physical, cognitive, or emotional reasons



Emergency Planning Considerations

Everyone in your home should know what to do in an emergency, whether it's a power outage, fire, or natural disaster such as a flood or tornado.

- Do you have all your child's medical information and contact information?
- 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?





Key Strategies for Emergency Preparedness



Be Informed of
potential
situations

Talk with family
members, friends,
neighbors about
resources

Create your
personal
emergency
preparedness plan

Talk with medical
providers about
what your child
might need

Talk with your
child's school,
childcare facility,
nursing agency, or
day program

Have a paper list
of important
contact
information

Know how local
emergency alert
system works

Build an
emergency kit to
be ready at all
times

Tips for Specific Conditions

Different people have different conditions and needs. Think about things that you need and the steps you may need to take for your or your loved one's condition.

Communication

- Find a way to communicate during an emergency and practice it
- Put communication aids in your emergency kit
- Put batteries for your communication aids in your emergency supply kit

Hearing

- Keep things needed to hear and extra batteries in a place that can be easily found
- Use flashing light alarms around the house in case of emergencies
- Write down things need to be communicated to emergency response personnel

Cognitive

- Think of ways to remember important things
- Practice how to communicate needs

Visual

- Plan what to do if hearing cues usually used are lost
- Make emergency supplies with large print, bright tape, and/or Braille
- Make sure items used to get around, like a cane will be safe in an emergency

Mobility

- Store aids in a place that can be reached easily
- Put extra items you need for mobility in emergency kit
- Have low tech options for transfers in an emergency
- Ensure it is known the safe way to get out of home or other buildings

Mental Health

- Practice how to communicate needs
- Plan ways to deal with emotions, sudden change in environments, or sensory overloads

Emergency Preparedness

The Role of Providers



- Education & training for families
- Personalized emergency plans that cater to the unique needs of child
- Accessibility of medical records
- Promote vaccine adherence

- Maintain continuity of care
- Identify and manage mental health impact and facilitate psychological support
- Collaborate with community resources, emergency responders, and public health entities

- Advocate for disaster planning that considers children's needs
- Support vulnerable populations by identifying resources and support networks

- Re-establish normalcy by supporting the reintegration of children into routines
- Restore access to routine and comprehensive medical care
- Address emotional and psychological challenges faced by children

Addressing Risks with Families

Examples on addressing emergency preparedness risks and developing goals with families.

Develop and maintain a backup power plan to ensure life sustaining medical equipment remains operational during outages.

Practice using low-tech alternatives to care such as manual suction or gravity feeds to maintain care if power must be conserved.

Maintain an emergency evacuation plan that includes trained backup caregivers who can assist during an emergency.

Ensure our home exits are clear and accessible at all times. Multiple exit routes will be available in the event one is blocked/unsafe.

Wear my medical bracelet to alert others of my medical conditions and emergency contact information.

Coordinate with local emergency services to inform them of specific needs in the event of an emergency.

Sign up for alerts with our utility company to ensure power outages are communicated timely.

Create and update an emergency contact list that includes medical providers, DME, utility companies, and support networks.



Type of Disaster to Prepare For:

- Considerations:**



Resuscitation Status:
☐ Discussed ☐ Not Discussed
☐ Report Attached

UIC DIVISION OF SPECIALIZED
CARE FOR CHILDREN

Participant Information

Emergency Contact

Emergency Prep

109 (11/22)



Emergency Preparedness Resources



Resources	Where to Find
CDC: Children and Youth with Special Healthcare Needs in Emergencies	https://www.cdc.gov/children-and-school-preparedness/special-healthcare-needs/index.html
American Red Cross: Disaster Relief and Emergency Planning for People with Disabilities	https://www.redcross.org/get-help/how-to-prepare-for-emergencies/inclusive-preparedness-resources.html
CDC: Emergency Preparedness for People with Disabilities	https://www.cdc.gov/disability-emergency-preparedness/people-with-disabilities/index.html
Ready.gov: Diverse information on Emergency and Disaster Preparedness	https://www.ready.gov/people-disabilities
The September 26th Project: Emergency Preparedness Checkup for Autism and Special Needs Families	https://september26.org/
Family Voices: Emergency Preparation Tips for Families	https://familyvoices.org/wp-content/uploads/2018/06/EmergencyDisasterPlanning_FamilyHandout.pdf



Family Panel

Time for question-and-answer session about navigating emergencies from families.