AAC and Preparedness, Rescue and Relief Efforts: Ensuring the Safety and Rights of People with Complex Communication Needs

Sarah W. Blackstone, Anne Warrick, Pamela Kennedy
Has anyone here ever been in an emergency situation?

What kind? Natural or human-induced?
Was there any warning?
Were you prepared?
What did you do?
What did others do?
Communication access is a HUGE ISSUE

People with CCN are among most vulnerable

Preparation and planning are key to survival

People with CCN are NOT being considered in disaster planning, training or drills

ISAAC community needs to step up
### Making a difference

<table>
<thead>
<tr>
<th>People with CCN/Those who care about them</th>
<th>First Responders/Emergency Planners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to prepare</td>
<td>Need to raise awareness about needs of people with CCN</td>
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<tr>
<td>Need to “self identify”</td>
<td>Need to work toward needs being considered and addressed at local, regional, national and international levels</td>
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<tr>
<td>Need to be involved in disaster planning, training activities and drills</td>
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<td>Need to advocate</td>
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</table>
Who are vulnerable during a CHE?

- People with speech, hearing, vision impairments that result in CCN
- The very young
- People with limited understanding of spoken language
- People under severe stress or who are confused
- People who do not have access to tools/supports they need
- People with significant cognitive challenges
- People with 2nd language issues
- People with mobility limitations
- People who are sick/ill
People with significant communication challenges
Disaster Preparedness for People Who Have Limited Speech*: Taking Responsibility for Your Safety

* Focus on People with CCN who rely on AAC

- Are you prepared for an emergency?
- Are the people you care about ready?
- Is your “go bag” packed?
- Do you always carry a paper communication display with you?
<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Check List for People with Limited Speech</strong>&lt;br&gt; and Those Who Care About Them</td>
<td></td>
</tr>
<tr>
<td>1. Do you have a support team? Does everyone know what to do?</td>
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<tr>
<td>2. Do you have an evacuation plan in case you need to leave home or work in an emergency situation? Do you know: (a) Where you will go? (b) How you will get there? (c) Who will transport you/come with you? (d) What you will take with you? (e) What your rights are in a shelter?</td>
<td></td>
</tr>
<tr>
<td>3. Is your “Go Bag” packed?</td>
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<tr>
<td>4. Do you have paper (laminated) communication display(s) with you at all times? Do your displays include vocabulary for emergencies? Do you have written instructions about how to communicate with you at all times?</td>
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</tr>
<tr>
<td>5. Do you always carry a copy of your health information in a water proof bag in case of an emergency? Insurance card? Prescriptions? Other critical medical information?</td>
<td></td>
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<tr>
<td>6. Are you prepared to remain at home or work during an emergency? Do you have enough water and food stored for 7 days? A radio with extra batteries? Flashlights with extra batteries? Medical supplies? Enough of your own medicines for 7 days? A way to communicate? A way to call for help.</td>
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</tr>
<tr>
<td>7. If you think, “Never mind….this won’t ever happen to me?” THINK AGAIN. Emergencies can (and do) happen to anyone. Be PREPARED, not sorry.</td>
<td></td>
</tr>
</tbody>
</table>
1. Do you have a support team?

- Train as many people as you can (at least three).
- Put a plan in writing. Practice. Update. Include information about:
  - A. How you will be evacuated, sheltered.
  - B. How you will communicate.
- Prepare Your “Go Bags.” Have all necessary items available.
- Always have a backup plan. Not everyone may be able to get to you.
- If you cannot take advantage of TV, radio alerts because of hearing or vision problems, plan how you will be alerted.

2. Do you have an evacuation plan in case you need to leave home or work in an emergency situation? Do you know:

- (a) Where you will go?
- (b) How you will get there?
- (c) Who will transport you/come with you?
- (d) What you will take with you?
- (e) What your rights are in a shelter?
3. Is Your Go Bag Packed?
4. Do you have paper (laminated) communication display(s) with written instructions with you at all times?

- Keep a copy in your ‘Go Bag’
- Keep them with you
- What vocabulary?
- Example: Pamela Kennedy examples
5. Medical information

- Insurance card? Prescriptions? Other critical medical information?
- Waterproof bag/container.
- Emergency contacts, doctor’s names, instructions for activities of daily living, allergies, inhalers and medications
### Sample Emergency Health Information


<table>
<thead>
<tr>
<th>Date:</th>
<th>Updated:</th>
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</table>

#### Name
- **Address**
- **City**
  - **State**
  - **Zip**

<table>
<thead>
<tr>
<th>CONTACT METHOD</th>
<th>HOME</th>
<th>WORK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phone:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Cell:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fax:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>E-mail:</strong></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Birth Date</th>
<th>Blood Type</th>
<th>Social Security No.</th>
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<table>
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<tr>
<th>Health Plan:</th>
<th>Individual #:</th>
<th>Group #:</th>
</tr>
</thead>
</table>

#### Emergency Contact:
- **Address**
- **City**
  - **State**
  - **Zip**

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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fax:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>E-mail:</strong></td>
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</tbody>
</table>

#### Primary Care Provider:
- **Address**
- **City**
  - **State**
  - **Zip**

<table>
<thead>
<tr>
<th>Phone</th>
<th>Fax</th>
<th>E-mail</th>
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</thead>
</table>

<table>
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<tr>
<th>Disability / Conditions:</th>
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<table>
<thead>
<tr>
<th>Medication:</th>
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<table>
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<tr>
<th>Allergies:</th>
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<table>
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<tr>
<th>Immunizations</th>
<th>Dates</th>
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<table>
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<tr>
<th>Communication / Devices / Equipment / Other:</th>
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</table>

Excerpted from: Be a Savvy Health Care Consumer, Your Life May Depend on It! by June Isaacson Kailes. For more information about the guide, contact jik@pacbell.net or visit [http://www.jik.com/resource.html](http://www.jik.com/resource.html).
Billy Builds a Kit

by Pam Kennedy
Billy Smith goes to Riverdale Grade school.

Billy uses a device to help him talk.

He points to a symbol on the device's screen.

Each symbol picture stands for a word.

The device's computer speaks the word for Billy.

One day, Billy's teacher asked the class a question.
Billy Smith goes to Riverdale Grade School. Billy uses a device to help him talk. He points to a symbol on the device’s screen. Each symbol picture stands for a word. The device’s computer speaks the word for Billy.
One day Billy’s teacher asked the class a question. She asked how many emergencies they could name. Billy named: fire, flood, tornado, earthquakes and many more. The teacher asked, “Are you ready for an emergency?”
Billy did not know what to do in an emergency. The teacher gave the class some homework. She gave the symbols he would use in an emergency. She asked each child’s family to make an emergency kit.
Billy was excited. He wanted his family to be safe in an emergency. He looked at the teacher’s list. The list had: food, water, medicine, blankets, a flashlight, radio and batteries.
Billy used his new symbols to talk to his family. He could also use the symbols in a real emergency. If he was alone, he could use them to talk to rescuers. He could use them to talk to doctors. He could tell everyone what help he needed.
Billy’s family saw they had a job to do. They needed to make an emergency kit. They gathered everything on the teacher’s list. They talked about what to do in each emergency. Billy was happy; he knew his family would be safe.
What would you do in an emergency? Have you and your family talked about emergencies? Do you have an emergency kit ready to go? Get ready for trouble BEFORE it happens. Someday you may be very glad that you did.
The End
First Responders and Emergency Management Personnel

- Firefighters, police, ambulance drivers, nurses, doctors, etc.
- Government officials
- Policy Makers
- Disability advocates
- Organizations and entities: National International, Regional, Local
## Communication Access for People with Limited Speech

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>QUESTION</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>1. Do you know how to communicate with someone whose speech you cannot understand?</td>
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<td>2. Do you know how to get the information you need by asking “Yes/No” questions?</td>
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<td>3. Do you know about speech generating devices (SGDs) and how people use them?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Do you know about communication boards/books/displays and how people use them?</td>
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<td></td>
<td>5. Do you have, or does your facility provide communication displays for people who are unable to be understood using their natural speech?</td>
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#1. Augmentative and alternative communication (AAC) refers to a variety of methods that allow people to communicate when speech is limited.

1. **Alphabet boards.** Letters and words on a board that a person can point to and make words and sentences.

2. **Communication displays with pictures.** Pictures and symbols on a board/display/book that a person can use to express thoughts, feelings, ask questions, etc.

3. **Speech generating devices.** Electronic devices that produce speech output (talk) when a person selects letters, words, pictures or symbols.

4. **Gestures.** Everyone uses gestures. Familiar communication partners can often interpret gestures when a stranger cannot.

5. **Manual sign language.** People who are deaf require someone who knows sign language to act as an interpreter when communicating with hearing people. Other people with communication challenges may also rely on some manual signs.

6. **Interpreters/Translators.** People who can understand a specific language may translate/interpret for others (e.g., sign language, Mandarin, Spanish). Family members and friends who are familiar
#2 Communicating with someone whose speech is limited

- Begin by identifying basic communication methods
- After the mode is identified, ask a few basic questions.

#3 Speech Generating Devices (SGDs)

IMPORTANT: To view short video clips about augmentative and alternative communication (AAC) and examples of several children and adults using AAC tools, please go to [http://www.youtube.com/watch?v=Eb_URYj_L_k](http://www.youtube.com/watch?v=Eb_URYj_L_k)
#4 Personal communication displays/boards/books.

#5. Emergency-oriented Communication Displays
Advocates of People with Complex Communication Needs

1. Encourage inclusion of people with CCN in preparedness planning/drills
2. Encourage AAC community to participate
3. Be aware of key laws/policies
4. Develop community outreach
5. Identify transportation issues
6. Identify shelters
Important Steps to Take: International AAC Community

Identify NEEDS

ACTIONS: Working together
Resources

**Websites**

- www.aac-rerc.com
- www.ussaac.org and www.issaac-online.org
- www.news-2-you.com
- www.usdoj.gov/crt/ada/emergencyprep.htm
- www.jik.com/disaster.html
- http://disabilities.temple.edu
- www.fema.gov
- www.redcross.org
- wwwcdihp.org/products.html
  #evac_guide

**Print Materials**

- *Augmentative Communication News*
  v.19#4
- *Billy Builds a Kit*
- Disaster Wheels
- Commercially available communication displays
- Others?
To access this presentation and information provided go to

www.aac-rerc.com

Thanks to the AAC-RERC, USSAAC and News-2-You