DEAF AND HARD OF HEARING POPULATION

Hearing loss can occur at any stage of life and can result from varying causes, including but not limited to congenital birth defects, exposure to excessive loud noises, chronic and infectious disease, injury to the head or ear, or the results of aging.[1] Clinically, hearing loss is measured using a pure-tone hearing threshold on a decibel (dB) hearing loss (HL) scale.[2,3] Degree of hearing loss ranges along a continuum, from **mild** (26-40 dB HL), to **moderate** (41-60 dB HL), to **severe** (61-80 dB HL), to **profound** (over 81 dB HL).[4] During an audiological evaluation, an audiogram—a graph that shows the results of a pure-tone hearing test—is used to measure and show how loud sounds must be to be heard at different frequencies. In addition, an audiological evaluation of hearing will include speech thresholds and speech discrimination scores. These show the person's ability to process speech at a comfortable loudness level.[d] Even though there are some commonalities among individuals who have hearing loss, there is a wide variety of identities and complexity of needs among them. Broadly, those who have a hearing loss can fit into two populations: Hard of Hearing and Deaf. Even within these two groups, there is great diversity of identity and needs, which are defined below. However, throughout this report, when referring to the hearing loss population as a whole, Deaf and Hard of Hearing will be used in an all-inclusive manner.

INDIVIDUALS WHO ARE HARD OF HEARING

Individuals who are **Hard of Hearing** have a mild-to-severe hearing loss and comprise the vast majority of the Deaf and Hard of Hearing population. Age is the strongest predictor of hearing loss, with the highest prevalence among those who are 65 and older.[5,6] Having usually developed a hearing loss later in life, Hard of Hearing individuals generally prefer to communicate with the spoken word. Depending on the severity of their hearing loss, Hard of Hearing individuals can use a multitude of devices designed to amplify sounds to aid them in hearing the spoken word during conversations with others (**see Appendix C**).[7]

In addition to the amplification aids and devices mentioned above, Hard of Hearing individuals may utilize caption technology, which describes the audio or sound portion of a speech, presentation, program, or video, to help them when communicating with others. Captions are words displayed on a screen that allow individuals who are Deaf or Hard of Hearing to follow dialogue (**see Table 2.1**).[8]

TABLE 2.1 Captioning Technology for Communication Access

TECHNOLOGY	DEFINITION
Communication Access Realtime Translation (CART)	Communication Access Realtime Translation (CART), are word for word captions created as an appointment or event takes place. A stenographer uses a stenotype machine with a phonetic keyboard and special software. A computer translates the phonetic symbols into English captions almost instantaneously. The slight delay is based on the captioner's need to hear and code the word, and on computer processing time. CART can be used for programs that have no script.
Onsite CART	A method of providing CART where a stenographer is set-up on location with needed tools to provide captioning directly at the location where the appointment, meeting, presentation or event is taking place.
Remote CART	A method of providing CART where the Deaf or Hard of Hearing Individual and stenographer are not physically located in the same place. The person with hearing loss can read captioning of the appointment/meeting via a tablet, smartphone or laptop connected to the internet.
Captioned Telephone	A captioned telephone has a built-in screen to display in text whatever the other person on the call is saying. Captioning on a telephone takes place through the use of automatic speech recognition (ASR) capabilities and specially trained operators.
Open and Closed Captions	Captions may be "open" or "closed." Open captions are always in view and cannot be turned off, whereas closed captions can be turned on and off by the viewer (using the menu settings on any television). Closed captioning is available on digital television sets, including high-definition television sets.

Source: https://www.nidcd.nih.gov/health/captions-deaf-and-hard-hearing-viewers

d Dowd K. Executive Director. The Audiology Project. Written Communication. January 30, 2020.

Some Hard of Hearing individuals may also benefit from a cochlear implant, a small electronic device that is surgically inserted under the skin and directly stimulates the auditory nerve, bypassing damaged portions of the ear. In addition to the surgically implanted portions, cochlear implants have an external portion that sits behind the ear. A cochlear implant does not restore normal hearing but gives a good representation of the sounds in the environment and can often help the user understand some speech. A cochlear implant alone may not provide enough amplification and/or speech recognition aid to assist Hard of Hearing individuals to hear well when talking with medical professionals. A person may need access to an accommodation such as CART or the use of a personal FM system to gain access to communication.[e]

INDIVIDUALS WHO ARE DEAF

When an individual has a profound (over 81 dB) hearing loss, they are considered deaf.[f] An individual who is deaf has little or no hearing capabilities. Among those who are deaf, there is great diversity of how individuals identify themselves. This identification is typically determined by the age of the onset of deafness (particularly whether the individual had acquired verbal language skills prior to onset), preferred method of communication, or having a profound hearing loss along with another condition.[9] Individuals who are deaf and consider themselves part of a large, wider deaf community identify themselves as a Deaf person or **Deaf**. Deaf people have a source of pride in their deafness and see it as a part of their cultural identity. Most members of the Deaf community were either born deaf or become deaf during childhood. When Deaf people do not have acquired verbal language skills or prefer not to use them, their primary methods of communication are focused on the expression of language using movement of their hands and faces.[9,10] **Sign language** is the primary method of communication for Deaf people and is grammatically rich and sophisticated, with the same linguistic properties as spoken languages. Some Hard of Hearing individuals with severe hearing loss may also rely on sign language as their primary method of communication. Sign language is not universal and different variants of sign language are used in different countries and regions. **American Sign Language** is the subset of sign language primarily used in the United States. When communicating with people who do not know sign language, sign language users prefer to rely on a sign language interpreter, an individual trained in translating between a spoken and a signed language, to translate, interpret, and convey messages on their behalf.[9,11] In addition to a **sign language interpreter**, Deaf people and others who know sign language have other interpretation tools available to them, depending on their needs (see Table 2.2).

Individuals who become deaf later in life, typically after the acquisition of language, are considered **Late-Deafened**. They usually have some verbal language skills, but because of their profound hearing loss often rely on visual information, text, notes, or speechreading. An example of an accommodation through text or visual information would be utilizing CART during medical appointments. Some individuals who are Late-Deafened use sign language, but the majority don't. They also do not commonly consider themselves part of the Deaf community mentioned earlier. Late-Deafened and Deaf individuals may prefer captioning, speech reading, or written English if they never learned American Sign Language. Cochlear implants can also be beneficial for some Deaf and Late-Deafened individuals.[5,9]

TABLE 2.2 Interpretation Options for Individuals who are Deaf and Hard of Hearing

INTERPRETATION OPTIONS	DEFINITION
Cued Language Transliterator	A trained individual who uses a visual mode of communication that uses hand shapes and placements in combination with mouth movements and speech to make the phonemes of spoken language look different from each other.
Oral Transliteration	The practice of using clear enunciation, slightly slower speech than the original speaker, and expressive—not exaggerated—mouth and face movements to convey the speaker's message verbatim for Deaf or Hard of Hearing people who use speech and/or speechreading as their primary way of communicating.
Sign Language Interpreter	A sign language interpreter is someone has been taught to interpret in sign language effectively, accurately, and impartially, both receptively and expressively. In North Carolina, an interpreter must be licensed and meet certain standards set by state law.
Video Remote Interpreting	The use of video conferencing technology to access an off-site interpreter to provide real-time sign language for conversations between hearing people and people who are Deaf or who have hearing loss.
Video Relay Services	Video relay services (VRS) enables sign language users to communicate with other users of sign languages and hearing individuals over the phone through video equipment.

Sources :NC Division of Services for the Deaf and Hard of Hearing https://files.nc.gov/ncdhhs/documents/files/sli_factsheet_0.pdf; U.S. Department of Justice, Civil Rights Division, Disability Rights Section https://www.ada.gov/effective-comm.htm ; Federal Communications Commission https://www.fcc.gov/consumers/guides/video-relay-services

e Davis T. Hard of Hearing Services Coordinator, Division of Services for the Deaf and Hard of Hearing, North Carolina Department of Health and Human Services. Written communication. December 31, 2020.

f Throughout this report both "deaf" and "Deaf" are used. The spelling deaf is used to discuss the condition of profound hearing loss and/or those who are deaf but do not identify culturally as Deaf. The spelling Deaf is used to discuss those individuals who are deaf and identify as part of the Deaf community. The Deaf community is distinguished by its preference for using American Sign Language (ASL) and its distinct culture.

When an individual has both a hearing loss and vision loss, they are considered **DeafBlind**. The **DeafBlind** population is very diverse in degree of hearing/vision loss, age of onset, communication modalities, and how they identify themselves. In addition to the communication challenges faced by all Deaf and Hard of Hearing people, DeafBlind individuals face unique challenges related to orientation and mobility, access to environment information, and transportation. Some DeafBlind individuals utilize **Support Service Providers** (SSPs), specially trained guides who can assist a DeafBlind person with transportation and access to written material and provide support with informal communication and environmental information. If a DeafBlind person knows sign language, they can rely on sign language interpreters who are trained and proficient in the sign language modifications for the DeafBlind to translate, interpret, and convey messages on their behalf (see Table 2.3). Interpreters qualified to work with DeafBlind individuals are also familiar with human guiding techniques, incorporating visual information and utilizing techniques to convey environmental and social feedback information.[12–14] Other methods of communication used by DeafBlind people include reading and writing in Braille or large print, or the use of assistive technologies that allow the use of telephones or computers.

TABLE 2.3 Sign Language Modifications for the DeafBlind

MODIFICATION	DEFINITION
Close-Vision Interpretation	An interpretation modification that can be used for a DeafBlind Individual with limited residual vision. The sign language interpreter positions themselves close to the DeafBlind person and signs within a small space, usually at chest level.
Tactile Sign Language Interpretation	An interpretation modification that can be used for a DeafBlind individual with "restricted or" no residual vision. The DeafBlind Individual puts one or both of their hands over the interpreter's hands to feel the shape, movement, and location of signs.
Tracking	An interpretation modification that can be used for a DeafBlind individual with limited residual vision. The DeafBlind individual holds the interpreter's forearm or wrist to follow signs and keep the signs within their field of vision.

Source: American Association of the DeafBlind. http://www.aadb.org/factsheets/db_communications.html

HEARING LOSS EFFECT ON HEALTH, QUALITY OF LIFE, AND HEALTH CARE COSTS

In addition to the impact that hearing loss has on one's ability to communicate with others, hearing loss can also have a detrimental effect on one's physical, mental, and psychosocial well-being.[15–17] There is a breadth of research that has found an association between hearing loss and a host of conditions and diseases including diabetes, cardiovascular disease, Alzheimer's disease, and related cognitive effects of dementia.[18–21] Persons with hypertension have been shown to have increased risk for hearing loss, and those with diabetes have a higher prevalence of hearing loss.[23] Among persons with diagnosed hearing loss, there are increased risks for Alzheimer's disease, cognitive impairments associated with dementia, and depression.[23] Hearing loss can also affect quality of life. Individuals with a hearing loss are at increased risk for social isolation, loneliness, and falls.[19,20] Hearing loss, especially if left unidentified and untreated, can contribute to higher health care costs and utilization for Deaf and Hard of Hearing individuals.

Multiple research studies find that individuals with a hearing loss that is not treated have higher total health care costs and health care utilization compared to individuals with a hearing loss receiving treatment.[21–23] Deaf American Sign Language users may have higher health care costs and health care utilization because of not going to medical providers for preventive treatments due to lack of communication access or receiving insufficient treatment because of inadequate access to communication accommodations.[g] In the long term, hearing loss can also contribute to increased mortality rates, especially in older adults.[24] Outcomes are also impacted for persons who are DeafBlind who face increased mortality risks over those persons who are only deaf or only blind.[25] Specifically, studies have found that persons who are DeafBlind face "a 62% increased risk of dying 10 years later, independent of age, sex, self-rated health and the presence of known mortality markers."[26]

COMMUNICATION ACCESS LAWS: FEDERAL PROTECTIONS FOR INDIVIDUALS WITH HEARING LOSS

Protections to ensure that individuals with disabilities have equal opportunities to receive services are written into various federal laws. **Section 504 of the Rehabilitation Act of 1973** is a federal law that was enacted to prohibit discrimination based upon disability and applies to all entities that receive federal funds (i.e., hospitals and providers that participate in Medicare or Medicaid programs).[27] Title VI of the Civil Rights Act of 1964 is an analogous federal law to Section 504 of the Rehabilitation Act of 1973 that also prohibits discrimination, but does so based on race, color, or national origin. While both of these laws and others enacting identity-based protections have established anti-discrimination rights for those specified groups, and penalties for when a violation occurs, they have not been successful in preventing continued and systematic issues of disparities—specifically in the health care field.[28]

g Williamson L. Communication Access Manager, Division of Services for the Deaf and the Hard of Hearing, North Carolina Department of Health and Human Services/ Written communication. December 30, 2019.

In 1990, the **Americans with Disabilities Act (ADA)** was enacted with the intent of ensuring that people with disabilities have the same rights and opportunities as everyone else. The ADA serves as an additional protection for persons with a disability, defined under federal law as those with

> "a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment. Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working."[29]

The ADA prohibited disability-based discrimination, including by public and private entities, regardless of whether they receive federal funding.[28] The ADA is divided into five sections labeled as Titles to distinguish the differences between the entities covered. The type of organization covered under each Title is known as a "covered entity." The Titles and covered entities include:[29]

- **Title I (Employment):** "Prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions, and privileges of employment. (Covers employers with 15 or more employees)."[30]
- **Title II (Public Entities & Public Transportation):** "Prohibits state and local governments from discriminating against 'qualified individuals with disabilities' by excluding them from services and activities due to their disability."[31]
- **Title III (Public Accommodations & Commercial Facilities):** "Prohibits discrimination on the basis of disability in the activities of places of public accommodations (businesses that are generally open to the public and that fall into one of 12 categories listed in the ADA, such as restaurants, movie theaters, schools, day care facilities, recreation facilities, and doctors' offices) and requires newly constructed or altered places of public accommodation—as well as commercial facilities (privately owned, nonresidential facilities such as factories, warehouses, or office buildings)—to comply with the ADA Standards."[31]
- **Title IV (Telecommunications Companies):** "Amends the Communications Act of 1934 to require telecommunications companies (common carriers) to provide functionally equivalent services to individuals with disabilities"[29]; including devices for Deaf and/or people who are hearing impaired that enable them to communicate through their carrier's service.
- **Title V (Miscellaneous Provisions):** Provides miscellaneous provisions covering the entire ADA, some of which include: "prohibiting retaliation against individuals who enforce their rights under the Americans with Disabilities Act (also protecting people without disabilities if they do things like advocate or testify on behalf of individuals with disabilities)" and noting "the ADA does not invalidate or override any other laws (federal, state, or local) that provide equal or greater protections or remedies for people with disabilities."[32]

Due to discrepancies in the interpretation of some language in the original ADA law, in 2010 the United States Department of Justice (USDOJ) published revised regulations for Title II and Title III entities.[33] These revised regulations further define these covered entities, the purpose of *effective communication*, and what to consider when determining: if communication is effective, the types of auxiliary aids or services covered entities are required to provide under Title II or Title III, who decides if a service is needed, when companions are covered, when using accompanying adults or children as interpreters is prohibited, and the limitations of the ADA (when providing the aid or service becomes an undue burden to the covered entity).

AUXILIARY AIDS AND SERVICES UNDER FEDERAL LAW

The most relevant section of the USDOJ revised regulations publication may be the portions describing "who decides which aid or service is needed" and the "test" for determining whether an "auxiliary aid or service" facilitates effective communication.[33] Determining who decides whether the aid or service is needed depends on the type of covered entity (Title II or Title III). Title II entities are

> "***required*** to give primary consideration to the choice of aid or service requested by the person who has a communication disability. The state or local government must honor the person's choice, unless it can demonstrate that another equally effective means of communication is available, or that the use of the means chosen would result in a fundamental alteration or in an undue burden (see below). If the choice would result in an undue burden or a fundamental alteration, the public entity still has an obligation to provide an alternative aid or service that provides effective communication if one is available."[33]

Conversely, Title III entities are only

> "***encouraged*** to consult with the person with a disability to discuss what aid or service is appropriate. The goal is to provide an aid or service that will be effective, given the nature of what is being communicated and the person's method of communicating."[33]

There are four other factors to consider when determining if an auxiliary aid or services is considered an effective form of communication in addition to considering the nature of what is being communicated, and they are "the length, complexity, and context of the communication as well as the person's normal method(s) of communication."[33] Additionally, these factors should be considered on a interaction-by-interaction basis.

> *Other solutions may be needed where the information being communicated is more extensive or complex. For example: In a doctor's office, an interpreter generally will be needed for taking the medical history of a patient who uses sign language or for discussing a serious diagnosis and its treatment options.*
>
> *Source: https://www.ada.gov/effective-comm.htm*

These revised regulations also explain more in depth about the auxiliary aids and services, or ways to communicate with people who have communication disabilities, mentioned above. Examples of them (i.e., a qualified sign language interpreter, oral interpreter, cued-speech interpreter or tactile interpreter) and details that qualify their uses are given.[33] One very important illustration of this is the revised guidelines' definition of a "qualified" interpreter, which "means someone who is able to interpret effectively, accurately, and impartially, both receptively (i.e., understanding what the person with the disability is saying) and expressively (i.e., having the skill needed to convey information back to that person) using any necessary specialized vocabulary."[33] A qualified interpreter should be used whether the interpreter is "on-site," or in the room with the patient, or is interpreting through a video remote interpreting (VRI) service. One point that should be clarified is the difference between communication with companions versus direct communication with individuals. Sometimes a family member, friend, or associate of a person needing medical care is the appropriate person with whom the covered entity should be communicating. In these instances, these "companions" are the ones who are entitled to auxiliary aids or services if they need a communication accommodation to understand what is being said or done. An example of this is a Deaf parent of a child receiving medical attention; the Deaf parent is entitled to communication assistance under federal law. [33]

Federal law explicitly states the burden of providing effective communication is always placed on the covered entity. So, the person needing communication access accommodations cannot be expected or required to bring someone with them to interpret for them. Some exceptions do apply, such as in the case of an emergency, but even so, covered entities are also not allowed to rely on these exceptions—especially when there is a reason to believe the communication is not appropriate, effective, and/or may be harmful to the relationship.[33] As previously mentioned, there are limitations to a patient's request for a certain accommodation if the provider can "demonstrate that another equally effective means of communication is available, or that the use of the means chosen would result in an undue burden (significant difficulty or expense)."[33] There is ambiguity in determining what will constitute an undue burden on a covered entity, but current economic conditions and resources can be and are taken into account. The factors used in determining an undue burden for Title II and Title III entities do vary (**see Table 2.4**).

These USDOJ revised regulations conclude with recognizing the importance of covered entities providing staff training on the information provided, even taking into consideration that "covered entities may have established good policies, but if front line staff are not aware of them or do not know how to implement them, problems can arise."[33] To this point, and even after the revised interpretations of ADA terms by the USDOJ, in the Spring of 2013 as a part of their Barrier-Free Health Care Initiative, the USDOJ released a report that they had reached settlements with eight health care providers to stop their discrimination against persons with hearing disabilities—finding them in violation of the ADA. A civil monetary penalty of up to $55,000 (limitation for a provider or entity that violates the ADA) was assessed in all these settlements but varied in who they were paid to between the complainants and the United States. Each settlement also included a provision that "the health care provider [would] agree to change their policies to provide effective communication, including sign language interpreters, free of charge, and to train all staff on their new policies and procedures and the effective communication requirements of the ADA."[34]

While the bedrock of disability civil rights law has been in place for 30 years, as with all laws, clarifications and update still occur. In May of 2016, the United States Department of Health and Human Services (HHS) finalized regulations for Section 1557 of the Affordable Care Act (ACA). Section 1557 seeks to coordinate existing federal non-discrimination laws, including the ADA, and regulations and policies as they apply to health coverage by "prohibiting certain entities that administer health programs and activities from excluding an individual from participation, denying program benefits, or discriminating based on race, color, national origin, sex, age or disability."[35]

TABLE 2.4 Determining an Undue Burden for Title II and Title III Entities

TITLE II (STATE AND LOCAL GOVERNMENTS)	TITLE III (BUSINESSES AND NONPROFITS)
• Cost of the particular aid or service considering all resources available to fund the program, service, or activity	• Nature and cost of the aid or service relative to their size, overall financial resources, and overall expenses
• Effect of this additional cost on other expenses or operations	• A business or nonprofit with greater resources is expected to do more to ensure effective communication than one with fewer resources.
• Must be made by a high level official, no lower than a department head	• If the entity has a parent company, the administrative and financial relationship, as well as the size, resources, and expenses of the parent company, would also be considered.
• Must include a written statement of the reasons for reaching that conclusion	

Covered entities are not required to provide any aid or service in those rare circumstances where it would fundamentally alter the nature of the goods or services they provide to the public

Like Section 504 of the Rehabilitation Act of 1973, Section 1557 of the ACA "applies to health programs and activities that receive Federal financial assistance from HHS but also to health programs and activities administered by HHS, including the Federally-facilitated Marketplace and the state-based marketplaces established under the ACA."[35] An example of this more expansive list of the types of entities subject to Section 1557 is provided below (**Figure 2.2**). The most important aspect of Section 1557 may be its interpretation of ADA effective communication rules. "To the extent that [they] differ between Title II and Title III HHS adopted the Title II rules for all entities subject to Section 1557." [35] With the implementation of Section 1557, all providers subject to the regulation are considered ADA Title II entities and must give "primary consideration" of the type of communication accommodation to the patient.

FIGURE 2.2 Examples of the Types of Entities Subject to Section 1557

- Health care providers, such as physicians' practices, hospitals, community health centers, nursing facilities, home health agencies, clinical laboratories, residential or community-based treatment facilities, intermediate care facilities for people with intellectual/developmental disabilities, hospices, and organ procurement centers
- Health-related schools and education and research programs
- State agencies, such as Medicaid, Children's Health Insurance Program, and public health
- Health insurance issuers and third-party administrators
- United States Department of Health and Human Services programs, such as Centers for Medicare and Medicaid Services, – Health Resources and Services Administration, Centers for Disease Control and Prevention, Indian Health Services, Substance Abuse and Mental Health Services Administration the Federally-facilitated Marketplace, and the Basic Health Program
- State-based Marketplaces
- Employers offering employee health benefit programs (in certain circumstances)

Source: Kaiser Family Foundation. https://www.kff.org/report-section/summary-of-hhss-final-rule-on-nondiscrimination-in-health-programs-and-activities-issue-brief/

COMMUNICATION CHALLENGES FOR DEAF AND HARD OF HEARING CONSUMERS IN HEALTH CARE SETTINGS

Despite federal laws passed to ensure that people with disabilities, including those who are Deaf and Hard of Hearing, are not discriminated against, Deaf and Hard of Hearing individuals still face barriers in obtaining communication access in many settings, including health care.[36] Under federal law, health care providers are required to ensure that their communications with Deaf and Hard of Hearing individuals are effective. When auxiliary aids or services (e.g., qualified interpreters, assistive listening devices) are required for effective communication, the provider is responsible for covering the cost. Although the right to auxiliary aids and services has been enshrined in federal law for almost [30] years under the ADA, Deaf and Hard of Hearing patients and their families report facing many challenges when accessing health care services.[37] These challenges appear throughout the health care experience, from difficulty scheduling services and interacting with office staff, to communication problems during exams and procedures, conflicting views on what constitutes an effective communication aid, the risks posed by medication safety, and other concerns raised by inadequate communication.[37] Even when interpreters and other communication aids are provided, issues such as whether interpreters are knowledgeable and able to clearly interpret medical issues and a lack of understanding of how to use other communication aids and the technology support needed to use some communication aids hamper the ability of Deaf and Hard of Hearing individuals to access health care services.[38] The lack of effective communication in health care settings remains a major barrier to health care for individuals with hearing loss. Broadly, these challenges can be attributed to an inadequate understanding of how to provide communication accommodations for Deaf and Hard of Hearing Individuals; what is required by federal law among health care providers; and insufficient policies, procedures, and practices at hospitals, long-term care facilities, and other health care facilities.

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