



The USSAAC Webinar Series

Tuesday, June 5, 2018
7:00 PM Eastern

People Who Use AAC in Emergencies and Disasters: Tales from the Trenches

Presenters:

Sarah Blackstone, Ph.D., CCC – Co-chair, USSAAC Disaster Relief Committee (DRC)

Amy S. Goldman, M.S., CCC - Technical Assistance Specialist, AT3 Center, Member, USSAAC DRC

Facilitator: Liz Begley, M.A., CCC – Speech Pathology Services, USSAAC DRC

Webinar Logistics



ASHA CEUs – live webcast

- Free - USSAAC members;
\$25 – non-USSAAC members
 - Participant form and instructions on website
 - Can only receive CEUs for live webinar
 - **NOTE: You need to scan and send participant form to smeehan8@ku.edu by June 26, 2018**
- Archived webcasts
<https://www.isaac-online.org/english/news/webinars/>
 - Enter questions in the chatbox. We will answer as time permits.

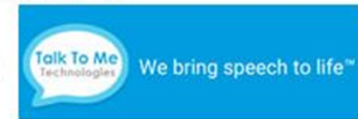


WHAT WILL YOU LEARN?

- Describe three challenges faced by people who use AAC in an emergency or disaster, e.g. whether sheltering in place, evacuating, or moving to a mass shelter.
- Name three actions people with disabilities can take to be personally prepared for emergency or disaster
- List 2 resources for emergency-related vocabulary, including downloadable resources and apps

Supporters

USSAAC would like to recognize and thank our Institutional and Corporate Members for their support



"If you are waiting for a situation to develop, you are going to lose your ability to change the outcome."

Craig Fugate, former FEMA Administrator

Ethical and professional responsibilities of providers

- Individuals shall honor their responsibility to hold paramount the welfare of persons they serve (**ASHA** Code of Ethics, Principle 1)
- Individuals shall honor their responsibility to the public when advocating for the unmet communication and swallowing needs of the public (**ASHA** Code of Ethics, Principle 3)
- Occupational therapy personnel shall demonstrate a concern for the well-being and safety of the recipients of their services. (**AOTA** Code of Ethics, Principle 1)

Ethical and professional responsibilities of providers

- Physical therapists shall participate in efforts to meet the health needs of people locally, nationally, or globally. (**APTA** Code of Ethics, Principle 8)
- Hold paramount the welfare of persons served professionally (**RESNA** Code of Ethics)
- Special education professionals engage in professional activities which benefit individuals with exceptionalities, their families...(CEC Code of Ethics “C”)

Providers should be prepared!

- Have a personal preparedness plan: You can't help others if you are not prepared.
- Be familiar with your employer's plans for evacuating or sheltering in place if the event occurs suddenly and when clients are on premises.
- How will you communicate with colleagues and clients? Are records stored electronically (where) and how can you access them if you can't get into your office?
- Private practitioners should have a plan to assure continuity of operations (COOP) and the ability to resume practice as soon as possible after the event.
- Payer-mandated requirements (e.g. CMS requirements for home health, hospitals, LTC) <https://mms.mckesson.com/content/business-resources/workplace-safety/disaster-preparedness-planning/>

Tales from the Trenches

2017 Disasters

- Hurricane Harvey – TX
- Hurricane Irma – FL, VI
- Hurricane Maria – PR
- Wildfires – CA



USSAAC
THE VOICE OF AAC

- “GO TO” organization for people who use AAC

recovers



Pass It On
CENTER

National Assistive Technology Device Reutilization Coordination and Technical Assistance Center



PORTLIGHT
Inclusive Disaster Strategies



American
Red Cross



Family
Houston

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Texas

VR
Vocational
Rehabilitation



FEMA



USSAAC's Disaster Relief Committee – 9/2/2017 → ongoing

HarveyAAC.Recovers.org and AACDisasterRelief.Recovers.org



AAC Disaster Relief

The United States Society for Augmentative Communication (USSAAC) can help people with severe communication disabilities to regain access to lost AAC tools. Currently, working with families impacted by 2017 disasters in TX, PR, VI, CA, FL.

I Have A Need
Get assistance:
connect with the goods
and services you need.

I Want to Give
Send supplies:
connect with people
who need them.

I Want to Volunteer
Lend a hand:
connect with people
who need your help.

Locate or suggest donation centers, shelters, and other recovery resources:
Find Resources

Emergency Information
Emergency: 911strong text
Edit Info Documents

1 of 6

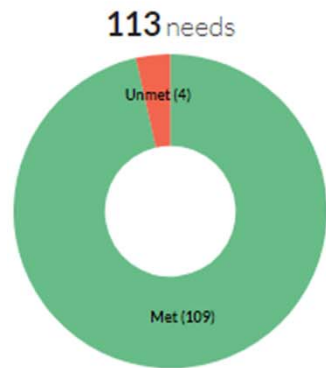
Community Updates
Post Updates
****HURRICANE PREPAREDNESS CHECKLIST: BE PREPARED FOR TROPICAL STORMS BY KNOWING THE FACTS**** Edit
posted 25 days ago by CERV from Community Emergency Response Volunteers of the Monterey Peninsula
No comments yet • Labels: preparation
• Ensure you have a way to receive warnings-a NOAA weather radio, the AccuWeather app on your phone or the radio/television. Sign up for alert notifications that are specific to your town or region. • Know your local hurricane evacuation route(s), as well as shelters outside the evacuation zone. • ...
Read More
f t +
Select Language
Powered by Google Translate

- Amy, Sarah, Wendy Quach
USSAAC Board. CA & PA
- Harvey Pressman
Co-chair DRC, CA
- Liz Begley, Miriam Boesch, Amber Thiess,
TX
- Carole Zangari, FL
- Mara Hernandez, PR
- Allison Januszewicz, VI
- Tina Caswell, NY

The Process

AAC Relief: Hurricane Harvey »

Community Dashboard



[View Needs](#)



[View Donations](#)



[View Volunteers](#)

recovers

HarveyAAC.Recovers.org

[Getting Started](#)

26 updates posted

[Post an Update](#)

16 messages sent

[Message Center](#)

4 public resources

[Post a Resource](#)



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Anonymous

Anonymous Foundation

American Red Cross

Silver Donors (\$1,000 - \$4,999)

Talk to Me Technologies

Romich Foundation

Small Footprint



www.ussaac.org





In-Kind Donations

Alexicom

American Red Cross

AssistiveWare

ATinNH (New Hampshire's Assistive Technology Act Program)

Attainment

Lingraphica

Low Tech Solutions

Pyramid Educational Consultants

Saltillo

SmartyEars

SpeakMODalities

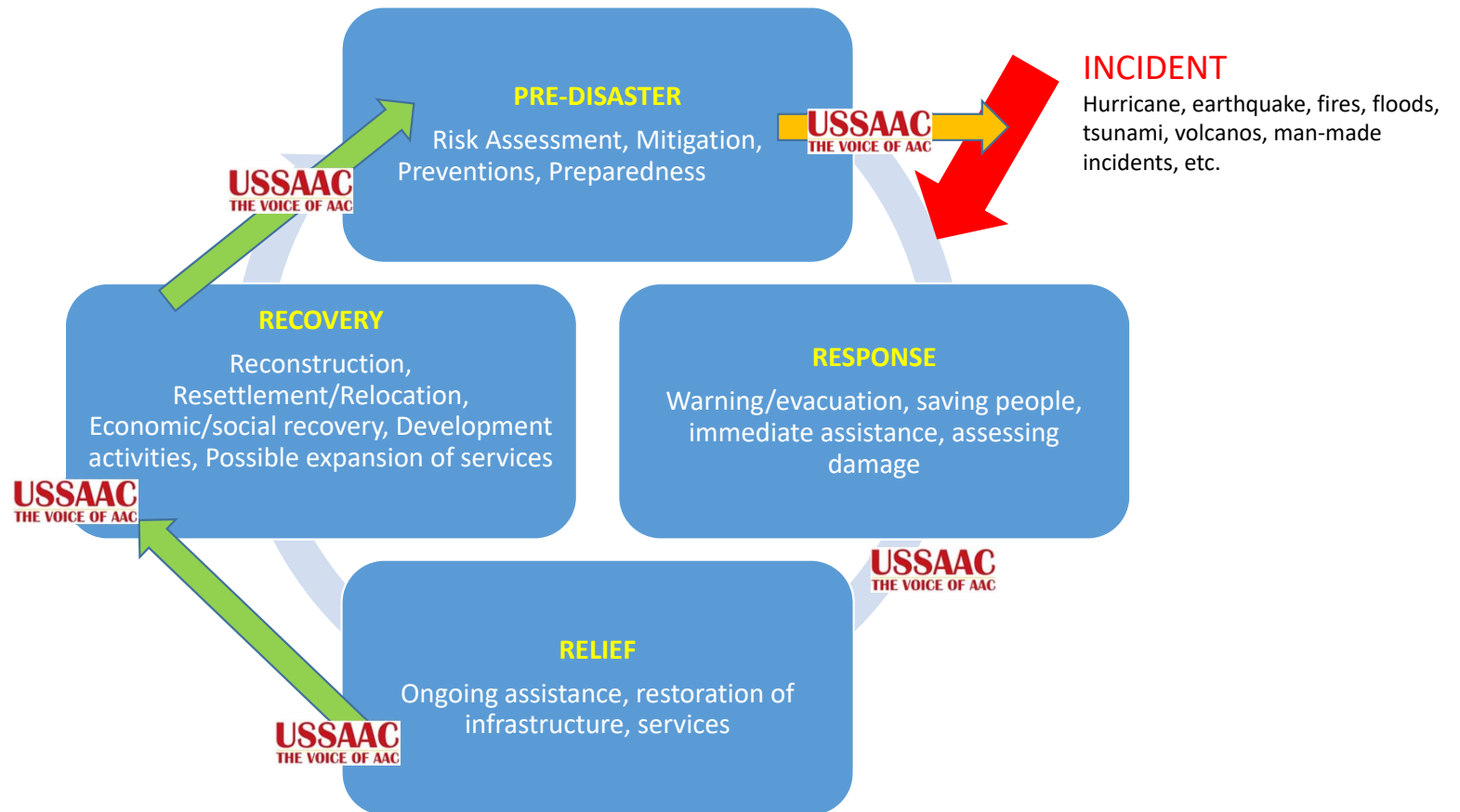
Talk To Me Technologies

WATR (Wyoming's Assistive Technology Act Program)

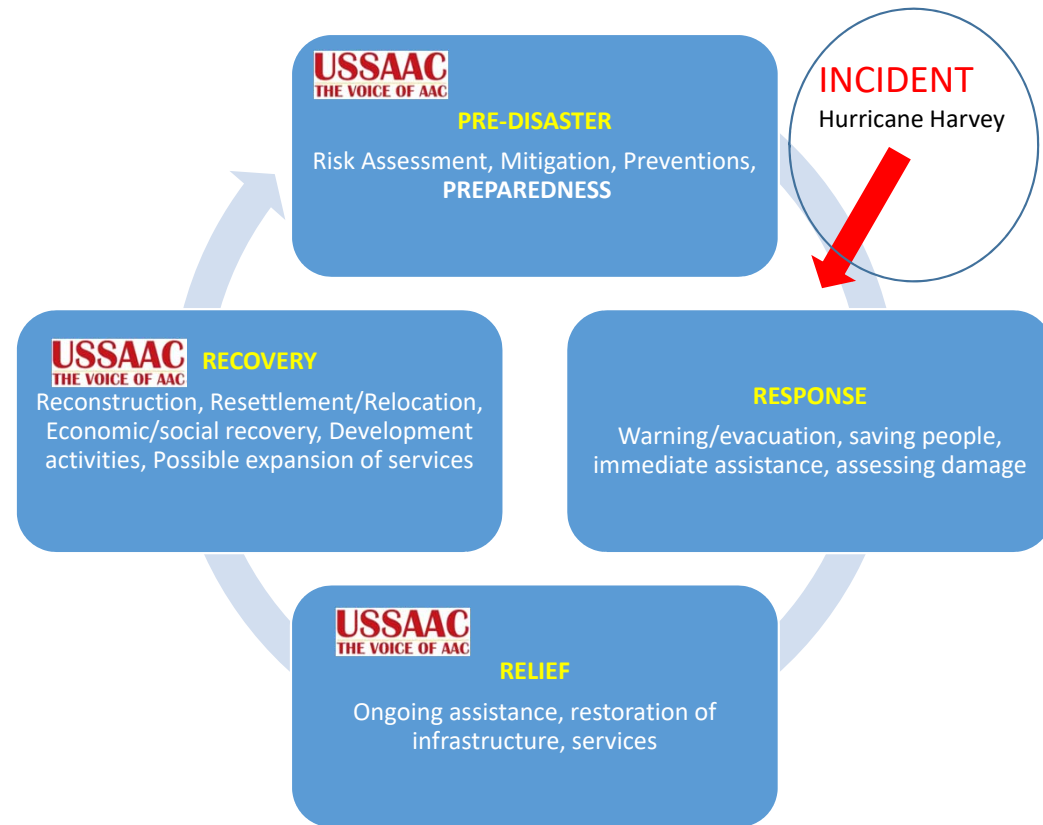
Thank You

The Disaster Cycle

USSAAC! In it for LONG HAUL



Thanks to Travassos family for sharing their story



Our First Family



Andrey loves the Dallas Cowboys!



Alissa. I want to bake pumpkin pie, can I?



A story of resilience and persistence

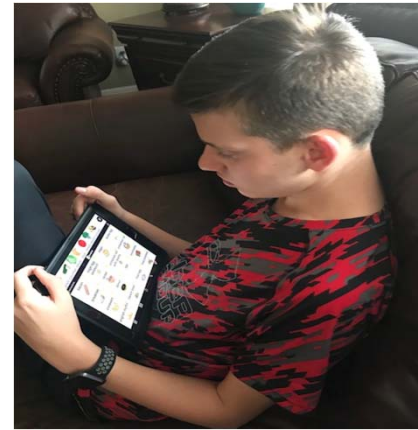
More of our new USSAAC members



Chris and Chandler, Houston, TX



Samantha, Katy, TX



Zach, Cypress, TX



Chandler's mom @ Family 2 Family Conference with Liz Begley



Evan, Houston, TX



Mario, USVI

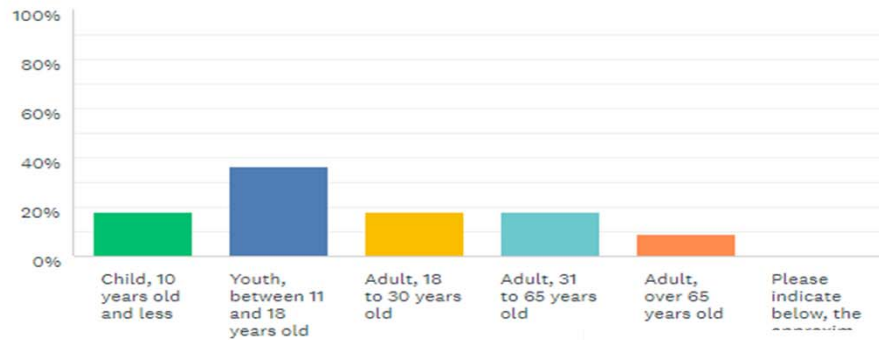


Evan, bi-lingual
Houston, TX

Survey Results

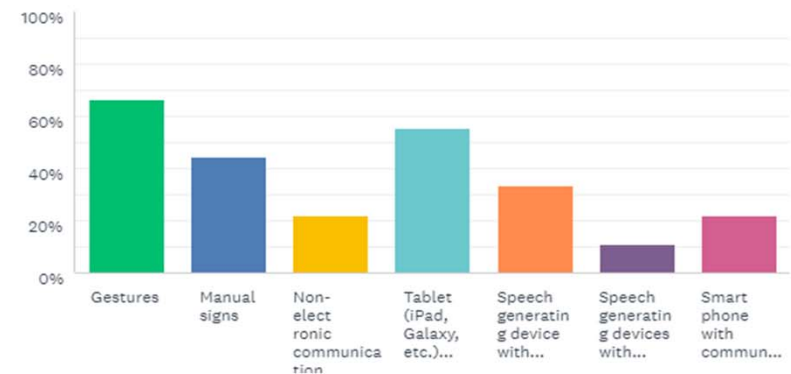
How old is the person impacted by the disaster who uses (needs) AAC?

Answered: 11 Skipped: 0



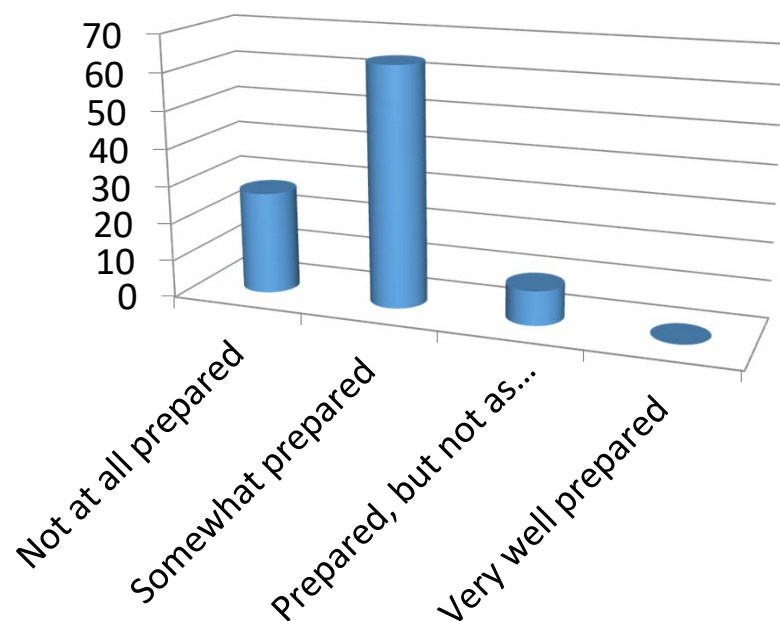
What types of AAC tools /technologies did the person use prior to the disaster? Please check all that apply and feel free to comment.

Answered: 9 Skipped: 2



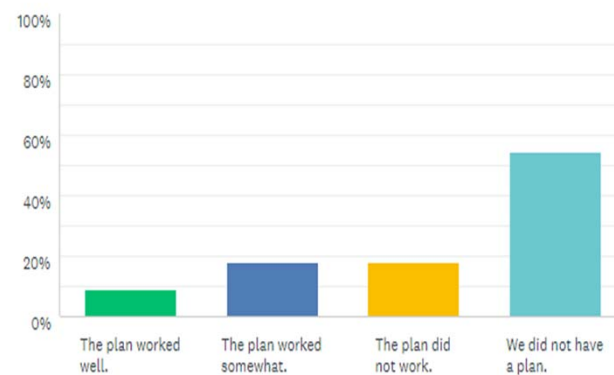
Before....Who was prepared? Who had a plan?

Prepared Before Hurricane Harvey?

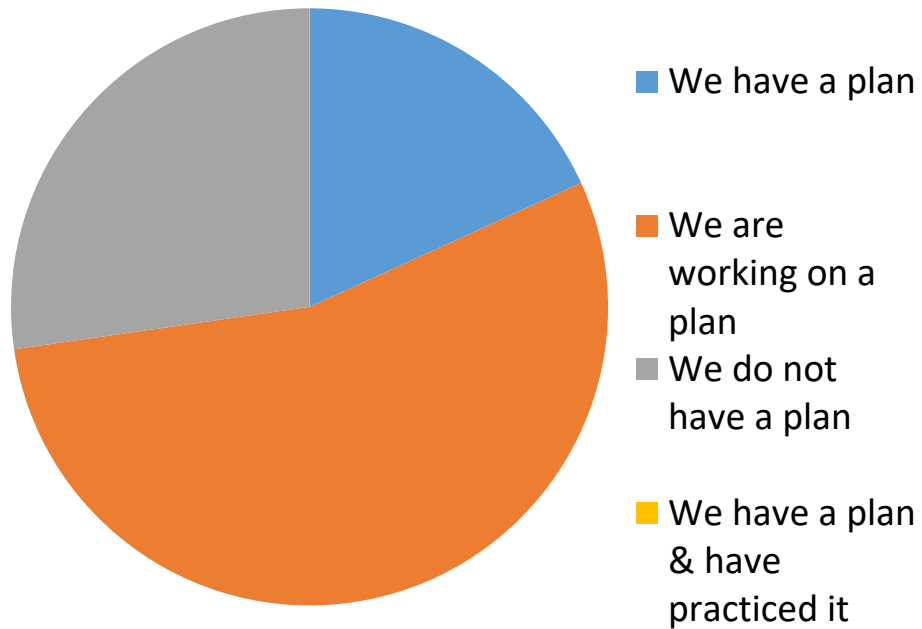


Before the disaster, did you and your family have a plan in place that included consideration of how you would deal with existing AAC tools/technologies? If so, briefly describe your plan in the comments section.

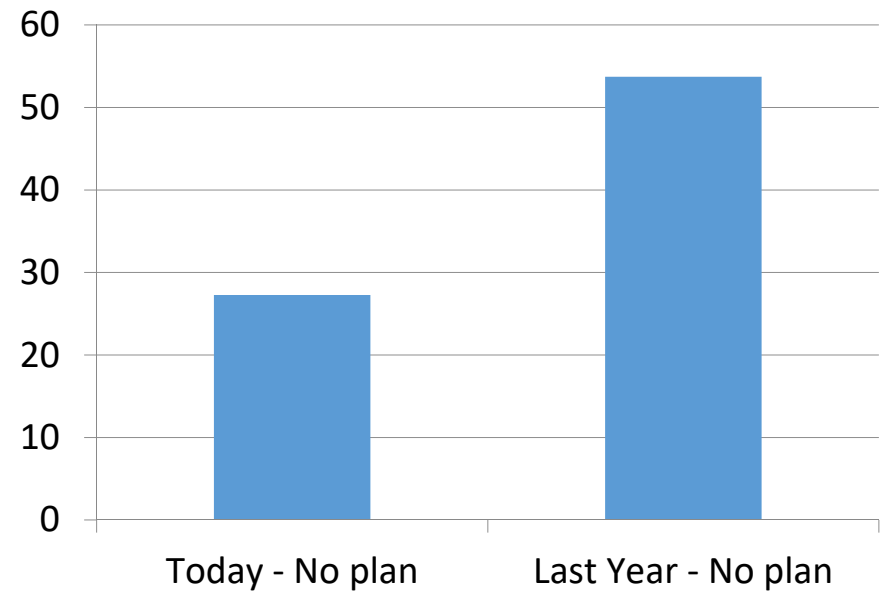
Answered: 11 Skipped: 0



Today.....Who has develop a plan?



More families have or are developing plans



My Emergency Readiness Plan – INTRODUCTION



Introduction

START MAKING A PLAN TO BE READY FOR EMERGENCIES!

WHAT IS AN EMERGENCY?

An emergency is an event that can threaten public safety, health and welfare. Emergencies can be natural, like a hurricane, tornado or winter storm. They can be man-made, like a building fire, subway crash or chemical spill.

Emergencies may not be something you think about every day, but they can happen at any time. All Pennsylvanians should be ready for an emergency. If you are a person with a disability, emergencies can make it more challenging for you to take care of your daily needs. So start making an emergency readiness plan now!

To help you make an emergency readiness plan, you can use this booklet called “My Emergency Readiness Plan.” There is room in the booklet to add information about you and your daily needs, and what to do to take care of your daily needs during emergencies.

THE BOOKLET HAS FOUR STEPS:

- **Step 1:** My Important Information
- **Step 2:** My Plan For Taking Care Of Myself
- **Step 3:** Should I Stay Or Should I Go?
- **Step 4:** After Emergencies Are Over

When You Are Done With All Of The Steps In The Booklet, You Will










Tips for People who use AAC and their Families

- Make a plan for evacuating (leaving) or sheltering-in-place (staying)
- Plan how you will evacuate with all your AT and AAC.
- Plan on what you will do if you cannot evacuate with your AT and AAC (you need to leave it behind). How will you communicate? How will you replace your device(s)?
- Have a go-kit or go-bag (one in each environment and one for each person and pet).
- Plan on what you will do if your support providers (paid or unpaid) cannot get to you.

Go Bags



Disaster Preparedness for People Who Have Limited Speech: Taking Responsibility for Your Safety

YES	NO	Check List for People with Limited Speech and Those Who Care About Them
		 1. Do you have a support team? Does everyone know what to do?
		 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? (See "Go Bag" on page 3.)
		 4. Do you have paper (laminated) communication display(s) with you <u>at all times</u> ? Do your displays include vocabulary for emergencies? Do you have written instructions about how to communicate with you <u>at all times</u> ?

Emergency Checklist for People With Communication Access and Functional Needs

Yes	No	Does Not Apply	Needs Work	Do you know your rights? With rights come responsibilities. Are you ready? Are those you depend upon ready?
				1. I have a way to communicate with responders.
				2. I have an identification card with me at all times (name, address, primary contact information, allergies, blood type, medications, key contacts: family, service providers, interpreters).
				3. I have a copy of my health information in a waterproof bag (insurance card, doctor's names and contact information, prescriptions, and other up-to-date medical information).
				4. I carry written instructions (in English) about how I communicate, including what language(s) I speak and understand and what technologies I use.
				5. My emergency plan considers all my needs: communication, medical and health, independence, safety, transportation (mobility)
				6. I have a way to get alerts and updates.
				7. I have a way to call for help.
				8. I have a support team that knows me and what to do.
				9. I have prepared to "shelter-in-place" at home, at work, and other places where I spend lots of time (food and water stored for 7 days, radio with extra batteries, flashlights with extra batteries, way to keep my communication technologies working [batteries, charger]).
				10. I have an evacuation plan from home or work. I know (a) where I will go, (b) how I will get there, (c) who will transport me/come with me, (d) what I will take with me, (e) what my rights are in a shelter, and (f) how I will contact family members/friends to let them know where and how I am.
				11. My Go-Bag is packed. It includes clothing, medications, money, personal information and equipment, toiletries, water, some food, and comfort items.
				12. Other.

Note: Adapted from AAC RERC website (<https://www.aac-rerc.org/enr/>)

**MY IMPORTANT DOCUMENTS
OR PAPERS**



- Copy of driver's license or photo ID
- Social Security card
- Copies of prescriptions and medical equipment warranties or manuals
- Legal papers such as birth, adoption and marriage certificates
- Bank account/credit card information
- Insurance policy numbers and information
- Copies of utility bills (to prove where you live)
- Important school or work papers

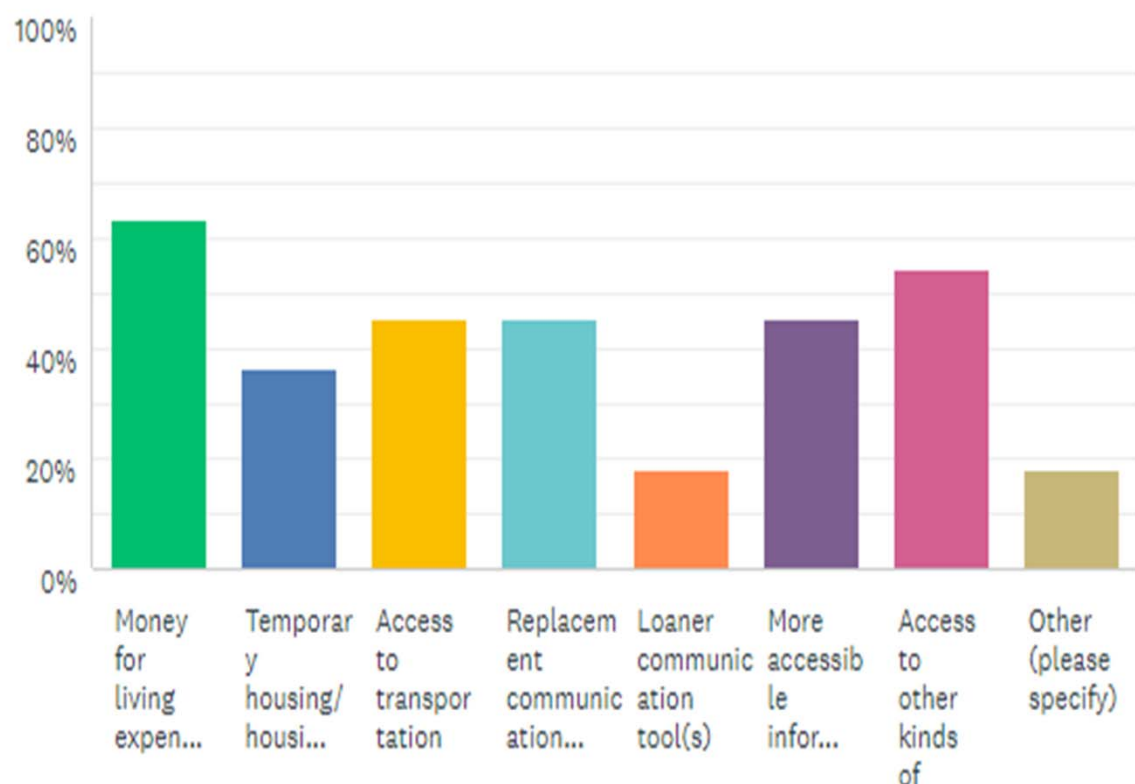
[illegible]

Tips for People who use AAC and their families: Preparing Your AAC and AT

- Keep a compatible charger for each item in your go-kit.
- Keep your devices as fully charged throughout the day as possible.
- Invest in a back-up battery charger and/or solar battery charger compatible with your device that holds several charges . Keep it charged.
- Personalize your SGD with vocabulary that might be useful in event of emergency or disaster.
- Create and maintain low tech systems (e.g. hard copy print out of display or alphabet board).
- Keep a working spare device (e.g. your “old” SGD) at a family member’s home 100+ miles away; make sure it is kept charged.

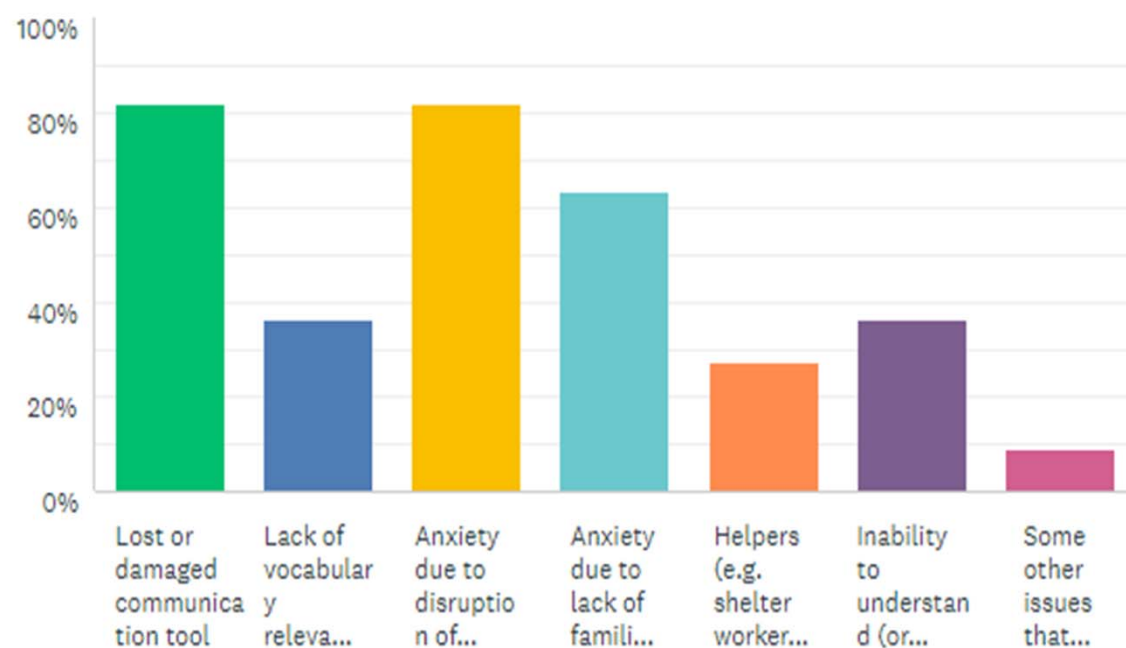
What resources were NOT available to you and your family that would have helped? (Check all that apply)

Answered: 11 Skipped: 0



After the disaster, what issues did you find impacted the ability of the person who uses AAC to communicate effectively? Check all that apply?

Answered: 11 Skipped: 0



Vocabulary

- **Join USSAAC's ongoing efforts** to support access to relevant vocabulary led by Liz & Tina
- **Review and add vocabulary?** Think about what are the most likely scenarios in your area?
- **Involve PWUAAC actively in developing specific phrases and/or icons.** Encourage them to ask questions and comment about what may happen to them during a disaster.

fire



flood



tornado



Phrase Ideas: Before the disaster

- Will the disaster (wildfire, flood, hurricane) reach us ?
- Will we be safe?
- Where is our Go Bag?
- Can I put my _____ in the Go Bag?
- Everyone is talking about this at school.
- I'm feeling _____



Emergency Checklist with Symbols

Phrase Ideas: Shelters or Alternative Housing

- It's too noisy!
- I've never slept on a cot!
- Are my _____ (friends, teacher, grandparents, pets) safe?
- When can we go home?
- When can I go back to school?
- I'm feeling _____
- I miss my _____



Phrase Ideas: Recovery phase

- Relevant phrases will be determined by what happened before and during the disaster.
- As with all important events (positive and negative), individuals who rely on AAC want to share what happened
 - With many people
 - Over an extended period of time.
- Visual Scene Displays may be excellent match for the recovery phase.



We lived in a hotel for nearly EIGHT months after Hurricane Harvey. This is me, my brother and my baby sister at the hotel.

General Considerations

- BACK UP your device pages to the cloud and print out paper copies of important pages for your Go Bag
- Better to have disaster vocabulary and not need it (shelter related topic board), than need it and not have it!



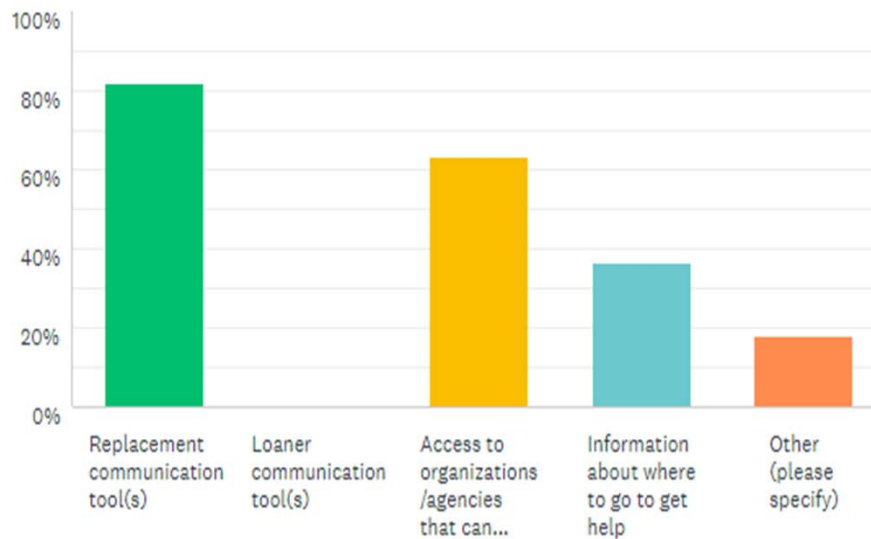
Billy Build a Kit by Pam Kennedy
USSAAC.org/



Show Me: Emergency Shelter Book/app
<https://www.mass.gov/service-details/show-me>

During the first few months after the disaster, what AAC resources did you find most helpful? (Check all that apply)

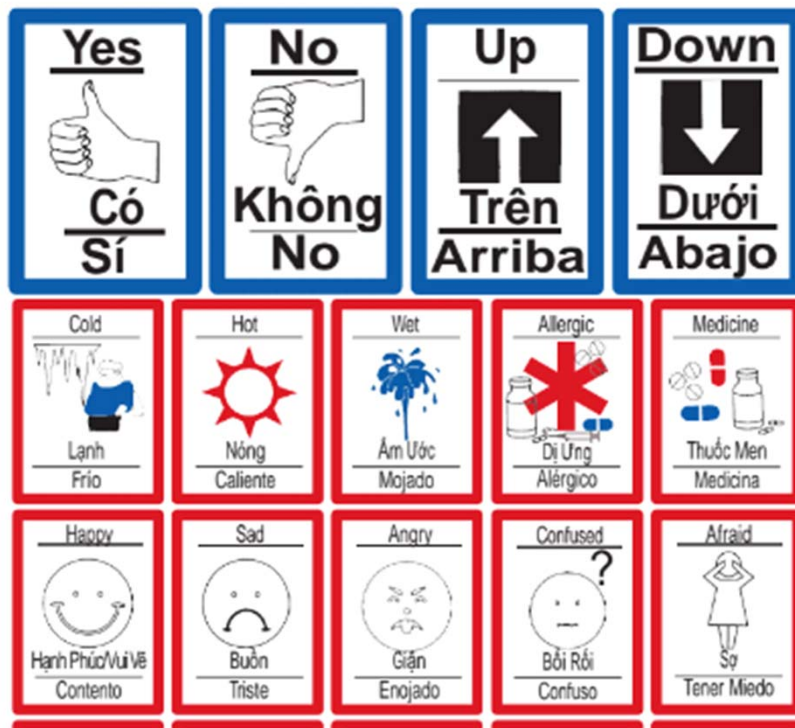
Answered: 11 Skipped: 0



- Always have an emergency plan!
- Be prepared even if you are not in flood zone.
- Register early for assistance
- Move and/or lift up as much furniture as possible on paint cans, bricks, etc.
- Contact organizations for help

- Talk to your kids about emergency situations due to natural disaster so they will be aware when time comes
- Place your children into a therapy immediately to help deal with stress and changes in routine
- Try to replace all favorite stuff or what you know makes them comfortable
- Try to pretend everything is fine because your children feel your state of mind .
- Have equipment, (in this case - aids, hot box, cable, case, batteries) available in a designated water proof container
- Bring the communication device with us when we evacuate.
- Always keep devices charged and if you have to evacuate take charger!

AAC tools and technologies: Critical components in Emergencies and Disasters



- *Effective communication is **the JOINT establishment of meaning.***
 - *a two-way process (expressive and receptive) in which messages are negotiated until information is correctly understood by both parties.*
- **Maintain Cultural Humility** – *ability to maintain an interpersonal stance that is other-oriented in relation to aspects of **cultural** identity most important to the person.*

Be a Part of the Solution! (People who use AAC and their families)

- Make a plan – practice the plan!
- Learn about and participate in emergency planning efforts in your community.
- Be a volunteer! Participate in disaster drills; join a VOAD.
- Identify yourself to first responders and emergency personnel but understand the limitations of registries.
- Sign up for emergency alert systems.
- Understand the terminology – e.g. storm warning vs. storm watch.

Be a Part of the Solution! (Providers)

- Make a plan – practice the plan!
- Learn about and participate in emergency planning efforts in your community.
- Be a volunteer! Train first responders and emergency personnel in how to communicate with people who have limited speech (e.g. Mankey & Rang, https://www.youtube.com/watch?time_continue=1&v=1wuZGcyt-EY)
- Join a VOAD.
- Provide users with appropriate vocabulary and terminology.
- Create and share social stories about emergencies and disasters.

Resources: USSAAC's website (in process of updating)

<https://www.ussaac.org/emergency-preparedness>

- <https://www.ready.gov/individuals-access-functional-needs>
- <http://praacticalaac.org/praactical/emergency-preparedness-for-the-aac-family/>
- <http://praacticalaac.org/praactical/praactical-resources-lockdown-code-red-other-school-safety-drills/>
- <https://disabilities.temple.edu/aacvocabulary/e4all.shtml#index>
- <http://praacticalaac.org/praactical/praactical-resources-storm-preparation-and-recovery/>
- <http://www.patientprovidercommunication.org/pdf/32.pdf>
- http://www.augcominc.com/newsletters/index.cfm/newsletter_3.pdf

Helpful Information

ASHA CEUs

<http://www.ussaac.org/webinars>

- Free to USSAAC members
- \$25 for non-members
- Go to website for participant form and Certificate of Attendance
- Scan and email your completed [CEU form](#) to smeehan8@ku.edu NO LATER THAN TWO WEEKS from tonight.

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• Please fill out our short survey

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- Video and slides for all webinars
- Available in a few days

Thank you



AACcess All Areas
ISAAC 2018
GOLD COAST
AUSTRALIA
 21-26 JULY 2018

ISAAC is excited to announce that registration is now open for the 18th Biennial Conference of the International Society for Augmentative and Alternative Communication, being held at the Gold Coast Convention and Exhibition Centre on the **Gold Coast, Queensland, Australia, from July 21 through 26, 2018.**

The ISAAC 2018 Conference provides four days focusing on the latest in research and clinical innovations in AAC plus social events with fantastic networking and entertainment. The conference also includes an exhibit with opportunities to meet representatives from companies who work for best outcomes in communication for all.

As well as the main conference, registration for the Pre-Conference Workshops and AAC Camp is also open. ISAAC 2018 Pre-Conference Workshops offer an opportunity to hear about best-practice in AAC from presenters around the world. The AAC Camp, "Let's Get Real" is themed around reality TV and will provide lots of fun and learning for AAC users of all ages.

Register today at www.isaac-online.org and we'll see you on the Gold Coast, Australia in July 2018!