

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?

Complex Humanitarian Emergencies (CHE)

- ▶ 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

People with CCN/Those who care about them

- ▶ Need to prepare
- ▶ Need to “self identify”
- ▶ Need to be involved in disaster planning, training activities and drills
- ▶ Need to advocate

First Responders/ Emergency Planners

- ▶ Need to raise awareness about needs of people with CCN
- ▶ Need to work toward needs being considered and addressed at local, regional, national and international levels

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?*

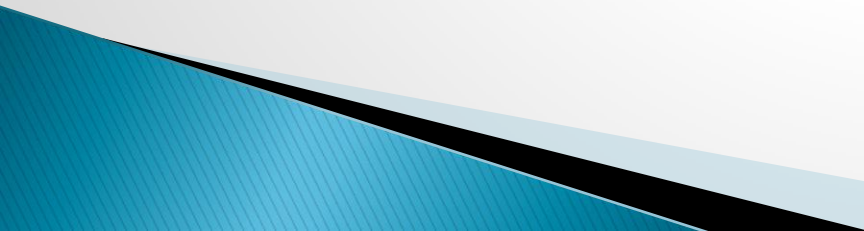
YES	NO	Check List for People with Limited Speech and Those Who Care About Them
		1. Do you have a support team? Does everyone know what to do?
		2. Do you have an evacuation plan in case you need to leave home or work in an emergency situation? Do you know: (a) Where you will go? (b) How you will get 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?
		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 with you <u>at all times</u> ?
		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?
		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.
		7. If you think, “Never mind....this won’t ever happen to me?” THINK AGAIN. Emergencies can (and do) happen to anyone. Be PREPARED, <u>not</u> sorry.

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.

Resources: Go to http://www.cdihp.org/products.html#evac_guide to access the [Emergency Evacuation Preparedness Guide](#). Accessed on 7/15/08.

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

I'm Pam Kennedy.	I can't speak but can understand you.	They're looking for a place for me.	Jessie needs to go out.	Jessie is out of food.	Are access roads still flooded?	Any new updates?	did	and	backside
Please ask questions when you need to.	I have family in Bismarck.	I don't know how much I lost yet.	Jessie needs water.	My chair needs to be charged.	Any refugees found homes since I was on?	hurt, hurts	shoulder	chest	thigh
I have cerebral palsy and epilepsy.	My vital info is on my PC. I'll get it.	The basement was flooded.	Jess is confused, stressed out.	Has anyone else been found?	Has anyone called regarding my status?	head	arm	ribs	knee
I, my	need	wrist splints	am/feel	nauseous	dizzy	eyes	wrist	stomach	shin
pen	morning meds	pain meds	like	pain meds	swelling	ear	hand	back	ankle
paper	evening meds	inhaler	seizure	headache	double vision	nose	finger	waist	foot
yes	no	OK	Oops!	Wait.	computer	mouth	left	right	bad, badly

A	B	C	D	E	F	G	Hi	Bye	How are you?
H	I	J	K	L	M	N	Sorry!	Wait.	please
O	P	Q	R	S	T	U	Thank you!	You're welcome	listen
V	W	X	Y	Z	Space	.	blanket	pillow	computer
0	1	2	3	4	5	6	paper	pen	a drink
7	8	9	Jessie	I, me, my	you, your	he, him, his	oops!	OK	soup
yes	no	know	don't know	want, need	help	bathroom	seizure	?	I can't swallow that.

I/me/my 	you/your 	dog 	soldier 	family 	friend 	man/he 	woman/she 	mom 	dad 
home 	present 	happy 	done 	eat 	drink 	go 	hi/bye 	arm 	loud 
want 	past 	sad 	move 	sandwich 	soda 	question 	thank you 	hand 	help 
don't 	future 	angry 	chair 	soup 	water 	front 	on 	head 	stink 
toilet 	hurt 	afraid 	bed 	bread 	back 	down 	off 	stomach 	yuck 
good 	wrong 	bad 	pillow 	more 	inside 	up 	sick 	foot 	very 
yes 	wait 	no 	blanket 	flood 	outside 	okay 	medicine 	leg 	next page 

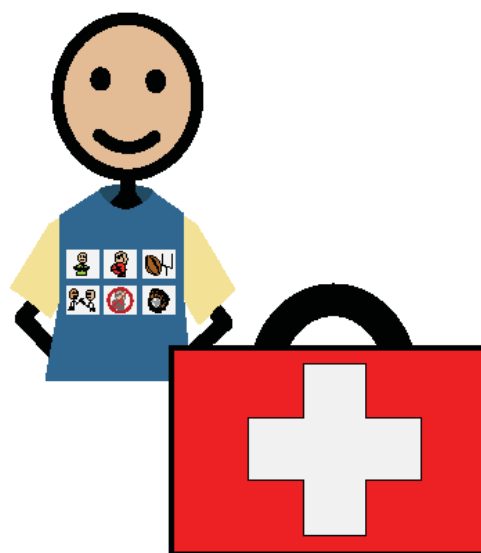
5. Medical information

- ▶ 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			
<small>Kalles, J.I. (2004) <i>Emergency Evacuation Preparedness: Taking Responsibility For Your Safety: A Guide For People with Disabilities and Other Activity Limitations</i>, p.40. http://www.cdihp.org/evacuation/att_b.html#ehi_form Accessed on 7/15/08</small>			
Emergency Health Information		Date:	Updated:
Name			
Address			
City		State	Zip
CONTACT METHOD	HOME	WORK	
Phone:			
Cell:			
Fax:			
E-mail:			
Birth Date	Blood Type	Social Security No.	
Health Plan:	Individual #:	Group #:	
Emergency Contact:			
Address			
City		State	Zip
CONTACT METHOD	HOME	WORK	
Phone:			
Cell:			
Fax:			
E-mail:			
Primary Care Provider:			
Address			
City		State	Zip
Phone	Fax	E-mail	
Disability / Conditions:			
Medication:			
Allergies:			
Immunizations		Dates	
Communication / Devices / Equipment / Other:			
<small>Excerpted from <i>Be a Savvy Health Care Consumer, Your Life May Depend on It!</i> by June Isaacson Kalles, For more information about this guide, contact jk@pacbell.net or visit http://www.alk.com/resource.html</small>			

http://www.cdihp.org/evacuation/att_b.html#ehi_form
 Accessed on 7/15/08

Billy Builds a Kit



by Pam Kennedy

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Billy Smith goes to Riverdale Grade school.



Billy uses a device to help him talk.



He points to a symbol on the devices screen.



Each symbol picture stands for a word.



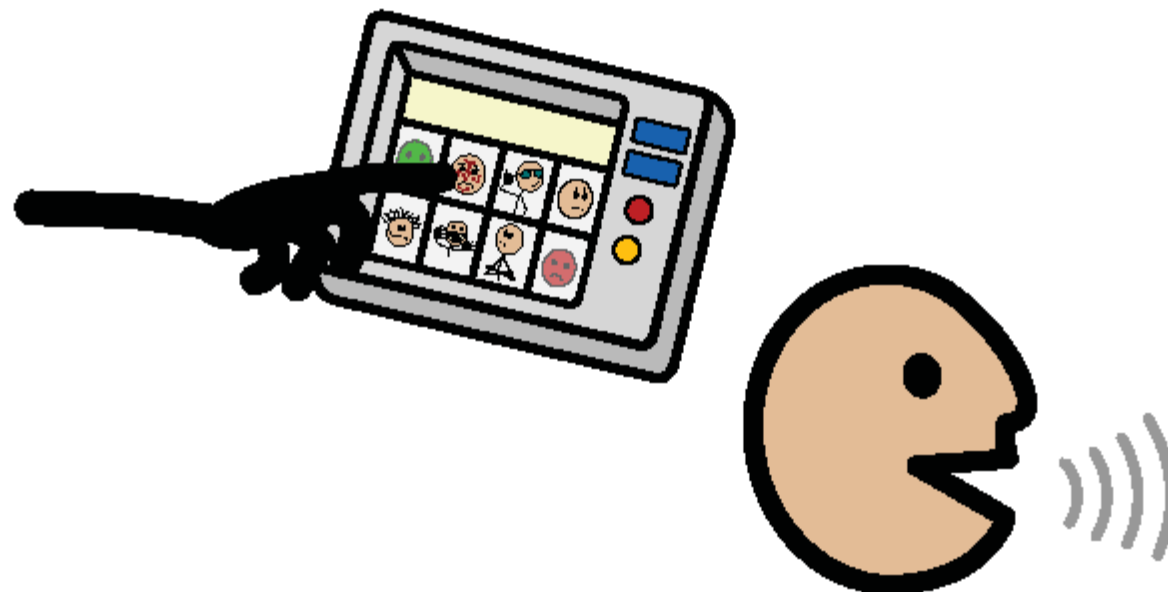
The device's computer speaks the word for Billy.



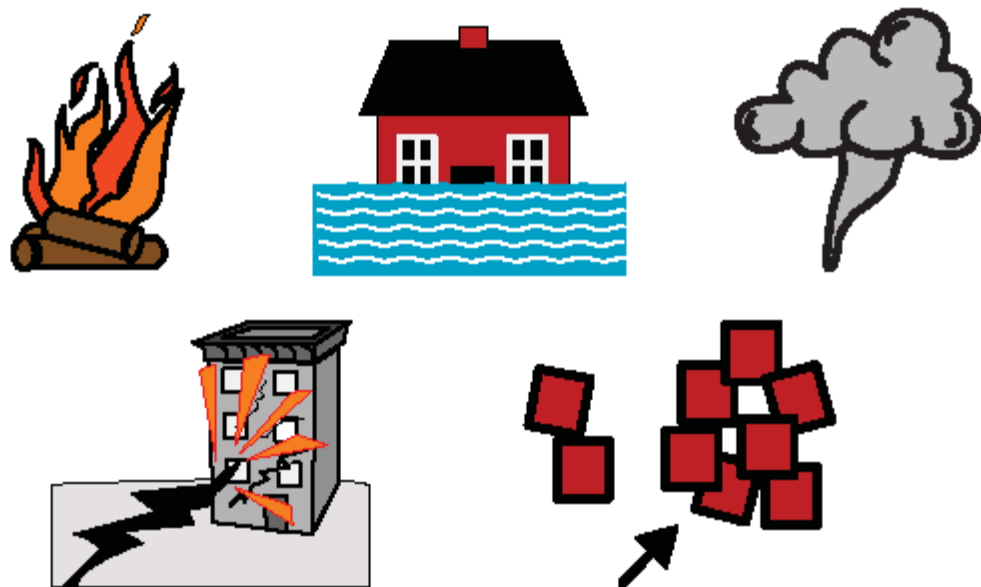
One day, Billy's teacher asked the class a question.

1





**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.**



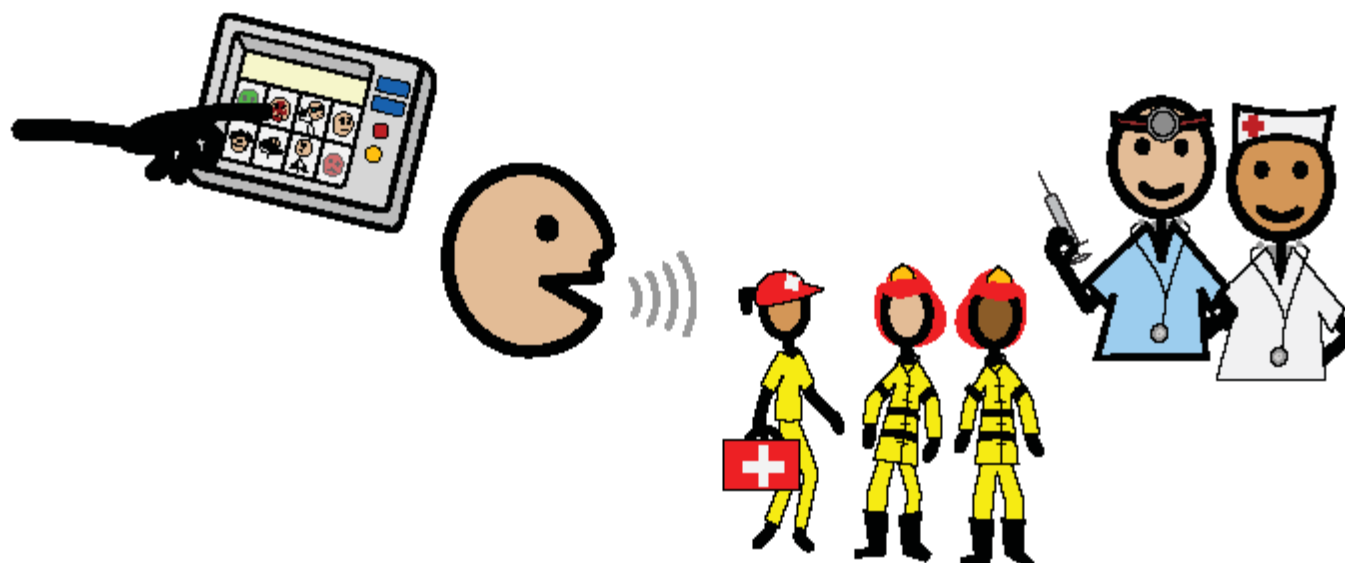
One day Billy's teacher asked the class a question. She asked how many emergencies they could name. Billy named: fire, flood, tornado, earthquakes and many more. The teacher asked, "Are you ready for an emergency?"



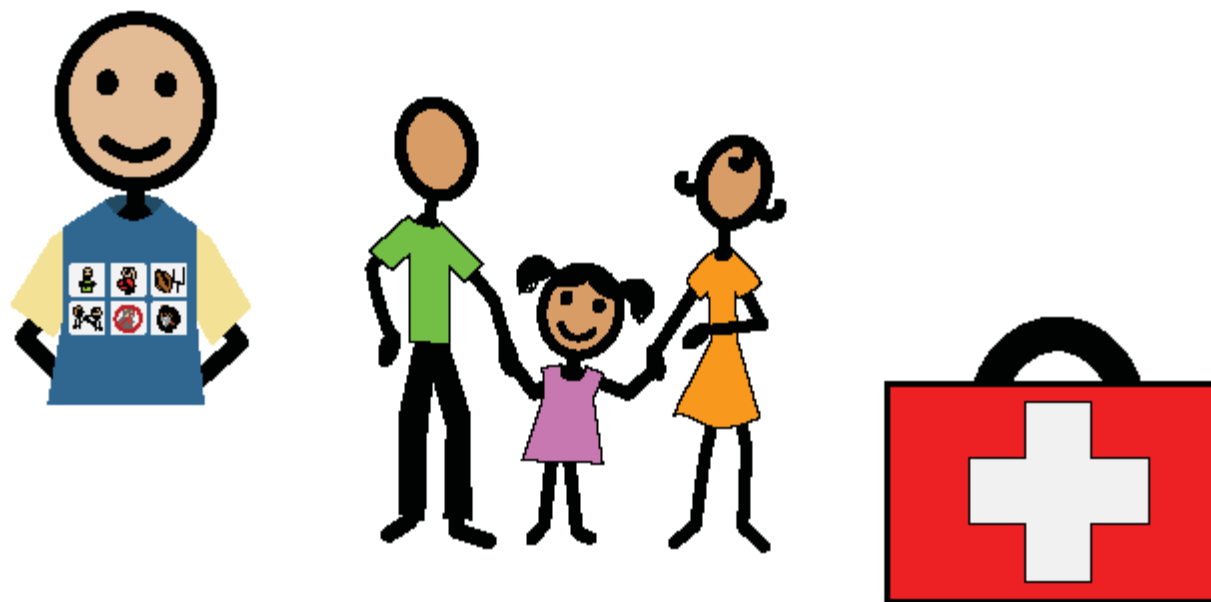
Billy did not know what to do in an emergency. The teacher gave the class some homework. She gave the symbols he would use in an emergency. She asked each child's family to make an emergency kit.



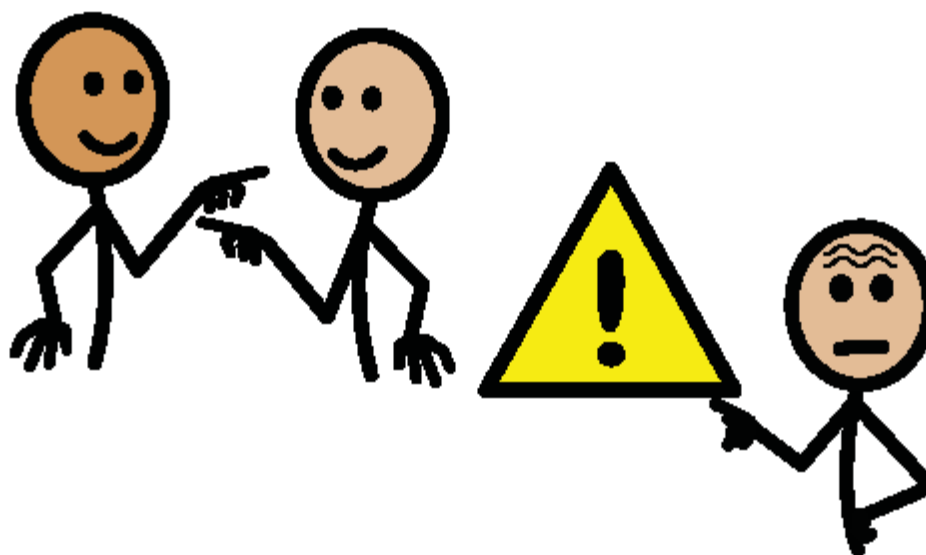
Billy was excited. He wanted his family to be safe in an emergency. He looked at the teacher's list. The list had: food, water, medicine, blankets, a flashlight, radio and batteries.



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

Disaster Preparedness Tips For Emergency Management Personnel

Communication Access for People with Limited Speech

YES	NO	QUESTION
		1. Do you know how to communicate with someone whose speech you cannot understand?
		2. Do you know how to get the information you need by asking "Yes/No" questions?
		3. Do you know about speech generating devices (SGDs) and how people use them?
		4. Do you know about communication boards/books/displays and how people use them?
		5. Do you have, or does your facility provide communication displays for people who are unable to be understood using their natural speech?

#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 can not.
- ▶ **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.

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

#3 Speech Generating Devices (SGDs)



#4 Personal communication displays /boards/books.

#5. Emergency-oriented Communication Displays



	A	B	C	H	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z	
L	si yes	beber drink	cuándo when	dónde where	doctor doctor	enfermera nurse	no no																					0
O	frio cold	dolor pain	picor itch																									1
G	calor hot	dolor de cabeza headache	mareado dizzy																									2
O	Fiebre temperature	problemas de corazón heart problem	ahogar choke																									3
	baño bathroom	bacinilla bedpan	botella urinal	compresa sanitary napkins	pañal diaper	cepillar los dientes brush teeth	lavar wash																					4
																												5
																												6
																												7
																												8
																												9



PAIN CHART

Level of pain

FRONT BACK

I WANT pain medicine

THIS PART OF MY BODY

- Itches
- Stings
- Hurts
- Cramps
- Can't move
- Is numb
- Aches
- Burns
- Throbs
- Is tender

THE PAIN IS

- Constant
- Intermittent
- Radiating
- Throbbing
- Dull
- Sharp

MONTH DAY

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
- ▶ www.cdihp.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