PACIFIC ADA CENTER PRESENTS

ADA NATIONAL NETWORK LEARNING SESSION:

STRENGTHENING EMERGENCY COMMUNICATION STRATEGIES AMONG RESPONDERS AND PEOPLE WHO ARE DISPROPORTIONATELY IMPACTED

Sarah W. Blackstone, Ph.D., CCC-SP
Monterey, CA
CERV of the Monterey Peninsula
Augmentative Communication Inc.
AAC – RERC
cerv501c3@gmail.com
www.cerv501c3.org

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Welcome to the Emergency Management and Preparedness - Inclusion of Persons with Disabilities webinar series. I'm Lewis Kraus from the Pacific ADA Center, your moderator for this series. This series of webinars is brought to you by the Pacific ADA Center as a collaborative effort between the ADA National Network and FEMA's Office of Disability Integration and Coordination. The ADA National Network is federally funded to provide training, technical assistance and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232. I have now put that up on the chat window for you. FEMA's ODIC covers the same 10 regions with regional disability integration specialists. More information about FEMA can be found at www.fema.gov, then type ODIC into the FEMA website search.

This webinar series will share issues and promising practices in emergency management inclusive of people with disabilities and others with access and functional needs. The webinars provide an opportunity for emergency managers, people with disabilities and others with access and functional needs, first responders, planners,
community organizations, and other community partners to exchange knowledge and information on promising practices in inclusive emergency preparedness and management for the whole community. This year's topics will cover emergency preparedness and disaster response, recovering mitigation, as well as accessibility and accommodation issues under the Rehabilitation Act, the Americans with Disabilities Act of 1990, the ADA, and other relevant laws.

The series alternates monthly between ADA National Disability Rights Network Learning Session and FEMA Promising Practices. We encourage you to review the series website and familiarize yourself with the full array of sessions available in this series at www.adapresentations.org/schedule.php. These monthly webinars occur on the second Thursday of the month at 2:30 Eastern, 1:30 Central, 12:30 Mountain, and 11:30 Pacific time. By being here, you are on the list to receive notices for future webinars in the series. The notices go out two to three weeks before the next webinar and open that webinar to registration.

For those of you who are new to this webinar series and its software, we will now review some of the features of the webinar platform before we begin the session today. In this session, only the speakers will have audio. The audio for today's webinar is being broadcast through your computer. Make sure your speakers are turned on or your headphones are plugged in. You can adjust the sound by sliding the sound bar left or right in the Audio & Video panel. If you are having sound quality problems, go through the audio wizard which is accessed by selecting the microphone icon with the red gear on it in the Audio & Video panel.
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The webinar is being recorded and can be accessed on the www.adapresentations.org website under the archive section next week.

You can follow along the webinar platform with the slides. If you are not using the webinar platform, you can get a copy of the PowerPoint presentation next week. This session is being recorded and will be available, as I said, for review next week.

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The Whiteboard where the presentation slides are shown can be resized smaller or larger by choosing from the dropdown menu located above and to the left of this Whiteboard. The default is "Fit Page." And you can reposition and resize the chat, the participant, the captioning, and the Audio & Video panels by detaching and using your mouse to reposition or stretch or shrink. Each panel may be detached using the icon with several lines and the arrow next to it in the upper right-hand corner of each panel.
When you are -- at the conclusion of today's presentation there will be an opportunity for everyone to ask questions. You can submit your questions using the chat area within the webinar platform. The speakers and I will address them at the end of the session. So feel free to submit them as they come to your mind during the presentations.

To submit the questions, just go to the chat area text box and enter your question there or press ctrl M and enter text in the chat area. If you are listening by phone and not logged into then with far, you can e-mail questions to adatech@adapacific.org.

If you are experiencing any technical difficulties during the webinar, send a private chat message to the host by double clicking Pacific ADA Center in the participant list. A tab titled Pacific ADA Center will appear in your chat window. Type your comment in the text box and enter. And for those of you on keyboards only, F6 and arrow up or down to locate Pacific ADA Center and select to send the message. You can also e-mail it to adatech@adapacific.org or you can call 1-510-285-5600.

Before we start today's session, I wanted to note the passing of our good friend and colleague Richard Devylder. If you have been to our webinars over the years, you will remember Richard as a frequent contributor due to his status as one of the foremost authorities on emergencies and people with disabilities. Richard was the Chief of the Office of Access and Functional Needs at the California Governor's Office of Emergency Services, an office he created as Special Advisor to the Secretary of the
California Emergency Management Agency focusing on the access and functional needs of people with disabilities in disasters. While there Richard provided guidance in reviewing and reshaping emergency management systems, policies and practices in communicating, evacuating, and sheltering Californians with disabilities. He was a leader and one of the most important voices in emergency disasters and people with disabilities.

From those of us at the Pacific ADA Center, we send our most heartfelt condolences. We will all miss him.

Today's ADA National Network Learning Session is titled "Strengthening Emergency Communication Strategies Among Responders and People who are Disproportionately Impacted." The ability to receive information and communicate efficiently and effectively with first responders and other health personnel during an emergency or disaster can be essential to survival. Community professionals, organizations, and agencies can and should strive to increase community resilience as a key component of what they do every day with individuals they support.

This presentation will identify those who are disproportionally impacted and discuss the converging communication challenges many face, share information from first responders regarding what strategies work best for them when communication is difficult and suggest practical ways community professionals can increase community resilience by preparing people with communication issues for emergencies. The
information presented in this webinar is intended solely as informal guidance and is neither a determination of legal rights nor responsibilities by NIDILRR or FEMA.

Our speaker today is Sarah Blackstone. Sarah is President of Augmentative Communication, Inc. and Founder/Board Member of the nonprofit Community Emergency Response Volunteers of the Monterey Peninsula. She is editor/author of the book "Patient Provider Communication: Roles for Speech Language Pathologists and Other Health Professionals" which includes a chapter integrating emergency and disaster resilience into your everyday practice. She coordinates the patient/provider communication forum and website with her husband, Harvey Pressman. You can find that at patientprovidercommunication.org.

Sarah, I will turn it over to you.

>> Sarah Blackstone: Hello, everybody. Happy Thursday. Can you hear me? Am I ok, Lewis?

>> Lewis Kraus: You sound fine. Go ahead.

>> Sarah Blackstone: Ok. Great.

As Lewis said, today we're going to discuss strengthening emergency communication strategies between first responders and people who are disproportionately impacted in an emergency or disaster scenario. He mentioned the
learning objectives for today to discuss the impact of converging communication challenges on people who have access and functional needs during emergencies and disasters. I'll be reporting some perspectives from first responders regarding the communication issues they face every day. We will be discussing roles and opportunities for community professionals, organizations, and agencies to increase community resilience by preparing their clients and the people they care about to prosper under unfortunate circumstances. And that is a quote from Anne Marie Jones whom I respect very much and who will be quoted again in this presentation. And finally, I'm going to be sharing some resources with you in case you're interested in taking some of this on.

So let's get started. Bad things happen. That's a fact. They can be catastrophic, as depicted in this slide, affecting large populations and areas. You see hurricanes and the impact, tornadoes, forest fire, tsunami, earthquake, terrorist attack, pandemics, etc. They're unpredictable and, thankfully, rare. Our residents across the country become complacent, hence you prepare.

Bad things also happen every day to families in our communities. We characterize these as emergencies typically. Many are also unpredictable but they happen frequently. Again, few are prepared.

The examples depicted in this slide are medical emergencies like heart attack, stroke, drug overdoses, psychotic break, accidents, cars, cycles, falls, poisonings, or trauma-related gunshot wounds, stabbings, etc. In each case, first responders triage is
not always necessarily to the emergency departments; sometimes to other facilities like mental health centers or social service clinics.

In the field of emergency management, a prevailing theme is you can't predict when bad things may happen but you can prepare for when they inevitably do. No one can prosper without access to communication. Specifically, if individuals impacted by an incident can't access, understand, or respond to an alert, are unable to communicate successfully with first responders through speaking or writing or are unable to use their technologies, whether it's hearing aids, glasses, speech generating device, alphabet board, or they become separated from or can't access the daily supports and services they depend upon: sign language, language interpreters, familiar communication partners, service animals then their health, safety, independence and very survival may be at risk.

We're going to be talking about three types of communication support and ways to mitigate for outcomes. We're going to talk briefly about alerts and updates, which are most often relevant in disasters. We're going to talk about interactions between first responders and the people impacted, which are always relevant from the perspectives of both we're going to be considering this topic. And we'll also be talking about community involvement in preparing people with communication issues to maintain their health, independence, safety, and transportation which they can't do unless they're able to communicate. And this, again, is always relevant in emergencies and disasters.
Alerts and updates. This is the slide on that. This is not my area of expertise and not the focus of today. Briefly, the slide underscores the need for alerts and updates and the need that these alerts and updates reach everyone. Inadequate and poor warning and alert systems result in delayed and inadequate response medical care and an unnecessary disruption in services supporting people and caregiver networks.

The message here is, obviously, we are using multiple methods to reach people and when we reach them, and we must reach them, we need to repeat the message, announce it, describe it, caption it, picture it, e-mail it, tweet it, text it, interpret it again and again.

So we're now going to focus on the interactions that need to occur between first responders and people impacted by an incident. First, however, let's define communication so we can frame our discussion. According to psycholinguists -- and this definition was recently adopted by the Joint Commission for use in healthcare -- effective communication is the joint establishment of meaning using a variety of strategies, including the simultaneous use of multiple channels or modes such as speech, gestures, signs, facial expressions, electronic and non-electronic technologies.

The key phrase here is "Joint establishment of meaning." Successful communication is understood as a two-way process where messages are negotiated using a variety of common symbols, whether these be spoken words, manual signs, text, gestures or graphics until the information is correctly understood by both parties.
With regard to healthcare, for example, the Joint Commission has said that this means providers must be able to understand and integrate the information garnered from patients and that patients must comprehend accurate, timely, complete, and unambiguous messages from providers in a way that enables them to participate responsibly in their care.

When emergencies or disasters happen, those impacted need to be able to communicate successfully with responders and vice versa. Although speech is typically the fastest and most reliable way to share information face-to-face, it obviously is not always an option. So non-verbal methods such as gestures, facial expressions and body language often carry important meaning. However, these non-verbal modes can restrict the kind of information that can be conveyed. So people need access to language. They may not be able to generate speech or use speech for any number of reasons but access to language is key.

I'd like to share the story of a friend of mine, Pam. She's written about her experience and over the past 15 years helped many others to prepare for unfortunate events. Let me read you some of what she said.

The dyke was breeched April 19, 1997 at about 2:00 a.m. When the sirens awoke me, I was terrified because no one was there to get me up. As a result, I was stuck in bed until 10:00 a.m. the next morning when my personal assistant came via boat. We barely had enough time to get me in my wheelchair, grab my medications, my computer with text-to-speech software and Jessie, my golden retriever service dog,
before the National Guard arrived in the truck. The rescue team knew about Jessie and me even though we had never met. Thankfully my personal assistant told them I could communicate by writing, indicate yes and no by traditional means, and use text-to-speech software on a computer and some manual signs and gestures.

I was told that I couldn't be evacuated to the same shelter as my friends and family because of my disabilities. Instead, the soldiers had set up a makeshift nursing home at the elementary school in their special education room. When I arrived at the room, a soldier at the shelter said, "I know it's cramped but you and your service dog, Jessie, will share this space with a man in a wheelchair who cannot speak, read or write. You will need to take turns sleeping on the cot."

As it turned out, Pam couldn't transfer to the cot so she ended up spending days in her chair. The soldier also explained Pam would not be able to use her computer voice during peak hours because they were sharing their generators with other shelters to conserve electricity. When the soldier asked her if she had brought anything else to help her communicate like a notebook or an alphabet board, she had to respond no. He said he would find her a pen and some paper so she could write.

Pam spent days in the shelter. Luckily the mayor of the town happened to stop by and recognized her. As a result, she made it possible for Pam to use her computer at night. One of the things that Pam did at night was to make herself some communication boards. This slide shows the boards that Pam made for herself. As you'll see, one
contains the alphabet and just a few words, many of which are greetings and questions. And the other one contains phrases and, again some words.

But Pam didn't stop there. This is the board she made for her roommate. He was not literate so she used symbols, pictographs. These must be taught. Together this gentleman and she identified vocabulary he wanted like soldier, future, stink, outside, loud. And she helped him learn to use the symbols to communicate.

The C-MIST paradigm shown in this slide reflects the access and functional needs that address community resilience. These also reflect Pam's story. She is a woman with access and functional needs. The threat -- the flood threatened her safety, her support network, her independence, her transportation, and her health. If she had been unable to communicate, she could not have managed as well as she did. As communities address resilience, this paradigm is very, very helpful.

Here's a list of groups of people whom have access and functional needs, many of which the ones checked are those that Pam had as well. So people with hearing, speech, vision, and cognitive challenges like Pam and her roommate, the very young, people with limited understanding of language spoken by first responders, people under severe stress and those who are confused, like Pam and her roommate; people who do not have access to the tools and support they need, like Pam and her roommate; people with mobility limitations, again like Pam and her roommate; people who lack access to transportation, which Pam did; and people who are ill or have chronic health conditions that require medications or treatments or are injured, again, like Pam who had
swallowing difficulties and took medications every day that she was dependent on for her health.

Here's another useful paradigm that's specific to communication. It shows five groups of people who are at risk for experiencing barriers to communication that affect their access and functional needs.

Populations with communication challenges include not only people with preexisting communication disabilities like Pam but also individuals with limited health literacy, individuals who have language differences, and individuals who have culturally diverse issues that may affect interactions between first responders and themselves.

The numbers actually are staggering. 46 million people have a diagnosis that include hearing, speech, voice, and language disorders. 47 million people who live in the United States have limited English proficiency. 90 million have limited health literacy. An unspecified number have cultural, sexual, and religious differences that may hinder communication between providers, first responders, and individuals impacted.

So let's just do the math. These estimates represent 2/3 of the entire population in the United States. In addition, the diagram clearly illustrates that many individuals have multiple or converging challenges. We have no data on these numbers. In any case, multiple challenges make communication even more difficult, especially during high-stake encounters. For example, what would have happened if Pam didn't speak English and neither did the first responders? What about if she had not had an
assistant or service animal? And particularly what if she had not been a strong self-advocate and then an advocate for another?

We're going to meet another person now, Maria. She confronted a medical emergency. Let me tell you about Maria. She's a 48-year-old woman from Mexico and she speaks only Spanish. She lived in a small apartment with her husband and four children. Her converging communication vulnerabilities included limited health literacy, limited English language proficiency, and a speech impairment caused by a severe stutter. Maria is able to read and write in Spanish but to a very limited extent. When she takes her children to the clinic, she typically needs assistance communicating with providers. Often a family member accompanies her and even more often an older child acts as interpreter.

One afternoon Maria had a significant pain in her abdomen and asked a neighbor to drop her at the emergency room. At the hospital, they immediately called for a Spanish language interpreter. The nurse also grabbed a communication display to clarify the location of her pain and it's severity. When the interpreter arrived, he had difficulty understanding Maria's speech because of her severe disfluency. He asked her to write and provided her with a pen and paper. She immediately started to gesture as well as write, [Speaking Non-English Language]. The interpreter surmised and confirmed with Maria that she was worried about her children because they needed to be picked up from school. She was asking the staff to immediately call her husband to take care of them.
A combination of approaches enabled the emergency room staff to meet Maria's needs and treat her. In addition, they allowed her to express other areas of severe concern that she had. First they tried to establish respect and trust. They immediately requested interpreter services using the communications display with graphics and gestures to initiate basic communication about her pain until the interpreter arrived. Although the interpreter had trouble understanding her speech, he was able to figure out what she wanted to say using a variety of available methods. So despite Maria's multiple communication and converging challenges, the team and Maria jointly established meaning and her needs were able to be met.

This slide shows the complexity of Maria's and Pam's converging communication issues. Pam experienced a severe communication disability as well as less than ideal contextual factors.

Maria, in fact, didn't speak or understand English very well, had limited health literacy because she really wasn't familiar with the health system and how it worked. She had a severe disfluency. In addition to that, she was worried and fearful for herself and her children, so very anxious. And although we didn't talk about it, she had cultural issues relating to authority that also could interfere with her ability to be treated.

We need to document not only the types of experiences people have who have converging communication challenges. We also need to document the communication issues, barriers and solutions, from the perspective of first responders. To do so, we need to talk to them. Recently, CERV of the Monterey Peninsula has been conducting
interviews with first responders in an effort to identify issues that they face. We've been asking the following questions:

How important is effective communication in your job? What communication issues do you typically face? What kind of information do you need from the people who are impacted? What training have you had in supporting effective communication? And what strategies do you depend on and which other strategies do feel might be helpful?

Today we've interviewed six first responders. I'll introduce them briefly. We've interviewed three firefighters from Seaside: Brian Dempsey, the Chief of the department, Jason Sullens, an engineer, and Jason Black, a captain. We also interviewed captain Roger Reed from Monterey Fire and Captain Tammy Hagler who is an EMT, retired, and who has worked in Arkansas, Tennessee, and Louisiana. And finally, we interviewed Dave Potter, the Emergency Operations Coordinator in Monterey. And we're not done. So this is preliminary information that we're sharing today.

So let's take a look at some of the things that they said and we can learn from. First we asked: How important is effective communication in your job? And all of them said it's critical. It's a critical part of the job. Solving communication challenges is paramount. Our job is all about communication.

Captain Reed said during an emergency or disaster scenario people can be at their worst. And if there are communication problems, we need to be able to quickly
solve them. Captain Hagler said "Communication is key. You have to be able to communicate with your patient." Chief Dempsey noted that of all the calls they get in a day, at least 70% are medical emergencies. And Captain Black said, "In a medical emergency we need to bring calmness to chaos and gather information," also, "Family members want to help. So ongoing communication with family is also very important." Not just because of the person impacted because the family is impacted as well. And finally, Dave Potter, the retired firefighter and now head of the Monterey emergency operations program, "Communication is a huge part of my job," he says, and includes communication with the community.

Since the early '90s, a number of people with limited English proficiency in the United States has more than doubled. In 2001, approximately 21% or 60.6 million of individuals who are ages 5 and older spoke a language other than English at home and almost half, 40%, of these individuals, or 25 million, were considered to have limited English proficiency. All of the first responders we interviewed said their number one communication issue relates to language barriers. More than 8% of the total population has limited English proficiency. Depending upon where you're living -- of course, this could be even greater.

So in response to the follow-up to that, what do you do, what do you rely on, Captain Hagler said in Arkansas, Tennessee, and Louisiana, where she was an EMT, they used the language line all the time. Chief Dempsey, who before he came to California worked in a Chicago suburb, said that in that area, Spanish was the primary language
but Mandarin, Vietnamese and other Asian languages were also prevalent. And, again, in that area he said they often relied on the language line.

In Monterey, Seaside and Pacific Grove, there are more than 26 languages in schools. So children are coming to school with more than 26 languages in addition to English. Although some of the first responders speak Spanish, which is our primary second language, many do not. So what do they do? They have cheat sheets that are very specific and have very specific information and questions they could ask people in Spanish. They often rely on family members, they say. Children often act as interpreters. They are learning English in school and they often are the primary interpreter during an incident.

These first responders don't use the language line very often. But they know it's there. And in a disaster we have resources in our area like the defense language institute and other resource that can be called on. So although it's a huge problem, first responders feel by and large able to deal with at least the more common languages.

So in addition to language issues, what other challenges with communication do first responders interviewed note? Listed on the slide are dementia, stroke, Parkinson's disease, autism, people who have hearing, speech, vision, and cognitive issues, and behavioral issues that result in communication challenges.

Lots of people are at risk for communication during an emergency or disaster situation as shown in the diagram, those with limited English proficiency are most likely
self-identify as having a communication disability, also at risk. Many people may have their abilities temporarily or recently compromised because of medical issues going on or just the stress of the situation. And, in addition, there are people who may or may not be aware that they are having difficulty communicating.

As I mentioned earlier, the triage destination needs to address the needs. So sometimes first responders take individuals to the emergency room. Other times social services. Other times they refer the person to a clinic or program or do nothing because that's the preference of the individual who has been impacted.

I asked several people what their most challenging experience was. I'm going to share one with you from Captain Hagler. She's the EMT. She said her most challenging experience was a woman -- they were on a call and the woman had lost a significant amount of blood. She had had a nose bleed but she was bleeding profusely and nothing was stopping the bleed. And Captain Hagler says they were very concerned about how much bloodshed lost. She was deaf, blind, and had no speech so the EMTs had no way to communicate with her. Her son was there but he was also blind and hearing impaired.

So what did they do? She said, “We worked it out.” The EMTs wrote questions. The son used a magnifier to read the questions and then interpret for his mother. And they were able to transfer her to the emergency room, to the hospital with a good outcome, accompanied, of course, by her son and the magnifier.
Another question, a key question, we asked the first responders is: What information do you need from people impacted by an event or incident? They need to know the name, age, complaint, medical issues, allergies what provoked the event. They need information about pain level and whether their condition is improving or deteriorating. They're trying to identify the problem, get accurate information so they can prioritize solutions and triage effectively. To sum it all up, they said basically we have to quickly gather information and we often have limited resources.

First responders do an amazing job. They are consummate professionals, highly skilled, and compassionate people. We asked the kinds of strategies they use and there was kind of a consensus about the basics. Show respect. Observe and evaluate the situation. We also consider in that assessment body language, position, and gestures. We need to be aware of our own behavior and the impact it might have on the interaction. What's our size, the position, our authority, facial expression, our emotional state? If possible, we need to identify a person who is familiar with the individual's communication. And also we need to remember to consider and address family concerns and efforts to help.

In response to the question, well, what strategies do we use, there seems to be another consensus area. We try to remain calm and professional. One person said -- I think it was Captain --"We learn to be like a duck." I said, "What does that mean?" "We're real calm above the surface and down below the water we may be pedaling like crazy. We may be as anxious or more anxious than the individuals whom we're trying to help."
Another comment was getting down to the person's level. And by that they meant if the person -- if the individual is in a wheelchair, if it's a child, if the person is sitting down or lying down, be where that person is to make communication more effective.

Being sensitive to cultural differences was another very common comment. One of the issues -- or one of the ways I like to think about that is showing cultural humility. So not knowledge but humility, being aware that people have different cultures and not assuming you know what that means in that particular instance.

Another strategy is determine the language and find the interpreter. We know that's really important.

Reaching out to family and friends to help. Being aware of how to help children help us. Because they said they are often the ones who do help and they're used to doing that. They also use police dispatchers because oftentimes there is multiple languages that they can access that way. And they will ask a person if they can write and they will use gestures slowly and mindfully, they say. Being careful not to startle somebody or touch somebody without asking.

Other strategies that they mentioned: Using a communication support person. Again, asking if somebody knows how the individual communicates, so a familiar adult or familiar child; using an interpreter if there is a language barrier or the person uses
sign language, both onsite or through a language line or apps, trying if possible to access a professional interpreter; using a variety of tools. We mentioned paper, pencil, gestures, also yes/no questions which we'll talk about later because they can be a challenge. Using communication displays like we saw with Pam, pain scales, and apps.

Another question we asked was: Well, what training have you had? This was interesting because most everybody said basically we're learning on the job. We really haven't had much specific training for communication. Everyone agreed the training is really important, that they train all the time.

And one of them said tools can't make a difference unless you know how to use them.

Also, knowing what tools and strategies to use as well as when to use them can make a huge difference. There's two quotes that I want to share. One is when the only tool you own is a hammer, every problem begins to resemble a nail. So having a big bag of tools with lots of strategies is important. And if the only tool you have is a hammer, it's hard to eat spaghetti.

Let's consider some specific tools and strategies. I'm going to briefly go through the following: Yes/no, pain scales, communication displays, and communication apps.

As Captain Reed and Chief Dempsey said, the challenge is knowing how to ask yes/no questions. And you need to do so with caution. So here's how. First, number one, you ask somebody: Show me how you say yes. Pause, wait, observe. Then show
me how you say no. You want to repeat the person's action to confirm. For example, "Ok, you'll tell me yes like this." Because what we're trying to do first is establish a reliable signal for yes and for no. If you have time -- or if you feel it's really important, first responders might also ask the person to tell me how you might say I don't know or something else.

Once we can establish clear signals, then you can begin asking questions. It's important to ask questions one at a time. For example, say, "Are you in pain?" And pause for a response. Then ask, "Do you feel sick?" And pause for a response. Don't say, "Are you in pain or feeling sick?" For obvious reasons. In any case, we give the person time to respond while we wait, listen carefully, and watch closely.

Just an aside, listen and silent are actually spelled using the same letters. It's a good strategy.

Number five, once you have established reliable yes/no, you might ask, "Is there someone here who can help you communicate?," "Can you write?," "Will you understand if I write to you?"

You can get a copy of these on the CERV website or through the Pacific ADA Center.

Here's an example of a communication display that helps identify the location. As you can see, there's a front version and a rear version of a body. The level of pain in the middle. So from no pain to worse. That could be a scale of zero to 10. This is an
old-fashioned thermometer which, by the way, nobody uses anymore so I'm not sure why we're doing it that way anymore. But there you go.

And then also the type of pain. So constant pain, intermittent pain, radiating throbbing, or it itches, stings, cramps. All of those are key information areas that first responders say they need.

This slide illustrates a variety -- this slide illustrates another pain scale and some comments that the first responders made.

They said, "I really like this. The patient can point." Another person said, "You know, these pain scales are used in emergency rooms. People do better with graphics." Captain Reed reminded us we need to identify changes over time so that if the person -- is the person getting better, feeling better, is the pain better, is it worse because that gives them feedback about the effectiveness of whatever the treatment they are doing and allows them to communicate that to the next phase of the triage.

In this slide you'll see a variety of displays, communication displays. Some of these are available online and can be downloaded. They're all commercially available.

The point of communication displays is allowing access to language so that information can be exchanged. In one picture on this slide you see a large number of types of displays, the emergency communication for all is a display that was developed during the Haitian earthquake and is available in Haitian, Creole, English, and Spanish.
The one on the bottom left was developed in Florida for use after a hurricane. You see depicted there a nurse in the emergency room looking at that. And then there are two with the alphabet on them. It's for people who are literate and can spell. Even though spelling is very slow, that provides access to language that isn't restricted by somebody's deciding what needs to be on a display.

Comments from the first responders about communication displays. When we show them the displays, a variety of them, Captain Black said "These are excellent. They could help prompt me. Tools like this are absolutely important." Captain Reed said "Pictograms are great but getting them to the end user is hard," meaning getting firefighters to use them is hard. Chief Dempsey said, "Multiple tools need to be available. They are a great help for direct communication. My job is to get these to my team." And Jason Sullens said, and reminded us several times during our interview, "We need to have all the tools but we also need to know how to use them effectively."

This slide shows the results of a study that we did a couple of years ago, comparing the vocabulary on six displays that are available, widely available and widely used. So what you see is that there were a total of 289 words and phrases across the six displays. The only two words that were on all six displays were yes and no. So less than 1% of overlap on all six displays. And I would suggest that yes and no do not need to be on these displays because it's much quicker to get it a different way.

On five displays, we had 1.7% of overlap and three additional words: Hot, cold, hungry, eat. Four displays, 3.4% and a couple of additional words: blanket, afraid, pain,
short of breath, pain scale. There were 203 words on these six displays on which there were no overlap, 70%. No overlap.

So what does this suggest? These findings are surprising because under most circumstances the interactions that need to occur are brief, focused, and very specific. So I would suggest that we need to collect usage data what displays to interact and use under what conditions, satisfaction data, what works, and also consider what graphic representations could be misinterpreted and what symbols or words to avoid also that could convey a wrong message or be culturally offensive.

So that's research in progress. Now briefly let's consider apps. In the past year social media has doubled. And we know that different groups have different preferences for the use of social media. And I'm not going to go into much of this, just to say that there's a widespread recognition that mobile technologies are how the public communicates today with each other and that emergency and disaster preparedness area, recovery and response, resilience, we have to adapt to this fact.

Currently, apps are used in the disaster and emergency area for educational purposes like thousand get ready, medical history in case of emergencies. There is many apps for that. Instructions like how to stop bleeding, alerts, locators and panic buttons are available, and communication but not so much in the area of face-to-face or interpersonal communication between responders and individuals impacted.
The first responders said things like I know they're out there but we don't use them. In my job as emergency operations coordinator, we're looking increasingly to social media and apps to support our efforts through the incident.

It appears that most of the available apps today support communication between responders and triage facilities or emergency operation centers. In fact, FEMA specs for app development state the key importance for communication but never mention communication with people impacted by the event in terms of direct face-to-face, supporting face-to-face interaction.

So what you see here are some examples of apps that I found, the emergency communication for all is now available not only on paper but through an app. There is an app that's specific for people with autism that can be helpful. Also, an app that looks at language and the needs, language interpreters, sign language interpreters, sign language texting. And finally a shelter app.

So as I said, it's a whole other topic. It's not my area of expertise but we realize the importance of apps and getting it right with apps.

What about training? The first responders said: Nothing prepared us to address day-to-day communication issues; that we do address -- I believe they do a really good job. I'm quite sure of that. In most cases.
Trial and error. Training is necessary but because the problems that we face slow us down and slow our ability to provide services down. Captain Hagler said in her area EMS system was constantly training and it always included communication and they had a set curriculum. And Chief Dempsey said that their training is ongoing. The curriculum, though is dictated by the state. We suggest there's a need to develop training modules as well as emergency exercises for responders and people with communication access and functional needs to demonstrate ways of coping with barriers and make these available online.

One example of a useful tool. You can order or download tips for first responders. There's a page each. This has a three-ring notebook kind of thing. It's a page each that people with various kinds of challenges -- those are listed on the slide.

First responders want to do their job and effective communication is key. They face communication issues every day and they need a full bag of tools and strategies to feel comfortable. They need to train to use them.

So, just to summarize, the basics in terms of what we learned from the first responders, their basics is they start with respect and professionalism. They depend on support persons, professional interpreters, non-professional interpreters, communication intermediaries, children, and other community support workers. And they use technology like language lines and less so communication displays but certainly paper, pencil.
Let's shift the discussion now to making communities more resilient by engaging communities, teachers, agencies, and organizations. I'm going to start with a quote from Anne Marie Jones. She says, "In the future readiness will not be measured by binders and plans nor resilience and [Inaudible] be framed around disasters. Readiness and resilience will be woven into everyday habits and behaviors. In the future, we will invest the time and talents of our community in building individual and collective capacity to solve problems. Rather than merely saying I've got a kit, be proud to say I've got your back.”

We're going to be talking about preparing clients for emergencies, roles of professionals, schools, organizations, agencies, building community resilience from the bottom up and addressing preparedness as part of one's everyday practice. Unlike first responders who deal with unfortunate circumstances and emergencies every day, people with communication challenges don't get to practice how they're going to respond in an emergency. Learning by doing may be therefore, too little, too late and lead to negative outcomes.

This is important. Let's consider what community professionals can do. They can certainly ask questions and provide simple tools during the many times that people who have communication issues that they typically understand, know about, and can deal with, come to their offices or clinics, agencies. They could easily be asked: Are you carrying medical information with you in case of an emergency? Is it up to date? Teachers and therapists, again who see people who have communication challenges all the time could ask: What assistive technologies do you need in an emergency? Are you
going to be able to access them? Who are your human supports? How are you going to stay in contact with them? Do you carry something with you to explain your communication problems and other needs?

Preparing to prosper after unfortunate events requires that an individual has medical information with them. Now, who could help them with that? Certainly doctors, clinic personnel, anybody in the healthcare system. That should be part of the visit. They should also, if they have communication access and functional needs, have communication information with them that tells how they communicate, how they want people to communicate with them, and what technologies or human supports they could need.

Who could help them? Obviously their own advocacy skills and their families but also teachers and healthcare providers, speech pathologists, position assistants, occupational and physical therapists, etc. Even faith-based organizations. Asking questions like: Can you receive alerts? What if you can't access an interpreter or what if you don't have hearing aid batteries or a speech-generating device?

Here's some examples of an ICE card, in case of emergency card, which everyone should carry with them at all times and most people don't. But individuals who have communication access and functional needs must carry something. So there's medical passports you see depicted, also USB, a bracelet or something you can carry in your pocket or around your neck or in your purse. There is particularly developed
communication passports that can be downloaded from the internet or purchased online.

In addition, there's some really nice tools. One example is a group in South Africa who have developed information that people can carry with them. I have a hearing impairment or visual impairment, etc. I'll just read: The hearing impairment when talking to me, reduce background noise, touch my shoulder or waive my hand to get attention, establish eye contact before you start talking, etc., etc. So something like that that's personalized can be very effective.

Another example. This is a free downloadable software from Widgit software in the United Kingdom in multiple languages, members have worked with them on medical encounters and bedside messages. The information in terms of accessing them is available.

So in this example, there's some general questions. Can I get help filling out these forms? Please speak more slowly. Then there's some questions for the doctor or for the first responders. Please talk directly to me. I can understand, etc. So the vocabulary on these comes from research that's been done on what people actually need to say during a medical encounter.

Another example are some shelter supports. This is one called Show Me available from Massachusetts. Again, this is downloadable. It includes information
about language, arrival issues, medical needs, food allergies, people in places and support.

Preparing to prosper in an unfortunate situation gives a community resilience -- is a community resilience event. It is preparation and training that are the key. We know that. Abe Lincoln said, "If I had eight minutes to chop down a tree, I'd spend the first six sharpening my ax." His thought highlights the importance of preparedness individuals with communication access and functional needs are atmosphere risk in any emergency and disaster scenario. The ability to receive information and communicate with responders is essential to survival. That is why we encourage community professionals and organizations that employ them to emerge from the sidelines and engage more directly in emergency preparedness and community resilience.

Pam shares some lessons learned. She now wears a waterproof fanny pack when she goes out that has a lot of stuff in it. She keeps a go bag in her closet near the exit. In addition, she's alerted local police and fire. She's alerted her network of family and friends and signed up for alert to monitor -- as well as monitoring weather and warnings. She says she makes a real effort to be in her wheelchair in case she needs to evacuate.

This slide shows a checklist for people with communication access and functional needs. We'll put it on the website. It will be available if you would like it. It also can be kept in records at doctor's office, therapy, offices, clinics, etc. Just six
questions. Do you have a support team? Does everyone know what to do? It's yes, no, does not apply, and needs work. Do you have a medical passport? Do you carry it with you at all times? Do you have an evacuation plan in case you need to leave home? Is your go bag packed? Do you have written instructions about communicating? And are you prepared to remain at home or at work during an emergency?

So our takeaways, emergencies happen every day, everywhere, and to everyone. And they're often health-related. People are disadvantaged when they are unable to communicate effectively with first responders. And many, many, many people have communication challenges. Community workers are in the best position to make a difference for these individuals and help them prepare because they know them and their families. They have resource and access to knowledge that can help them. And they care about their clients and really want them to be safe.

So illustrating, again, emergencies happen every day. They're a daily occurrence in our communities. We've shown that many have communication issues but can interfere with first responders providing services efficiently and effectively despite anyone's best effort. Communication is key to maintaining health, safety and supports, independence and even transportation. The very nature of emergency and disasters make communication more difficult because of a variety of reasons, including that people may or may not even be aware they're having difficulty.

This slide illustrates that there are a large number of places that people with communication access and functional needs go routinely and where the people that
work there know and care about them, and that that means there are opportunities that -- every day there are opportunities to encourage preparedness and build our communities' resilience.

We've discussed alerts, interactions, and thousand prepare people and make it a community resilience effort.

These next few slides share some resources that you can access and get more information, including books and websites. Some of them are referencing things I've mentioned previously. And then there's two long pages of references.

And finally, the major message and our biggest challenge, communication. Communication is not I talk you listen or you talk I listen. Communication is the joint establishment of meaning.

Thank you for your attention. Thank you, Lewis, for this opportunity. I welcome any questions. If we run out of time and you still have questions, just e-mail or call and I'm happy to continue the discussion.

>> Lewis Kraus: Thanks so much, Sarah. That was fabulous. I do want to encourage all of you who are listening to submit your questions in the chat window and I will read them off and Sarah will answer them.
All right. Let's go with some questions that we already have. Regarding your research, one question was: Did you ask first responders what communication methods were used to communicate with people who are elderly, had strokes, or have Asperger's and have difficulty communicating and what suggestions did you obtain?

>> Sarah Blackstone: Yes. Those were among the groups that they specifically mentioned. It's not the same for each group. Some general things that they said is don't move too fast, patience, but also just really watching the individual to see -- to try to discern whether you're getting through.

I know Captain Reed said when you're dealing with somebody who has dementia, you have to move very slowly and say things a couple of times and expect that they might understand. So slow it down. And that was true -- I think that's certainly true for Asperger's as well. Acknowledging with autism and Asperger’s that these individuals may be freaking out, and ask them if there's something they know that they can do to stop freaking out. Because sometimes they do know, they just don't know how to access it.

>> Lewis Kraus: Ok. Great. The next question is about that University of New Mexico tips for responders tool that's available for download and printing. Is it for sale or is it just free and available. Do you know?
>> Sarah Blackstone: It's both. You can download it and laminate it but it's really nice. It's not that expensive. I can't remember but I think it's under $10. We generally buy a bunch of them at the same time. So, yes, you can purchase them as well.

>> Lewis Kraus: Ok. One question came in about how do you address literacy gaps between responders and clients.

>> Sarah Blackstone: I think that's where -- access to language, I really want to reiterate that point. It's so important. When people are not literate, they don't have access to language unless you help by providing them with some language that they can then point to in some way or another. So communication displays can be very helpful. That way with a caveat that you may have to help them learn what the symbols are on the display. And sometimes that's very difficult. So how these displays are constructed, I think is a really important area that needs a lot of work.

Some people can do pretty well with gestures. Sometimes drawing. Sometimes people who aren't literate may have ways of signaling certain messages that somebody in the family might understand. So asking things like are there ways that the individual signals already.

Not having access to language is a big problem. It can seriously interfere with good care.
>> Lewis Kraus: Ok. Great. The next question is about -- I'm not sure if it's a question. I'm going to try to rephrase it for the person who wrote it. Those who choose to shelter in place and rely on electronic communication may be in a disaster area with prolonged power outages and are deprived of alerts. Do you have any points to make about communication with people who are sheltering in place and using electronic communication?

>> Sarah Blackstone: Well, my point would be that people who use electronic communication shouldn't think that's the only method they are going need in an emergency situation as Pam so well illustrated. For a number of reasons. In Katrina, my husband and I became very active during and after Katrina for a couple of years. We learned many, many people when they had to leave left their communication devices behind or they had been damaged. And unless you have, like Pam now has, backup communication displays that are specifically designed so that you can communicate, what you might want to have to communicate, you can't really depend on the electronics. You need the backups, too.

>> Lewis Kraus: Ok. That's great.

There was a question and a reference to the fact that the slides have all of this lovely information that Sarah left for everyone. So I've just put in the chatroom a reminder of where you can go to get all of that. It is not posted yet. I realize it's not posted yet. It will be by next week as well as the archive will be available next week. So just a reminder about that.
There's another comment here about we printed the Temple University message boards and gave them out for hurricane preparedness as backups to the electronic boards and they were very popular. Are you familiar, Sarah, with the Temple University message boards?

**>> Sarah Blackstone:** Yeah, actually, that's the emergency communication for all boards. So I showed them several times on the slides. They were developed at Temple University.

Sorry. I just took a glass of water and now I'm almost choking.

So they are -- they are really helpful. As I said, they were developed for after the Haitian earthquake and have been followed up on and are now available in other languages, Spanish as well, and also as an app.

It was interesting that all the first responders we talked to were very, very positive about the potential of communication displays and yet none of them routinely use them. What I think they were saying is because we don't -- we've never really been trained to do that. It's true that you do need some training because it makes you communicate in a way that's different. And most people aren't comfortable communicating in a way that's different if they only do it, you know, once. They were very positive and yet also saying, you know, we really don't know how to use these things.
So, just as a response to that, it sounds like maybe one of the outcomes of what you're suggesting here, and it's probably obvious but I want to restate it, is maybe in some of the drills that jurisdictions do or organizations do, that maybe they should at least a segment of it if not the entire thing include something around communication practice and awareness, huh?

>> Sarah Blackstone: Very much so and they should allow people to drill it, too. Because, again, watching and listening about it is very different than actually drilling where somebody -- ideally it would be somebody who really did have a challenge but even somebody who is acting as though they don't speak the language or they don't -- you know, they have no -- they can't hear you, they don't know what you're saying or they're very confused and you need to talk them down.

>> Lewis Kraus: Ok. Very good.

We realize that many of you may still have questions for Sarah and apologize if you didn't get a chance to ask your question. You can contact your regional ADA Center at 1-800-949-4232 to ask a general question or your contact on the screen for contacting Sarah if would like to ask her some questions further after this session.

I want to remind everyone you're going receive an e-mail with a link to an online session evaluation. Please, please complete that evaluation for today's program. We really value your input. We've been using it and putting it to good use. We hope that
you're seeing changes and things are adapting for what you were pointing out. And our speakers like to hear how you've been rating them as well.

We want to thank Sarah today for sharing time and knowledge with us. Thank you so much, Sarah.

>> Sarah Blackstone: Thank you. And thank you to everybody for hanging in.

>> Lewis Kraus: And a reminder that today's session was recorded and will be available for viewing next week at the www.adapresentations.org/archives.php address.

Thank you so much, everyone, for attending today's session. We look forward to seeing you on September 10 for our next webinar, "The FEMA Promising Practices Preparedness for People with Chemical Sensitivity and People with Developmental Disabilities."

Have a good rest of your day.

Bye-bye.