Emergency Readiness Toolkit for Parents of Children with Disabilities and Special Health Care Needs

October, 2010

Funded through a grant from the Deborah Munroe Noonan Memorial Research Fund, Bank of America, N. A., Trustee

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Acknowledgements

This Toolkit and the related training were developed by Sue Wolf-Fordham, E.K. Shriver Center, University of Massachusetts Medical School, with the help of an Advisory Board. The Advisory Board included parents and emergency response professionals. Parents included Maura Buckley, Mark Corr, Linda Freeman, and Susan Holmes. Emergency response professionals included Police chief Mark Corr, Lexington, MA, Police Department, and Liisa Jackson, Massachusetts Region 4A Medical Reserve Corps Coordinator. We thank them for all of their hard work.

The Deborah Munroe Noonan Memorial Research Fund, Bank of America, N.A., Trustee funded this Toolkit and the related training.

Thank you to the following organizations and people for permission to share their materials in this Toolkit:

- The American Academy of Pediatrics
- American Council of the Blind
- Cambridge, MA Public Health Department
- Institute of Disabilities, Temple University
- June Isaacson Kailes
- Washington State Department of Health

Thank you to the following people for their additional help with editing, graphic design and/or layout:

- Angelica Aguirre, University of Massachusetts Medical School E.K. Shriver Center
- Maura Buckley
- Suzanne Gottlieb, Director, Family Initiatives, MA Department of Public Health
- Patrick Gleason, University of Massachusetts E. K. Shriver Center
- Melissa Maslin, University of Massachusetts E. K. Shriver Center
- Amanda Rossetti, Leadership Education in Neurodevelopmental Disabilities (LEND) fellow

Foreword

Message from Emergency Responders

Mark Corr is the Police Chief in Lexington, MA. He has a teenage son with autism: “I ask families and caregivers of children with disabilities to think. What would you do in a disaster? What if Mother Nature threatens with wind and rain, snow and ice, or fire? What about manmade events like explosions, chemical spills and building collapses? Having no food, water, heat or a safe place to stay is very serious. Emergency personnel plan in advance, buy supplies and practice for emergencies. Do you have a plan? Your child with a disability has special needs. You are the best person to plan and prepare for their needs if something unexpected happens. This Toolkit offers help on what to do before something goes very wrong.”
**Liisa Jackson** is the Coordinator of MA Medical Reserve Corps Region 4A. The Medical Reserve Corps provides emergency medical and shelter services. “Families must prepare as much as possible before emergencies. Having a comprehensive emergency plan helps first responders by freeing up their time to help those with the greatest needs. If you follow the steps shared in this Toolkit we will be able to provide the proper care for your family during an emergency.”

**One Family’s Experience**

“Jill” has two sons with severe autism and a son with a severe learning disability. “On 9/11 I realized that our family needed to prepare for emergencies in different ways than other families,” Jill says. She added, “I worried that an emergency responder wouldn’t know how to handle my kids.” She explains, “My kids can have major behaviors in noisy, crowded situations. They might hurt themselves or others. They might damage property.”

While on a trip the family had a car accident and went to a local hospital. “We were in a small town out of state. The hospital staff had no experience with kids like mine. It was awful. The staff didn’t understand why we couldn’t leave the kids alone. I knew we would have to explain the kids’ needs and take better care of ourselves if something else happened.”

- **Planning**

  Jill thought about what might happen in an emergency. “I thought about the ‘what if’s,’” she said. “We did a lot of planning. Think about what you would need to keep your family safe and comfortable if you were on a desert island.”

  She thought about each person’s needs for food, water, and comfort. She thought about their sensory issues and medicine. She thought about how to entertain her kids.

- **Developing a Support Network and Gathering Supplies**

  Jill developed a network of family and friends she could count on to help her in an emergency. The family also purchased a generator for back-up power.

  Jill then gathered supplies, based on her kids’ needs. She collected:
  - Canned food that her children would eat. She got particular food for her child with food aversions.
  - Water and powdered drink mix (her kids won’t drink plain water).
  - First aid kit (one child cuts himself easily).
  - Soft fleece blankets (for warmth and sensory calming).
  - Flashlights and extra batteries.
  - Some of her children’s favorite toys and diversions, including Legos®, fidgets, and video games.
  - Plastic drop cloths for the family to make their own quiet “tent” within the bigger space of an emergency shelter.
Emergency Readiness Paid Off

Jill’s planning paid off during 2008’s severe ice storm. “The kids did great. We felt more comfortable knowing we were prepared.”

Jill says, “Special needs families like mine need to always have a ‘plan B.’ If you’re ready for an emergency or disaster then you have one less thing to worry about each day. Having a plan in advance keeps my family comfortable and stable, which means fewer ‘meltdowns.’ Keeping a stable and familiar routine no matter what happens is part of daily life for a family with special needs.”
Introduction

“During a December ice storm we were stuck at home for days. We lost heat and electric power. We couldn’t run my son’s ventilator and suction machine. We didn’t have a generator. We learned too late that the fire department and the electric company loaned emergency generators. They were all out when we called. Luckily my boyfriend knows a lot about cars. He brought the car battery indoors to charge the equipment. Every 6 to 8 hours he brought the battery back out to the car to recharge. We were lucky.”—Parent of a child with complex health care needs

Why Create This Toolkit?

We wrote this Toolkit to help parents and guardians of children with disabilities and special health care needs (ages 0-21) plan for the surprises and disruptions that may occur during disasters and emergencies. We are parents, guardians and emergency responders who have faced these events themselves. We understand the challenges families like yours face.

Disasters and Emergencies

Disasters and emergencies come in all shapes and forms. They are not just events we watch on the national news. They may not affect a large area. A “disaster” or “emergency” can be a local natural event like a winter storm or flood. It might be a human-caused event like a chemical spill or a house fire. Pandemics like the H1N1 flu may also be disasters or emergencies. A disaster may just impact one family (like a house fire). It may be a big event that impacts a region or the whole state (like a blizzard).

Terms Used in the Toolkit

In this Toolkit we use the words “emergency” and “disaster” to mean the same thing. We use the words “disabilities” and “special health care needs” to mean the same thing. We use the words “parents” and “guardians” to mean the same thing.

Families Challenged by Disability May Be At Risk

We wrote this Toolkit to help families plan in advance for things that might happen during an emergency.

Think about your own child’s needs.

- What if your home lost power during a Nor’easter?

  Medicine wouldn’t stay cold if the refrigerator didn’t work. A power wheelchair battery might not charge. Medical equipment, like a nebulizer, might not work. Your phone might not work.
• **What if your home lost heat during a snow storm? What if you couldn’t run a fan or air conditioner during a heat wave?**

If your child is sensitive to temperature changes she might become uncomfortable or ill because of extreme heat or cold.

• **What if your family was snowed in? What if debris from a windstorm blocked your road so you couldn’t leave? What if other people couldn’t come to you?**

You might run out of food, medicines and supplies for your child. Maybe you couldn’t leave your house to get more. The Personal Care Assistant (PCA), home health aide or respite staff might not be able to come. Vendors (like an oxygen delivery company) might not be able to get to you. Vendors’ offices might be closed.

• **What if a storm, flood or other surprise event disrupted your child’s daily routine?**

Your child might not be able to watch TV or play videogames. She might not be able to eat her usual food. She might not be able to sleep in her own bed. She might not be able to do familiar calming things. She might get upset if your home looks different due to storm damage. Her behavior might change and become unsafe.

• **What if you had to leave your home for safety? What if you had to leave because emergency responders told you to go?**

The routine at someone else’s home or a hotel might differ from your child’s usual routine. A public shelter might not be wheelchair accessible. A shelter might be uncomfortable. A shelter might be noisy or crowded. Your child might get upset there. Shelter workers might not understand your child’s needs. They might not know the best way to help him. You might need to tell them what to do to help your child.

• **What if an emergency happens when your family is not together? What if it happens when your child is at school or day care?**

You might not be able to reach your child. You might worry about where he is or if he’s safe. You might not know whether the school or day care has made emergency plans.

This Toolkit can help you think about your child’s likely emergency needs. There are “fill in the blank” forms to help you think and plan. There are suggestions for sharing information with others. There are print and Internet resources to read at home.
How To Use This Toolkit

This Toolkit has 10 parts plus this Introduction and the Foreword. Sections 1 to 8 have key information to help you get ready for emergencies. Section 9 has a “Top 10” list with key readiness steps. If you read only one part of the Toolkit, read that one. The last part of the Toolkit has Internet links and a glossary of terms. The back of the Toolkit has extra print resources to read at home.

The Toolkit has checklists and forms to fill out. If you take the time to fill out these forms, you will be well on your way to being better prepared. You will also be able to help others help you and your family.

Toolkit Symbols

You will see symbols in the Toolkit as reminders. Each part of the Toolkit has its own symbol and there are symbols that are in more than one part of the Toolkit.

<table>
<thead>
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<th>Symbol</th>
<th>Description</th>
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| 📝 | The pencil means there are forms to fill out. The Toolkit has 5 forms to fill out:  
(1) Emergency Information Form;  
(2) Emergency Information Form Instructions, to help you fill out the Emergency Information Form;  
(3) Medical Information Form;  
(4) Household Communication and Connection Plan;  
(5) Comfort Items Checklist. |
|💡 | The light bulb means there is a Tip Sheet with information about a specific topic. There are 6 Tip Sheets:  
(1) Keep Spoken Instructions Simple;  
(2) Special Needs Registries and Indicators;  
(3) How to “ICE” Your Phone;  
(4) Emergency Supplies;  
(5) To Go Bag;  
(6) Protecting Your Federal Benefits in Case of Emergency. |
|.circle | The orange circle means to check the back of the Toolkit for more print resources. There are 6 sections with more print resources:  
Section 1 Sharing Information in an Emergency;  
Section 2 Emergency Communication and Connections;  
Section 3 Sheltering At Home;  
Section 6 Family Discussions and Coping Techniques;  
Section 7 Family Discussions For Teens and Their Parents;  
Section 8 Pets and Service Animals. |
| 📸 | The picture of a child reminds you to think about your child’s unique needs. |
**Why Prepare in Advance?**

Americans are optimists by nature. We think that a disaster can’t happen to us. But like most Americans, MA families will likely face an emergency during their lifetimes. In fact, in a recent survey of MA parents of children with disabilities, 37% of those asked said that they had experienced an emergency.

Many experts feel that we have more disasters today than we used to. They feel that disasters are more serious and costly than years ago. And we know that disasters can strike without warning, at any time and place.

**Challenges People with Disabilities Face During Emergencies**

We know from September 11, 2001 and Hurricane Katrina, as well as small local events, that emergencies can impact people with disabilities more than other people. Emergency systems seem to be made for people who can talk, walk, run, drive, see and hear. Emergency planners expect people to respond quickly to instructions, alerts and evacuation orders. People with disabilities may face challenges with these tasks.

There may also be a communication gap between the disability community and emergency planners because both groups are not used to working together.

**Challenges Children Face During Emergencies**

Often local emergency plans exclude children. Local plans may not reflect children’s physical and emotional needs or lack of ability to care for themselves. During Hurricane Katrina thousands of children were separated from their parents, sometimes for a long time.

Children with disabilities may be at greater risk than other children when facing disasters. These children may need a special diet. They may need medicines, medical equipment or assistive technology. They may need lots of specialized medical, therapeutic or educational services. They may need to have the same routine each day. They may need help with Activities of Daily Living (ADL’s) like eating or dressing. They may need an environment that always stays the same. They may need to have someone watch them all the time so they stay calm and safe.

**Getting Ready for Emergencies Is Easy and Smart**

Getting ready for emergencies is easy. It’s the best way to protect your child with a disability and your family.

Preparing can:

- Save lives and reduce injuries.
- Reduce damage to your home or things you own.
- Lower fear and worry.
- Reduce unknowns and likely disruptions.
- Help families feel strong, in control and self-sufficient.
- Cut down the amount of time it takes to get your life back in order afterwards.

We respond to disasters automatically. We respond by instinct. Thinking, knowledge and prior experience affect our response. People who have planned in advance know how to cope. When disaster strikes they know what to do to take care of themselves and their families.

We often plan for surprise events. When we get insurance or listen to airplane safety instructions we are planning for the unexpected. When we take part in a fire drill we are planning for the unexpected.

Many parents of children with disabilities are used to planning for their children’s usual and special needs. They have good planning skills. Emergency planning is part of being the parent of a child with a disability.
Emergency Myths and Facts

1. **Myth:** Everyone is equally at risk from disasters.

   **Fact:** Experts tell us that people are more or less at risk based on their social class, ethnicity, race, sex, and social contacts. These traits help you bounce back more quickly. Planning can also help you bounce back more quickly.

2. **Myth:** In an emergency or disaster all I have to do is call 9-1-1. Someone will come protect me.

   **Fact:** Big emergencies strain emergency responders. They may not be able to quickly get to everyone who needs help. People may have to cope on their own, at least for a little while. Plan to take care of yourself and your family for at least **72 hours** (3 days) without help from responders.

3. **Myth:** Getting ready is too costly and too complex.

   **Fact:** There are lots of simple and cheap things you can do to get ready for emergencies. Don’t pay attention to companies selling unnecessary and costly gear. There are simple and free ways to prepare. For example, you could talk to your family about planning together. You could think about the “what if’s” and how to handle them. You could think about which friend or family member could act as an out-of-area contact. You could write down your child’s key medical and care information.

4. **Myth:** It is impossible to really prepare for an emergency.

   **Fact:** Not true. Even in a big event, such as Hurricane Katrina or the 2004 Pacific tsunami, some preparing is better than none. And a “weapon of mass destruction” terror attack does NOT mean “Total Destruction.” These things are survivable. It will be easier to survive if you are prepared.

   Parents can’t affect when or where a disaster might happen. But they can affect how a disaster might impact their family.

5. **Myth:** Nothing like that could ever happen here or to us.

   **Fact:** Some parts of the U.S. are more prone to certain types of disasters. We know about earthquakes in California. We know about hurricanes on the Florida coast. But the truth is that no place on earth can completely avoid disasters. Many Americans travel. So you really don’t know where you’ll be or what you’ll be doing when something happens that you don’t expect.

   The American Academy of Pediatrics tells us that 95% of Americans think that a disaster won’t happen to them. But in fact disasters affect 60% of us. Each year hundreds of thousands of
Americans experience a disaster. And the American Red Cross reports responding to 70,000 emergencies in the U.S. each year.

6. **Myth:** Emergencies are only big dramatic events like Hurricane Katrina or the September 11, 2001 terror attacks.

**Fact:** Emergencies can be big events impacting lots of people, or they can be much smaller. Local events such as the 2006 Danvers, MA explosion, the 2007 Gloucester, MA fire, traffic accidents and small-scale chemical spills can affect a family, neighborhood or part of a state.

Even local events can cause lots of damage and disruption. In 2008 the Central MA ice storm caused millions of dollars worth of damage. And the 1995 Great Barrington tornado caused an estimated $25 million dollars of damage. As we write this Toolkit, heavy rain has caused lots of flooding in many parts of the state. We are beginning to see disruption to daily life and damage to property in some parts of the state.

**More Info:**

MA weather changes quickly. MA has winter storms and extreme cold, hurricanes, thunderstorms and Nor’easters. We have floods and extreme heat. In fact, floods are the number-one natural disaster in our state and country. Among disasters, floods cause the most property damage and greatest number of deaths in the U.S. Emergencies like pandemics can happen anywhere.

People learn about emergencies in many ways. They learn from radio, TV and newspapers. They hear about these events from the Internet, friends and family. They might also have a **weather radio** that picks up weather-related and other emergency broadcasts. Some cities and towns have their own emergency alert system, such as Reverse 9-1-1. With Reverse 9-1-1 the town can send the same emergency message to all local home phones at the same time.

The media often uses terms like weather “**watch**” and weather “**warning**.” A “**watch**” means that a weather emergency might be coming. A “**warning**” means that a weather emergency is on its way and we should plan for it.

Fact sheets in the back of the Toolkit describe what to do before, during and after different types of emergencies.

- **Winter Storm Fact Sheet** (from the American Academy of Pediatrics).
- **Flood Fact Sheet** (from the American Academy of Pediatrics).

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- Hurricane Fact Sheet (from the American Academy of Pediatrics).
- Earthquake Fact Sheet (from the American Academy of Pediatrics).
- Tornado Fact Sheet (from the American Academy of Pediatrics).
- About Terrorism (from the Washington Military Department and Washington State Department of Health).
- Pandemic Flu (from the Washington Military Department and Washington State Department of Health).

These fact sheets have information about how to prevent the spread of germs.

- Prevent the Spread of Germs (from the Washington Military Department and Washington State Department of Health).
- Cover Your Cough (from the Washington Military Department and Washington State Department of Health).

There are also disaster fact sheets about specific disabilities.

- Disaster Tips for the Deaf and Hard of Hearing (from the Washington Military Department and Washington State Department of Health).
- Disaster Tips for People with Mobility Impairments (from the Washington Military Department and Washington State Department of Health).
- Disaster Tips for People with Special Medical Needs (from the Washington Military Department and Washington State Department of Health).
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Section 1: Sharing Information About Emergency Needs

This section is the most important part of the Toolkit. Think about your child’s key health and care information. What should you share with responders, shelter workers and others about your child?

This section has forms to fill out about your child’s emergency needs. This section has Tip Sheets with useful ideas to help you communicate with emergency responders and others.

To fill out:

- **Emergency Information Form.** Short form to quickly share key information about your child’s health or care needs.

- **Emergency Information Form Instructions.** Checklist to help fill in the Emergency Information Form.

- **Medical Information Form.** Information about your child’s health, allergies and medicines. Information about your child’s medical or adapted equipment and supplies.

Each family must decide if these forms are right for them. They may choose to leave some or all parts of a form blank or to make their own forms. Families must make sure that the forms they fill out have accurate information about their child.

Tip Sheets:

- **Keep Spoken Instructions Simple.** How to speak to a responder about your child’s needs.

- **Special Needs Registries and Indicators.** Description of written forms for sharing information with responders.

More Info:

- **What To Do Until Help Arrives For a Child Medical Emergency** (from the U.S. Health Resources and Services Administration). Basic information about handling a child’s health emergency.
Leave blank
Emergency Information Form

Child’s Name ____________________________  Nickname ____________________________  Language Spoken/Understood ____________________________
Birth Date ____________________________  Today’s Date ____________________________  Completed By ____________________________
Height ____________________________  Weight ____________________________  Hair/Eye Color ____________________________
Gender ____________________________  Blood Type ____________________________  Identifying Marks ____________________________
Child’s Address ____________________________  Parent’s/Guardian’s Name and Address ____________________________

Home Phone ____________________________  Home Email ____________________________  Work Phone ____________________________  Work Email ____________________________  Mobile Phone ____________________________

The most critical information to know about my child is:
1. __________________________________________________________________________________________
2. __________________________________________________________________________________________
3. __________________________________________________________________________________________
4. __________________________________________________________________________________________
5. __________________________________________________________________________________________

Communication (critical issues):
Key personality traits: __________________________________________________________________________
Key signs of normal function: __________________________________________________________________
Potentially life threatening conditions: ___________________________________________________________________
Conditions needing constant attention: __________________________________________________________________

Medicines: _____N/A _____Takes medicines. See separate list on Medical Information Form.
Life sustaining medicines: _______________________________________________________________________

OK for my child to skip a dose of these medicines: __________________________________________________________________
Medical or adapted equipment: _____N/A _____Uses specialized equipment. See separate list on Medical Information Form.
Special Diet: _____N/A _____Special diet. See Medical Information Form.

My child _____is _____is not wearing a Medical Alert.
Planning documents for life threatening condition:
________________________________________________________________________________________
________________________________________________________________________________________
Is there a custody agreement? _____ Who has custody? _______________ Court Order Number______________

Primary Emergency Contact ________________________________ Secondary Emergency Contact ________________________________

Home Phone Work/Mobile Home Phone Work/Mobile

Address Address

Health Insurance Company: __________________________ Policy Number: __________________________

My child normally needs a caregiver, baby sitter or personal care assistant (PCA) _____ hours/week _____ all the time.

During a disaster or emergency my child is likely to need help or support in the following areas:

Communicating, Reading, Writing, Thinking:______________________________________________________________

Behavior Management and Mood:______________________________________________________________

Hearing and Sight:______________________________________________________________

Mobility, Movement and Physical Stamina:______________________________________________________________

Taking Medicines and Monitoring Medical Conditions:______________________________________________________________

Activities of Daily Living (dressing, grooming, tooth brushing, bathing, toileting, eating, drinking, sleeping):______________________________________________________________

Service Animals:______________________________________________________________

Transportation:______________________________________________________________

Cultural Practices:______________________________________________________________

Other Information:______________________________________________________________
Leave blank
Leave blank
EMERGENCY INFORMATION FORM INSTRUCTIONS

Follow these instructions to complete the Emergency Information Form

The Emergency Information Form asks for 3 kinds of information.
(1) **Personal Information**: Identifying information about your child. Information about custody, emergency contacts and health insurance. This information is at the top of both pages.
(2) **Critical Information**: The most important information you want to share about your child is in the yellow box on the front of the form. We suggest that you fill in this section of the form last.
(3) **Help and Support Needs**: The key supports, help and care your child is likely to need in an emergency. This information is on the back of the form. You may want to repeat some of this information in the Critical Information section.

Emergency Help and Supports Checklist

Use the checklists below to think about your child’s needs. *Later*, add the most important information from the checklists to the Critical Information Box and the Help and Support Needs sections on both sides of the Emergency Information Form.

**Background Question**: My child normally needs a caregiver, baby sitter or personal care assistant (PCA) _____ hours a week _____ all the time.

**During an emergency or disaster my child is likely to need help or support in the following areas:**

- **Communication, Reading, Writing, Thinking** (speaking or understanding)
  - My child communicates by:
    - speech
    - sign language
    - vocalization
    - gesture
    - pointing to letters
    - pointing to words
    - pointing to pictures
    - electronic communication device
    - communication notebook
    - typing on the computer
    - artificial larynx
    - writing
    - other:
  - My child’s communication is understandable
    - all the time
    - some of the time
    - only to those who know him or her well
    - not understandable
  - The best way for you to communicate with my child is:
o My child needs extra time to respond.
o My child needs sign language interpretation.
o My child can read lips.
o My child may become confused when dealing with unfamiliar or unusual activities.
o My child needs directions explained in simple steps or basic concepts.
o My child has problems following directions.
o My child has problems remembering things.
o My child _____can_____cannot read.
  • My child needs Braille.
  • My child needs large print.
  • My child can’t read but understands recorded materials.
  • My child needs someone to read and explain information to him or her.
o My child _____can_____can’t write with a pencil or pen.

o **Behavior Management and Mood**

  o My child’s mood can change quickly.
o My child has a hard time adjusting to new places or new people.
o My child has a hard time adjusting to crowded or noisy rooms.
o My child may act impulsively.
o My child has a hard time adjusting to changes in routine.
o My child may not show his or her feelings in his or her facial expression.
o If my child is afraid he or she may show it by:

  ________________________________________________________

  o If my child is in pain he or she may show it by:

  ________________________________________________________

  o My child _____can_____can’t tell me where the pain is.
o If my child is nervous he or she may show it by:

  ________________________________________________________

  o If my child is happy he or she may show it by:

  ________________________________________________________

  o If my child feels sad he or she may show it by:

  ________________________________________________________

  o To help my child feel calm you may need to:

  ________________________________________________________

  o To help my child feel safe you may need to:

  ________________________________________________________

o **Hearing and Sight**

  o My child has low vision or is blind.
o My child wears eye glasses.
o My child has trouble seeing even with glasses.
o My child uses a white cane for walking.
o My child needs help getting around even with a white cane.
o My child has a service animal.
o My child can walk by holding onto a sighted person’s arm.
o My child needs someone to help orient him or her to the layout of new places.
o My child is deaf or hard of hearing.
o My child wears hearing aids.
o My child understands and can communicate via sign language.
o My child can read lips.

o Mobility/Movement and Physical Stamina

o My child walks independently.
o My child walks independently while using a _____walker _____cane _____crutches.
o My child needs help when walking with his or her _____walker _____cane _____crutches.
o My child can walk while holding onto someone’s hand.
o My child can walk very short distances with a lot of help from an adult.
o My child can’t walk independently and uses a _____ manual _____ power wheelchair independently.
o My child can’t walk independently and needs someone to push the manual wheelchair.
o My child is at risk for falling.
o My child tires easily and needs to rest often.
o My child has poor balance or coordination.
o My child needs someone to help him or her get into different sitting or lying positions.
o Sometimes my child’s body moves in ways she or he can’t control.
o My child may lose his or her sense of direction or has a poor sense of direction.
o My child needs help moving from one wheelchair to another.
o My child needs a lift or transfer board to transfer from one place to another. If a lift or transfer board is not available my child will need ______ people to help him or her for a safe transfer.
o My child can walk up and down stairs by himself or herself.
o My child can walk up and down stairs with help.
o If my child needs to be carried, the best way to carry him or her is:

__________________________________________________________________________
o It is unsafe to use the firefighter’s carry with my child.
o My child needs help getting in or out of bed.
o My child needs help getting in or out of a chair.

o Taking Medicine and Monitoring Medical Conditions

o My child can take his or her medicine independently.
o My child needs to be reminded to take medicine.
o My child needs someone to prepare his or her medicine.
o My child needs someone to give him or her medicine.
o My child has a medical condition that is unstable or needs constant adult attention.
[You will be able to share more information about this on the Medical Information Form.]
o My child has a medical condition that is unstable or needs constant adult attention. He or she can self-monitor. [You will be able to share more information about this on the **Medical Information Form.**]

o My child needs help with ongoing medical therapy (e.g. IV therapy, catheterization, ostomy, wound care): ________________________

o My child needs certain essential medical supplies (other than medicine): ________________________

[You will be able to give a complete list of medical supplies on the **Medical Information Form.**]

o My child has a medical device implant (e.g. heart defibrillator, pacemaker, vagus nerve stimulator, Baclofen pump): ________________________

o My child uses adapted equipment or assistive technology, such as a wheelchair, a communication device, adapted cup, feeding tube, technology to breathe, etc. (You will create a complete list of durable medical goods, assistive technology and medical supplies in the **Medical Information Form.**)

**Activities of Daily Living**

**Dressing and Grooming**

- My child needs help dressing and undressing.
- My child needs help buttoning or fastening clothes.
- My child needs help with grooming (such as hair brushing).
- My child needs verbal reminders with dressing or grooming.

**Tooth Brushing and Bathing**

- My child needs help brushing his or her teeth.
- My child can brush his or her teeth independently.
- My child needs verbal reminders to brush his or her teeth.
- My child can shower or bathe independently.
- My child needs help bathing or showering.
- My child uses adapted equipment to shower or bathe.

**Toileting**

- My child wears disposable underwear or diapers.
- My child may have bathroom accidents.
- My child needs help changing underwear.
- My child needs an adapted toilet or a toilet with handholds.
- My child needs to be catheterized every _____ hours.
- My child’s ostomy bag needs to be emptied every _____ hours.
- My child needs to be taken to the bathroom every _____ hours.
- My child needs help undressing or dressing in the bathroom.
- My child needs help wiping or cleaning him or herself.
- My child needs help sitting on the toilet or getting up from the toilet.
- My daughter needs help when she has her period.
• Once seated on the toilet my child can be by himself or herself until ready to get up.
• My son ____ sits to urinate _____stands independently to urinate _____needs help to stand to urinate.

o Eating/Drinking

• My child needs a special diet:
• My child needs special drinks:
• My child is fed through a tube.
• My child wears a dental appliance that impacts eating or drinking.
• My child can feed him or herself independently.
• My child needs someone to feed him or her.
• My child needs an adapted utensil or bowl.
• My child needs an adapted cup and/or straw.
• My child does not handle hot foods well; food should be warm.
• My child is a choking risk.
• It is difficult for my child to eat liquid foods like soup.
• My child needs his or her food cut into small pieces (about the size of _________________.

o Sleeping

• My child needs help getting in and out of bed.
• My child needs a special bed, like a hospital bed.
• My child needs bed rails, the head of the bed raised or other bed adaptations.
• My child has a condition that requires monitoring during the night (e.g. seizures, apnea, breathing):

• My child needs to be repositioned while he or she sleeps.
• During the night, my child needs:

(for example, medicine, water, to be woken up to use the toilet, etc.)

o Service Animals

• My child uses a service animal. Name and kind of animal:
• This is how he or she uses the service animal:
• My child’s service animal does not adapt well to emergencies.
• My child will need help while the service animal adjusts.
o **Transportation**

  - My child needs transportation that will accommodate his or her wheelchair.
    - My child has a manual wheelchair which can be folded for transport.
    - My child has a power wheelchair and will need to be transported in a vehicle with a lift.
  - My child has a power wheelchair and a manual chair (in an emergency a manual chair is preferred).
  - Bring my child’s adapted or medical equipment and supplies when transporting him or her.
  - My child can sit in a bus or car without a car seat or other adaptation.
  - My child needs specialized seating in a car or bus.

o **Cultural/ethnic/religious practices**

  - Important cultural practices you should know about my child are (for example, “my child doesn’t eat pork and eats only Halal meat,” “my child needs to follow our family religious practice and wash her hands in a certain way before she eats,” “my child has been taught not to look directly at a person of the opposite sex,” “my child eats with her hands-this is a cultural custom”):

    ____________________________________________________________

  - **Other Information:**

    ____________________________________________________________

    ____________________________________________________________
The Most Critical Information About Your Child

The yellow section on the front of the Emergency Information Form is the most important part of the form, the Critical Information Box.

Think about your child’s “elevator story.” If you were riding in an elevator and had just a few minutes to tell someone the most important emergency information about your child, what would you say? Those key points go in the Critical Information Box. Use short, simple phrases and common terms to talk about your child. Avoid medical or special education terms since responders and other emergency helpers may not know them.

Look at the Emergency Help and Supports Checklist to jog your memory. Think about the 3-5 most important pieces of information someone should know to help your child in an emergency. Each child’s situation will be different. For example, one child may need to have his communication device with him at all times. Another child’s daily blood tests would be the most important thing. For another child behaviors might be the main issue.

Communication: Write down the key issues your child has speaking, understanding, and following directions.

Key personality characteristics: Include both “positive” and “negative” traits so responders and other emergency helpers can better understand your child. Examples include: “cooperative,” “gets anxious easily” and “may run away if challenged.”

Key signs of normal function: Behaviors and health information (sometimes called “baseline information”) that someone who doesn’t know your child might not know as normal. Examples include making movements or sounds your child can’t control, drooling or basal temperature.

Potentially life threatening conditions: List your child’s potentially life threatening conditions. Examples include a seizure disorder, heart condition or life threatening allergies.

Conditions needing constant attention: List conditions that need constant attention or supervision. Examples include checking insulin levels, daily blood or other tests, and constant safety monitoring.

The Medicines, Medical or adapted equipment and Special Diet sections of the form call for only the most important information. Later you can add less important information to the Medical Information Form. The Medical Alert section asks if your child wears medical alert bracelets, necklaces or has an alert tag attached to sneakers or elsewhere.

Planning documents for life threatening condition: Some parents have a planning document in which they describe the kind of treatment they want or don’t want for their child under 18 years old in case of a life threatening condition. Some people over 18 year old years old have a health care proxy under Massachusetts law. If this doesn’t apply to your child, write “N/A
Leave blank
Medical Information Form

Child’s Name: first name, last name

Date of Birth: month, day, year

Health Insurance information

- Insurance group number, policy number, contact information:
- Insurance group number, policy number, contact information:
- Medicaid number, contact information:

Medical Conditions: List your child’s diagnoses or conditions. List warning signs that the condition may be getting worse.

Asthma, Allergies, Sensitivities and Sensory Issues:

My child has environmental, food, medicine, or other allergies or sensitivities.

- My child cannot stand too much heat or cold.
- My child is sensitive to the sun.
- My child has a weak immune system. He or she needs to keep away from others. He or she gets sick easily.
- My child has asthma or reactive airway disease.
- My child has life threatening allergies. Describe:
- My child _____has had _____has not had an anaphylactic reaction.  Describe:
- My child has non-life-threatening allergies. Describe:
- My child takes medicine for his or her allergies. See the medicine list below.
- My child is sensitive to chemicals. Describe: _____________________________
- My child has sensory issues:
  - My child does not like to be touched.
  - My child does not like some textures:
  - My child does not like some noises:
  - My child has other sensory issues: ____________________________
**Medicine and Special Formulas:** List prescription and over the counter medicines, vitamins, supplements and special formulas.

- My child ___can ____cannot miss a dose of medicine or special formula: __________
- My child needs medicine ___ once a day ___several times a day.
- Pharmacy name, city, state, phone and email: ____________________________________________________________________________

<table>
<thead>
<tr>
<th>Medicine Name Mark with * if can’t skip</th>
<th>Dose (How Much)</th>
<th>Times Taken</th>
<th>How Taken (such as by mouth, shot, other)</th>
<th>Why Taken</th>
<th>P, OTC, O**</th>
<th>Care, equipment, materials needed (examples include refrigeration, oral syringe, tubing, bandages, adapted spoon)</th>
</tr>
</thead>
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</table>

**P=Prescription medicine     OTC=Over the Counter medicine     O=Other medicine
* Medicine that can’t be skipped**
# Medical Devices, Supplies, Adapted Equipment and Assistive Technology

<table>
<thead>
<tr>
<th>Equipment and Supplies</th>
<th>Used For</th>
<th>Manufacturer and Model Number</th>
<th>Vendor Name</th>
<th>Vendor Address, Phone Number and Email</th>
<th>Comments (include information about batteries and electricity)</th>
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</tbody>
</table>

Other Information about battery, electricity or other needs:

Basic instructions for most important equipment:
### Necessary Tests or Treatments

<table>
<thead>
<tr>
<th>Test or treatment child has on a regular basis that must continue in an emergency</th>
<th>How often</th>
<th>How long child can go without treatment</th>
<th>Where child receives treatment; other comments</th>
</tr>
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</tbody>
</table>

*If your child receives dialysis or other life-sustaining treatment, think about knowing more than one place to receive the treatment.*
Vaccines

Mark the vaccines that your child has had. Leave blank any you don’t remember and check with your child’s primary care doctor.

My Child’s Vaccines:

<table>
<thead>
<tr>
<th>For children from birth to age 6:</th>
<th>For children and youth ages 7-18:</th>
</tr>
</thead>
<tbody>
<tr>
<td>_____ Hepatitis B.</td>
<td>_____ Tetanus, Diphtheria, Pertussis (Whooping Cough). Also known as Tdap.</td>
</tr>
<tr>
<td>_____ Rotavirus.</td>
<td>_____ Human Papillomavirus also known as HPV.</td>
</tr>
<tr>
<td>_____ Diphtheria, Tetanus, Pertussis (Whooping Cough). Also known as the DPT or DTaP.</td>
<td>_____ Meningococcal, also known as Meningitis or MCV.</td>
</tr>
<tr>
<td>_____ Haemophilus influenza type b. Also known as the Hib.</td>
<td>_____ Influenza, also known as flu shot.</td>
</tr>
<tr>
<td>_____ Pneumococcal also known as pneumonia.</td>
<td>_____ Pneumococcal, also known as pneumonia.</td>
</tr>
<tr>
<td>_____ Inactivated poliovirus also known as polio or IPV.</td>
<td>_____ Hepatitis A.</td>
</tr>
<tr>
<td>_____ Influenza, also known as flu shot.</td>
<td>_____ Hepatitis B.</td>
</tr>
<tr>
<td>_____ Measles, Mumps, Rubella also known as MMR.</td>
<td>_____ Inactivated Poliovirus, also known as polio or IPV.</td>
</tr>
<tr>
<td>_____ Varicella, also known as chicken pox.</td>
<td>_____ Measles, Mumps, Rubella also known as MMR.</td>
</tr>
<tr>
<td>_____ Hepatitis A.</td>
<td></td>
</tr>
<tr>
<td>_____ Meningococcal, also known as Meningitis.</td>
<td>_____ Varicella also known as chicken pox.</td>
</tr>
</tbody>
</table>

Explanations (for example the reason your child did not have a certain vaccine)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
**Doctors, Dentists, Therapists, Hospitals, Home Health Agencies**

Put a 1, 2, or 3 next to the names of the doctors you want called first, second and third.

<table>
<thead>
<tr>
<th>Doctors (primary and specialists)</th>
<th>Specialty (for primary care provider write in “primary”)</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
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</table>

**Dentist:**
**Hospital:**
**Home Health Agency:**

**Important Past Illness and Medical Condition History** (Past illness, surgery and anesthesia complications. Important baseline findings and key test results. Include dates.)

- **AVOID** these medical procedures:
  
  ______________________________________________________

- Past illnesses and hospital stays (and dates):
  
  ______________________________________________________

- Past surgeries and anesthesia complications (and dates):
  
  ______________________________________________________

- Key baseline findings and test results (and dates):
  
  ______________________________________________________
Checklist for Equipment, Supplies, and Assistive Technology

Use this checklist to think about your child’s medical equipment, supplies and technology.

<table>
<thead>
<tr>
<th>Eye Glasses or contact lenses</th>
<th>Adapted phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing aids and hearing aid batteries</td>
<td>Adapted computer</td>
</tr>
<tr>
<td>Implants, orthotics and prostheses</td>
<td>Oxygen (flow rate?)</td>
</tr>
<tr>
<td>Eating and drinking utensils or aids</td>
<td>Dentures or orthodontic braces or dental devices</td>
</tr>
<tr>
<td>Writing equipment</td>
<td>Monitors:</td>
</tr>
<tr>
<td>Hearing equipment</td>
<td>Sanitary supplies</td>
</tr>
<tr>
<td>Communication equipment</td>
<td>Ostomy supplies</td>
</tr>
<tr>
<td>Wheelchairs and related supplies, battery and charger</td>
<td>Urinary, bowel and incontinence supplies</td>
</tr>
<tr>
<td>Walkers, canes, crutches and related supplies</td>
<td>Ventilator</td>
</tr>
<tr>
<td>Suction equipment</td>
<td>Feeding pump</td>
</tr>
<tr>
<td>Dialysis equipment</td>
<td>Diabetes kit</td>
</tr>
<tr>
<td>CPAP machine</td>
<td>Nebulizer</td>
</tr>
<tr>
<td>Other:</td>
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</tbody>
</table>

Questions for your equipment or supply vendor:

- Is there other equipment we could use if the usual equipment fails or there is no power? Is there portable equipment? Battery operated equipment?
- Would a DC inverter be useful? DC inverters convert DC current into conventional AC electricity that runs lots of things in the home. You might use a DC inverter to charge a device with a car cigarette lighter, for example. Check with the vendor before buying an inverter to make sure you buy the right one.
- Can the vendor bring extra supplies if bad weather or another emergency seems likely?
- How should the extra equipment be cleaned? How should it be maintained?
- Does the vendor have a plan to refill or replace equipment or supplies lost due to an emergency?
| Leave blank |
Tip Sheet: Keep Spoken Instructions Simple

During an emergency you may need to very quickly tell an emergency responder or shelter worker the key information they will need to know about your child.

Think about your child’s “elevator story.” If you were riding in an elevator with someone else and had just a few minutes to tell him or her the most important emergency information about your child, what would you say? This might be similar to the information you have written in the Critical Information Box on the Emergency Information Form.

Mark Corr, the Police Chief in Lexington, Massachusetts, encourages families to “script” three or four lines in advance. Be ready to quickly tell first responders on the scene about your child’s needs. Think about how to gain the first responder’s attention and provide key information for the responder to help your child. Chief Corr recommends against long, detailed explanations at the scene. In planning the “script,” think about how much detail is necessary. Think about the best way to convey information out loud without using complicated medical terms.

Examples of what mom, dad, a guardian or other responsible adult could say (and could teach a child to say if he or she is able):

- “This is Bill, my 13 year old son. I am his mother, Ellen. There is no power in the neighborhood. Bill has chronic lung disease and needs power for his oxygen equipment before we can evacuate.”

- “My daughter Elaine is autistic and won’t leave the building with the fire alarm sounding. I am her father. If we touch her now she will fight us.”

- “Take Tanya’s communication device. It’s on the table next to the wall in the living room.”

- “The traditional firefighter’s carry can harm my son Juan because of his breathing problems. Carry him by….”

- “Omar is non-verbal. He can’t speak but he can hear and understand simple information and short sentences. He can point to basic single words if you write them down.”

- “You will have to carry Judy out. She can’t walk by herself and the ramp is blocked so she can’t use her wheelchair. I will fold up her wheelchair and follow you.”

- “Jenna is blind and will need to hold on to you to walk. Take her left arm just above the elbow and she will follow you out of the house, walking slightly behind you.”

- “We have important medication in the fridge, on the second shelf, that you need to take when we leave.”
Special Needs Registries

Some MA cities and towns keep lists of people with disabilities who need extra help during emergencies. These lists may be called “Special Needs Registries.” They may also have other names. These lists tell local emergency responders someone’s likely needs before an emergency happens. The information helps responders plan for and meet emergency needs.

You decide whether or not to take part in a Registry.

Each town decides whether or not to have a Registry. Each town also decides how to set up and use its Registry. A Registry may be a simple paper list of residents with disabilities who need extra help during emergencies. Or a Registry may be an Internet-based database with lots of information.

A Registry may or may not relate to the 9-1-1 emergency phone number.

Each town decides how people sign up. Each town may ask for different information on its sign up form. Some towns ask for lots of information. Some towns ask for less information. Contact your police or fire department or town hall to take part in your local Registry. Follow directions on the form to fill it out. Then return it to your town. Remember to update the form as your child’s needs change or if you move.

State Disability Indicator Form

MA also has a state-wide form, called the “State Disability Indicator” form. This form may be filed with your town. The form lets the town know that someone in the household has a disability.

You decide whether or not to fill out and file the Indicator form.

The Indicator form relates to the 9-1-1 emergency phone number.

Once the form is filed, a brief message appears on the 9-1-1 operator’s computer in response to a call from your home. The operator shares this information with responding police, fire or emergency services.

The 9-1-1 operator will know if someone in the home is on life support. He or she will know if that person has mobility impairment. He or she will know if that person is blind, deaf or hard of hearing or uses a TTY teletypewriter. He or she will know if that person has a speech or cognitive impairment. The operator won’t know any more details.

You may download the Indicator Form from the internet.
You may also print and fill out the copy below. Follow the directions on the form to fill it in. Then return it to your town’s police, fire or emergency services. Remember to update the form as your child’s needs change or if you move.
Leave blank
DISABILITY INDICATOR FORM
Important Information and Instructions

You are required to complete this form if you want your police department, fire department, or other emergency agency to know about you when you call 9-1-1 in an emergency.

*PLEASE NOTE: IT IS IMPORTANT TO SUBMIT A NEW DISABILITY INDICATOR FORM UPON CHANGE OF SERVICE PROVIDER, TELEPHONE NUMBER, OR ADDRESS.*

When your 9-1-1 call is answered at your local Public Safety Answering Point, the 9-1-1 system automatically displays your name, address and telephone number on the dispatcher’s screen.

At your request, codes will be displayed on the dispatcher’s screen that will identify the disability indicators that have been reported for you or someone living with you at your address. These codes will help the dispatcher at the 9-1-1 Public Safety Answering Point to communicate with the caller and provide useful information to your responding public safety agency.

The information is confidential and will only appear at the dispatcher’s location when a 9-1-1 call originates from your address.

The information you provide for input to the 9-1-1 system will remain until you request a change or make a request to have it removed. It is your responsibility to notify your 9-1-1 Municipal Coordinator when there is a change in the information described on this form. When there is a change, complete another form and send it to your 9-1-1 Municipal Coordinator.

If the disability indicator form is not completed properly, the information will not be entered into the 9-1-1 system.

When filling out the form, be sure to:

1. Give your telephone number, name, and address
2. Check the box or boxes
3. Sign and date the form
4. Return the form to your 9-1-1 Municipal Coordinator for processing

Any questions should be referred to your 9-1-1 Municipal Coordinator at:

Name: ________________________________
Telephone Number: ____________________

9-1-1 MUNICIPAL COORDINATORS:
RETAIN ORIGINAL FOR YOUR RECORDS All forms must be signed by both parties or it will be returned.
Fax all disability indicator forms to Verizon 9-1-1 Database Management at 1-800-839-6020
9-1-1 Disability Indicator Form-Individual Record

The filing of this document with your 9-1-1 Municipal Coordinator will alert public safety officials that an individual residing at your address communicates over the phone by a TTY and/or has a disability that may hinder evacuation or transport. This information is confidential and will ONLY appear at the dispatcher’s location when a 9-1-1 call originates from your address.

*PLEASE NOTE: IT IS IMPORTANT TO SUBMIT A NEW DISABILITY INDICATOR FORM UPON CHANGE OF SERVICE PROVIDER AND ADDRESS.*

Telephone Number: Area code (____) __________________________ Voice TTY

Telephone Service Provider ________________________________

Name: ________________________________

Address: ________________________________

Town & Zip code: ________________________

Please check approved designations for inclusion in the 9-1-1 Database to assist public safety dispatchers in responding to an emergency at your address: Any changes should be communicated to your 9-1-1 Municipal Coordinator promptly.

Check all that apply to indicate that someone at the address:

☐ “LSS” Life Support System: has equipment required to sustain their life.
☐ “MI” Mobility Impaired: is bedridden, wheelchair user or has another mobility impairment.
☐ “B” Blind: is legally blind.
☐ “DHH” Deaf or Hard of Hearing: is deaf or hard of hearing.
☐ “TTY”: communication via the phone may be by TTY.
☐ “SI” Speech Impaired: has a speech impairment.
☐ “CI” Cognitively Impaired: is cognitively impaired.
☐ PLEASE REMOVE any designation presently on file.
☐ PLEASE CHANGE existing designators to those shown above.

NOTICE: By initiating this document I understand that I am responsible for notifying my 9-1-1 Municipal Coordinator of any changes with regard to the status of the above disability indicator(s). I further agree, I will indemnify, defend and hold the State 911 Department, Verizon, my public safety dispatch location and municipality harmless from and against any claims, suits and proceedings (including attorney fees associated therewith) resulting from or arising out of the initial provision or updating of this information.

I understand this information will remain as part of my 9-1-1 record until such time as I notify my 9-1-1 Municipal Coordinator to changing or delete the same.

Signed: ________________________________ (Customer) DATE: ____________________

Signed: ________________________________ (Municipal Coordinator) DATE: ____________
Section 2. Emergency Communication and Connections

Staying Connected When Disaster Strikes

Families want to stay together when disaster strikes. They want to reconnect with each other if they get separated. Staying connected with your family will reduce stress and provide support. Staying connected will speed disaster recovery.

Families challenged by disability may need extra help and support during emergencies. Emergency responders might not reach your family right away. *History tells us that often friends, neighbors and co-workers help first in an emergency, before emergency responders arrive.*

Remember to Think About Siblings and Other Family Members

While this Toolkit focuses on children with disabilities and special health care needs, think about siblings and other household or family members. What kind of plans do they need? Will they need help from the support network? Do you want to keep all the siblings together or do you want different Support Network members to help different siblings?

Develop An Emergency Support Network

Think about the kinds of help your child might need in an emergency. Build a Support Network to help. Support Network members should know you and your child. Train them to help your child. Ask them to check in during an emergency. Make sure they can get to your child if you need them to. Experts suggest having a Support Network of at least 3 people. One person should be from each place where your child spends a lot of time. Have more than one person in the Support Network because at any one time someone might not be able to help. Don’t rely only on personal care assistants (PCAs) for emergency help because a PCA might not always be able to reach you.

Choose Out-Of-Area Contacts

An “out-of-area” contact is someone who lives more than 100 miles away. Pick at least 2 out-of-area contacts. Your family and the Support Network should know how to reach them in an emergency. Local phones may not work during an emergency. It might be easier to call your out-of-area contact than to call someone close by.

Family members should call the out-of-area contact in the order listed on the form. Family members can call if they become lost or separated. They can call if they change plans or locations. They can call if something important happens. Support Network members can call to share information. They can call to say that the family is OK.

Emergency Support Networks

✔ Who should be in a Support Network? Think about friends, relatives and neighbors. Think about people you work with or spend lots of time with. Think about people from your House of Worship. Think about parent support group members or members of other groups. Think
about parents of your child’s friends or people you know from the community. Choose dependable people. Pick people who are physically and emotionally able to help. Pick people who can get to your child in an emergency. They don’t have to be the people that you are closest to.

✓ Tell your Support Network about your child’s likely emergency needs. Tell them where emergency supplies are stored. Show them how to use your child’s equipment. Share your child’s Emergency Information Form. Share the Household Communication and Connection Plan.

✓ Think about giving a trusted person an extra key to your home.

✓ Let your Support Network members know about each other and your out-of-area contacts. Ask them to contact each other during an emergency. Put it in writing.

✓ Members of your Support Network may also have emergency or other support needs. Think about the ways that your family might be of help to them.

**Communicating During And After An Emergency**

✓ Communication may be hard during emergencies. **Cordless landline phones won’t work without electricity.** Old-fashioned corded phones that plug into the wall don’t need electric power. These phones will work when there is no power, if the phone lines are working. During some emergencies, cell phones don’t work when circuits are overLoaded. But text messaging may still work at that time.

✓ Think about how to contact your Support Network if the phones and electric power are out. How will you let them know that you and your child are OK? Let them know about the effects of the disaster on your family. Tell them about the family plans for evacuation and for sheltering at home. Ask them to touch base with your out-of-area contacts.

✓ Let your Support Network know when your family is going out of town.

✓ Each household member should know how to contact other household members, the Support Network and out-of-area contacts. They might put the information in a wallet. They might keep it in a school bag. Be sure household members have coins or a prepaid phone card if they will need to use a pay phone. And keep a copy of the Household Communication and Connection Plan in your “To Go Bag.” (See Section 4, Sheltering Outside Your Home more information.)

✓ Some families share their Communication and Connection Plan using social networking or other tools. QuickShare has an online form that lets you to create email text with emergency information to share with others. To learn more about QuickShare go to [http://ready.adcouncil.org/beprepared/quickshare.html](http://ready.adcouncil.org/beprepared/quickshare.html)
Facebook is another social networking tool that some families use to share emergency information. To learn more about Facebook go to http://www.facebook.com/

Note: The authors do not endorse specific social networking tools. Each family must decide for itself if these tools are right for them.

Reuniting

Pick two places to meet if your family becomes separated. One place might be right outside your home in case of a sudden event like a house fire. The other place might be outside your neighborhood in case you can’t stay at home.

The Red Cross Safe and Well website is an online tool to share short standard messages with your family, Support Network and out of town contacts during an emergency. https://disastersafe.redcross.org.

The U.S. government runs the National Emergency Family Registry and Locator System during big disasters to help family members find each other. https://asd.fema.gov/inter/nefrls/home.htm

The National Center for Missing and Exploited Children runs the National Emergency Child Locator Center during certain disasters to help find lost children. http://www.missingkids.com

To Fill Out

✓ Household Communication and Connection Plan. The form has space to write down family member contact information. There is space for listing Support Network members and out-of-area contacts. There is also space for service contacts.

Each family may decide if this form is right for them. They may choose to leave some or all parts of a form blank or to make their own forms. Families must make sure that any forms they fill out have accurate information about their child.

Tip Sheet

• How To “ICE” Your Phone. Instructions for setting cell phone In Case of Emergency (ICE) contact information. Emergency responders have been trained to look for this information if they come to help you.

More Info

✓ Emergency Communication Aids (from the Institute on Disabilities, Temple University). Emergency communication boards for people who are deaf, hearing impaired or who have a speech disability.
Leave blank
The ________ Household Communication and Connection Plan

## Household Contact List

<table>
<thead>
<tr>
<th>Household Members</th>
<th>Home and Work Address (day care; school, day or work program name and address)</th>
<th>Work and Home Phone Numbers (cell, landline, pagers)</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household Head:</td>
<td></td>
<td>Home:</td>
<td>Home:</td>
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<td></td>
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<td>Work:</td>
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<td></td>
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<td>Cell:</td>
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<td>Household Head:</td>
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<td>Home:</td>
<td>Home:</td>
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</tbody>
</table>
## Local Support Network Contacts and Out-of-Area Contacts

<table>
<thead>
<tr>
<th>Local Support Network Contacts</th>
<th>Home and Work Addresses</th>
<th>Work and Home Phone Numbers (cell, landline, pagers)</th>
<th>Email</th>
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</thead>
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<td>1.</td>
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</tbody>
</table>

### Out-of-Area Contacts’ Names (at least 100 miles away)

| 1. | | |
| 2. | | |
### Emergency Services Contacts

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Phone and Email</th>
<th>Contact Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Police (Emergency)</td>
<td>9-1-1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Police (Non-emergency)</td>
<td></td>
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<td></td>
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<tr>
<td>Fire Department</td>
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<tr>
<td>Ambulance or Emergency Medical Service</td>
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<td></td>
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<tr>
<td>Local Emergency Manager*</td>
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</tbody>
</table>

*Some towns may have an emergency manager and some may not.

### Utility and Service Company Contacts

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Phone and Email</th>
<th>Contact Person</th>
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</thead>
<tbody>
<tr>
<td>Water and Sewer:</td>
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<tr>
<td>Electric Company:</td>
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<td>Gas Company:</td>
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<td>Phone Company:</td>
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<tr>
<td>Cable/Internet Company:</td>
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<tr>
<td>Electrician:</td>
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<tr>
<td>Plumber:</td>
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<tr>
<td>Contractor:</td>
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<tr>
<td>Landlord/Building Maintenance:</td>
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</tbody>
</table>
Insurance Information (auto, home, life)

<table>
<thead>
<tr>
<th>Name</th>
<th>Policy Number and Other Information</th>
<th>Phone Number</th>
<th>Website/Email</th>
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</thead>
<tbody>
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</tbody>
</table>

For safety you may not want to write down your policy number. But you may want to write down key phone numbers and emails. Your insurance company may be able to look up your policy number if you give them your contact or other information.
Tip Sheet: How to “ICE” Your Phone

ICE means In Case of Emergency

Your cell phone may be able to help emergency responders identify you and contact your family during emergencies or disasters.

Your cell phone Contact List may already have a place for you to program In Case of Emergency numbers. Or, you can program your cell phone Contact List with the code word ICE (In Case of Emergency). Do this by adding ICE as the name of one of your contacts.

Here’s how:
1. Open your cell phone’s Contact List. Check whether ICE is already an entry or if there is a symbol like the Red Cross symbol.
2. If you see ICE or the Red Cross symbol select it. Then enter the names and phone numbers of your emergency contacts.
3. If you don’t already have an ICE contact, start a new contact. Enter the word ICE, with the names and phone numbers of your emergency contacts.
4. To list more than one contact, name the entries ICE1, ICE 2, ICE 3, etc.

   Example:
   ICE 1: Husband-Richard
   ICE 2: Mother-Rose
   ICE 3: Son-Danny

Emergency responders know to look for the codeword ICE when they turn on your phone. They can then call your emergency contacts if they need to.
Section 3: Sheltering At Home

Families may need to stay at home during an emergency.

Emergency Supplies

Experts suggest keeping 3 days’ worth of supplies in case you are stuck at home. See the “Emergency Supplies” Tip Sheet below for more info.

Power Loss

Power loss can happen during many kinds of emergencies. Children with disabilities who need technology to stay healthy or calm may find power loss a challenge.

Think about your child’s emergency technology needs. Think about a need for backup power sources.

Does your child:

☐ Depend on life-sustaining technology? Examples include oxygen, ventilators, IVs, apnea monitors or other equipment.
☐ Have medicines or supplies that must be kept in a refrigerator?
☐ Use a power wheelchair or scooter?
☐ Have trouble with very hot or cold temperatures?
☐ Rely on videogames, a computer, TV, DVDs or videos to stay calm and feel in control?

If so, think about backup power sources.

Backup power sources:

☐ Ask the equipment vendor about potential back up power sources. Ask if you can use a car battery or car charger for backup power.
☐ Think about a cooler chest with dry ice for medicines that need to be kept cold. Think about a small battery powered refrigerator.
☐ Think about paper communication boards as back up for an electronic communication device.
☐ Think about buying a generator. Stores like Home Depot® or Lowe’s® sell them.
☐ Think about hand held battery operated games, small radios, or a portable DVD player for calming your child or keeping her busy.
☐ Think about a second battery for your portable computer.
☐ Think about a crank radio or battery-powered radio to stay informed during a power loss. Make sure the radio is small enough to take with you.
☐ Think about a manual wheelchair as back up for a power wheelchair. See MassMATCH to learn more about used manual wheelchairs. http://www.massmatch.org/ Keep a “patch kit” for wheelchair tire nicks.
Think about a battery checker to test batteries. They cost about $15 at a store like Radio Shack® or Sears®.

Think about the different size batteries you may need. Store extra batteries.

Utilities

You may need to turn off utilities (water, gas, oil, electric power) during an emergency. Know where your utility shut-offs are. Learn how to safely turn off water, gas, oil and electric power. See Turning Off Utilities below. Contact your utility company for more information. According to experts, if you turn the gas off a professional must turn it back on. Don’t try to turn it back on yourself.

Shelter-in-Place

Some emergencies can send small pieces of “junk” into the air that might be bad to breathe. If this happens emergency officials might tell you to “shelter in place” at home. See Clean Air below to learn about sealing off rooms, if needed. See Purifying Household Water to learn about keeping your water safe.

To Fill In:

✔ Comfort Items Checklist. A list of your child’s comfort items.

Each family may decide if this form is right for them. They may choose to leave some or all parts of a form blank or to make their own forms. Families must make sure that the forms they fill out have accurate information about their child.

Tip Sheets:

• Emergency Supplies. Tip sheet about emergency supplies for home use, based on materials from the Cambridge, MA, Public Health Department.

More Info:

➢ Supplies:
  o Set Your Clocks Check Your Stocks Get Ready Recipes (from the American Public Health Association). No-cook recipes that don’t need water.

➢ Power Loss and Generators:
  o Power Loss (from the Washington Military Department and Washington State Department of Public Health). Fact sheet about power loss and keeping food safe.
o **Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices** (from author June Isaacson Kailes). Guide specifically geared to people with disabilities and special health care needs who use technology.

o **Fact Sheet: Using a Generator When Disaster Strikes** (from the American Red Cross). Red Cross safety tips about using a generator as an alternate power source.


➢ **Utilities**

  o **Turning Off Utilities** (from the Washington Military Department and Washington State Department of Health). “How to's” for turning off utilities such as gas and water.

➢ **Sheltering-in-Place**

  o **Ready America Clean Air** (Ready.gov). FEMA “how to” about nose and mouth protection and protection from outside air, if needed.

  o **Purifying Household Water** (from the Washington Military Department and Washington State Department of Health). How to store water safely and how to purify water.
| Leave blank |
Comfort Items Checklist

In an emergency, my child would need the following comfort items to make him or her feel safe and calm:

1. ________________________________________________________________________
2. ________________________________________________________________________
3. ________________________________________________________________________
4. ________________________________________________________________________
5. ________________________________________________________________________
6. ________________________________________________________________________

Consider adding these items to your child’s To Go Bag.

Comfort Item Examples:
- A soft blanket
- A fidget toy
- Favorite doll or character toys
- Favorite video
- Favorite music CD player or MP3 Player
- A favorite handheld game
- Art supplies
- Favorite books or magazines
- Jump rope or other small exercise item
- Small foam toys
- Small balls
- Family photos or photo albums
Leave blank
**Tip Sheet: Emergency Supplies to Keep at Home**

**Food and Water**

Have a 3-day food and water supply for each person in your home. Remember individual diets, medical diets and supplemental Nutrition. Think about pet food.

- **Bottled Water**
  - 1 gallon, per person, per day
  - Store in a cool, dry place

- **Dry & Canned Foods (that don’t need a refrigerator)**
  - Canned fruits, vegetables & meats
  - Manual can opener, plastic eating utensils, paper plates & napkins/paper towels
  - Juice boxes, canned milk
  - Dried fruit, nuts, crackers, dried cereal, cereal bars
  - Baby food and formula
  - Pet food

**First Aid Kit**

Have a First Aid Kit which includes everyday hygiene products as well as items like bandages and prescription medicine. Store extra medicine if you can. Keep extra copies of prescriptions. (See Toolkit Section 1 for more information about your child’s medicine.)

- **First Aid Materials**
  - Bandages, gauze, rubbing alcohol, antibiotic ointment, thermometer
  - Medical gloves and tape, scissors
  - Pain reliever

- **Health Products**
  - Soap, toilet paper, tooth paste, toothbrush, feminine hygiene supplies, moist towelettes, garbage bags and twist ties

**Tools & Special Items**

- Flashlights
- Battery-powered radio
- Extra batteries (not rechargeable)
- Old fashioned corded phone (because cordless phones will not work when power is out)
- Tools you might need to turn off utilities (for example, a wrench to turn a tight knob)
Emergency Readiness Toolkit for Parents of Children with Disabilities and Special Health Care Needs

☐ Whistle to signal for help
☐ Important documents such as birth certificates and bank account numbers; extra cash

Other Tips

✔ Building your supplies doesn’t need to cost a lot. Start with supplies you already have and build your supplies over time. Think about less costly items. Canned beans are an inexpensive source of protein, for example.

✔ Check food for spoiling before you eat it. Date foods and rotate them as needed. Check food expiration dates printed on the container. Experts recommend rotating bottled water every 6 months. Don’t stock salty foods; they can make you thirsty.

✔ Check your stockpile once or twice a year. Put it where you won’t be tempted to “borrow” from it.

✔ Other supplies you might want to keep ready in a special and easily accessible place:
  - Extra clothing and footwear
  - Blankets or sleeping bags
  - Gloves and long underwear
  - Items to divert your children like books and games/toys that don’t require electricity (e.g. Legos®, blocks, dolls, stuffed animals, art supplies, hand held battery operated games)
  - Home fire extinguisher
  - Inventory of important and valuable things in your home (this can be a written list, photos or video)
  - Paper and pencil/pen
Section 4: Sheltering Outside Your Home

Deciding To Stay Or Go

The U.S. Government on its ReadyGov website, http://www.ready.gov, suggests you leave your house if you feel it is not safe or if local responders suggest or order you to leave. Think about friends or family to go to. Think about a hotel or motel where you might stay. Experts say to think of a public shelter as a last resort. Shelters won’t be as comfortable as a friend or relative’s home. Shelters are meant to be short-term places to stay if you have no other choice.

Public Shelters

MA public shelters may be in different buildings, such as schools or churches. Towns often decide which shelter to open right before, or during, an emergency. Shelter opening times may be broadcast on local TV and radio stations. To learn about your town’s potential shelters, contact your local police, fire station or town hall. For a list of many MA shelters, go to http://www.dpcma.org/Issues/tabid/705/articleType/ArticleView/articleId/46/MEMA-Shelter-List.aspx. (This list includes information about accessibility. But this list does not seem to include shelters in Boston, Worcester or Springfield. For shelters in these cities, contact the local City Hall.) While the law requires that public shelters and shelter services be accessible to people with disabilities, this might not always be the case.

Shelters can be stressful. Shelters are “bare bones,” says Lisa Jackson, MA Medical Reserve Corps. They can be crowded and noisy. People have little privacy. Shelters usually have heat, electric power, toilets, showers, telephones, meals, and cots to sleep on. Shelters provide basic medical and mental health care. You do not need to stay in a shelter to use shelter services.

Shelter staff, including medical staff, may not know about your child’s disability. You may need to talk to shelter staff about your child’s unique needs. You may want to give your elevator speech. You may want to share your child’s Emergency Information Form.
Shelters meant for the general public can usually meet most people’s needs. But sometimes the state Department of Health opens shelters for those with more complex medical needs. During an emergency, your town’s fire, police and Emergency Medical Services would know about a shelter for those with complex medical needs. Ask them if you and your child should go to this kind of shelter, based on your child’s needs.

“To Go” Bag

Pack 3 days worth of supplies in a “To Go” bag if you leave your home. See the Tip Sheet below for more info about what to take with you.

Transportation

Think about 2 ways out of your home. Think about 2 routes to get to your next location. Do you have your own transportation if you leave your home? If not, plan for backup transportation from a friend or relative. Don’t just rely on public transportation.

Getting Ready to Leave Your Home

- Turn off utilities. Unplug electronics.
- Protect windows and doors from possible water damage.
- Tell Support Network and out-of-state contacts.
- Leave a note as to where you are going on the kitchen table, counter or refrigerator.
- Check your transportation.
- Ready your emergency evacuation device (like an evac chair) if you have one to get your child out of the house.
- Update photos of valuables, if you have time.
- Review reunion plans. Know where you will meet up with others in your family. See Toolkit Section 2.

Evacuation Equipment for Children with Disabilities

Some families may want equipment to use to move their child out of the house. They may want to advocate with their landlord (in a big high rise), their child’s school, workplace or with their child’s service providers or health care centers to have this equipment. Two websites with information about this equipment are:

- http://www.safescape.org/ Project Safe Escape
- http://evac.icdi.wvu.edu/accomm/index.htm Project SAV-EVAC

Returning Home

- Ask your local town hall or emergency responders if it is safe to come back home.
- Check for home hazards like damage to the building or damage from power loss. Check for chemical, flood or other damage.
- Review information in Section 6 about coping with emergencies.
Tip Sheets

- **“To Go” Bag:** Evacuation kit supply list, based on materials in “Emergency Preparedness Begins At Home,” DVD from the Advanced Practice Center for Emergency Preparedness, Cambridge, MA Public Health Department.

- **Protecting Your Federal Benefits in Case of Emergency:** How to receive federal benefits with electronic deposit. Benefits can be deposited in your bank if there is no mail delivery or if you leave your home.
Tip Sheet: “To Go” Bag

Pack lightly. Plan to be out of your home for 24 to 48 hours (1 to 2 days). Label all items.

☐ Change of clothing.

☐ Bottled water for 3 days for each family member. Snack food such as cereal bars. Special food and formula.

☐ Prescription medicine in original bottles. Medical equipment and supplies. Experts suggest having 14 days worth of medicine and equipment, if possible. Keep a copy of prescriptions. Extra batteries and equipment chargers.


☐ Items to keep children busy. Think about craft or art projects. Comfort items such as a favorite toy, game or fidget.


☐ Key documents.
  o Health insurance cards. Insurance information for home, apartment and car. Medicare and Medicaid cards.
  o Emergency medical information for your child. Copy of Individualized Educational Program (I.E.P.) or Individualized Service Plan (I.S.P.).

☐ Flashlight and extra batteries.

☐ Battery operated radio.

☐ Date book. Paper and pen or pencil.

☐ Blankets and pillows if going to a shelter.

☐ Shelters often don’t permit smoking. Smokers might bring nicotine gum or patches.

☐ Pack the forms from this Toolkit: Emergency Information Form, Medical Information Form, Household Communication and Connection Plan, Comfort Items List.
- Pet or service animal supplies. Pack current vaccine info. Remember food and water. Remember feeding dishes and bedding. Bring a pet carrier with label. Shelters generally allow service animals but not pets.

- Current family photo. Use the photo for comfort or to help identify family members who get separated.
Tip Sheet: Protect Federal Benefits in Case of Emergency

The U.S. government urges people with disabilities to get electronic federal benefit payments. This means the government directly deposits benefit checks in your bank account. No check comes through the mail. Social Security is one benefit someone might receive this way.

Go to http://www.ready.gov/America/getakit/disabled.html to learn more. The website says, “Switching to electronic payments is one simple, significant way people can protect themselves financially before disaster strikes. It also eliminates the risk of stolen checks.”

The website describes 2 ways to receive electronic federal benefits:

- “Direct deposit to a checking or savings account is the best option for people with bank accounts. Federal benefit recipients can sign up by calling (800) 333-1795 or at www.GoDirect.org.
- The Direct Express® prepaid debit card is designed as a safe and easy alternative to paper checks for people who don’t have a bank account. Sign up is easy – call toll-free at (877) 212-9991 or sign up online at www.USDirectExpress.com.”

Each family should decide whether receiving federal benefits electronically is right for them.
Notes
Leave blank
Section 5: When Children and Parents Are Not Together

You and your child may not be together when a disaster strikes. You might be at work and your child might be at school. He or she might be at an after school program or with another caregiver. Your older child or teen might be home alone.

You can plan for these situations. Talk to your child about emergencies and staying home alone. Talk to your child’s school and service provider about their own emergency plans. Share with them the plans you have made for your family.

Talking to Your Child’s School

In 2005 a Maryland high school evacuated due to a fire. Everyone left the building except two students in wheelchairs. The boys were left in a second floor stairwell. One of the boys was reported to have become very upset when he realized that he and his friend were left behind. The boys’ parents successfully advocated with the school system to change its emergency plans.

You might talk about your child’s emergency plans and procedures at an Individualized Educational Program (IEP) meeting. (Some states include emergency plans as a separate part of the IEP form.) Think about sharing this Toolkit’s Emergency Information Form with the school and with your child’s school transportation company.

Questions to Ask your Child’s School

A certain staffer or teacher may have responsibility for emergency planning at school. He or she may not have the answers to all of your questions the first time you ask and you may need to have a follow up meeting. Think about posting a reminder to yourself to follow up. There are a number of key questions to ask.

☐ Does the school have an emergency plan? If so, who is responsible for making and carrying out the plan?

☐ What is the plan for your child? This is particularly important if she or he has a physically disability or would have problems moving quickly in an emergency.

☐ Communication about emergencies.

  o  Is there a phone number the school activates in emergencies?
  o  Does the school put emergency information on its website?
  o  How will parents learn if their child has been evacuated?
  o  How will parents and children contact each other in emergencies?
  o  How will students inside and outside of the school learn that an emergency is happening?

☐ Evacuation plans and sheltering-in-place plans
Emergency Readiness Toolkit for Parents of Children with Disabilities and Special Health Care Needs

- What are the school’s evacuation plans? Where will your child be evacuated to?
- Does the school plan to evacuate all students? Some schools may plan to move students in wheelchairs to “areas of refuge” where they will wait for emergency responders.
- What are the school’s shelter-in-place plans? Is the shelter-in-place space accessible? Are there accessible bathrooms nearby?
- Does the school have supplies on hand to meet the basic needs of everyone likely to be inside during an emergency?
- Does staff have training on handling children’s likely emotional issues during an emergency?
- Does the school have plans for additional staffing in case staff leave the building or don’t come to work during an emergency?

□ Reuniting with the Family

- What plans has the school made to promptly reunite parents and children?
- Where is the site for reuniting?
- What identification will parents need to bring with them to pick up their children?
- How should parents arrange for another adult to pick up their children if they can’t come to the school?

□ Transportation

- Do all school bus drivers have 2 way communication devices? Do they know how to learn about emergencies and call for instructions and help?

□ Your Child’s Emergency Needs

- Will the school store emergency supplies for your child? These might include medicine, medical supplies, food for special diets, toothbrush and toothpaste, change of clothes, comfort items and things needed for sleep.
- How will your child be evacuated from the building? Will he or she need help? If your child uses a wheelchair will he or she be evacuated in the chair or carried? Is it safe for your child to be carried with the traditional fire fighter’s carry?

□ How has the school evaluated its plan and decided that it works well?

Talking to Your Child’s Service Providers

Talk to your childcare and other service providers about your family’s emergency plans.

□ Ask about your service provider’s emergency plans for your child. How will they continue to provide services in an emergency? What services will and won’t be available? Do they have other staff who will take over in case the usual staff is not available?

□ How does the provider plan to contact you in an emergency?
Think about asking that the provider’s service plan for your child address emergency issues. For example, if your child has an Individualized Service Plan (ISP) through the MA Department of Developmental Services, consider having emergency readiness issues and plans listed in the ISP.

Talking to Your Child About Staying Home Alone

- Does your child know his or her address and phone number?

- Does your child have some form of identification with him or her all the time?

- Does your child know how to use the phone to call you? To call 9-1-1 (and when to call)? To call your Support Network and out-of-area contact? Does your child know how to email you?

- Does your child have a personal alarm system to call for help? Does he or she know how it works?

- Does your child know the safest place to wait in the house until help arrives? Is that place accessible to your child and does it have all of the supplies he or she might need?

- Does your child know who emergency responders are? Does your child know how to ask for help from police, fire, Emergency Medical Services? Does he or she know not to be afraid of or hide from responders?

- Does your child know where a flashlight is and how to use one?

- Does your child know how to describe his or her disability and emergency needs? (For more info go to Section 7 of this Toolkit.)
Section 6: Family Discussions and Coping Techniques

Introduction

Sections 6 and 7 are about family discussions and coping tips. The way you talk to your child about getting ready for emergencies will depend on his or her age, understanding and ability. You may want to use all or part of both sections in your talk. Your older or more able child may want to read Section 7 him or herself.

Talking About Emergency Planning

✓ Tell children that families do things every day to stay safe. They buckle seat belts in the car. They put harmful things out of young children’s reach. Preparing for emergencies is another way to keep the family safe.

✓ Explain what an emergency is. The American Academy of Pediatrics (AAP) urges, “[T]ell children that a disaster is something that could hurt people or cause damage. Explain that nature sometimes provides ‘too much of a good thing’—fire, rain, or wind. Talk about things that could happen during a storm, like the fact that the lights or phone might not work.”

✓ The AAP suggests talking to children about emergencies likely in your area. Teach them related actions to take. Teach them to notice danger signals like smoke detectors and fire alarms, and what to do if they hear them.

✓ Teach your children about the people who can help them during an emergency. Teach them not to be afraid of fire fighters, police, paramedics or other emergency responders.

✓ Teach your children how and when to call 9-1-1. Teach them how and when to contact you if you are away. Make sure they know about the Family Communication and Connection Plan. They should know whom to contact if they get separated from you.

✓ Some children may be able to help get ready for an emergency. They might check emergency supplies. They could learn how to change flashlight batteries. They might pack their own “To Go” bag. Encourage them to help if they can.

Talking to Children When An Emergency May be Coming or Has Happened

✓ Share your family’s emergency plans. Tell them what to expect. Show your children the Household Communication and Connection Plan. You may want to put a copy of the plan in their school bag. Show them how to reach your out-of-area contacts. Teach them who is in your Emergency Support Network and how to contact them. Talk about the family

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evacuation and reunion plan. Talk about the Emergency Information Form. Teach them to describe their disability if they are able. Talk to your children at their own level, based on age and understanding.

✔ Try to stay calm, even though it’s normal to feel scared or worried during an emergency. Parents can cope by: (1) getting accurate information from reliable sources; (2) keeping normal routines; (3) avoiding drugs and limiting alcohol; (3) exercising, eating and sleeping well; (4) staying in touch with friends and family; (5) keeping a sense of humor.

✔ Children pick up parents’ fears and worries. The AAP says, “Children’s fears also may stem from their imagination, and you should take these feelings seriously. A child who feels afraid is afraid. Your words and actions can provide reassurance.”

✔ After emergency children may worry that it could happen again. They may think that someone will get hurt or die. They may worry that they will be separated from their family or left alone.

✔ Experts agree that you should be honest with your child and explain what’s going on. Base the amount of information and detail on your child’s level of understanding.

✔ Limit TV exposure and exposure to the media. Don’t get caught up in the “hype.”

✔ Keep to children’s routines and regular schedules as much as possible.

Review and Practice Your Plan

Review your plan and check supplies every 6 months. Note it in your calendar. Practice an evacuation using 2 routes. Go to your reunion spot. Talk to Support Network members twice a year.

More Info


- Helping Children After a Disaster (from the Washington Military Department and Washington State Department of Health). Children’s behaviors after disasters and ways that parents can help.


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• **Helping Children Cope with Disaster** (from the American Red Cross). Tips from the Federal Emergency Management Agency (FEMA) and the Red Cross. Includes information by age.
Section 7: Family Discussions For Teens and Their Parents

Use this part of the Toolkit to help start a discussion with your teenager.

Teens and Emergency Readiness

“Teens should learn about getting ready for emergencies. They should learn about communicating with first responders. They should learn to advocate for their own emergency needs. It's about independence.” Nate Trull

Nate Trull is a self-advocate and chairperson of the Powerhouse Self-Advocating Group. He works at a restaurant and in a college cafeteria. He trains teen and adult self-advocates with developmental disabilities about emergency readiness.

“I use a wheelchair and have Cerebral Palsy. When I was home alone recently we lost power. A few minutes later, our alarm system started beeping loudly. I couldn’t find a flashlight to see the alarm control panel. I wanted to enter the code to stop the noise. The beeping was getting really loud and annoying. Our phone didn’t work so I couldn’t call my parents. I had to get creative. I noticed that even though the phone wasn’t working, the display screen lit up if I pressed a button. So I brought the phone over to our alarm system. I held the phone up with one hand and used the light to find the right numbers and shut off the alarm. Now I have a flashlight I can reach in my room. I have a phone that will work without electricity. It was easy to get prepared.” Patrick Gleason

Patrick Gleason is a staff writer for the E.K. Shriver Center, University of Massachusetts Medical School. He is studying for a Master’s Degree in Professional Writing.

What Teens Needs to Know

- What is an emergency? What kinds of emergencies are likely in my area?

  An emergency can happen with little or no warning. Emergencies might disrupt daily life or cause property damage. People might need to act quickly to keep themselves safe.

  During an emergency the lights, heat or phone might not work. There might be flooding or storm damage. Your home, street or town might look different. A service provider might not be able to reach you. You might not be able to go to the store to pick up supplies.

  Knowing what to do in advance can make coping easier.

- What do I need to know to keep myself safe in an emergency?
Do you have a copy of your family’s Communication and Connection Plan? Do you know how to reach your parents and other family members in an emergency? Do you have an emergency Support Network? Do you have out-of-area contacts? Do they know how to reach you? Read Toolkit Section 2.

Do you know how to reunite with your family if you become separated? Do you know how and when to use the Red Cross “Safe and Well” website? Go to https://disastersafe.redcross.org.

Do you know the kind of emergency help that you might need? Do you know how to quickly and clearly describe your disability to emergency responders? Can you describe your medicines? Can you give directions about using your equipment? If you use a wheelchair or have a physical disability do you know if the traditional firefighter’s carry is safe for you? Do you have a completed copy of an Emergency Information Form? Read Toolkit Section 1.

Where are emergency supplies kept in your home? Can you find them easily if you are home alone? Read Toolkit Section 3.

Do you know how to ICE your cell phone? To ICE your cell phone means to add “In Case of Emergency” contacts. Read the Tip Sheet in Toolkit Section 2.

Do you know about your school or work site’s emergency plans? See Toolkit Section 5.

More Info

- **Resilience for Teens** (from the American Psychological Association). Tips for teen resilience during hard times, including emergencies.

- **For Parents: Helping Teens Build Resilience After Hurricanes** (from the American Psychological Association). Tips for parents. While geared towards hurricanes, the advice applies for many events.

- **Responding to Stressful Events Helping Teens Cope** (from the Public Health Agency of Canada). Lots of advice about dealing with stress.
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Section 8: Pets and Service Animals

Families with pets or service animals should make an emergency plan for their animals. Shelters generally **allow service animals**. But if the animal is out of control and the owner doesn’t control it or the animal poses a direct threat to others’ health or safety then the animal isn’t allowed in the shelter. Shelters generally **do not allow pets** for health and safety reasons. A new federal law requires state and federal emergency plans to address the needs of people with pets and service animals. Some states are developing pet shelters.

Pets may become lost during emergencies. There are a number of services that help locate lost pets.


Note: The E.K. Shriver Center does not endorse any of these services. Families should decide for themselves if one of these services would be right for them.

More Info

- **Preparing Your Pets for Emergencies Makes Sense. Get Ready Now** (from Ready.gov).
- **Emergency Preparedness for your Service Animal or Pet** (from the American Council for the Blind).
Section 9: Top 10 List of Steps to Get Ready for Emergencies

If you do nothing else to get ready, think about taking 10 key steps.

1. **Hold a Family Discussion.** Talk to your family about emergencies. Pick a date to start getting ready.

2. **Know about Likely Emergencies.** Know what can happen in your area. See the Federal Emergency Management Agency (FEMA) website to learn more. [http://www.fema.gov/hazard/index.shtm](http://www.fema.gov/hazard/index.shtm)

3. **Build a Support Network.** Pick friends, family, neighbors and others whom you might call on for help. Share your emergency plans with them.

4. **Talk to Schools, Care and Service Providers.** Talk to your child’s school, care and service providers about your child’s emergency needs and plans. Ask about their plans.

5. **Find Likely Public Shelters.** Ask your local town hall, police, fire or Emergency Medical Services. Or go to the Disability Policy Consortium website [http://www.dpcma.org/Issues/tabid/705/articleType/ArticleView/articleId/46/MEMA-Shelter-List.aspx](http://www.dpcma.org/Issues/tabid/705/articleType/ArticleView/articleId/46/MEMA-Shelter-List.aspx). (This list does not seem to include Boston, Worcester or Springfield.) Ask about possible shelters in the town in which you work. Write down the information and keep it in your “To Go” bag.

6. **Get Supplies:** Get 72 hours (3 days) worth of emergency supplies that your family might need. Have food, water, hygiene and medical supplies. Have things to distract your child. Keep the supplies in a special place. Make sure all family members know where the supplies are kept.

7. **Fill Out the Forms in this Toolkit:** Fill out the Emergency Information Form and the other forms. Share the forms with your Support Network and 2 contacts outside the state.

8. **Make Your Home Safer:** Make your home safer by installing smoke detectors and a fire extinguisher if you can. Contact your local fire department to learn to use them. Know how to turn off your water, gas, and electricity. Your utility company can show you how.

9. **Get Back Up Equipment:** Think about having “low tech” backups. Your child might use paper communication boards as a backup for an electronic communication device. Think about backup power sources such as a generator or car charger to power a wheelchair battery. Keep extra batteries and chargers on hand. Speak with vendors about backup power.

10. **Build Back Ups Into Your Plan:** Build backups into your plan. Do not depend on only one person, place or process. For example, think of two different hospitals that might meet your child’s needs. If you couldn’t reach one you might go to the other. Think about 2 sources for dialysis treatment. Think about 2 sources for diabetes or other key supplies. Think about 2 different people you could call on for help.
Section 10: Additional Internet Resources and Glossary

Internet Resources

American Sign Language (ASL)

- The Accessible Emergency Information website.  
  http://sites.google.com/site/preparedness4deaf/preparedness-videos  The website has videos on developing an emergency plan and dealing with specific events. There is audio, text and ASL interpretation with the video.

Braille

- The Accessible Emergency Information website.  
  http://sites.google.com/site/preparedness4deaf/braille-format-2  The website has emergency preparedness materials in Braille. Braille files are in .ABT format and .BRL format.

Children

  http://www.homesafetycouncil.org/AboutUs/Programs/pr_wr_w005.asp  Learning activities for elementary school children. Parent information about preparing for emergencies.
- Julia and Carolos Get Ready for Disaster. This is a downloadable and customizable story from  http://californiavolunteers.org/familyplan/plan.html.  The story walks children through many preparedness steps.

Emergency Readiness and Pregnancy


Emergency Readiness at Work

Red Cross

- Prepare Your Home and Family webpage.
  [http://www.redcross.org/portal/site/en/menuitem.d8aaecf214c576bf971e4efe43181a0/?vgnextoid=72c51a53f1c37110VgnVCM1000003481a10aRCRD&vgnextfmt=de fault](http://www.redcross.org/portal/site/en/menuitem.d8aaecf214c576bf971e4efe43181a0/?vgnextoid=72c51a53f1c37110VgnVCM1000003481a10aRCRD&vgnextfmt=default)

U.S. Government (FEMA and Department of Homeland Security) (including information in languages other than English)

- Ready Gov is the U.S. government website about emergency preparedness. The website has information for individuals, families and businesses. There is also information in languages other than English (on the website go to the top left part of the screen for links to information in Spanish, Haitian Creole, Chinese and other languages).
# Glossary of Terms Used in the Toolkit

**Adapted Equipment or Adaptive Equipment.** Items to help with daily living activities. Eating, sleeping, bathing, dressing, moving and communicating are daily living activities.

**Communication Device.** A computerized or battery operated device for communication. The device is used instead of, or in addition to, a voice.

**Communication Plan.** A written plan that lists family members’ names and contact information. The plan also lists names and contact information for key people outside the family. During an emergency families would contact these people to share information.

**Emergency Responder.** Police, fire fighters, emergency medical technicians (EMT’s) and paramedics, and people who work in emergency shelters.

**Evacuation.** Leaving your home or other place during an emergency because emergency responders have told you to leave or because it is not safe to stay.

**Federal Benefits.** National programs that give money to people with disabilities. Examples include Social Security, Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI).

**Federal Emergency Management Agency (FEMA).** FEMA is part of the U.S. Department of Homeland Security. FEMA coordinates the federal government's role in U.S. disasters and emergencies.

**Personal Care Assistant (PCA).** A person who helps someone with a disability with Activities of Daily Living (ADLs).

**“To Go” Bag.** A bag with emergency supplies. A family would take the bag if they left their home in an emergency.

**Service Providers.** State and private agencies that provide services and support to people with disabilities. Examples are the MA Department of Developmental Services (DDS) or a local Arc or similar agency.

**Special Needs Indicators. Special Needs Registries.** Lists kept by some local police or fire departments with the names and likely emergency needs of people with disabilities. Parents who want their children to be listed on a registry list should fill in the registry forms and file them with their local police, fire department or town hall.

**Support Network.** The people that a family can call on for help in emergencies. The family and the Support Network talk to each other before emergencies about the kind of help that may be needed.