

CHAPTER 5

Integrating Emergency and Disaster Resilience Into Your Everyday Practice

Sarah W. Blackstone and June Isaacson Kailes

Introduction

The dike was breached on April 19, 1997, at about 2:00 AM. 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 AM 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 a truck. The rescue team knew about Jessie and me even though we'd 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, some manual signs and gestures (Kennedy, 2008, p. 4).

This chapter addresses issues related to people who have difficulty communicating during and after an emergency or disaster. It focuses on why and how speech-language pathologists,

audiologists, interpreters, educators, and other professionals need to become more active in emergency readiness, response, and resilience in their communities. It encourages these professionals and the organizations they work for to take on more responsibility for making sure their clients and patients can communicate successfully in an emergency or disaster.

Why? Because they are in the best position to do so. They alone can identify many of the individuals at risk and then help them and their families to prepare for the personal or family emergency that is likely to happen, as well as the catastrophic event that everyone hopes will never happen (Blackstone, 2008). Ideally, if community professionals would join readiness, response, and resilience efforts, then our communities would come one step closer to addressing an as yet unmet mandate to provide communication access.

The Need

In the field of emergency management, a prevailing theme is that you cannot *predict* when bad things may happen, but you can *prepare*

for when they inevitably do. If individuals who are impacted by an incident (a) cannot access, understand, or respond to an alert; (b) are unable to communicate successfully with first responders through speaking or writing; (c) are unable to use their technologies (hearing aids, glasses, speech generating devices, alphabet boards); or (d) are separated from, or cannot access, the supports and services they depend upon (sign language or language interpreter, familiar communication partner, service animal), then their health, safety, independence, or survival may be at risk. Communities can respond in ways that will mitigate negative outcomes only if they understand the kinds of issues that their citizenry faces.

At present, far too few disaster response workers are trained to deal effectively with people who face communication barriers, and far too few people with disabilities or conditions that affect their ability to communicate are adequately prepared to deal with emergency situations. In the United States, for example, some 61% of the 54 million Americans with disabilities have not made plans to quickly and safely evacuate their homes in an emergency, and nearly one third have not made plans to evacuate from their workplace (Rader, Edmunds, & Bishop, 2010). In addition, according to the National Organization on Disability, only 14% of community-based disability service providers know how to access their emergency management systems (National Organization on Disability, 2005).

Since 1990 the number of people with limited English proficiency (LEP) in the United States has almost doubled (increasing by 81%). In 2011, approximately 21% (60.6 million) of people ages 5 and older spoke a language other than English at home, and almost half (40%) of these individuals (25.3 million) were considered to have limited English proficiency. This represents more than 8% of the total U.S. population (Chhandasi, Batalova,

& McHugh, 2011), placing these individuals at considerable risk due to language barriers during disasters and emergencies.

The World of Emergency Preparedness

Terminology

The vocabulary associated with the field of disaster management is unique. Most people are unfamiliar with the elements of emergency planning, preparedness, response, recovery, and resilience. Terms like “certified first responder,” “emergency medical technician,” “mitigation,” “incident command structure,” “cycle of preparedness,” “shelter-in-place,” and “evacuation” are often unfamiliar or not well understood by people outside the emergency management field.

In this chapter we use the term “disaster” to refer to catastrophic events. These events may be natural or human caused, ranging from a pandemic, a powerful hurricane or storm, devastating tornado, earthquake, tsunami, mudslide, fire, or flood to an explosion, chemical spill, mass shooting, war, or terrorist attack. Disasters threaten life, property, public safety, and the environment. They cause damage of sufficient severity and magnitude to warrant an organized response and deployment of resources from local, state, and sometimes federal government and disaster relief organizations.

We use “emergency” to identify events that are typically handled with local resources and procedures. Personal emergencies occur every day in every community. They include medical emergencies (heart attack, stroke, seizure), accidents (falls, vehicle crashes), and injuries (sports related, burns, gunshots). Emergencies also result from localized incidents, such as a storm that causes power outages and hazardous road conditions, a fire that

spreads to multiple buildings, a chemical spill, or a flash flood.

Resilient communities carefully plan and prepare to deal with personal and local emergencies as well as with disaster scenarios. Emergency managers understand the necessity of involving leaders in government, community organizations, agencies, and businesses. Ideally, emergency planning and preparation should begin in every home. Resilient communities have the best outcomes, because they prepare not only from the top down, but also from the bottom up.

We use the term “responders” to refer to the trained professionals and volunteers who are involved before, during, and after an incident. Professional responders include paramedics, emergency medical technicians, fire fighters, police officers, nurses, doctors, workers in shelters and other emergency facilities, and emergency management planners. Volunteer responders include groups like community emergency response teams (CERTs), Red Cross volunteers, Citizen Corps, Medical Reserve Corps, and the disaster medical assistance teams (DMATs) and Medical Teams International. All responders are trained to work within an Incident Command System (ICS) structure to ensure coordination of resources and to address safety issues. Job descriptions and level of “responder” training vary significantly depending on professional backgrounds and assigned roles (e.g., command, logistics, damage assessment, traffic control, search and rescue operations, triage, sheltering, evacuation, medical care, recovery, public information, mitigation).

National Incident Management System (NIMS)

In 2004 the U.S. Department of Homeland Security introduced the National Incident Management System (NIMS). This system is

intended to support efficiency in emergency management and incident response activities through the adoption of a common set of principles using a shared terminology (<http://www.fema.gov/about-national-incident-management-system>). Implemented widely at local, state, national, and international levels, the National Incident Management System achieves and maintains preparedness through a continuous cycle of planning, organizing, training, equipping, conducting exercises, evaluating, and taking corrective action (U.S. Department of Homeland Security, 2013) (Figure 5–1). The preparedness cycle requires coordination among all entities involved in emergency management and incident response. Given the numbers of individuals, groups, businesses, organizations, and government agencies deployed during a disaster, this is no easy task.

Groups not well represented in planning are among those most likely to be overlooked during an incident. They include, among others, disability groups (e.g., persons with hearing, reading, seeing, understanding, speaking, and remembering limitations), as well as people who do not speak English or have other limitations that interfere with effective communication. These groups are rarely “at the table” or represented during emergency planning and community resilience meetings. In part, this reflects the difficulty they have advocating effectively for themselves because of their communication barriers. For this reason, it is especially important for community professionals and organizations that provide support services to these groups to become more involved in emergency preparedness.

Incident Command System

The Incident Command System (ICS) is a key component of the National Incident Management System (NIMS). It is widely used by

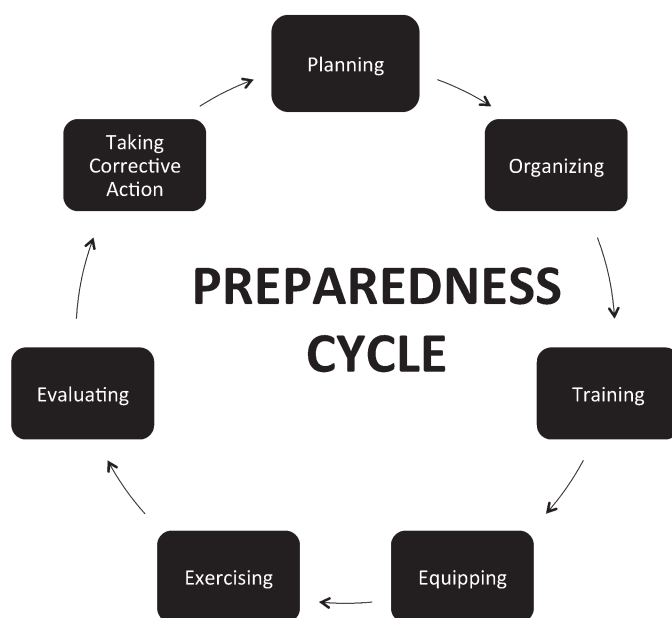


Figure 5–1. Emergency preparedness cycle.

responders and government agencies for day-to-day events and planning. As a result, the ICS is a familiar and well-practiced approach that helps entities organize how they plan, prepare, respond, and recover. There are five key system functions: (a) command (responsible for all aspects of the incident; during large incidents command is often supported by a safety/security function and a public information officer function); (b) operations (responsible for all operations applicable to the primary mission of an incident, including communications); (c) planning and intelligence (responsible for collecting, evaluating, and disseminating information related to an incident); (d) logistics (responsible for providing facilities, services, and materials related to an incident); and (e) finance and administration (responsible for all financial, administrative, and cost analysis aspects of an incident).

Taking the time to understand the culture and system of emergency management and incident response activities can help community professionals collaborate more meaning-

fully with responders and emergency managers and agencies to promote greater inclusion in emergency planning, better results in response and recovery, and ultimately, more inclusive, resilient communities. The Federal Emergency Management Agency (FEMA) offers free web-based training through the following websites:

- National Incident Management System Training: <http://training.fema.gov/EMIWeb/IS/courseOverview.aspx?code=IS-100.b>
- The Incident Command System Training: <http://training.fema.gov/EMIWeb/IS/courseOverview.aspx?code=IS-100.b>

Who Benefits From Communication Access?

“Vulnerable” populations have been defined as individuals who share an essential charac-

teristic that can have an immediate and ominous bearing on their readiness, response, and recovery in an emergency or disaster. Hopper (2010) defined “communication vulnerable” as applied to the field of emergency management as people having limited English language proficiency; limited speech, sight, or hearing; no dependable social relationships; or inadequate communication skills.

The degree and duration of communication vulnerability during a personal medical emergency, a local incident, or a disaster can range from mild to severe, from transient to permanent, and can be highly influenced by the context or situation. Communication breakdowns occur not only if someone has a disability or speaks a different language, but also when communication partners (e.g., first responders, shelter workers, physicians) lack the skills they need to communicate effectively with a particular individual. For example, a person who is deaf with high-literacy skills may not be vulnerable as long as responders can read and write and she has a paper and pencil available (Matherly & Mobley, 2011). However, if she communicates exclusively using American Sign Language, she may have difficulty communicating effectively with anyone who does not. Likewise, individuals who do not understand or speak English may be considered poets in their own language communities but be highly vulnerable if communication partners speak only English.

People With Communication Access and Functional Needs

The terminology now preferred to identify individuals and groups who are communication vulnerable during emergency and disaster events is “people with communication access and functional needs.” This term includes the following groups: (a) individuals who self-identify as having a communication disability (e.g., people who have difficulty hearing,

speaking, understanding, seeing, reading, and writing secondary to a developmental, acquired, or degenerative condition); (b) individuals with limited English proficiency; (c) individuals who may (or may not) be aware they have difficulty communicating, including individuals with significant cognitive challenges or mental health conditions and young children (Peek & Stough, 2010); and (d) individuals whose communication abilities are temporarily compromised because of a recent injury, extreme stress, or lack of access to medications that treat, for example, their depression, anxiety, or psychosis.

The term used in the past to describe “vulnerable populations” was “people with special needs.” Clustered under that umbrella were people with disabilities (including serious mental illnesses); people with limited English proficiency; children ages 15 years and under; and adults 65 years and older. According to the 2000 U.S. Census, the “special needs” category accounted for 49.44% of the entire U.S. population (Kailes & Enders, 2007). Additional groups were soon recognized as “at risk” in disaster and emergency events. These included people who were homeless, lived in institutionalized group quarters, were morbidly obese, were pregnant, were on kidney dialysis, and lived in “zero-vehicle” households. Together these groups accounted for well over 50% of the U.S. population, rendering the term “special” essentially meaningless. In addition, diverse disability communities have long considered the term “special needs” offensive (Kailes & Enders, 2007).

Kailes and Enders reasoned that a “special needs” approach to emergency planning and response was unacceptable because it (a) lumped together individuals from diverse groups based on their impairment, medical diagnosis, or label, thus doing a disservice to each group; (b) could not be operationalized; and (c) did not provide needed guidance. They first proposed the term “persons with access and functional needs” in their article “Moving

beyond ‘Special Needs’: A function-based framework for emergency management and planning” (2007) to reflect a more inclusive, community-based perspective that is consistent with the widely accepted World Health Organization International Classification of Functioning, Disability and Health (World Health Organization, 2014) (<http://www.who.int/classifications/icf/en/>) and the social model of disability (Shakespeare & Watson, 2001). By recognizing common risk factors within a community, emergency management professionals are more likely to understand the unique demographics of their community, which means responders are more apt to assist those most in need of help (Roth, 2011, 2014).

The Communication, Maintaining Health, Independence, Safety, and Support, Transportation (C-MIST) Framework

The *C-MIST* framework depicted in Figure 5–2 identifies five areas related to access and functional needs: *communication* access, *maintaining health*, respecting and maintaining *independence*, ensuring *safety* and support, and providing *transportation* (BC Coalition of People with Disabilities, 2008; Kailes & Enders, 2007; Kailes & Neiman, 2013).¹ Although independence during an emergency or disaster is a goal for individuals, families, and communities, it is only achiev-

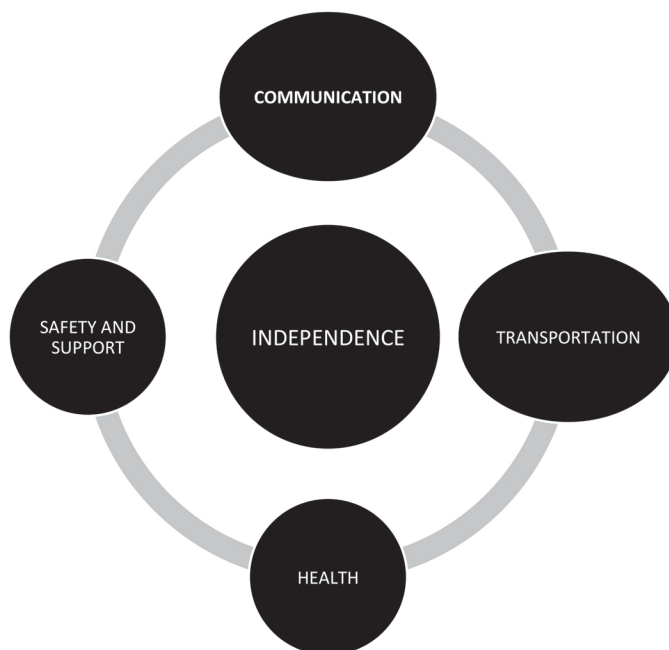


Figure 5–2. *Communication, maintaining health, independence, safety and support, transportation (C-MIST): An access and functional needs framework. Reprinted with permission from June Isaacson Kailes.*

¹Originally developed by June Isaacson Kailes. Updated in 2011 by FEMA, the National Council on Disability, the Texas Governor’s Committee on People with Disabilities, the American Red Cross, and the U.S. Departments of Homeland Security, Justice, Health and Human Services, and Transportation.

able through coordinated efforts within the preparedness cycle. The Federal Emergency Management Agency (FEMA) uses C-MIST as the standard for health preparedness, emergency planners and managers, and local public health departments. It also is endorsed by the Department of Homeland Security National Response Framework (Federal Emergency Management Agency, 2013a; Roth, 2014).

A feature of the C-MIST framework is acknowledging that individuals may face difficulties in multiple areas. For example, Pamela Kennedy required assistance in all areas.

“I was told that I couldn’t be evacuated to the same shelter as my friends and family because of my complex communication needs.” Instead the soldiers had set up a “makeshift nursing home” at the army base’s elementary school, in their special education room. When Pam arrived at the room, a soldier at the shelter said, “I know it’s crammed, 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.” (Kennedy, 2008, p. 4)

The soldier also explained that 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 asked 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’s story highlights the importance of communication as a prerequisite skill needed to access all other functions. Under everyday conditions, Pam is quite independent. However, in the shelter, her health, safety, and independence depended upon her being able to tell

responders (a) that she was unable to swallow solid food, (b) exactly how she would need to take her prescribed medications, (c) that she would not be able to transfer from her wheelchair to the cot safely without assistance or unless they found a cot that was more accessible, (d) that she was worried about her family, and (e) that she felt uncomfortable being asked to “room” with a man who was a complete stranger and with whom she was unable to communicate. In short, being limited in her ability to communicate affected not only her health, but also her safety and independence.

Luckily Pam is literate and resourceful, able to write, and thus could use language to express herself freely and communicate successfully. Simply responding to a responder’s or a shelter-worker’s “Yes” and “No” questions would not have been sufficient.

Laws and Policy

Legislation and public policy play a key role in securing the rights of people (like Pam) with communication access and functional needs. Listed in Appendix 5–A are some of the laws in the United States that address the rights of people across the preparedness cycle. The Americans with Disabilities Act and other laws apply in the following:

- Preparation
- Notification
- Evacuation and transportation
- Sheltering
- First aid and medical services
- Temporary lodging and housing
- Transition back to the community
- Clean up
- Other emergency and disaster-related programs, services, and activities (Roth, 2011)

In 2009, the Civil Rights Division of the U.S. Department of Justice published *The*

ADA Best Practices Tool Kit for State and Local Governments (U.S. Department of Justice, 2009). This technical assistance document is aimed at teaching state and local government officials how to identify and fix problems that prevent people with disabilities from gaining equal access to state and local government programs, services, and activities. Section III, entitled “General Effective Communication Requirements Under Title II of the ADA” is a useful resource for community professionals and for individuals with communication access and functional needs because it addresses questions such as the following: What is effective communication? What are auxiliary aids and services?

Providing Communication Access During Disasters and Emergencies

Quick, Accurate, Timely, Decisive

Communication underlies the ability of emergency managers and first responders to assess and respond to circumstances on the ground, sort levels of medical needs (conduct triage), treat, transport, handle intakes at shelters and medical facilities, and document encounters. First responders need to communicate quickly, sometimes with a large number of people, under less than optimal conditions. They also need to share information with one another, as well as make sure the right information flows up through the chain of command.

Communication during an emergency or disaster must be quick, accurate, timely, and decisive. For example, if a man has a seizure or a stroke and a family member calls 9-1-1, when the emergency medical technicians (EMTs) and firefighters arrive, they need information about the man’s medical history, what happened to him, and “consent” to

transport him to the hospital. Communication exchanges are limited, focused, and specific, and any problems need to be handled quickly. When critical health information is readily available, the chances of survival increase, and the likelihood of long-term morbidity decreases (Barsan, 1996).

During a disaster, the greater the numbers of people involved, the greater the communication challenges may be. For example,

Mr. Rusk, age 82 years, has a severe bilateral hearing loss and mild-moderate dementia. He lives with his daughter who works full time and therefore is often not at home. Under normal circumstances Mr. Rusk is independent. The day a tornado devastated his neighborhood, everything changed. He hadn’t heard the sirens, had not received any alerts, and had only moments to “shelter-in-place.”

After the event, first responders were deployed to conduct “search and rescue.” One team saw a disheveled Mr. Rusk standing outside a damaged house. When they questioned him, he seemed disoriented and did not appear to understand them. They suspected he might have sustained a head injury or have dementia. As they continued to question him, he became increasingly agitated and upset, so they decided to transport him to a nearby medical facility.

Mr. Rusk did not require medical attention. He simply had not understood what the responders were saying. He was scared, confused, and worried about his daughter.

While no permanent harm resulted from his trip to the hospital, scarce resources and time were expended to transport him, determine he was not injured, and then reconnect him with his daughter.

This scenario could have unfolded differently. If Mr. Rusk had given the responder team an emergency information card, the encounter would probably have worked out better.

Types of Emergency Communications

To accommodate the diverse communication needs of individuals during emergencies and disasters requires recognizing the interrelated nature of communication barriers represented by the C-MIST (communication, maintaining health, independence, safety and support, transportation) framework. Inadequate communication and poor warning and alert systems result in delayed and inadequate medical care and unnecessary disruption in services supporting people and caregiver networks (National Council on Disabilities, 2009). In disaster situations, communication breakdowns between survivors and responders can have dire consequences, degrading health and causing unnecessary pain, treatment errors, and even death. Reports of miscommunication, or a lack of communication between first responders and people impacted by these events, especially those with disabilities, were common after Hurricane Katrina (2005), as well as after other disasters (Hopper, 2010; Matherly & Mobley, 2011).

People with communication access and functional needs must be sure they can (a) receive alerts and instructions; (b) interact face-to-face with people they do not know; and (c) have a way to maintain contact with family members, friends, and community helpers during and after an incident so they can maintain their health, independence, and safety. After a disaster, the daily services and supports individuals usually depend upon (e.g., personal communication aids and devices, paid assistants, familiar communication partners, service animals, and professional interpreters) may not be available for days or even weeks.

The initial disaster was the hurricane itself that ripped the coastlands of Louisiana and Mississippi to shreds and left New Orleans a wasteland. The secondary disaster was the unbelievably poor communication and response that occurred between federal, regional, state, and local relief agencies and efforts after the hurricane. The combination of these two back-to-back disasters has caused catastrophic damage to a vast human population . . . (including a) record numbers of deaths, injuries, refugees, and expenses as well as a city of approximately 1,300,000 million people that will need to be almost entirely rebuilt. (Piper, 2006, p. 40)

Alerts and Updates

Individuals with communication challenges need to be able to call for help, as well as access emergency services and receive alerts, updates, and instructions in multiple formats, no matter where they happen to be. A major emphasis in disaster planning focuses on “alerting” systems. Among the current options are radios (ham, two-way, local stations, National Oceanic and Atmospheric Administration [NOAA] weather radio) and systems that include the following (Mitchell & LaForce, 2013):

- Television (captioned, alerts, NOAA weather stations, and news tickers/crawlers)
- Phones (landline)
- Reverse 9-1-1 (cell phone) (people have to sign up for this service)
- Sirens
- Direct observation
- Text message/e-mail/Twitter (people have to sign up for these services)
- Internet news

Effective alerts require redundancy to ensure that all people who need the information get it at the right time, using the right formats. This includes (a) alerting and updating people in different locations; (b) providing the right message (in terms of content, length, and format); (c) monitoring delivery and response; and (d) ensuring that processes are initiated and suspended at the proper times (Kailes & Neiman, 2013). Recommendations are to do the following:

- Announce it
- Describe it
- Caption it
- Picture it
- E-mail it
- Relay it
- Share it
- Tweet it
- Text it
- Post it
- Interpret it (language and sign)
- Repeat it (frequently)

Calling 9-1-1 for help in North America provides a caller access to police, fire, and ambulance services. Enhanced 9-1-1 uses GPS and triangulation techniques to ensure location-based accuracy for cell phone networks. The Next Generation 9-1-1 (abbreviated NG9-1-1) will allow the public to place a 9-1-1 call from a phone, to transmit text, images, video and data to a 9-1-1 center. In January 2013, Canada took its first step toward Canadian implementation of NG9-1-1 services. In October 2013, several U.S. states began to implement versions of NG9-1-1. This initiative aims to update the infrastructure across the United States and Canada to improve public emergency communications services.

Face-to-Face Interactions

When emergencies or disasters happen, those impacted need to be able to communicate suc-

cessfully with responders. Although speech is typically the fastest and most reliable way to share information face-to-face, it is not always an option. Nonverbal methods, such as gestures, facial expressions, and body language also carry important meaning. However, nonverbal modes also can restrict the kind of information that can be conveyed.

The most common communication barriers people face in the United States today are language based, meaning the person experiencing the emergency and the responder do not speak the same language. In a medical emergency, a family member, support person, caregiver, or friend is often nearby and able to provide first responders with basic information (e.g., “She had a seizure. She has diabetes.”). However, during a disaster scenario, families are often separated and the natural supports people depend upon may not be available. Also, once someone is transported to a hospital or a medical staging area, medical personnel typically require more detailed information (e.g., medical histories, current medications, allergies, etc.). Also, they may need “informed consent” before ordering a procedure or tests to further assess or treat. In short, the more complex the situation, the greater is the need for communication. Patients need to understand what is happening to them, as well as be able to express their needs, and ask and answer questions. Communication supports may include interpreter services, communication boards, forms that are translated and available in plain language and large print, as well as modifications that responders need to make to their own communication behaviors in order to promote successful face-to-face interactions, such as speaking clearly and slowly, using understandable terms rather than jargon, being respectful, taking into account cultural differences, and learning how to elicit responses that go beyond “yes” and “no” (Collier, Blackstone, & Taylor, 2012).

Wireless Technology and Social Media

Social media and wireless technologies have changed the way people communicate. Children and adults across the age span now interact over distances, more frequently, and in ways not previously possible. While literacy skills are still required, photographs, symbols, sound, speech and even tactile modes (e.g., vibrations) have opened up more communication channels and substantially boosted access to information and communication with others. Not surprisingly, mobile devices are fast becoming a critical communications tool in emergencies and during disasters. That said, it is important to remember that these technologies, like other communication services, depend on the existence of intact infrastructures, and that electronic devices require a reliable power source or they will stop working.

According to a study by the International Association for the Wireless Telecommunications Industry (Organisation for Economic Co-operation and Development, 2014), 89% of the U.S. population are mobile broadband subscribers (<http://www.ctia.org/resource-library/facts-and-infographics/archive/us-mobile-broadband-versus-oecd>). The Centers for Disease Control and Prevention's National Center for Health Statistics reported that in 2013 more than two in five U.S. homes, or 39.4%, had *only* a wireless phone (Blumberg & Luke, 2013), which is almost three times the number reported in 2007 (13.6%). Schools, senior centers, family, and friends are teaching people across the age span to use social media.

During disasters, people use these devices to access information, monitor relief efforts, check on weather developments, and connect with family members and emergency personnel. One example is Dan Woolley, an American filmmaker who was caught under a pile of rubble when the Haiti earthquake hit, injuring both his leg and his head (Woolley, 2011).

A first aid app on his iPhone instructed him on the best way to create a tourniquet for his leg and a bandage for his head. It even warned him against falling asleep after a head trauma. He set his iPhone's alarm clock to go off every 20 minutes as a precaution. These strategies worked, and he survived long enough to be rescued after 65 hours. He used the Pocket First Aid and CPR Smartphone App for the iPhone and Android (American Heart Association).

In the past few years, use of social media platforms has more than doubled. In 2013, for example, the Wireless Rehabilitation Engineer Research Center (RERC) reported survey results that showed that people with disabilities increasingly rely on social media to receive and share emergency information, as well as television, radio, and landlines (Morris, Mueller, & LaForce, 2013). They reported that 98% of states in the United States now use social media (Twitter 88%, Facebook 59%, and YouTube 29%) and 73% of cities use social media (Twitter 59%, Facebook 59%, and YouTube 14%) to disseminate emergency information.

Different groups show preferences for different methods. For example, people who are hard of hearing (46%) and people with speech disabilities (47%) reportedly prefer receiving alerts using "voice over mobile" or "text messages." People who are deaf prefer "video relay service" (72%) or text messages (64%) (Mitchell & LaForce, 2013; Morris, Mueller, & LaForce, 2013). The Federal Emergency Management Agency (FEMA) is also looking to social media as a key component of emergency planning and community resilience. "Rather than trying to convince the public to adjust to the way we at FEMA communicate, we must adapt to the way the public communicates . . . We must use social media tools to more fully engage the public as a critical partner in our efforts" (Fugate, 2011).

Emergency managers also take advantage of wireless technologies. These technologies

expand their capacity to communicate. Also, community groups quickly become involved in recovery efforts after a disaster. One example of a web-based tool aimed at building community resilience at a grassroots level is <http://www.Recovers.org>. This website serves as a central hub that connects residents, organizations, and local government agencies in communities across the country. For example, the morning after Hurricane Sandy tore through New York and New Jersey, lowereastside.recovers.org was set up so that people could post information on what they needed and how others could help victims of the storm. That same day, after someone posted a request for food, water, and flashlights for 50 senior citizens who could not get down the stairs, 10 people responded with offers of aid. Within a week, more than 5,600 people had registered as volunteers.

Some communities are not waiting until disaster strikes. For example, Monterey.Recovers.org, Seaside.Recovers.org, and Pacific Grove.Recovers.org, adjacent communities along the central coast of California, are located in earthquake, tsunami, and severe drought zones. The Monterey CERT (Community Emergency Response Team) program, Monterey and Seaside Fire Departments, and a nonprofit organization have initiated and are implementing recovers.org platforms. The goal of these efforts is to build awareness, promote preparedness, and increase collaboration among community organizations, businesses, churches, and individuals prior to any major incident to increase resilience. The motto of these grassroots efforts is “You can’t predict, but you can prepare.”

The Changing Role of Providers: Promoting Preparedness

Preparing for emergencies should be a routine component of service delivery within profes-

sions that include speech-language pathology, audiology, interpreter services, independent living specialists, education, and health care. These community professionals care about the people they support—their clients, patients, and students. Trusted professionals can, as part of routine visits, discuss emergency preparedness. For example, Mr. Rusk’s audiologist could have given him an emergency identification card and asked his daughter to help him fill it out. The card would include personal and critical medical information as well as a statement about Mr. Rusk’s hearing difficulties. “I can’t hear well but I can read. Please write down your questions or message.” An audiologist might also encourage the family to make sure Mr. Rusk could receive (and respond to) warnings and alerts (e.g., on his cell phone or television).

During Mr. Rusk’s yearly physical, his doctor or an office worker could ask a few “yes” or “no” questions about emergency preparedness. “Is your identification card up to date? Do you have supplies to shelter-in-place or evacuate?” After taking his blood pressure, a nurse might ask his daughter questions such as, “Have you thought about what you will do if we have a tornado? If your dad has a heart attack or stroke?” By simply asking such questions, staff would encourage Mr. Rusk and his daughter to prepare for the types of emergencies that happen to people every day, as well as a less likely disaster scenario. They might even give them emergency medical cards to carry and a list of items they might need to shelter-in-place or evacuate.

Speech-language pathologists, interpreters, audiologists, social service workers, educators, and health care professionals from other disciplines *know* which of their clients have communication challenges. They are, therefore, in the best positions to help. As part of service delivery, these professionals can encourage their clients (and those who support them) to develop an emergency plan, put in place support teams, acquire relevant

resources, and conduct periodic drills. Service providers might also encourage some clients to become advocates. For example, Pam routinely shares her “lessons learned” with others (Kennedy, 2015).

Pam now always wears a waterproof fanny pack when she goes out. It contains a printout of her medical information, insurance cards, paper communication boards, accommodation requirements, emergency contacts, doctor’s names and phone numbers, problems swallowing and need for special food preparation, cell phone and charger, inhalers, and pain medication.

She keeps a Go-Bag in the closet near an exit in her home. It includes two changes of clothes, copies of her emergency communication displays, medication, medical supplies, water, food, and dog food in resealable, water-tight containers. If she ever needs to be evacuated again, she is ready.

When Pam recently moved, she called her local police and fire departments to let them know where she lives. She also works with her network of family and friends on a personal disaster plan, because she knows she can’t rely on emergency responders to rescue her unless absolutely necessary. Her network knows to contact each other and where they will go in case they need to evacuate. Also, she has signed up for alerts and now monitors weather watches and warnings online. When a warning is issued to evacuate or shelter-in-place, somebody calls her to make sure she is okay, and she makes every effort to be in her wheelchair and with someone who knows her in case she has to evacuate.

Providers can ask clients, family members, or caregiver questions such as, “Have you

thought about how you/your family member will communicate with responders in an emergency?” “Do you know how you/your family member will receive a warning or alerts?” “Do you/your family member carry important personal and medical information in a wallet/purse at all times.” “Is there an up-to-date copy of this information on your refrigerator?” “How will you communicate with someone who doesn’t speak your language?” “What if you/your family member can’t access hearing aids, batteries, a speech generating device, a communication board or book, a power source, a sign language interpreter, a communication assistant?” “How will you/they manage?”

Individuals with limited English proficiency need to be able to help identify the language they speak, and responders have to know how to help them do that. People who have dementia or live with serious chronic conditions need to be able to provide critical medical information. Parents need to consider what they and their children will do should they become separated. Will children with communication challenges, for example, be able to tell responders who they are, where they live, and who to contact? Also, persons with hearing, reading, seeing, understanding, speaking, and remembering limitations (especially those with dementia, severe aphasia, autism, and Down syndrome) need to be able to communicate basic information and inform responders how to communicate with them.

Accessible, free resources are available on the Internet. Some were developed specifically for people with disabilities, seniors, or children and are easily shared with clients and their families. Appendix 5–B has a partial list of FEMA, Red Cross, and other websites that offer emergency preparedness materials, including helpful videos developed specifically for people with communication challenges. Appendix 5–C contains a simple Checklist for People With Communication Access and

Functional Needs that providers can use with families, and keep a copy in their records to refer to in future visits. These resources are available to download at <http://www.patientprovidercommunication.org> or <http://www.cerv501c3.org>.

Identification Cards

Everyone should have basic emergency information with them at all times: name, address, primary contacts, language, medical conditions, current medications, allergies, and blood type. In addition, people with functional limitations should have information about the equipment they use, service animals, methods of communication, and other requirements they might have. Free printable cards are available for downloading (just Google “emergency identification cards”) and can easily be given to clients during office visits.

One example of a commercially available wallet-sized card is In Case of Emergency (ICE), shown in Figure 5–3 (also available as an Android app). The ICE card fits in a wallet, and when unfolded, contains emergency information (name, birth date, language, blood type, insurance number and emergency contacts), health information (doctor, existing conditions, allergies, medication, etc.), as well as a communication sheet, including a way to respond to “yes/no” questions and a pain scale. For example, if Mr. Rusk had an ICE card, he may have more easily communicated with first responders.

Communication Passports

If an individual wants to have more information available, the Accident and Emergency Communication Passport provides a free, downloadable option designed for people



Figure 5–3. Widgit Health Folding Identification Emergency Card for purse or wallet. Reprinted with permission from Widgit Symbols © Widgit Software 2002–2014, <https://play.google.com/store/apps/details?id=com.detlon.android.ICE> continues

with communication disabilities to use in shelters and refugee camps. It has three sections: Things you must know about me (Red); Things important to me (Amber); and

My likes and dislikes (Green) (Figure 5–4) (Royal Berkshire NHS Foundation Trust, 2013). Go to <http://www.widgit-health.com/downloads/A-and-E-passport.htm>

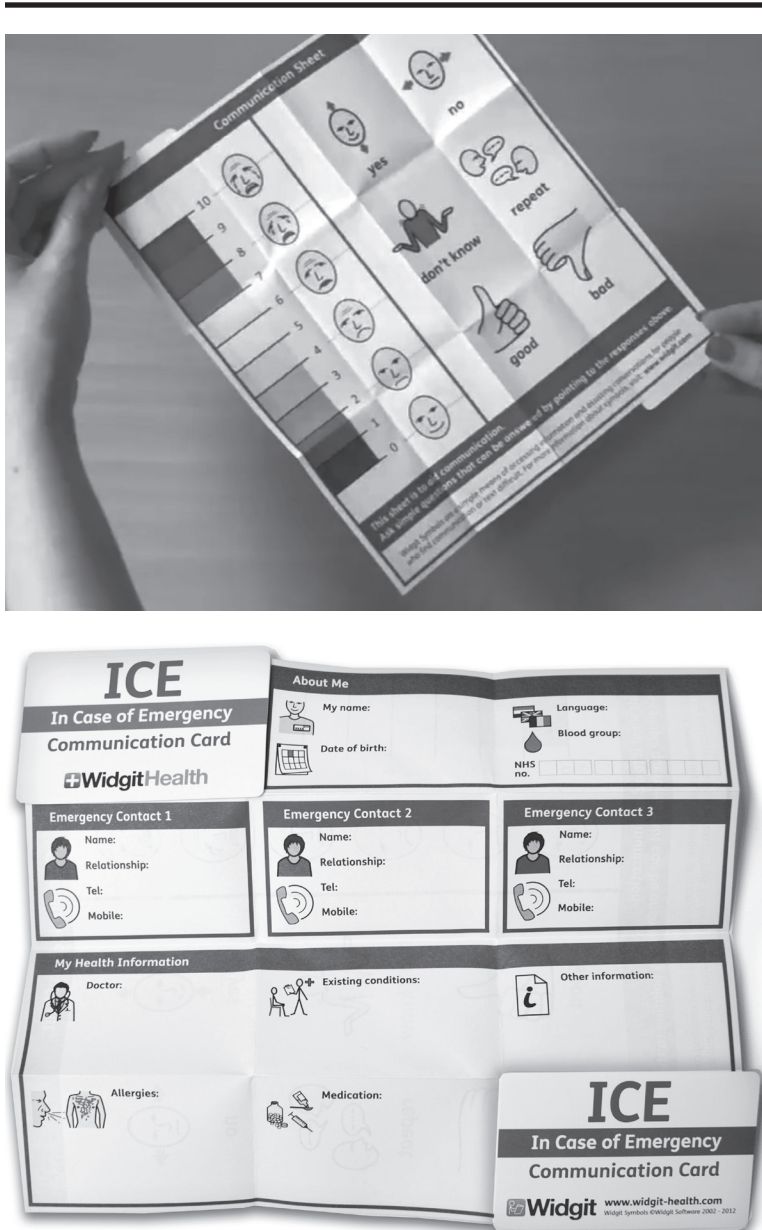


Figure 5–3. continued

Communication Passport

Accident and Emergency



Nursing and medical staff
please look at my passport
before you do any
interventions with me.



Name:

Things you must know about me

These things are important to me

My likes and dislikes

Things you must know about me



Name:

Like to be known as:



Phone:

Email:

Address:



Date of birth:



Next of Kin contact:

Relationship (e.g. Mum):

Phone:

Address:



How I communicate/what language I speak:



My support needs and who gives me the most support:



Who I live with:

Widgit Symbols © Widgit Software 2002 - 2013

www.widgit-health.com

2/8

Figure 5–4. continued

119

Nonelectronic Communication Boards and Books

Communication boards and books are useful for people who have difficulty understanding, speaking, hearing, and remembering. Depending upon the person and his/her circumstances, relevant vocabulary is selected and then represented using the alphabet, words, and phrases for those who are literate, or pictographs, emoticons, or photographs for those who are not. Graphic symbols are *not* universally understood, so individuals need to learn to use what vocabulary is on their emergency communication boards and how to use it. Ideally, copies of emergency boards/displays are kept in the client's home, Go-Bag, workplace, and/or school. For individuals who rely on communication boards, some emergency vocabulary should also be included on displays they use every day.

A recent review of the vocabulary for six widely used emergency and medically related communication boards revealed a total of 289 different words/messages. Surprisingly, a majority of the vocabulary (203 words) appeared on only one display. "Yes" and "no" were the only words on every display, and "hot," "cold," and "hungry/eat" were on five displays. This suggests there is little consensus about what vocabulary to include on emergency displays, and that it is important to individualize displays. Some examples of communication displays are pictured in Figures 5-5 through 5-7.

The boards in Figure 5-5 are useful to people who can point directly to each letter or word to develop a message. Those who are not physically able to point can use alternative access strategies (e.g., assisted scanning). This means instructions about how someone uses a display and instructions for how another



Figure 5-5. This alphabet board contains letters, numbers, and a few words. Anyone who is literate and able to spell can use an alphabet board. It is advisable to include simple instructions on the board for communication partners. Reprinted with permission from Toby Churchill, Ltd.

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	pen	paper	a drink
7	8	9	I, me, my	you, your	he, him, his	She, her, hers	Oops!	OK	soup
yes	no	know	don't know	need, want	help	seizure	bathroom	?	I can't swallow that.

I'm Pam Kennedy.	I can't speak but I understand you.	They're looking for me.	Jessie needs to go out.	Jessie is out of food.	Are access roads still flooded?	Any 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	headache	ear	hand	back	ankle
paper	evening meds	inhaler	seizure	double vision	swelling	nose	finger	waist	foot
yes	no	OK	Oops!	Wait	computer	mouth	left	right	bad, badly

Figure 5–6. Pamela D. Kennedy's communication boards, prepared to communicate with shelter workers and first responders. Reprinted with permission from Pamela D. Kennedy.

Emergency Communication 4 ALL.....Picture Communication Aid

FREE SPACE (for your custom message)

I can't speak but I can hear and understand you.

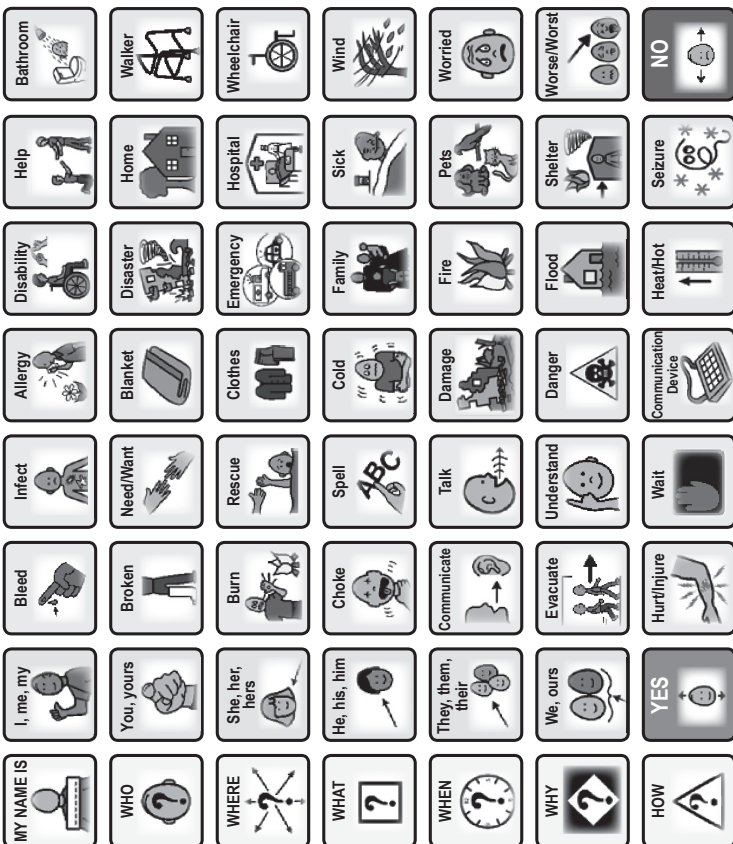
My technology needs to be charged.

My vital information is on the back on this page.

Please contact my family.

Ask me questions if you need to, but please wait patiently for my replies.

I will point to where I hurt.



The Picture Communication Symbols
© 1981-2009 Dynavox Mayer-Johnson
LLC. Used with permission. All rights
reserved worldwide.

Copyright © 2009 (www.disabilities.temple.edu/aacvocabulary/e4all.shtml) Developed by Diane N. Bryen & Rachel Revitch through a grant from the National Institute on Disability and Rehabilitation Research #H133E033018.

Figure 5–7. Emergency Communication 4 ALL. Two-sided. Available in English, Spanish, and Haitian-Creole. Reverse side enables people to enter personal information. Downloadable at <http://disabilities.temple.edu/aacvocabulary/e4all.shtml>. Reprinted with permission from the Institute on Disabilities at Temple University.

person can assist the person should be included on the display. For example, “Please repeat what you think I’m saying as I point, so I will know if you understand.”

After the flood, Pam designed her own communication boards, pictured in Figure 5–6. One display enables her to ask for specific information quickly using a limited, relevant vocabulary. The alphabet display gives her the ability to say anything she wants. She arranged these displays back-to-back. She keeps a copy in her Go-Bag.

Another two-sided emergency communication board is pictured in Figure 5–7. Developed at Temple University’s Institute of Disabilities for people with complex communication needs, this display is free and downloadable in English, Spanish, or Haitian Creole. One side has emergency vocabulary (e.g., questions, ways to talk about injuries, what is happening, and basic needs). The other side provides personal information (identification, medical data, contact information, and types of support and equipment the person requires).

Electronic Devices and Communication Software/Apps

Vocabulary on electronic devices can be represented by text in one or more languages, as well as photos, pictures, pictographs, speech output, and sounds. Communication apps are increasingly available for use on smartphones and tablets to help bridge language barriers by offering translation options (Pressman, Pietrzyk, & Schneider, 2011). One example is Canopyapps (<http://www.canopyapps.com>), which translates medical phrases covering history, physical exam, procedures, and reassessment in multiple languages (Spanish, Chinese, Arabic, Bengali, Filipino, Hindi, Korean, Malay, Portuguese, Russian, Vietnamese, etc.). When needed, a responder can call for a medi-

cal interpreter with a click from the app. Telephone interpreting services are also widely available today.

Speech generating devices (SGDs) offer individuals who are unable to speak because of severe speech disabilities a way to communicate. Today, children and adults of all ages use SGDs, which are available in increasingly smaller and lighter forms. These devices include communication software and access options, such as switches and eye pointing technologies, for people who are unable to point directly to select desired messages.

The Changing Role of Providers: Promoting Resilience

During any emergency or disaster, the whole community benefits when (a) families can stay together, (b) natural support systems are preserved, (c) acute medical incidents are prevented or reduced, and (d) medical providers can focus limited emergency resources on the people who require skilled medical care.

During and after a large incident, local responders are quickly overwhelmed. This means they probably cannot get to most residents quickly. That is why everyone is encouraged to plan to be on their own for at least three to seven days (Federal Emergency Management Agency, 2013b). Even so, most families, businesses, and organizations have not developed an emergency plan or amassed the supplies and equipment they will need to survive for up to 7 days on their own, despite daily news reports of the most recent natural and human-caused catastrophic events. Sadly, many people with communication access and functional needs have done little or nothing to prepare. There are many reasons given:

1. Few individuals are aware of the significant risks they face personally if they do

not plan and prepare. Following each catastrophic event, people say, “If only we had known, we’d have been better prepared.”

2. Widespread apathy or downright denial persists. “It’s not going to happen to me, or my family, or in my community.”
3. Families feel they lack the resources they need to prepare. “We don’t have the time or money to get prepared.”
4. Professionals and organizations feel they lack the resources they need to prepare themselves or their clients, or simply do not understand why it needs to be given greater priority.
5. Incentives for building community resilience at a grassroots level are often omitted from federal, state, and local funding and thus are not a focus of emergency management personnel.

What kind of incentives work? What motivates people (individuals, providers, families, businesses, organizations, and local governments) to allocate the time and resources required to keep the people they care about safe?

Taking Responsibility for Communication Access

Community professionals have not only an opportunity but a responsibility to help populations they support plan for personal emergencies. Community organizations (churches, community centers, clinics, schools) and businesses (e.g., adult day care programs, nursing homes, and senior centers) are uniquely able and qualified to help their communication vulnerable clients prepare. They have a responsibility to do so.

An example of such an effort was recently undertaken by the U.S. Society for Augmentative and Alternative Communication (USSAAC). USSAAC represents people with

complex communication needs (a high-risk group) and the professionals, family members, and manufacturers of technologies that support them. The organization recently mailed to its board members, who are elected to represent a specific region of the United States, an Emergency Communication Tool Kit. Each member was asked to contact his/her local fire and police departments, local hospitals, and emergency programs and offer to show them the Emergency Communication Tool Kit. In addition, several board members contacted USSAAC members who have chronic communication challenges and offered to help them to become advocates for emergency preparedness in their communities. One board member, who is herself unable to produce intelligible speech, made it her business to contact not only firefighters but the Coast Guard where she volunteers regularly. Tool kit elements sent to the members were specifically selected to support the needs of people who have difficulty speaking.

Other groups have different needs, so tool kit elements are selected accordingly. Examples of some tool kit elements are included in Table 5–1. One example of a commercially available tool kit (developed for use in hospitals) is On The Spot Communication (<http://www.aactechconnect.com/onthespot.cfm>) from AAC TechConnect. Items included are a dry erase board and clipboard with writing strategies, a magnifier, several types of communication displays, an eye link board that allows people to spell with their eyes, a PocketTalker to help people who are hard of hearing, a pointing device, key guard, talking photo album, laser light, and strategy book.

Another example of provider involvement making a difference is the Community Emergency Response Team (CERT) volunteer and former deputy sheriff who asked his family physician whether he would consider giving all his patients an Emergency Medical Passport. The doctor was excited about participating.

Table 5–1. Potential Communication Kit Components for Use by Responders During Emergency/Disaster Scenarios

Designed For	Tool	Languages	Description	More Information
People with hearing impairments	Pocket Talker Pro	n/a	Portable volume amplifier for people who are hard of hearing	http://www.ada.gov/hospcombrprt.pdf http://www.michdhh.org/hearing/comm_tips.html#general http://www.cdss.ca.gov/cdssweb/entres/forms/English/pub391.pdf
People who are deaf and use American Sign Language	Basic Medical Sign Language	American Sign Language	Brochure (four pages of illustrated signs); to assist one-on-one communication while awaiting a qualified/certified Sign Language interpreter	http://www.cdss.ca.gov/cdssweb/entres/forms/English/pub391.pdf
Intensive care units	Vidatak Boards	20 languages	Communication boards/app for iPad for literate adults in multiple languages; also a symbol version in English/Italian/Icelandic for children and adults with limited literacy skills	http://www.vidatak.com/index.html
EMERGENCY				
Emergency rooms	Servision boards: small and large	Multiple	Emergency communication boards developed for first responders; widely used in some municipalities	http://www.eadassociates.com/products.html#cpb
Ambulances	I Speak List	75 languages	The phrase “I speak _____”; helps responders recognize what language(s) someone speaks	http://www.dhs.gov/xlibrary/assets/crcl/crcl-i-speak-booklet.pdf
Search and rescue				
Triage	Health Care Communication Sheets	English	Two-sided health care communication board; 50 boards per pad; suitable for lamination; vocabulary includes medical, physical, and emotional information, pain scales, yes and no prompts, letters and alphabet	http://www.greenhousepub.com/hecacobo.html
Shelters				

continues

Table 5–1. *continued*

Designed For	Tool	Languages	Description	More Information
EMERGENCY	Communication4All	English, Spanish, Haitian-Creole	Includes symbols, numbers and letters, body images; general information on one side; individual's personal information on other side	http://www.disabilities.temple.edu/aacvocabulary/e4allhttp://www.disabilities.temple.edu/aacvocabulary/e4all.shtml
Emergency rooms				
Ambulances				
Search and rescue	Emergency Room	French with six additional languages	Communication board with key phrases in six different languages and instructions on how to avoid communication breakdowns; distributed to all emergency rooms in France	http://www.patientprovidercommunication.org/userfiles/file/newsletter/IPPCA12011.pdf
Triage	Communication Kit			
Shelters				
<i>continued</i>				
	Speak Unlimited	English	Communication boards prepared by emergency medical personnel and law enforcement in Pennsylvania; adapted for use along the Gulf Coast	http://www.papremisealert.com
	First Responder	Spanish		
	Communication Boards	Vietnamese		
	Point-to-Talk booklets	20 languages	44-page booklets with basic information, patient needs, general vocabulary, and present health problems; developed at Massachusetts General Hospital	http://www.mgh.harvard.edu/interpreters/pointtalk.asp
People who need writing aids	Boogie Board	n/a	Electronic writing tablet that allows user to write or draw images on an LCD screen; used in hospitals/intensive care units	http://www.improveelectronics.com
People with visual loss	Magnification board		A simple 8" × 11" magnification board for people with visual impairments	

He saw the value in helping his patients fill out their card. He also printed it so they could take a copy with them, and he could keep a copy in each patient's medical record to review at subsequent visits.

Finally, a speech-language pathologist now includes emergency preparedness as part of therapy with all her students. She teaches relevant language, role-plays different scenarios with small groups, talks with students about Go-Bags, and makes sure each student has an identification card. Not only is she building preparedness and support community resilience, but these activities fit in nicely with school activities already underway.

Supporting Responders and Emergency Managers

Table 5–1 gives examples of materials for responders to help them learn more about vulnerable groups; identify languages spoken; locate pain and gauge its severity; query people about nausea, dizziness, and other common symptoms; ask “yes” or “no” questions; and listen effectively. For example, firefighters in Seaside, California, carry a list of common questions translated into Spanish. Included are phrases they need to get key information: “Do you need help? What happened here? Where do you hurt? Are you having pain? Where is it? Breathe deeply. Do you have any medical problems? Do you need an ambulance? What is your name? What is your address? What is your telephone number? How old are you? What is your date of birth?” Additional vocabulary has been added over time.

Tips for First Responders

An easy-to-use set of cards was designed to help first responders and emergency medical personnel who work in ambulances, emergency rooms, trauma centers, shelters, and

other contexts learn about people with autism, cognitive disabilities, brain injuries, seniors, people who are mentally ill, blind or visually impaired, deaf or hearing impaired, pregnant women, and so on. The cards are available in a small laminated “notebook” or as a free download (<http://www.cdd.unm.edu/dhpd/tips/tipsenglish.html>). They are also available with text only (<http://www.hhs.gov/od/about/tips.html>) (Figure 5–8).

How to Ask “Yes” or “No” Questions

Responders sometimes rely on “yes/no” questions to get the information they need. Figure 5–9 is a helpful reminder about *how* to ask “yes” or “no” questions so you get accurate and complete information. Go to <http://www.patientprovidercommunication.org>.

How to Listen Effectively

“Listen and silent are spelled with the same letters” (author unknown).

Effective listening is a skill. Learning how to listen carefully in emergencies includes confirming that the message sent is the message received. Good listeners know how to paraphrase meaning. Figure 5–10 is an example of how a picture display can help a first responder “listen” to a patient's efforts to identify the location of pain.

Identifying the Language Someone Speaks and Understands

The U.S. Department of Commerce has free, downloadable language identification flashcards to identify 51 different languages (Limited English Proficiency: A federal interagency website, 2004). Go to <http://www.lep.gov/ISpeakCards2004.pdf>. The Department of Homeland Security uses a booklet to help

Tips 5th Edition for First Responders

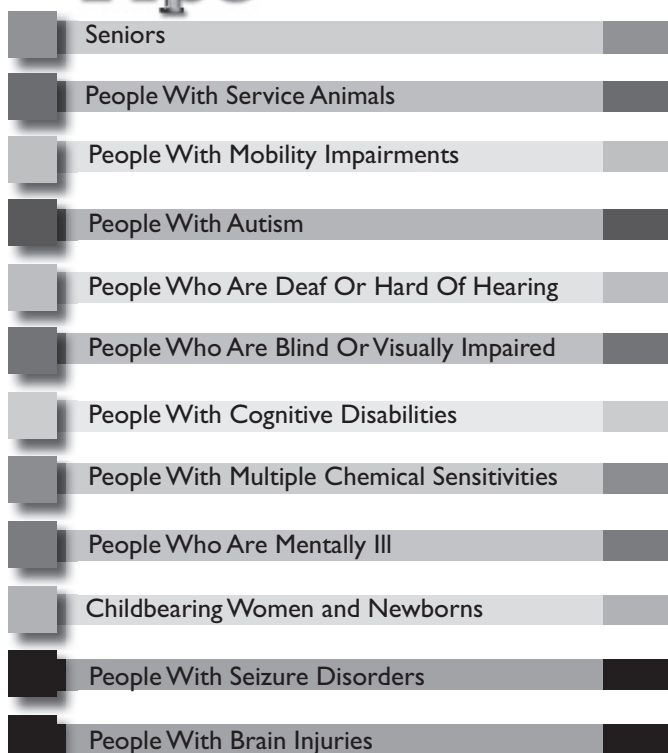


Figure 5–8. *Tips for First Responders 5th Edition. Reprinted with permission from Dr. Anthony Cahill, University of New Mexico, Center for Development and Disability.*

- “Show me how you say YES.”
- “Show me how you say NO.”

NOTE: Always offer at least a third option. This could be “Something else.” “I don’t know.” “Maybe.” “Please repeat.” or “I don’t understand.”

- Ask the person to indicate a way to communicate that option. “Show me how you say...”

ALWAYS Pay attention to the person’s gestures, nods, sounds, eye gaze and eye blinks.

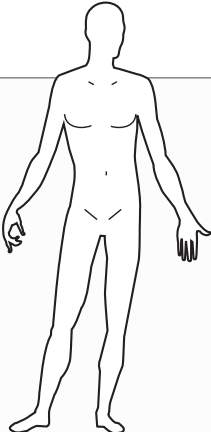
ALWAYS Ask questions one at a time.

ALWAYS Ask questions that can easily be answered.

ALWAYS Give the person extra time to respond.

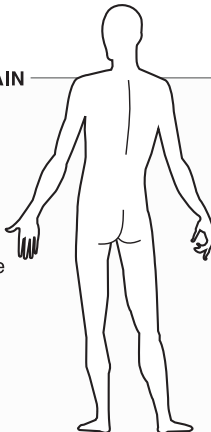
Figure 5–9. *How to ask “yes” or “no” questions.*

PAIN CHART



● LEVEL OF PAIN

10		Worst
9		
8		
7		Severe
6		
5		
4		Moderate
3		
2		
1		Slight
		None



● THIS PART
(Of My Body)

☐ Itches

☐ Stings

☐ Hurts

☐ Cramps

☐ Can't Move

☐ Is Numb

☐ Aches

☐ Burns

☐ Is Tender

● THE PAIN IS

☐ Constant

☐ Intermittent

☐ Radiating

☐ Throbbing

☐ Dull/Aching

☐ Sharp

THIS BOARD BELONGS TO:
(Place Label Here)

I WANT Pain Medicine

MEMO:

● PLAN OF CARE: ☐ YES ☐ NO ☐ Please Explain ☐ I Need Reassurance

☐ Where ☐ When ☐ What ☐ Stop ☐ What Is The Plan? ☐ When Can

☐ How ☐ Why ☐ Who ☐ Continue ☐ How Am I Doing? ☐ I Go Home?

KEEP THIS BOARD WITH PATIENT AT ALL TIMES For more information on Vidatak E2 Boards www.vidatak.com © 1999 Vidatak U.S. Patent No. 6,422,875. All rights reserved. Item No. 001 • English

MADE IN CHINA

Figure 5–10. Vidatak Communication Board to identify location and degree of pain. Reprinted with permission. HealthCare Communication Board, distributed by Attainment Company, Inc., manufactured by Vidatak.

The responder says, “Do you feel any pain?” When the person responds, (e.g., nods YES), the responder confirms saying, “You told me YES, you are in pain.”

Next the responder asks, “Where is your pain?” and WAITS.

If the person cannot point to a body part with her finger, hand, or eyes, the responder introduces a communication display or asks permission to touch the

person. Say, “When I point to the part of your body on the display that hurts, tell me YES.”

Going slowly, the responder begins pointing and watches carefully to see when the person locates the pain. Confirm by saying, “Are you telling me you feel pain in your chest?”

If the person refuses to be touched, the responder can point to his or her own body.

identify more than 75 written languages (U.S. Department of Justice, 2010). Go to http://www.census.gov/2010census/partners/pdf/langfiles/LAG_flashcard.pdf (U.S. Census Division, 2010) to view flashcards and [http://](http://www.dhs.gov/xlibrary/assets/crcl/crcl-i-speak-booklet.pdf)

www.dhs.gov/xlibrary/assets/crcl/crcl-i-speak-booklet.pdf to review the Language booklet.

These tools do not replace an interpreter. When no interpreter is available, responders often need to depend upon family members

to help. When they are not available or able, responders can use pictographic communication displays. Several are available in multiple languages. In addition, translation apps for wireless technologies and phone interpreters are increasingly available.

Paper and Pencil and Whiteboards

When speech is not an option, the fastest way to establish effective communication is often through writing or drawing, if the individual impacted can read and write. Since responders carry paper and pens with them, this option is almost always available.

Future Directions

Research has documented the critical importance of effective communication during and after emergencies and disasters—no matter how small or large the incident. Communication is a key component of the C-MIST (communication, maintaining health, independence, safety and support, transportation) framework and the Incident Command Structure (ICS). Yet, most communities do not have inclusive strategies or policies in place that address the communication access needs of diverse populations. In part, this is because individuals with significant communication challenges are unable to participate fully in community meetings so they often do not attend or even if they do, may feel excluded. Steps are needed to change their level of participation, as well as existing policy and practices. To make this happen, community professionals and the organizations that provide these individuals with services must get involved.

One need is to help document the typical communication challenges responders face during emergencies and disasters. To do

so, we need to talk with them. What communication problems do responders actually confront? What strategies do they currently depend upon? How effective are these strategies in solving communication problems and under what circumstances? For example, what issues do emergency medical technicians (EMTs) face when transporting someone in an ambulance or helicopter, or what do firefighters confront when responding to a medical emergency or a fire? What communication supports do animal-related organizations like the Society for the Prevention of Cruelty to Animals (SPCA) officials need when trying to help evacuate people with their pets? What communication challenges do emergency room personnel face? Trauma center professionals? Shelter workers? Volunteers deployed to do search and rescue?

Having easy access to useful communication displays can help save lives. However, the vocabulary represented needs to be carefully selected because there is very limited space or “real estate” on these displays. Researchers need to help by documenting the most frequently occurring vocabulary needs across different situations. A precedent for this exists. Researchers in the area of augmentative and alternative communication (AAC) have conducted vocabulary studies for decades to help determine which vocabulary to include on displays for specific populations, across specific contexts. For examples, go to the University of Nebraska website (<http://aac.unl.edu/vocabulary.html>). Providers and manufacturers have used these studies to help design for communication displays for individuals as well as for use in specific environments/contexts. The same attention is needed in emergency communication. The impact of *not* having appropriate vocabulary available during an incident can be catastrophic. As illustrated in Figure 5–11, there currently exists a lack of consensus about what vocabulary to include

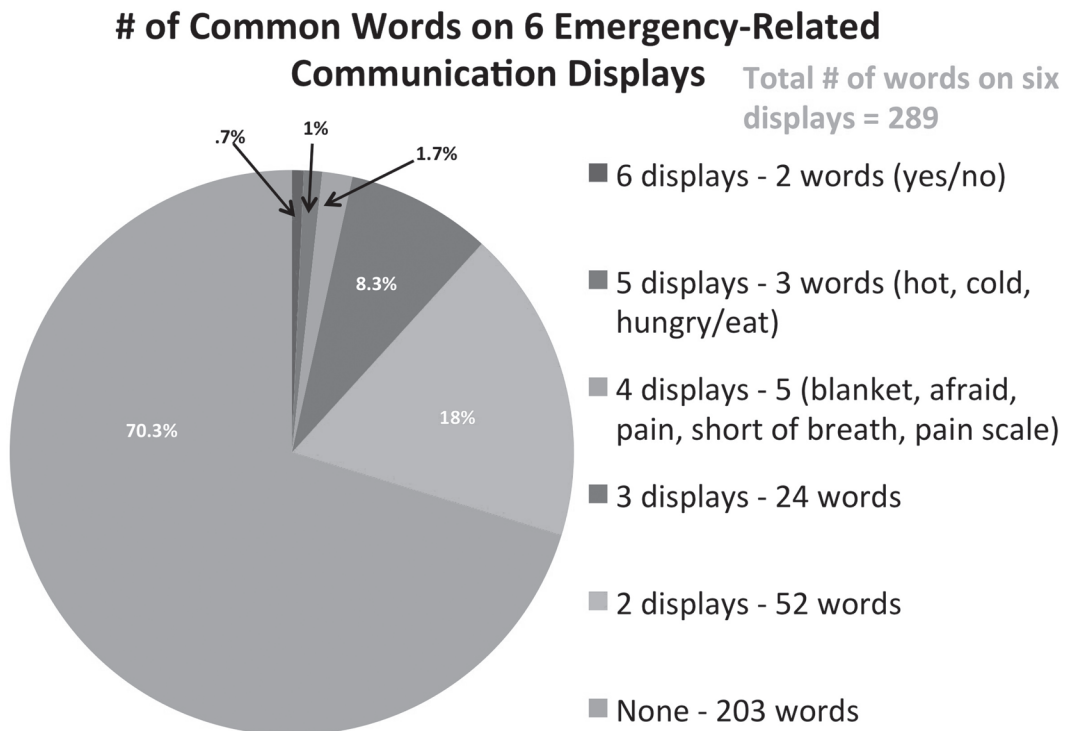


Figure 5–11. Study of six emergency related communication displays. Blackstone & Pressman, 2014. Reprinted with permission from Sarah W. Blackstone.

on emergency displays (203 out of 289 words/phrases [70%] were unique across six displays) (Blackstone & Pressman, 2014).

This finding is especially surprising because under most circumstances, interactions need to be brief, focused, and specific. There is also a need to collect usage data (e.g., what displays do interactants use under what conditions) and satisfaction data (what strategies and technologies do individuals impact, as well as responders prefer to use during emergencies and why). Research about the communication displays and other strategies will better inform providers, responders, and the manufacturers of apps and software. Another need is to conduct research that recognizes that graphic representations are easily

misinterpreted. There is a need for more user testing across cultures to try to avoid communicating the wrong message or a culturally offensive message.

Another area that requires attention is training. How do responders develop the communication skills they need to successfully cope with communication barriers during emergencies and disasters? What tools do they need and how do they learn to use these tools when there are many other areas they also need to master? How do speech-language pathologists and other support service personnel access the information they need and develop the skills that will enable them to help their clients, patients, and their families to prepare? These are important questions.

“When the only tool you own is a hammer, every problem begins to resemble a nail.” (Abraham Maslow)

“If the only tool you have is a hammer, it’s hard to eat spaghetti.” (David Allen)

The communication strategies, tools, and techniques responders rely on reflect their current knowledge and skills. There is 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 communication barriers discussed in this chapter. Ideally these would be available online.

Summary

Abraham Lincoln is quoted as having said, “If I had eight minutes to chop down a tree, I’d spend the first six sharpening my axe.”

Lincoln’s thought highlights the importance of preparedness. Individuals with communication access and functional needs are at high risk in any emergency and disaster scenario. The ability to receive information and communicate with responders is essential to survival. That is why this chapter encourages community professionals and the organizations that employ them to emerge from the sidelines and engage more directly in emergency preparedness and community resilience.

References

- Barsan, W. G. (1996). *Acute medical care in the United States. Proceedings of a National Symposium on Rapid Identification and Treatment of Acute Stroke*. Bethesda, MD: National Institute of Neurological Disorders and Stroke. Retrieved April 20, 2014, from http://www.ninds.nih.gov/news_and_events/proceedings/stroke_proceedings/barsnkey.htm
- BC Coalition of People with Disabilities. (2008). *Learning C-MIST: Train-the-trainer: Helping individuals with disabilities create Emergency Preparedness Plans*. Retrieved January 9, 2014, from <http://www.bccpd.bc.ca/docs/learning/cmist.pdf>
- Blackstone, S. W. (2008). Complex humanitarian emergencies. *Augmentative Communication News*, 19(4), 1–8. Retrieved May 3, 2014, from http://www.augcominc.com/newsletters/index.cfm/newsletter_3.pdf
- Blackstone, S. W., & Pressman, H. (2014). *Comparing vocabulary on emergency and disaster communication displays*. Retrieved from <http://www.patientprovidercommunication.org>
- Blumberg, S. J., & Luke, J. V. (2013). *Wireless substitution: Early release of estimates from the national health interview survey, January through June 2013*. Atlanta, GA: Centers for Disease Control and Prevention. Retrieved March 10, 2014, from http://www.cdc.gov/nchs/features/ask_the_expert_blumberg.htm
- Chhandasi, P., Batalova, J., & McHugh, M. (2011). *Limited English Proficient individuals in the United States: Number, share, growth and linguistic diversity*. Washington, DC: Migration Policy Institute.
- Collier, B., Blackstone, S. W., & Taylor, A. (2012). Communication access to business and organizations for people with complex communication needs. *Augmentative and Alternative Communication*, 28(4), 205–218. doi:10.3109/07434618.2012.732611
- Federal Emergency Management Agency. (2013a). *National Response Summary, 2nd ed.* Washington, DC: Author. Retrieved January 5, 2014, from http://www.fema.gov/media-library-data/20130726-1914-25045-1246/final_national_response_framework_20130501.pdf
- Federal Emergency Management Agency. (2013b). *National Response Framework*. Washington, DC: Author. Retrieved March 5, 2014, from <http://www.fema.gov/emergency/nrf>

- Fugate, C. (2011). *Understanding the power of social media as a communication tool in the aftermath of disasters*. Washington, DC: Senate Committee on Homeland Security and Governmental Affairs. Retrieved April 15, 2014, from https://www.fema.gov/txt/about/programs/legislative/testimony/2011/5_5_2011_use_of_social_media_in_disasters.txt
- Hopper, P. J. (2010). *Vulnerable populations and crisis communication: A model for accessible disaster preparedness campaigns* (Dissertation). University of Washington, Seattle, WA.
- Kailes, J. I., & Enders, A. (2007). Moving beyond "Special Needs": A function-based framework for emergency management and planning. *Journal of Disability Policy Studies*, 17(4), 230–237.
- Kailes, J. I., & Neiman, A. (2013). *Planning for individuals with disabilities and other access and functional needs*. Retrieved May 16, 2014, from enla.org/wp-content/uploads/2013/12/AFN-Intro-and-legal.pptx
- Kennedy, P. (2008). Next time I'll be ready. *Augmentative Communication News*, 19(4), 4–5. Retrieved May 16, 2014, from http://www.augcominc.com/newsletters/index.cfm/newsletter_3.pdf
- Kennedy, P. (2015). *Advocacy for People with Speech Disabilities: Emergency Preparedness Resources*. Retrieved January 15, 2015, from http://www.patientprovidercommunication.org/article_45.htm
- Limited English Proficiency. (2004). *I Speak Cards*. Washington, DC: Author. Retrieved May 1, 2014, from <http://www.lep.gov/ISpeakCards2004.pdf>
- Matherly, D., & Mobley, J. (2011). *Communication with vulnerable populations: A Transportation and Emergency Management Toolkit*. Washington, DC: Transit Cooperative Research Program. Retrieved January 14, 2014, from http://www.tcrponline.org/PDFDocuments/TCRP_RPT_150.pdf
- Mitchell, H., & LaForce, S. (2013). *9-1-1 and alert trends for people with disabilities*. Presented at the NENA 2013 Conference & Expo, Charlotte, NC. Retrieved March 17, 2014, from www.wirelessrrc.gatech.edu/sites/default/files/content/newroom/NENA_2013%20FINAL_with%20alt%20text_no%20bckgrnd%20graphics.pdf
- Morris, J., Mueller, J., & LaForce, S. (2013). *Social media, public media and disabilities*. Presented at the Annual International Technology and Persons with Disabilities Conference, San Diego, CA. Retrieved April 15, 2014, from <http://www.wirelessrrc.gatech.edu/sites/default/files/publications/CSUN%202013%20-%20Social%20Media%2C%20Public%20Emergencies%20and%20Disability.pdf>
- National Council on Disabilities. (2009). *Effective emergency management: Making improvements for communities and people with disabilities*. Washington, DC: Author. Retrieved March 4, 2014, from http://www.ncd.gov/policy/emergency_management
- National Organization on Disability. (2005). *Report on special needs assessment for Katrina Evacuees (SNAKE)*. Retrieved March 5, 2014, from www.nod.org/Resources/PDFs/katrina_snake_report.pdf
- Organisation for Economic Co-operation and Development. (2014). *OECD Broadband Portal, 1C*. Paris, France: Author. Retrieved from <http://www.oecd.org/internet/broadband/oecdbroadbandportal.htm>
- Peek, L., & Stough, L. M. (2010). Children with disabilities in the context of disaster: A social vulnerability perspective. *Child Development*, 81(4), 1260–1270. Retrieved January 6, 2014, from <http://cdra.colostate.edu/Data/Sites/1/cdra-research/peek-stough2010.pdf>
- Piper, P. R. (2006, June). A failure to communicate: Politics, scams, and information flow during Hurricane Katrina. *Searcher*, 14(6), 40. Retrieved January 5, 2014, from http://www.infotoday.com/searcher/jun06/Piper_Ramos.shtml
- Pressman, H., Pietrzyk, A., & Schneider, J. (2011). *Overcoming communication barriers in emergency situations: Some basic tools*. Monterey, CA: Central Coast Children's Foundation. Retrieved April 21, 2014, from patientprovidercommunication.org/pdf/23.pdf
- Rader, A., Edmunds, M., & Bishop, J. (2010). *Public Health Preparedness and Response for At-Risk Populations*. McClean, VA: Booz Allen Hamilton. Retrieved March 4, 2014, from <http://>

- mtlaboratoryforum.mt.gov/publichealth/phep/documents/PublicHealthAtRiskPopulations.pdf
- Roth, M. (2011). *Planning for the whole community: Integrating and coordinating the access and functional needs of children and adults with disabilities in preparedness, response, recovery*. Washington, DC: FEMA, Office of Disability Integration and Coordination. Retrieved January 8, 2014, from http://www.fema.gov/pdf/about/odc/all_hands_0411.pdf
- Roth, M. (2014). Getting real: Promising practices in disability-inclusive emergency management for the whole community: A case study of the United States. In D. Mitchell & V. Karr (Eds.), *Crises conflict and disability: Ensuring equality* (pp. 105–123). New York, NY: Routledge. Retrieved May 16, 2014, from http://books.google.com/books?hl=en&lr=&id=zjBEAwAAQBAJ&oi=fnd&pg=PA105&dq=emergency+alert+systems+for+hard+of+hearing+&ots=JvvASewQpN&sig=YU7BZnF5qKkprYwBDsFEWerk_cQ#v=onepage&q=emergency%20alert%20systems%20for%20hard%20of%20hearing&f=false
- Royal Berkshire NHS Foundation Trust. (2013). *The Accident and Emergency Communication Passport*. Warwickshire, United Kingdom: Widgeit.
- Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9–28.
- U.S. Census Division. (2010). *Language identification flash cards*. Washington, DC: U.S. Department of Commerce.
- U.S. Department of Homeland Security. (2013). *National response summary* (2nd ed.). Washington, DC: Author. Retrieved May 2, 2014, from http://www.fema.gov/media-library-data/20130726-1914-25045-1246/final_national_response_framework_20130501.pdf
- U.S. Department of Justice. (2009). *The ADA best practices tool kit for state and local governments*. Retrieved March 5, 2014, from <http://www.ada.gov/pcatoolkit/toolkitmain.htm>
- U.S. Department of Justice. (2010). *Language identification flash cards*. Washington, DC: U.S. Census Department. Retrieved May 1, 2014, from http://www.census.gov/2010census/partners/pdf/langfiles/LAG_flashcard.pdf
- Woolley, D. (2011). *Unshaken: Rising from the ruins of Haiti's Hotel Montana*. Grand Rapids, MI: Zondervan.
- World Health Organization. (2014). *International classification of functioning, disability and health (ICF)*. Retrieved March 16, 2014, from <http://www.who.int/classifications/icf/en/>

APPENDIX 5–A

Resources for People With Communication Limitations to Assist With Emergency Planning and Preparation

General information for people with disabilities	• http://www.fema.gov/media-library/assets/documents/897?id=1442: Downloadable booklet to help people with disabilities prepare and emergency plan to protect themselves, family, friends, personal care assistants, and others in the support network • http://www.fema.gov/media-library/assets/videos/78827: Instructional preparedness video containing information specific to Americans with access and functional needs • http://www.redcross.org/prepare/location/home-family/disabilities: Tips on getting informed, making a plan, assembling a kit, and keeping plans up to date • http://www.hhs.gov/od/documents/disabilityAmericanRedCross.pdf: Booklet with checklists designed to help people who have physical, visual, auditory, or cognitive disabilities to prepare for natural disasters and their consequences • http://www.jik.com/disaster-individ.html: Individual Emergency Preparedness for People with Disabilities, Their Families and Support Networks
Tip sheets for religious leaders	• http://projectinterfaith.org/page/disaster-tip-sheets: Tip sheets developed to assist American faith communities to provide mitigation education and preparedness training and to respond to crises and activate their congregations to coordinate volunteers, manage donations, provide mass care, attend to spiritual and mental health needs, and continue their many religious and social services post-disaster
People who are deaf or have hearing loss	• http://www.ilru.org/html/projects/disasterPrep/PDF-Prepare/Hearing_Impairments.pdf: Tips for people with hearing impairments
People with complex communication needs	• http://aac-rerc.psu.edu/index.php/pages/show/id/19: Guidelines for advocates and people with complex communication needs • http://www.augcominc.com: Newsletters on emergency communication, patient-provider communication, language boards, and so on
Seniors	• http://www.disabled-world.com/disability/emergency/: Disaster and emergency planning for seniors and persons with disabilities
People with visual impairments	• http://www.surpriseaz.gov/DocumentCenter/Home/View/2917 • http://www.ok.gov/health2/documents/Resource%20book%20for%20Blind%20and%20Low%20Vision.pdf: Guides for people who are blind or have visual impairments

continues

Appendix 5–A. *continued*

People with limited English proficiency	• http://www.hhs.gov/ocr/civilrights/resources/specialtopics/emergencypre/epresourcelep.html: Lists of resources
People with intellectual disabilities	• http://www.hhs.gov/ocr/civilrights/resources/specialtopics/emergencypre/epresourcelep.html: General information for people with a range of functional needs; see also FEMA and Red Cross websites

APPENDIX 5–B

Law and Policy

Some Federal Laws Prohibiting Discrimination in Emergency Programs on the Basis of Disability

- Americans with Disabilities Act of 1990
- The Robert T. Stafford Disaster Relief and Emergency Assistance Act, 42 U.S.C. §§ 5121-5206, as amended
- Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, as amended
- Fair Housing Act Amendments of 1988
- The Homeland Security Act of 2002, 6 U.S.C. §§ 101-557, as amended
- Individuals with Disabilities Education Act (EHA) of 1975
- Telecommunications Act of 1996
- Federal Disaster Assistance, 44 C.F.R. pt. 206
- The Post-Katrina Emergency Management Reform Act, 6 U.S.C. § 761(d), as amended

APPENDIX 5–C

Emergency Checklist for People With Communication Access and Functional Needs

Yes	No	Does Not Apply	Needs Work	<i>Do you know your rights? With rights come responsibilities. Are you ready? Are those you depend upon ready?</i>
				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 (<http://www.aac-lerc.psu.edu>).