

Elsa's Story

Can you see me?

| 8

Emergency Preparedness & The Deaf Community

A "failing grade" was given to the US Public warning and emergency communication systems serving the Deaf and Hard of Hearing post 9/11

*Claude Stout - 2004
Emergency Preparedness and
Emergency Communication Access:
Lessons Learned Since 9/11 and Recommendations*

Unexpected. Unprepared. Uninformed. These are the some of the words people used to describe their disaster experience. Depending on where one lives in the United States, major disasters – earthquakes, tornados, hurricanes, snow storms and wild fires – have come their way. Vulnerable populations such as those with hearing loss, sight impairment, or limited ambulatory ability are at increased risk of injury and death during a disaster. There are warnings via sirens, TV/Radio and cell phone apps to alert the public. Now, imagine, in addition to being unprepared, you are deaf or hard of hearing (Deaf/HH). This adds another layer of anxiety and trepidation as you cannot hear the siren or radio alert.

Furthermore, hearing impaired persons, trapped inside a building, usually cannot hear emergency responders. Which begs the question – are emergency responders trained to meet the specific needs of the Deaf community in a disaster? In this chapter we address the needs of the hearing impaired and educational training for emergency responders and healthcare professionals

Reflective exercise: You've just experienced a disaster - earthquake, tornado, flood, hurricane . . .

- 1. What was your first concern?*
- 2. What emotions surfaced?*
- 3. Were you prepared? Did you have a plan? An emergency kit? Water & food for three days?*
- 4. Now consider the same experience – from a Deaf person's perspective.*
- 5. What additional items are essential during a disaster?*

Elsa's Story

Elsa is heading for the doctor's office on the Vine, the local bus. Her fractured wrist aches dully, but at least it's the left one. Crouching under the maple leaf table that night the shaking started was wise. If only she hadn't slammed her arm on the wall getting out of bed. Dr. Elmwood is pretty nice, thank heavens, for a hearing person. Elsa had met her the morning after the 7.0 temblor when she'd managed to get to the Queen of the Valley Hospital and see someone.

“My bruises from the quake don't seem too big a deal any more, though my night alone at Embassy Suites in Napa is still really stark in my mind; something jostling me out of bed, the clock showing 3:20 AM, old film clips of elementary school drills Mrs. Potchatek showed us at Haman flashing before my eyes. I wish I'd come to this conference in the Valley with Francie, though. Sharing a room would have been cheaper, that's for sure. Another Deaf of Deaf friend would've made me feel more solid in the midst of the upheaval; she wouldn't have heard

the alarm either. And we could have calmed each other by quoting from Never Seduce a Scot or playing the Elephant Game.”

The ASL interpreter was late, but is now there sitting beside the doctor in his office. Dr. Elmwood must have been on call in emergency when Elsa came in before. She tries to explain to this doctor how it's just a throbbing in her wrist now, but he keeps looking down at his notepad or at the screen with Elsa's medical history.

“Sure wish Dr. Elmwood was here, “ Elsa muses. “She's always so focused on me. Maybe this guy thinks I can read his lips accurately! Fat chance.”

Elsa gestures expansively with her good arm and leaps out of her chair as she tries to explain how the painkillers don't help at night. Dr. Stone steps back, startled. The quake itself was terrifying and disorienting, so that's probably part of the problem, but Elsa would really love something that would let her sleep for seven hours and wake up without feeling fogged in. Dr. Stone looks at the screen and mumbles to the interpreter about how the damage to Napa's buildings are so much more permanent than those to human “victims.”

Defining Deaf

Deaf is defined three ways: Deaf, Culturally Deaf and deaf. Deaf, with a capital “D,” refers to a culture, a community which holds the belief that deafness is not a disability, but rather a personality attribute. In the literal definition, *Deaf* persons in this category have profound hearing loss, use American Sign Language (ASL), and are acculturated into the Deaf community. Elsa considers herself a member of the Deaf community. *Culturally Deaf* are those who are deafened pre-linguistically, prior to age three. Deaf with a small “d” refers to persons who are partially deaf, hard of hearing.

They do not use ASL as their primary language, and are not considered acculturated into the Deaf community.¹¹ Hearing loss is defined as “a little trouble hearing,” “moderate trouble,” “a lot of trouble,” or “deaf.” They represent

a distinct minority of less than one million persons living in the United States. The majority who have a hearing loss are age sixty and older.

Demographics

Being a Deaf/HH individual presents challenges to living in a hearing world. There are approximately ten million persons living in the United States who identify as Deaf. According to the 2012 Center for Disease Control Summary Health Statistics for U.S. Adults, 15% of those aged eighteen and older reported hearing trouble. The Gallaudet Research Institute (GRI) offered the following summary:¹²

Age	Population	Percent
> 6 years old	691,883	1.81%
Age 18-34	2,309,000	3.4%
Ages 34-44	2,380,000	6.3%
Ages 45-54	2,634,000	10.3%
Ages 55-64	3,275,000	15.4%
> 64 years	8,729,000	29.1%

Deaf individuals may have limited ability to read and comprehend information such as health education pamphlets. Almost 44% of Deaf students do not graduate from high school, and for those who do, only five percent graduate from college.¹³ It is imperative for those who work in the healthcare or emergency services, to receive educational training and communication skills to ensure Deaf individuals receive culturally competent healthcare.

Reflective exercise: American with Disabilities Act 1990

- 1. Can you name all the disabilities covered by the original ADA?***
- 2. The ADA expanded its definition in 2009 added what . . . and why?***
- 3. Have you received training to care for the Deaf/HH patient?***
- 4. Is your facility equipped to assist the Deaf/HH? The visually impaired? The non-ambulatory?***

History

The Americans with Disability Act of 1990 underlines the importance of equal access and equal care. Signed into law on July 26, 1990, by President George H.W. Bush, it was considered a civil right. It was patterned after the Civil Rights Act of 1964. The ADA, as it has come to be known, prohibits discrimination and ensures equal rights for housing, public accommodation, transportation, and employment. Additionally it provides opportunities to participate in state and local government programs and services. This act gave voice to the disabled, who prior to 1990, had not been considered a significant part of the population.

Disability, as defined by the ADA is *a physical or mental impairment that substantially limits one or more major life activities. This includes persons who have a history or record of such an impairment, or a person who is perceived by others as having such an impairment.* The initial definition of disability by the ADA in 1990 was so narrow that many persons did not qualify for services. As a result, people continued to face discrimination. In 2008 the Supreme Court ruled that the ADA was too narrowly defined, thus limiting access to resources for many disabled persons. In 2009 Congress passed the Americans with Disabilities Act Amendments Act (ADAAA) which broadened the definition of disability. The revised definition provided a broader scope of the term impairment and major life activities. While we are acquainted with the concept and purpose of the ADA, many of us are unaware of the specific disabilities covered in this amendment.

Impairment:

1. Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems, such as neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin, and endocrine; or

2. Any mental or psychological disorder, such as an intellectual disability (formerly termed “mental retardation”), organic brain syndrome, emotional or mental illness, and specific learning disabilities.

Major Life Activities: Major life activities include, but are not limited to:

- Caring for oneself, performing manual tasks, seeing, *hearing*, eating, sleeping, walking, standing, sitting, reaching, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, interacting with others, and working; and
- The operation of a major bodily function, including functions of the immune system, special sense organs and skin; normal cell growth; and digestive, genitourinary, bowel, bladder, neurological, brain, respiratory, circulatory, cardiovascular, endocrine, hemic, lymphatic, musculoskeletal, and reproductive functions. The operation of a major bodily function includes the operation of an individual organ within a body system.¹⁴

The definition was expanded to include the words “but not limited to,” which ensures rights for the disabled. Furthermore, accreditation by The Joint Commission requires that the needs of Deaf/HH patients are met. Standards R1 2.1, 2.3 and 2.2 guarantee the rights of the patient to “adequate communication which includes the presence of professionals to provide translator/interpretive services.” This include American Sign Language (ASL) translators. Furthermore, the Culturally Linguistically Appropriate Standards, developed by the Office of Minority Health, require all institutions to provide ASL interpreters, D/deaf telecommunication devices TTY/TDD; closed captioning television and real time video interpreting services. In addition, flashing light warning systems are required.

Barriers

National and international disasters often leave the Deaf/HH underserved. Why? One reason is that support organizations lack resources – staff time and the ability to create and distribute emergency preparedness material. In addition, emergency alerts, transmitted via television and radio, are not always accessible to the Deaf/HH community. Moreover, there is a wide variation in literacy rates. It is estimated that 30% of Deaf adults have weak ASL skills and can only read at a sixth grade level.¹⁵ As a result, misunderstandings occur, especially in an emergency situations.

In addition to low literacy, Deaf/HH persons may be hesitant to seek health care because of their inability to communicate effectively or perhaps due to a bad experience with a HCP or clinic. As a consequence, the seeds of distrust may cause a reluctance to schedule future appointments. Likewise, as with many hearing patients, if the HCP is seen as paternalistic, condescending or demeaning, one's association with the health care system is affected. It is important to recognize the limitations of language and literacy and to provide services to meet their needs, thereby improving relationships and health outcomes.

Cultural Beliefs & Values

With the assistance of family, friends, educators and colleagues, Elsa has overcome obstacles in her life. However, when the earthquake struck, she was alone – without the support of her community. She had come to visit friends in the Napa Valley and was staying at a downtown hotel. While she was able to check in with ease, no mention of her special needs was noted on the reservation. As a result, desk personnel had no idea that she would not hear the alarm at 3:20 a.m. to evacuate the building.

Commitment and loyalty are the cornerstone of the Deaf community. As mentioned, they do not identify as disabled, but rather as a member of a distinct cultural group with a center on the linguistic. In the the book, *The People of the Eye*, the authors assert that deafness is an ethnicity and must be given its due, socially and politically. While Deaf identity is not based on religion, race or class “there is no more authentic expression of an ethnic group than its language.”¹⁶

The Deaf culture, similar to other cultural groups, has a history, embraces values and beliefs, and use a specific language – ASL.

Cultural Beliefs & Values - Deaf Community

- Unity with other Deaf persons
- Use of American Sign Language
- Importance of Bilingual Education
- Communication - use of eye contact, gesturing & visual cues
- Music, films, literature, athletics, folklore that celebrate the Deaf culture

Communication

Stefany Anne Goldberg captures the essence of ASL language when she states that to properly ask a question you must “... first make a statement, then shrug your shoulders, cock you head to one side, open your eyes wide, and perhaps add an inquisitive expression to your face. To a hearing person this feels like overkill– like donning a Greek theater mask every time you need to find the bathroom. But communicating with your whole body is a fundamental part of ASL. It’s a visual idiom, a language of the eye.”¹⁷

American Sign Language is:

- A complete complex language
- Uses hands, facial gestures, and body posture to communicate
- Begins sentences with time, then noun, adjective & verb.
 - Physician says: You may need thyroid medication

- ASL interpreted as : In May, I'll need thyroid medication
- ASL may vary according to location, neighborhood, state and region

If a person became deaf pre-linguistically (usually before the age of three), they more likely use ASL as their form of communication. Other modalities that may be used in conjunction with ASL are Signed Exact English (SEE), Pidgin Signed English (PSE), Cued Speech, Lip Reading and the spoken word. Lip reading, long thought to be an effective method of communication, has proven less credible. Only 30-40% of spoken words are clearly understood. The sounds on the lips may look the same as other words, thus opening the door to misunderstanding.¹⁸ Furthermore, for the Deaf, English is considered a “foreign language,” therefore not understood easily. Similar to other languages, English words, especially medical terminology, do not exist in ASL. Health instructions, medication dosing, and warnings about adverse effects of medication are not easily translated. Potential misunderstanding may lead to poor health outcomes.

Reflective exercise: Communication/ Effective Ways to Communicate

1. ***List four risks to the Deaf patient when translation services are not available.***
2. ***Do you sign? Are there ASL personnel available in your facility to translate?***
3. ***What are some alternative methods you could use to convey a message to a Deaf patient?***

Family

The term *Deaf of Deaf* refers to Deaf parents who produce Deaf children. These children become acculturated into the Deaf culture and community. They use ASL as their primary language. Conversely, hearing children born to Deaf adults are known as *Children of Deaf Adults* (CODA). They generally use ASL as a primary language and learn English, their second language when they enter

school. They are considered “culturally Deaf” because although they can hear, ASL is their first and primary language. Those who lose their hearing later in life are called “physically deaf” but “culturally hearing” because their primary language is the spoken word.¹⁹

In the past, parents did not know if their child was deaf until age three when it was expected that they “should be speaking.” Today, screening programs designed to identify hearing loss in infants shortly after birth promotes early intervention and identification of resources for the parent and child. Regardless of a newborn’s ability to hear, Deaf parents communicate with them using ASL, as it is their primary language. However, when a Deaf child is born into a hearing family this creates a challenge, especially if the parents use only the spoken language. In Elsa’s case, her parents were “culturally hearing.” Perhaps akin to Deaf parents who wanted their child to use ASL, her parents wanted her to learn English, as that was their primary language. Parents’ perspectives and beliefs about hearing loss and communication may determine the direction that is taken. Early intervention, which includes discussion with experts and knowledge of options, allows parents to make an informed decision. Deaf parents of “hearing newborns” face the language decision. For Elsa’s parents the benefit of early intervention was time – time to accept this diagnosis and to plan accordingly. A decision to learn ASL in combination with English, provided the communication skills that benefited her socially and academically. Likewise, her siblings learned a “new language” too. As she grew up, experiencing her family’s love and support, she felt confident in her identity and purpose.

Health Care

From the Western medicine viewpoint, deafness is considered a pathophysiological condition in need of repair. Conversely, within the Deaf community, it serves as a proud identity and an appropriate descriptor for a deaf person. For those working in healthcare it is important to recognize the difference of opinion, and to acknowledge the pride held by those in the Deaf culture. This is the first step in establishing rapport and building a trusting relationship.

Healthcare institutions that insure that an ASL interpreter is available for the initial encounter demonstrate an understanding and acceptance of the patient's communication needs. Asking how one would like to be addressed and inquiring about family or support persons, prior to the discussion about the purpose of the visit, validates an interest in their well-being. During the appointment, it is imperative that the HCP listens attentively, acknowledge the concerns, and reflect a caring attitude. Usually, the visit closes when the HCP stands, closes the chart, and moves toward the door. However, in the Deaf culture these actions actually occur in reverse. Once the healthcare concerns have been addressed and resolved, the conversation (socialization) is expected to continue even as the patient prepares to leave. Important aspects of conversation to consider during a clinic/hospital conversation are:

- Acknowledge patient as a member of the Deaf community
- Create environment that promotes vision as primary sense
- Display consistent eye contact & visual attention
- Recognize visual signal/signs such as a pause, a facial expression to indicate essence of meaning of thought and/or conclusion to thought.
- Discern inclusion strategies such as waving, tapping shoulder, flicking light switch to get the persons' attention
- Insure interpreter is a certified translator versed in ASL and medical terminology. Interpreter should sit to the side or just behind the HC

Emergency Preparedness

The key to development and acceptance of Emergency Preparedness material for the Deaf community is collaboration with representatives from the Deaf/HH, EMT and HCP sectors. The educational material must include: cultural values and beliefs of the Deaf community, consideration of the educational level and literacy level of the person as well as examples of real-life scenarios. Determining quality and readability of written material is essential to assure clear understanding. The Department of Health and Human Services (DHHS) issued the *Quick Guide to Health Literacy* and its *Toolkit for Making Written Material Clean and Effective*. It provides the criteria for designing and evaluating educational pamphlets. The Suitability Assessment Method or SAM is an additional tool to insure that written material is clear and effective. An excellent example of such a pamphlet, *Disaster Preparedness and the Deaf Community*, was developed by the Red Cross in Rochester, New York in collaboration with members from the Deaf/HH community and Community Emergency Response Training (CERT) personnel. It is available online through the Rochester NY American Red Cross.

Cultural Awareness Education

A successful educational program for healthcare staff and emergency responders is contingent upon the belief that such a program is necessary and that participants have the desire to engage in the dialogue. In addition, the collaborative effort by members of the Deaf/HH, Emergency Responders and healthcare staff communities ensures attendance. An effective educational training program includes: an overview of the history of the ADA, the rights of the disabled, assessment of biases, barriers to care, cultural beliefs/values of the Deaf/HH, literacy level, communication and the identification of specific needs during a disaster. Presentation must include bilingual presenters – English speaking and ASL. Because the seminar material is developed by all parties, it gives credibility to the program. Outcomes include an assurance to the community that emergency responders and healthcare staff have the skills to care for the Deaf/HH in a disaster.

One such training is called the *Deaf Strong Hospital program*.²⁰ This educational training uses a role reversal to highlight the importance of interpreting services to improve cross-linguistic communication. Deaf volunteers serve as staff and HCPs. The hearing medical students are not allowed to speak and must act out illness scenarios. This training could be used for emergency preparedness programs as well. The hearing Emergency Responders and HCPs are disaster victims and the Deaf/HH are the first responders and health care staff. Each gain a heightened awareness and respect of needs of the other.

Reflective exercise: Health Education

- 1. What resources and support services are available in your community for the Deaf/HH?***
- 2. Have you received inservice on caring for the Deaf/HH?***
- 3. What health education material (pamphlets/videos) are available in your facility specifically for the Deaf/HH?***
- 4. Do your support groups include signers?***

Conclusion

As HCPs and ERs, we may not be adequately prepared to care for Deaf/HH patients. Minimal experience, coupled with limited knowledge of the the Deaf culture leads to poor health outcomes. In order to provide quality competent care and advocate for the Deaf/HH, we must be knowledgeable about their rights, needs and our responsibilities.

HCP & ER Staff Caring for the Deaf/HH

Acknowledge & Affirm

Deaf is a Culture

Discuss & Adjust

Provide ASL Interpreters

Include Family

Collaborate and Change

Deafness is Not a Pathophysiological Condition

* * *

Press release on the 16th anniversary of the Americans with Disability Act

The promise of the ADA was that all Americans should have equal access and equal opportunity, including Americans with disability. The ADA was about independence and the freedom to make our lives what we will. We celebrate that today, and we recommit ourselves to ending discrimination in all its forms.

President Barak Obama, 2011

Resources

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