

COMMUNICATION ACCESS LAWS AND OBLIGATIONS

Court cases and academic studies from around the country have documented that Deaf and Hard of Hearing individuals and family members often struggle to obtain effective communication in health care settings as provided for under federal law (see Chapter 2), however, there are no data to examine the size of the problem at the state level. Deaf and Hard of Hearing patients, family members, and advocates have a myriad of stories, some of which were shared with the task force. Their stories, highlighted throughout this report, illustrate the challenges Deaf and Hard of Hearing individuals face when trying to access health care services, communicating their health issues, and understanding information coming from health care providers. Failing to provide effective communication in a health care setting is a violation of federal anti-discrimination law. However, there is no obvious reporting mechanism for such violations. Complaints, when made, may go to health providers, health systems, the North Carolina Division of Services for the Deaf and Hard of Hearing (DSDHH)^h, Disability Rights North Carolinaⁱ, community organizations, or others. The lack of a shared reporting system means there is not an easy way to quantify and bring attention to the challenges that Deaf and Hard of Hearing patients face. Although Deaf and Hard of Hearing patients, family members, and advocates had numerous examples, most health care representatives on the task force were not aware that such serious challenges persisted.

THE NEED TO EDUCATE HEALTH CARE PROVIDERS

Many health care providers do not understand the requirements placed on them by the ADA and/or other communication access laws.¹ Health care providers report having little or no training on ADA requirements and demonstrate a failure to understand the basic tenets of disability civil rights law.¹ Also, health care providers may not have the correct assumptions about the health and communication needs of their Deaf and Hard of Hearing patients, potentially undermining the quality of care they provide. For example, a physician may believe that speech/lip reading or writing notes back and forth is an effective way to communicate with a Deaf patient even though those communication modalities are ineffective, especially in health care situations.² Since many health care professionals do not understand what is required of them by federal law or how to provide appropriate communication accommodations, and the benefits of doing so, education of the North Carolina health care workforce is paramount to increasing communication access for Deaf and Hard of Hearing individuals.

Educational toolkits—a collection of guides, resources, and educational materials—are often used to provide practical education and guidance for working professionals.³ An educational toolkit on understanding federal disability law and providing communication accommodations could be used to educate health care providers in North Carolina. Developing a toolkit that provides educational information in a format that is helpful to health care providers requires input from professionals who have a deep understanding of federal disability law and those who understand how health care is delivered.

CHALLENGES ACQUIRING THE SERVICES OF AN ON-SITE SIGN LANGUAGE INTERPRETER – *Elise's Experience*

Elise and her husband Jared are expecting their second child. When she was 11, Elise became Deaf after a meningitis infection. Since Elise lost her hearing as an older child, her speech is clear and understandable, however she relies upon American Sign Language to understand what other are saying. Most people that she meets do not realize that she is Deaf because of her clear speech and when told, they assume that she is an expert at lipreading. During her pregnancy with her first child, Elise had a wonderful experience with an OB/GYN who always provided an on-site sign language interpreter for her appointments. Unfortunately, her OB/GYN has determined this second pregnancy to be high risk and has referred Elise to a specialist. Elise and her husband have requested interpreter services from the specialist and have been told that interpreter services are not provided for initial appointments, but that if the doctor believes interpreting services are necessary, one will be arranged for later appointments. Jared knows some ASL but is not comfortable interpreting for Elise. Elise is very worried about her baby and is afraid that she will not understand what the doctor is saying without an interpreter.

The North Carolina Council on the Deaf and Hard of Hearing^j provides advice and instruction to the Department of Health and Human Services (NCDHHS) and the Department of Public Instruction on matters pertaining to services provided to deaf and hard of hearing individuals and their families. A similar council could provide advice and instruction to health care providers on matters pertaining to services provided to Deaf and Hard of Hearing individuals and their families in health care settings. This new advisory entity could work with the NCDHHS Secretary's Office, the DSDHH, and health care professional associations and licensing boards on the creation of the toolkit, other trainings, and strategies. The task force believes that a coordinated effort is needed to address the communications barriers that Deaf and Hard of Hearing individuals and their families experience in health care settings.

RECOMMENDATION 3.1:

Convene a Coalition to Increase Communication Access in Health Care Settings for Deaf and Hard of Hearing Patients

- A. The Secretary of the North Carolina Department of Health and Human Services (NCDHHS), through appropriate designees at the Division of Services for the Deaf and Hard of Hearing (DSDHH), should form and convene a coalition (the Coalition), and invite the following partners: North Carolina health care professional associations, North Carolina health care licensing boards, hospitals, long-term care facility representatives, and Area Health Education Centers.

^h The DSDHH provides services to Deaf, Hard of Hearing and Deaf-Blind individuals, their family members, and professionals, agencies and individuals seeking information or assistance. DSDHH provides these services through their central office and seven regional centers across North Carolina. Source: <https://www.ncdhhs.gov/divisions/dsdhh>

ⁱ Disability Rights North Carolina, is a 501(c)(3) nonprofit organization and member of the National Disability Rights Network, is the official Protection and Advocacy system for people with disabilities in North Carolina

^j As established North Carolina General Statutes 143B-216.31. & 143B-216.32., the North Carolina Council for the Deaf and Hard of Hearing advises the Department of Health and Human Services and the Department of Public Instruction on matters pertaining to services provided to deaf and hard of hearing individuals and their families.

B. The Coalition should:

1. Develop and implement strategies to increase understanding of disability civil rights law and improve communication access in health care settings for Deaf and Hard of Hearing populations including:

a. Partner with Disability Rights North Carolina (DRNC) and appropriate medical malpractice insurers to outline and develop a “toolkit” for health care providers, including the following:

- i. The impact that communication barriers can have on Deaf and Hard of Hearing individuals’ health, the communication barriers they face, communicating with them, and the various communication accommodations
- ii. The impact that lack of communication access, or ineffective communication, can have on the physical and mental health of individuals with hearing loss and the ameliorative impact that health care can have on appropriately treated or managed hearing loss
- iii. Resources on providing communication accommodations, including devices, to patients who are Deaf and Hard of Hearing
- iv. All federal communication accessibility laws, including, but not limited to, the ADA and the requirements for health care providers to provide their patients (and their family members) with effective communication
- v. DOJ guidelines on effective communication for the Deaf and Hard of Hearing
- vi. Guidance on appropriate referrals for support services and appropriate communication methods for individuals who are DeafBlind
- vii. Guidance on ensuring that consumer-facing communications include accommodations and are accessible for Deaf and Hard of Hearing individuals
- viii. DSDHH’s and DRNC’s availability to provide technical assistance

b. Develop and implement effective strategies to educate their members, licensees, and/or employees on:

- i. Federal and state requirements to provide effective communication methods when requested
- ii. The impact lack of communication access, or ineffective communication, can have on quality of life and quality of health care
- iii. Resources available for assistance
- iv. The “toolkit” for health care providers

c. Work with health care professional training program leaders to develop and implement effective strategies to educate future health professionals on:

- i. The legal requirements for providing effective communication
- ii. The impact lack of communication access, or ineffective communication, can have on quality of life and quality of health care
- iii. Cultural norms of Deaf and Hard of Hearing patients

d. Develop methods to track complaints, questions, and requests for resources relating to communication access accommodations in health care settings for individuals with hearing loss

2. Submit an annual report to the NC Council for the Deaf and Hard of Hearing on the progress of the Coalition in developing and implementing the strategies outlined above as well as any other work

With the DSDHH as the established authority for providing resources and information to Deaf and Hard of Hearing individuals, their families, and external organizations and professionals, it will play a key role in convening the Coalition and in the development of the educational toolkit detailed in Recommendation 3.1. Convening the Coalition with representatives from many health care organizations and creating and disseminating the toolkit and other education and outreach activities related to the work of the Coalition will require full-time dedicated staff. With approximately 70 DSDHH staff members in its central office and across its seven regional centers already dedicating their time to providing services and resources to the Deaf and Hard of Hearing population across the state,⁴ DSDHH will need increased organizational capacity at its central and regional offices. Full-time staff at the central office would coordinate the outreach, training, and education efforts of the Coalition statewide, and delegate tasks and duties to staff at regional offices as needed.

RECOMMENDATION 3.2:

Develop Organizational Infrastructure to Coordinate Division of Services for the Deaf and Hard of Hearing (DSDHH) Resources and Partnerships

- A. DSDHH should submit a budget request to the North Carolina Office of State Budget and Management (OSBM) to create up to eight total new positions responsible for resource and partnership development within DSDHH. These positions will include one program coordinator who will serve as the Secretary’s designee to the Coalition and seven regional specialists
- B. DSDHH should develop job descriptions for the program coordinator and regional specialists. Program coordinator responsibilities should include performing, and/or delegating to regional specialists, the following:

1. Lead the development of the communication access resources “toolkit” by managing relationships with the appropriate representatives from the entities to ensure the toolkit is tailored to that organization in the most effective manner
2. Seek funding opportunities from philanthropic organizations and “toolkit” partners for initial toolkit start-up costs
3. Develop and manage relationships with the appropriate health professional training entities to incorporate the information established in Recommendation 3.1C, and think of innovative ways to reach out to those students
4. Research and discuss with appropriate organizations innovative ways to achieve communication access in health care facilities
5. Develop relationships with advocacy organizations and other state agencies to disseminate information and create innovative educational resources for consumers
6. Provide consultation to support the implementation and expansion of Support Service Provider programming to address access to health care needs for the DeafBlind population
7. Track reports by consumers of noncompliance by health care providers; and track the resources being used by the DSDHH
8. Serve as the DSDHH liaison with health care providers, health care systems, or health care facilities for technical or resource support
9. Create and update tools with DRNC to provide resources to consumers about their rights

INCREASING UPTAKE OF ROUTINE HEARING SCREENINGS

Screening for hearing loss, especially in older adults, is important for overall health and well-being because once identified, treatment (i.e., use of hearing aid or amplification device) can be received to ameliorate the ill effects that hearing loss can have on health, the ability to communicate with others, and quality of life (see Chapter 2). However, many individuals who are Hard of Hearing do not receive treatment,⁵ with only 20% of those who might benefit from treatment receiving it.⁶ Many who have a hearing loss may not realize it because their symptoms are relatively mild or slowly progressing. Also, they may perceive they have a hearing loss but not seek treatment because they are in denial or reluctant to admit they have a hearing loss. Or, they may have difficulty recognizing or reporting their hearing loss because of the presence of cognitive decline or other conditions. The standard clinical test to screen for a hearing loss is pure-tone audiometry, also known as pure-tone testing. A health care professional trained in completing the procedure can use an audiometer^k to screen for hearing loss by checking certain frequencies or to evaluate hearing deficits more completely. During pure-tone audiometry, an individual is tested on the ability to hear tones at a series of discrete frequencies.^{7,8}

IDENTIFICATION OF HEARING LOSS – Larry’s Experience

Larry is a 60-year-old manager at his local hardware store. Recently, Larry has been having trouble understanding customers when the store is busy. Every year, his medical provider asks him if he has noticed any hearing changes, but never administers any further screening or refers him for a hearing exam. At home, Larry does not have any much trouble understanding his partner or his nieces and nephews when they visit him, so he is not sure whether he should mention his work experience at his next visit or not. He is also worried about what the doctor might say if he brings up his concerns. Larry’s mother had severe hearing loss near the end of her life, and it dramatically impacted how she communicated with her friends and loved ones. Larry worries that his difficulties at work could be a sign of early hearing loss, and is afraid of how it might affect his job and home life.

The equipment needed to perform pure-tone audiometry is inexpensive. There are a few clinical tests (see Table 3.1) that can be used by providers in primary care and other settings to identify individuals who potentially have a hearing loss that require little or no equipment and limited training. Simply asking an individual if they have a hearing loss is not a sufficient form of screening. As stated earlier, some people who are Hard of Hearing may be reluctant to admit it, may be in denial about their hearing loss, or may not know it. In addition, some Hard of Hearing individuals may not have an issue hearing speech in a quiet setting, such as in a medical exam room, but they have difficulty understanding speech in other settings where the ambient noise interferes with their auditory acuity.⁹

TABLE 3.1 Screening Methods for Hearing Loss

Whispered Voice Test	Medical provider whispers several numbers or words from behind the patient to assess how well the patient hears
Finger Rubbing	Rubbing fingers near the ear or using a tuning fork to assess how well the patient hears
Hearing Handicap Inventory for the Elderly-Screening Version	10-item self-administered questionnaire that assesses social and emotional factors associated with hearing loss and requires about two minutes to complete
AudioScope	Handheld screening instrument consisting of an otoscope (medical device which is used to look into the ears) with a built-in audiometer. It assesses the ability to hear tones of 20, 25, and 40 dB and takes approximately 90 seconds to administer.

Source: Bogardus Sidney T, J, Yueh B, Shekelle PG. Screening and Management of Adult Hearing Loss in Primary Care: Clinical Applications. *JAMA*. 2003;289(15):1986-1990. doi:10.1001/jama.289.15.1986

Using the aforementioned screening methods, providers can screen for hearing loss and then refer those they suspect of having a hearing loss to an audiologist or other hearing care professional for formal diagnosis. A potential hindrance to the referral of individuals with a hearing loss is the lack of routine hearing screenings by primary care providers. There are varying estimates that 40%-86% of primary care providers do not routinely screen their patients for hearing loss. Barriers to screenings cited by primary care providers include limited time, feeling there are more pressing clinical issues to address, and a lack of reimbursement.⁷ Further, the US Preventive Services Task Force rates the evidence “Indeterminate” with regard to routine screening for people over 50, and this federal task force is viewed as the gold standard for screening in primary care and sets a benchmark for required reimbursement by insurers. The reason for the “Indeterminate” recommendation is that many people with hearing loss choose not to purchase or wear a hearing aid and that cost is often prohibitive. Those barriers are addressed in other recommendations.¹⁰ In order to increase the uptake of routine hearing screenings by health care providers, there should be educational efforts geared toward them focusing on the importance of screening for hearing loss, so people can receive treatment and have amelioration from the potential ill effects of hearing loss.

RECOMMENDATION 3.3:

Educate Health Care Providers on the Health Benefits of Timely Hearing Screenings

The Coalition, through the Division of Services for the Deaf and Hard of Hearing, should: Partner with health care professional associations to educate providers on the co-morbidities associated with hearing loss and the importance of timely hearing screenings to mitigate the impact of these co-morbidities.

EDUCATING AND EMPOWERING THE DEAF AND HARD OF HEARING

Even if resources and educational opportunities on communication access laws and on how to provide appropriate communication accommodations are widely distributed and available to the health care workforce, there will still be instances where individuals who are Deaf and Hard of Hearing are denied requested communication accommodations. There could be a variety of reasons a requested accommodation is denied, including a health care provider not receiving relevant training and resources or willfully not complying with federal law due to costs or time constraints. In instances when an accommodation request is denied, the only immediate course of action available is to advocate for the accommodation oneself. However, the ability and effectiveness of a Deaf or Hard of Hearing individual to advocate for communication accommodations can be impaired by

1. the inability to effectively communicate their thoughts and feelings if an appropriate communication modality is not available;
2. not having adequate knowledge of federal disability laws and the rights afforded to them;
3. a lack of empowerment to speak up and advocate for themselves.

Like others with disabilities, people who have a hearing loss are often marginalized and feel a lack of empowerment to act on their thoughts, choices, and feelings.² Because of the marginalization and isolation felt by many who are Deaf and Hard of Hearing, they may be uncomfortable speaking up for themselves, asking questions, and advocating for themselves in health care settings.² The challenges they face in advocating for themselves in health care settings are compounded by low health literacy among people who are Deaf and Hard of Hearing.^{11,12} Deaf individuals face challenges in accessing health information, often not being able to process incidentally occurring information about health that individuals who have some hearing capabilities may be able to understand in everyday living and conversation.² Despite these challenges, self-advocacy for Deaf and Hard of Hearing individuals in health care settings may still be beneficial for receiving quality care and requested accommodations. Research studies have found that patients with self-advocacy skills are enabled to confidently search for health-related information regarding their medical condition; approach health care providers with more confidence, adaptability, and with less uncertainty; and are more satisfied with their health care experience.¹³

The National Association of the Deaf (NAD), a national civil rights and advocacy organization for individuals who are Deaf and Hard of Hearing,¹⁴ maintains that individuals who are Deaf and Hard of Hearing must learn to be effective advocates for themselves, and it provides several tips for being an effective self-advocate (see appendix D).¹⁵ NAD argues that even though there are federal laws that safeguard the rights of individuals with disabilities, inevitably people will violate these laws. In those instances, when laws are violated, individuals who are Deaf and Hard of Hearing need to be familiar with their rights, so they can advocate for themselves. Educating individuals who are Deaf and Hard of Hearing about their rights and how to advocate for themselves serves two purposes: empowering some to advocate for themselves and educating them about the potential recourse options available to them.

RECOMMENDATION 3.4:

Develop Resources and Educate Deaf and Hard of Hearing Consumers about their Rights

DSDHH, in partnership with Disability Rights North Carolina (DRNC), should create and update tools to provide resources to consumers about their rights, including:

1. All federal communication accessibility laws, including, but not limited to, the ADA and the requirements that health care providers must provide their patients with effective communication. An explanation of the DOJ guidelines and settlements should be included.
2. Forms that can be sent to health care providers explaining their requirements and simultaneously serving as a request for the patient’s communication accessibility accommodation.
3. Options to register complaints with:
 - a. Health care system patient relations departments
 - b. North Carolina DHHS ADA non-compliance reporting tool
 - c. North Carolina health care provider licensing boards
 - d. DRNC
4. DSDHH’s availability for consumer assistance and DRNC’s availability for legal guidance

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