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North Carolina Institute of Medicine

*Assuring Accessible Communication for
Deaf, Hard of Hearing, and DeafBlind
Individuals in Health Settings*



VISIT
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*In partnership with the **North Carolina Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing**, with additional support from **LeadingAge North Carolina***

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The North Carolina Institute of Medicine's (NCIOM) Task Force on Access to Health Services for the Deaf and Hard of Hearing was convened in March 2019 in partnership with the North Carolina Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing.

The task force was co-chaired by Mark T. Benton, Assistant Secretary of Public Health at the North Carolina Department of Health and Human Services (NCDHHS); and David Rosenthal, retired Director of the Deaf and Hard of Hearing Services Division at the Minnesota Department of Human. Their leadership and experience were important to the success of the task force's work.

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Many experts presented to the Task Force on Access to Health Services for the Deaf and Hard of Hearing. We would like to thank the following people for sharing their expertise and experiences with the task force (positions listed are as of the date of the presentation given):

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In addition to the above individuals, the staff of the North Carolina Institute of Medicine contributed to the task force's study and the development of this report. Adam J. Zolotor, MD, DrPH, President and CEO, guided the work of the task force. James Coleman, MPH, Research Specialist, served as the Research Assistant for the task force and was the primary author of the final task force report. Erin Bennett, Graduate Student Intern, assisted with writing and research for the final task force report. Kaitlin Phillips, MS, edited the final task force report and provided social media publicity for the task force. Emily Hooks, MEd, Research Assistant, assisted with editing the final task force report. Key staff support was also provided by Kisha Markham, Administrative Assistant and Don Gula, Director of Administrative Operations. Former staff, Robert Kurzydowski, JD, MPH, served as Project Director for the task force and contributed to the writing of this report; and Berkeley Yorkery, MPP, Associate Director, helped guide the work of the task force and made significant contributions to the writing of this report.

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ACA – Affordable Care Act

ACH – Adult Care Homes

ADA – American's with Disabilities Act

CART – Communication Access Real-Time Translation

CMS – Centers for Medicare and Medicaid Services

dB – decibel

DHSR – North Carolina Division of Health Services Regulation

DSDHH – Division of Services for the Deaf and Hard of Hearing

DRNC – Disability Rights North Carolina

HL – hearing loss

HSS – United States Department of Health and Human Services

LTCF – Long-Term Care Facilities

MDS – Minimum Data Set

NAD – National Association of the Deaf

NCAC – North Carolina Administrative Code

NCDHHS – North Carolina Department of Health and Human Services

NCHA – North Carolina Healthcare Association

NCIOM – North Carolina Institute of Medicine

OSBM – Office of State Budget and Management

QI – quality improvement

SNF – Skilled Nursing Facilities

SSP – Support Service Provider

USDOJ – United States Department of Justice

VRI – Video Remote Interpreting

Hearing loss is one of the most common health conditions in the United States, with approximately 48 million Americans having some degree of hearing loss.¹ In North Carolina alone, 1.2 million North Carolinians have hearing loss.² Among individuals with hearing loss, there is great diversity with varying levels of hearing, cultural identities, and communication methods. Some are born Deaf or Hard of Hearing, while others become Deaf or Hard of Hearing later in life. They may identify themselves as individuals who “have a hearing loss,” or are “Deaf,” “DeafBlind,” “Hard of Hearing,” or “Late-Deafened.” Individuals who are Deaf and Hard of Hearing often face significant barriers to receiving effective communication accommodations in health care settings,³⁻⁵ despite the Americans with Disabilities Act (ADA) of 1990, which requires the provision of communication accommodations for individuals with disabilities, including those with hearing loss. Under ADA requirements, communication, whether written or spoken, is effective when it is as clear and understandable to people with disabilities as it is for people who do not have disabilities. Effective communication in health care settings between patients and their medical care providers is key for a satisfactory health care experience. Complex, sensitive, and critical information is often conveyed in medical settings, and effective communication is essential to ensure that all information shared is understood clearly by all parties. The lack of effective communication in health care settings remains a major barrier to health care for individuals with hearing loss.

Communication is considered effective when all information shared between parties is clear and understandable for all involved. There is no “one size fits all” approach to effective communication. What is considered effective communication in health care settings is based upon what the patient needs in order to understand the information being conveyed to them and to accurately communicate his or her needs and questions to the health care provider. Health care providers caring for Deaf and Hard of Hearing patients have a number of options and accommodations that they can provide to ensure effective communication based on the unique needs of the individual. Communication accommodations for individuals with hearing loss include, but are not limited to, assistive listening devices, sign language interpretation, video remote interpreting, and tactile sign language interpretation.^{3,6} Despite the number and availability of communication aids and services, Deaf and Hard of Hearing patients and their families report facing many challenges to receiving communication accommodations in health care settings.^{7,8}

Deaf and Hard of Hearing individuals face barriers to effective communication across health care settings (inpatient, outpatient, hospitals, long-term care settings, etc.). Reasons for these barriers include providers and medical staff not having the requisite knowledge of what is required of them by federal law and regulations and assumptions that a “one size fits all” approach to effective communication is appropriate in most situations. The cost of providing services, and staff not understanding what services may aid in effective communication, or how to access those services, also pose challenges. When facing barriers to effective communication, Deaf and Hard of Hearing individuals are often

unable to successfully navigate health care systems and advocate for the accommodations they are entitled to under federal law. Recourse options for Deaf and Hard of Hearing individuals when denied accommodations include finding a new health care provider, registering complaints, reaching out to advocacy and governmental organizations for assistance, and filing lawsuits due to such denials being in violation of federal law. Since the passage of the ADA, there have been numerous lawsuits across the nation, including in North Carolina, where individuals with hearing loss have successfully sued providers and hospitals for not providing accommodations for effective communication.⁹⁻¹¹ Seeking legal action for the provision of accommodations may lead to change on the individual provider and hospital level, but lawsuits take time and money, and do not always lead to systemic change across health care settings. Reactive efforts alone cannot be relied upon to foster the system-wide changes needed in health care for individuals with hearing loss to have equal access to communication and to eliminate health care disparities among populations with disabilities.¹²

THE TASK FORCE ON ACCESS TO HEALTH SERVICES FOR THE DEAF AND HARD OF HEARING

In the Spring of 2019, the North Carolina Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing partnered with the North Carolina Institute of Medicine to convene a Task Force on Access to Health Services for the Deaf and Hard of Hearing. The primary charge of the task force was to study and assess the current state and limitations of health care services and communication accommodations for people who are Deaf and Hard of Hearing and the consequences of those limitations. To address these limitations, the task force developed consensus-based recommendations focused on educating the health care workforce and Deaf and Hard of Hearing consumers through the development and dissemination of educational materials; quality improvement and self-assessment of the policies, procedures, and system practices of health care systems and medical practices; and quality improvement and self-assessment of the policies, procedures, and system practices of long-term care facilities.

EDUCATING THE HEALTH CARE WORKFORCE

Many health care providers do not understand the requirements placed on them by the ADA and/or other communication access laws.¹³ 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.¹³ Also, health care providers may not understand the health and communication needs of their Deaf and Hard of Hearing patients, potentially undermining the quality of care they provide. 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.

RECOMMENDATION 3.1:

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

RECOMMENDATION 3.2:

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

INCREASING THE UPTAKE OF HEARING SCREENINGS

In order to increase the uptake of routine hearing screenings by health care providers, there should be educational efforts geared toward providers focusing on the importance of screening for hearing loss with their patients, so people can receive treatment and amelioration of the potential ill effects of hearing loss.

RECOMMENDATION 3.3:

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

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 in which individuals who are Deaf and Hard of Hearing are denied requested communication accommodations. In such instances, an immediate course of action for a Deaf and Hard of Hearing individual is to self-advocate for the accommodation.

RECOMMENDATION 3.4:

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

QUALITY IMPROVEMENT OF HEALTH CARE SYSTEM INTERPRETING SERVICES FOR DEAF AND HARD OF HEARING PATIENTS

In order to collect data and evaluate the quality of interpreting policies and practices used by hospitals and health care systems across North Carolina, hospitals, health care systems, and medical practices should engage in quality improvement efforts centered around communication access for Deaf and Hard of Hearing patients.

RECOMMENDATION 4.1:

Survey Health Care Providers on Methods of Meeting Communication Access Needs of Patients Who are Deaf or Hard of Hearing

RECOMMENDATION 4.2:

Survey Patients Who are Deaf and Hard of Hearing on Their Communication Access Needs

INCREASING ACCESS TO HEARING AIDS AND AMPLIFICATION DEVICES FOR THE HARD OF HEARING

Hearing aids and amplification devices can be of great benefit to Hard of Hearing individuals, enabling them to more effectively communicate with those around them. Despite the benefits of hearing aids and amplification devices, many individuals who are Hard of Hearing do not have access to them. In order to increase access to hearing aids and amplification devices, cost-benefit analyses of insurance coverage for hearing aids and pilot programs for the distribution of amplification devices need to be conducted.

RECOMMENDATION 4.3:

Conduct Cost-Benefit Analysis of Insurance Coverage for Hearing Aids

RECOMMENDATION 4.4:

Develop Pilot Programs to Distribute Personal Amplifiers in Medical Settings

SUPPORT SERVICE PROVIDERS FOR THE DEAFBLIND

In order to increase access to support service providers for the DeafBlind, so they have increased access to healthcare services, a cost-benefit analysis of a statewide program for support services providers for the DeafBlind needs to be completed.

RECOMMENDATION 4.5:

Conduct Cost-Benefit Analysis of Publicly Funded Support for Service Providers

AMENDING THE NORTH CAROLINA PATIENT'S BILL OF RIGHTS TO INCLUDE THE RIGHTS OF THE DISABLED

North Carolina's Patient's Bill of Rights, which states that patients cannot be discriminated against based on "race, color, religion, sex, sexual orientation, gender identity, national origin or source of payment" in health care facilities, and that a patient who "does not speak English shall have access, when possible, to an interpreter,"¹⁴ should be amended to include the right to not be discriminated against based on disability and access to sign language interpretation.

RECOMMENDATION 4.6:

Include Disability and Access to Sign Language Interpretation in the Minimum Provision of the Patient's Bill of Rights

STATEWIDE AUDIOLOGY SERVICES PROGRAM IN NORTH CAROLINA

To foster the uptake of clinical best practices for hearing screening and audiological services in North Carolina long-term care facilities, a statewide audiology service program should be established to promote and provide hearing screenings as well as consultation and education on hearing screenings, audiological services, and how long-term care facility staff can best meet the needs of residents who are Hard of Hearing.

RECOMMENDATION 5.1:

Improve Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities

QUALITY IMPROVEMENT AND EVALUATION OF AUDIOLOGICAL SERVICES IN LONG-TERM CARE FACILITIES

In order to collect data and evaluate the quality of interpreting services and the policies and practices used by North Carolina long-term care facilities regarding interpreting services, data should be collected from these facilities with the goal of implementing quality improvement activities to improve services for Deaf and Hard of Hearing residents.

RECOMMENDATION 5.2:

Survey Long-term Care Facilities on Communication Access Needs of Patients Who are Deaf or Hard of Hearing

RECOMMENDATION 5.3:

Update Procedures and Practices Pertaining to the Care of Deaf and Hard of Hearing Residents of Long-term Care Facilities

To ensure that staff in long-term care facilities have the requisite knowledge to provide communication accommodations and culturally appropriate care to Deaf and Hard of Hearing residents, there should be statewide educational efforts to improve understanding, knowledge, and skills.

RECOMMENDATION 5.4:

Educate Administrators and Staff in Long-term Care Settings on Providing Appropriate Services and Care to Deaf and Hard of Hearing Residents

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Hearing loss is one of the most common health conditions in the United States, with approximately 48 million Americans having some degree of hearing loss.¹ In North Carolina alone, 1.2 million North Carolinians have hearing loss.² Among individuals with hearing loss^a, there is great diversity with varying levels of hearing, cultural identities, and communication methods. Some are born Deaf or Hard of Hearing, while others become Deaf or Hard of Hearing later in life. They may identify themselves as individuals who “have a hearing loss,” or are “Deaf,” “DeafBlind,” “Hard of Hearing,” or “Late-Deafened.”^b Individuals with a hearing loss often face significant barriers to receiving access to effective communication accommodations in health care settings,³⁻⁵ despite the Americans with Disabilities Act (ADA) of 1990, which requires the provision of communication accommodations for individuals with disabilities, including those with hearing loss. Under ADA requirements, communication, whether written or spoken, is effective when it is as clear and understandable to people with disabilities as it is for people who do not have disabilities.⁶ Access to effective communication in health care settings between patients and their medical care providers is key for a satisfactory health care experience. Complex, sensitive, and critical information is often conveyed in medical settings and effective communication is essential to ensure that all information shared is understood clearly by all parties. The lack of equal access to communication in health care settings remains a major barrier to health care for individuals who are Deaf and Hard of Hearing.

Communication is considered effective when all information shared between parties is clear and understandable for all involved. There is no “one size fits all” approach to effective communication. What is considered effective communication in health care settings is based upon the patient’s preference for what they need in order to understand the information being conveyed to them and to accurately communicate their needs, choices, and questions to their health care provider. Health care providers caring for individuals who have hearing loss, which encompasses a wide range of hearing-loss related disabilities, have a number of options and accommodations that can be provided to ensure effective communication based on the unique needs of the individual. Communication accommodations for individuals with a hearing loss include, but are not limited to, assistive listening devices, on-site sign language interpretation, video remote interpreting (VRI), and tactile sign language interpretation, and Communication Access Realtime Translation (CART).^{3,7} Despite the number of communication aids and services available, Deaf and Hard of Hearing patients and their families often report facing many challenges when accessing health care services.^{8,9}

Deaf and Hard of Hearing individuals face barriers to effective communication across health care settings (inpatient, outpatient, hospitals, long-term care settings, etc.). Reasons for these barriers include providers and medical staff not having the requisite knowledge of what is required of them by federal law and assumptions that a “one size fits all” approach to effective communication is appropriate in most situations.

The fiscal cost of providing services and staff not understanding what services may aid in effective communication, or how to access those services, also pose challenges. When facing barriers to effective communication, Deaf and Hard of Hearing individuals are often unable to successfully navigate health care systems and advocate for the accommodations to which they are entitled under federal law. In addition, ineffective communication in health care settings can lead to poor health outcomes for patients, dissatisfaction with provided care, longer hospital stays, and unnecessary health care spending.^{10,11}

Recourse options for Deaf and Hard of Hearing individuals when denied accommodations include finding a new health care provider, registration of complaints, reaching out to advocacy and governmental organizations for assistance, and lawsuits due to such denials being in violation of federal law. Since the passage of the ADA, there have been numerous lawsuits across the nation, including in North Carolina, where individuals with a hearing loss have successfully sued providers and hospitals for not providing accommodations for effective communication.¹²⁻¹⁴ Seeking legal action for the provision of accommodations may lead to change on the individual provider and hospital level, but lawsuits take time, money, and often do not lead to systemic change across health care settings. Reactive efforts alone cannot be relied upon to foster the system-wide changes needed in health care for individuals with a hearing loss to have equal access to communication and assist in the goal of eliminating health care disparities among populations with disabilities.¹⁵

TASK FORCE ON ACCESS TO HEALTH SERVICE FOR THE DEAF AND HARD OF HEARING

In the spring of 2019, the North Carolina Department of Health and Human Services (NCDHHS) Division of Services for the Deaf and Hard of Hearing (DSDHH), partnered with the North Carolina Institute of Medicine (NCIOM) to convene a Task Force on Access to Health Services for the Deaf and Hard of Hearing. The task force was chaired by Mark T. Benton, Assistant Secretary of Public Health for NCDHHS, and David Rosenthal, retired Director of the Deaf and Hard of Hearing Services Division of the Minnesota Department of Human Services. The two co-chairs presided over task force meetings, brought meetings to order and closing, and facilitated discussions. There were an additional 49 task force and steering committee members who provided invaluable input, knowledge, and dialogue throughout the course of the task force. Sole funding was provided by DSDHH.

TASK FORCE SCOPE

The primary charge of the task force was to learn about the current state and limitations of health services to people who are Deaf and Hard of Hearing and the consequences of those limitations. Originally, solutions considered by the task force included the feasibility of a communication access fund (for qualified sign language interpretation); sign language

a Throughout this report, the terms “individuals with a hearing loss” and “Deaf and Hard of Hearing” are used in an all-inclusive manner. However, the task force respectfully acknowledges that there are clashing clinical and cultural perspectives on what it means to be Deaf or Hard of Hearing and that there is great diversity among individuals who are Deaf and Hard of Hearing, and how broadly the term “hearing loss” can be defined.

b Throughout the report “Deaf and Hard of Hearing” includes individuals who are Deaf, DeafBlind, Hard of Hearing, and Late-Deafened.

interpreter work force pipeline^c; best practices and technology solutions assuring effective communication, accessibility, and inclusion at all health care facilities, including assisted living and skilled nursing facilities; and provider education. Throughout the course of the task force, it was determined that the consideration of a communication access fund and the sign language interpreter pipeline should not be included within the task force scope. The establishment of a communication access fund, a pooled fund of monies drawn from the licensure fees of health care providers that could be accessed by providers to pay for sign language interpretation services,¹⁶ was originally considered to address financial barriers faced by some providers in paying for sign language interpretation. The consideration for a communication access fund was removed from the scope of work of the task force for two reasons: 1) Many providers are not aware of the communication access issues faced by Deaf and Hard of Hearing individuals in health care settings and educational efforts are needed as a first step solution; 2) There is a lack of data to quantify the depth of communications issues, and data would be needed to justify and inform the need for a communication access fund to policymakers and to regulatory bodies. Educational efforts targeted toward health care providers as a first step to increasing communication access for Deaf and Hard of Hearing individuals and data collection measures, which can be used to ascertain whether a communication access fund in North Carolina should be considered, are detailed in this report's recommendations.

The training, distribution, and qualifications of sign language interpreters were originally considered to ensure that there was an adequate pipeline of qualified sign language interpretation to provide services in health care and other settings. Expanding the sign language interpreter pipeline would involve extensive engagement and collaboration with secondary and post-secondary institutions and educators, taking the task force away from its health care access focus. It was concluded that sign language interpreter pipeline considerations were not within the purview of the task force and this was removed from its scope. Following these considerations, the scope of the task force was revised to include education of providers and other health care professionals, in addition to a focus on improving the policies, procedures, and system practices of health care systems, long-term care facilities, and providers to increase communication access.

REPORT STRUCTURE

The report of the NCIOM Task Force on Access to Health Services for the Deaf and Hard of Hearing includes five chapters, beginning with this brief introduction. Chapter 2 provides an overview of the Deaf and Hard of Hearing population, communication accommodations and services used, the legal and regulatory requirements for effective communication, and the barriers to communication access. Chapter 3 addresses educating the health care workforce and the development and dissemination of educational materials and best practices. Chapter 4 focuses on the policies, procedures, and system practices of health care systems and providers. Chapter 5 examines the current state of the policies, procedures, and system practices of long-term care facilities and improvements that can be made.

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^c The education, distribution, and retention of the sign language interpreter workforce.

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.⁴ 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>

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 Transliterater	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/ncdhs/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.

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.⁹ 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

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

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)
<ul style="list-style-type: none"> • Cost of the particular aid or service considering all resources available to fund the program, service, or activity • Effect of this additional cost on other expenses or operations • Must be made by a high level official, no lower than a department head • Must include a written statement of the reasons for reaching that conclusion 	<ul style="list-style-type: none"> • Nature and cost of the aid or service relative to their size, overall financial resources, and overall expenses • A business or nonprofit with greater resources is expected to do more to ensure effective communication than one with fewer resources. • 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.
<p>**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**</p>	

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.

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 almost³⁰ 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.

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/>

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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

^k a machine used for evaluating hearing acuity

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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Health care providers must first understand the legal requirements for the provision of communication accommodations and access for Deaf and Hard of Hearing consumers and be aware of available resources (see Chapter 3), then they must put in place systems to provide a requested communication accommodation to Deaf or Hard of Hearing patients. Health systems have policies and procedures in place to address communication access needs. These policies and procedures may not always provide effective communication and can create barriers to impede how successful communication is. For example, if a Deaf patient requests an on-site interpreter, but the health system preferentially uses video remote interpreters, effective communication may be limited.

ISSUES WITH VIDEO REMOTE INTERPRETATION IN A HOSPITAL SETTING – Samuel's Experience

Samuel began having severe abdominal pain during the night and drove himself to the hospital for evaluation. Samuel is Deaf and uses American Sign Language to communicate. When he arrived at the emergency room, he requested an on-site sign language interpreter, and was told that the hospital uses video remote interpreting (VRI) for Deaf patients. Samuel has never used VRI before, but his pain is so severe that he agrees to use the VRI even though he is having difficulty seeing the screen. Although the consultation begins okay, the picture quality on the VRI is poor and Samuel is having trouble understanding what the interpreter is conveying. He understands that he needs surgery, but is not sure why, or how serious his condition is.

QUALITY IMPROVEMENT OF HEALTH CARE SYSTEM INTERPRETING SERVICES FOR DEAF CONSUMERS

Despite hospitals and health systems having policies and procedures for communication access for Deaf and Hard of Hearing patients, evidence from Deaf people illustrates that the interpreting services provided to them at hospitals is often unsatisfactory, often leading to emotional distress and reduced quality of care.^{1,2} This disconnect between hospital and health system policies and the experiences and outcomes of their Deaf and Hard of Hearing patients illustrates there is room for improvement. Efforts to improve health care typically focus on improving access to care and quality of care. Quality improvement (QI) activities “consist of systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted patient groups.”³ QI work involves analyzing current systems and processes for areas where changes could lead to improved outcomes. QI work can happen at the state, regional, payor, health care system, practice, and individual provider level.

There are more than a hundred hospitals in North Carolina, with the majority of them owned or affiliated with a multi-unit health system.⁴⁻⁶ Every hospital and health systems has policies, procedures, and practices, including for providing interpreting services for Deaf patients, in order to be compliant with federal law. However, systematic data on the quality of interpreting services provided, common practices and procedures for the provision of

interpreting services, and complaints from Deaf patients about the quality of the interpreting services provided, or the lack thereof, is not readily available. Without data, it is difficult to objectively measure how well hospital and health systems meet the needs of their Deaf and Hard of Hearing patients and where there is room for improvement within the various systems. For example, Deaf people have had issues with the use of video remote interpreting (VRI) in hospitals.⁷⁻⁹ In hospitals and within health systems, VRI is becoming a more commonly used option for providing sign language interpretation because it is less expensive than hiring an on-site interpreter, can be used on demand without being limited by the travel and time constraints of booking an on-site interpreter, and can be used in situations when interpretation is needed immediately.^{10,11}

FIGURE 4.1 United States Department of Justice Performance Standard for VRI

Specific Performance Standards that must all be met if VRI is chosen:

- Real-time, full-motion video and audio over a dedicated high-speed, wide-bandwidth video connection or wireless connection that delivers high-quality video images that do not produce lags, choppy, blurry, or grainy images, or irregular pauses in communication;
- A sharply delineated image that is large enough to display the interpreter's face, arms, hands, and fingers, and the face, arms, hands, and fingers of the person using sign language, regardless of his or her body position;
- A clear, audible transmission of voices; and
- Adequate staff training to ensure quick set-up and proper operation.

Source: <https://www.ada.gov/effective-comm.htm>

An on-site sign language interpreter may charge a rate upwards of \$70-\$120 an hour (typically a two hour minimum), while rates for VRI are typically charged per minute.^{12,13} While the usage of VRI is to the advantage of hospitals/health systems because of convenience and cost effectiveness, as stated earlier, it can be problematic for Deaf patients. VRI can be impractical and problematic for Deaf patients on several fronts, including, but not limited to:

- If there is an issue with internet connectivity, the video feed may be choppy, go in and out, or be unclear.
- An on-site sign language interpreter can move and focus on either the Deaf patient or health care provider. The VRI interpreter can only see the body language and gestures of the individual(s) on whom the video feed is focused.
- A VRI interpreter may have a more challenging time filtering noises and attending to key messages as opposed to an on-site sign language interpreter.
- If the medical staff is unfamiliar with VRI technology, they may be unable to address any technical or logistical issues that may arise.
- If the Deaf patient cannot be properly positioned to see the screen because of the patient's condition and injury.^{7,10,11}

While VRI may appear to meet the needs of hospitals and health systems, if it is not offered in a manner that provides effective communication access for Deaf patients, the hospital/health system is not meeting its legal requirements. Work should be done to assess the impact of communication access options on the quality of care consumers receive and improvement efforts made where problems are identified. The collection of data is at the core of any quality improvement work. In order to collect data and evaluate the quality of interpreting policies and practices used by hospital and health systems across North Carolina, hospitals and health systems should engage in quality improvement efforts around communication access for Deaf and Hard of Hearing patients. As a first step in these efforts, information should be collected on the policies and procedures hospitals and health systems have around meeting the communication needs of Deaf and Hard of Hearing patients.

RECOMMENDATION 4.1:

Survey Health Care Providers on Methods of Meeting Communication Access Needs of Patients Who are Deaf or Hard of Hearing

- A. The Coalition should develop and disseminate a voluntary and uniform self-assessment form on providing care for Deaf and Hard of Hearing individuals and their family members. The self-assessment should be designed for health systems, facilities, and individual health care providers for quality improvement purposes.
- B. Coalition members, including professional associations and the North Carolina Healthcare Association (NCHA), should distribute the assessment to members and refer them to the toolkit for information on ADA legal requirements and quality improvement resources. Professional associations and the NCHA should also collect completed assessments and share them, without identifying information, with the Coalition.
- C. The Coalition should review collected self-assessments to identify areas where additional education and technical assistance is needed and to inform their annual reports to the NC Council for the Deaf and Hard of Hearing.

While collecting data for quality improvement, it is imperative that data on Deaf and Hard of Hearing patient satisfaction on the provision of interpretation services and other communication accommodations is included. Doing so establishes a baseline to evaluate the effects that any changes or additions to communication access policies may be having on patient satisfaction and outcomes for patients.

RECOMMENDATION 4.2:

Survey Patients Who are Deaf or Hard of Hearing on Their Communication Access Needs

The Division of Services for the Deaf and Hard of Hearing (DSDHH), on behalf of the Coalition, should survey Deaf and Hard of Hearing consumers on how well their communication access needs are met in health care settings. To do this, DSDHH should:

1. Work with the Coalition to develop a consumer survey.
2. Work with Disability Rights North Carolina and other advocacy and consumer agencies/groups to reach Deaf and Hard of Hearing consumers.

INCREASING ACCESS TO HEARING AND AMPLIFICATION DEVICES FOR THE HARD OF HEARING

Hearing aids^m and amplification devices can be of great benefit to Hard of Hearing individuals, enabling them to more effectively communicate with those around them (see Chapter 2). In particular, usage of hearing aids can ameliorate some of the ill health and cognitive effects of hearing loss such as cognitive decline and reduce the risk of falls, depression, and loneliness among the Hard of Hearing.¹⁴⁻¹⁶ There is some evidence that suggests usage of hearing aids by Hard of Hearing individuals can reduce hospital emergency department visits and hospitalization when compared to Hard of Hearing individuals who do not have a hearing aid.¹⁷ Despite the benefit of hearing aids, less than 20% of Hard of Hearing individuals use a hearing aid,¹⁸ and on average, they wait seven to 10 years after learning that they have a hearing loss before using a hearing aid.¹⁹ A major barrier to the uptake of hearing aids is the cost, with the national average for a single hearing aid being approximately \$2,000.¹⁹ Additional costs can be added if hearing aids are sold to consumers in bundled hearing rehabilitation packages.^{18,20} In North Carolina, hearing aids for adults are generally not covered by private or public health insurance plans.ⁿ Original Medicare does not cover hearing aids, and NC Medicaid and private payers are only required to provide coverage for hearing aids for children up to the age of 21.^{19o}

Outside of out-of-pocket costs for adults, there are statewide resources for North Carolina residents including the NCDHHS DSDHH Equipment Distribution Services Program. Through this program, a Hard of Hearing individual can obtain one hearing aid with a telecoil (for telephone communication purposes). However, this program is not available to all North Carolinians with a hearing loss. To qualify for the program, the Hard of Hearing individual with hearing loss must meet a specific audiological need, have certificate of disability, and must have an income of less than 250% of poverty level.^{19,21} There is some evidence that the value added by providing hearing aids to Hard of Hearing individuals outweighs the costs. A cost-benefit analysis study published in the *Journal of Applied Economics* found that the total benefits that providing a hearing aid had on improved quality of life and better health outcomes outweighed the initial costs of a hearing aid.²²

RECOMMENDATION 4.3:

Conduct Cost-Benefit Analysis of Insurance Coverage for Hearing Aids

The Coalition, through the Division of Services for the Deaf and Hard of Hearing, should convene representatives of North Carolina's public and private insurers and prepaid health plans to study and evaluate the potential benefits of providing coverage for hearing aids for members over the age of 21.

Although hearing aids can be useful for many Hard of Hearing individuals, not everyone with hearing loss needs or wants a hearing aid. These individuals could potentially benefit from the use of personal amplifiers in health care settings by allowing them better communication

^m Under current FDA regulations, a hearing aid can only be sold and fitted by a licensed audiologist or hearing aid dispenser.

ⁿ Some Medicare advantage (Part C) plans and private employer insurance plans in North Carolina do provide various levels of coverage for hearing aids for adults over the age of 21. In addition, NC Medicaid recipients who are long-term care facilities residents, can use their unmet medical needs benefit toward paying for hearing aids.

^o Per NC G.S. 58-3-285, health benefit plans in North Carolina are required to provide one hearing aid for each ear with hearing loss, up to \$2,500 per hearing aid every 36 months for covered individuals under the age of 22 years

and the ability to understand their treatment. In North Carolina, personal amplifiers are not covered by public or private payers, but are relatively inexpensive compared to hearing aids, with costs ranging between \$100 and \$200. In addition to the lower costs, personal amplifiers are easy to use for most patients, do not have to be fitted or specified for an individual, and are portable and can be rechargeable.¹⁹ Because of the low costs and portability, hospitals and medical practices could feasibly keep several personal amplification devices on hand to be used with Hard of Hearing patients to ensure effective communication. Through a program at John Hopkins Hospital, Hard of Hearing patients who need a personal amplifier are allowed to take one home. The rationale behind this is that if providing them the device allows them to better communicate and understand their treatment, it can reduce the likelihood that they return to the hospital.¹⁸

RECOMMENDATION 4.4:

Pilot Distributing Personal Amplifiers in Medical Settings

The North Carolina Healthcare Association should partner with the Coalition/ the Division of Services for the Deaf and Hard of Hearing (DSDHH) to develop a pilot program to distribute personal amplification devices in hospitals or other large medical settings.

SUPPORT SERVICE PROVIDERS FOR THE DEAFBLIND

The DeafBlind face unique challenges in their ability to communicate with others in health care settings. Their low visual acuity affects their ability to travel without assistance, which poses a major challenge to getting back and forth to doctor appointments or being able to go to the pharmacy to pick up a prescription.²³ Support Service Providers (SSPs) can help DeafBlind individuals overcome such challenges. SSPs are specially trained to serve as sighted guides for DeafBlind individuals. Services that SSPs can provide for the DeafBlind consumers include helping DeafBlind individuals process and access visual and environmental information, providing transportation, providing support in their daily aspects of life and acting as sighted guides.²⁴ It is important to note that SSPs are not trained to provide interpreting services for DeafBlind individuals, but support in their daily aspects of life, such as providing transportation and serving as a sighted guide during a medical appointment. However, it is expected that they follow the code of professional conduct established by the Registry of Interpreters for the Deaf.^{23,25} Despite the key services that an SSP can provide for a DeafBlind consumer, they are not considered “auxiliary aids and services” under the ADA. Public-serving entities like hospitals and doctors’ offices are not required to provide an SSP to a DeafBlind individual upon request.²⁶

Since public-serving entities are not required to provide an SSP, obtaining these services if needed is the responsibility of the DeafBlind person. SSP service can be provided by private, nonprofit, or public/governmental organizations. Twenty-one states have established statewide SSP programs for DeafBlind residents. These programs vary in how they are funded, designed, and operated. For funding, some programs rely on state government appropriations, grant funding, the use of Medicaid waivers, private donations, or a combination of all or some of these options.²³

North Carolina is not one of the states that has a statewide program for SSPs. DeafBlind employees of the North Carolina Department Health and Human Services can request an SSP through private vendors for work purposes, but there is no public SSP service for personal or health care use available in North Carolina.

DeafBlind consumers who need services for personal or health care use can obtain the service of an SSP professional through volunteers. The North Carolina Deaf-Blind Association has maintained a list of SSP volunteers in North Carolina since 2001 and there are around 300 names on the list. However, it is not known how many of the people on the volunteer list are active and still live in North Carolina. In addition, even though there are SSP volunteer services that can be used by DeafBlind consumers, services provided are not necessarily free, as volunteers at times must be compensated for food and gas.²³ North Carolina has undertaken efforts at the state level to establish an SSP program for personal use, such as for medical visits. DSDHH is currently in the process of evaluating data on the needs of DeafBlind people in North Carolina. This data could be used to determine the accessibility needs of DeafBlind consumers, including for health care, and the potential benefits that SSPs can provide statewide.

CHALLENGES FACED BY THE DEAFBLIND IN HEALTH CARE SETTINGS – *Jean’s Story*

Jean is DeafBlind and lives with her husband, a licensed interpreter, and two children. Jean became diabetic after her second pregnancy and routinely sees her primary care provider to monitor her condition. Since she is unable to drive, a family member or friend usually takes her to and from her appointments and also helps her with scheduling appointments. Her longtime primary care provider recently retired and closed his medical practice, so she is seeing a new doctor today. Her old doctor was aware of her needs and always had a tactile sign language interpreter available for her appointments. When Jean’s husband made her appointment with the new doctor, he requested a tactile sign language interpreter and was told the office would do its best to make one available. Today, when Jean arrived at the office with her husband, they discovered that the office has VRI ready for her—a service that Jean cannot use.

RECOMMENDATION 4.5:

Conduct Cost-Benefit Analysis of Publicly Funded Support Service Providers (SSPs):

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should assess the needs of DeafBlind North Carolinians to see where and how SSPs may play a role in improving health care access. DSDHH should review other states’ and cities’ SSP programs to determine the costs and benefits of public funding for SSPs. If there is a positive return on investment for publicly funded SSP programs, DSDHH should develop funding recommendations for such a program for the North Carolina General Assembly and/or the Division of Health Benefits.

AMENDING THE NORTH CAROLINA PATIENT'S BILL OF RIGHTS TO INCLUDE THE RIGHTS OF THE DISABLED

Ensuring that the rights of Deaf and Hard of Hearing individuals as patients are enshrined in organizational policies and government law and regulation is essential for solidifying the rights for Deaf and Hard of Hearing individuals to receive adequate care. There are laws, regulations, and policies at the federal, state, and organizational level across the United States that protect patients. The rights guaranteed by these laws and regulations include but are not limited to the right to privacy, to informed consent for medical treatment, and to receiving treatment despite a patient's ability to pay or form of payment.²⁷⁻²⁹

In North Carolina, there is a state level minimum provision of the Patient's Bill of Rights rule^p within North Carolina Administrative Code 10A NCAC 13B .3302, which lists 25 rights of patients in a facility subject to the rule.^q The rule explicitly states that patients cannot be discriminated against based on "race, color, religion, sex, sexual orientation, gender identity, national origin or source of payment"^r but does not include disability status, a category often included in anti-discrimination language. The rule also states that a patient who "does not speak English shall have access, when possible, to an interpreter."^s Although this rule should cover those who use American Sign Language, a language distinct from English, it could be further clarified to include non-spoken language. Thus, North Carolina's Patient's Bill of Rights could be used to further protect the rights that Deaf and Hard of Hearing consumers are granted under federal law.

RECOMMENDATION 4.6:

Include Disability and Access to Sign Language Interpretation in the Minimum Provision of Patient's Bill of Rights

- A. The Coalition, through the Division of Services for the Deaf and Hard of Hearing (DSDHH), should follow and utilize the rulemaking process outlined in North Carolina General Statute Chapter 150B: Administrative Procedures Act to propose a rule update to the North Carolina Medical Care Commission concerning 10A NCAC 13B .3302 MINIMUM PROVISIONS OF PATIENT'S BILL OF RIGHTS. This proposed rule change should include:
 - a. A revision of rule 10A NCAC 13B .3302 (13), which states "A patient has the right to medical and nursing services without discrimination based upon race, color, religion, sex, sexual orientation, gender identity, national origin or source of payment," to read "A patient has the right to medical and nursing services without discrimination based upon race, color, religion, sex, sexual orientation, gender identity, national origin, source of payment or disability."
 - b. An addition under rule 10A NCAC 13B .3302 (14), which states "A patient who does not speak English shall have access, when possible, to an interpreter," labeled as 10A NCAC 13B .3302 (15), which should read, "A patient who is Deaf or Hard of Hearing shall have access to effective communication accommodations when receiving medical and nursing services."
- B. The Medical Care Commission should approve updates to North Carolina Administrative Code 10A NCAC 13B .3302

^p The rule is administered by the North Carolina Department of Health and Human Services, Division of Health Services Regulation, Medical Care Commission. The North Carolina Medical Care Commission has the duty and power to promulgate, adopt, amend and rescind rules in accordance with the laws of the state regarding the regulation and licensing or certification, as applicable, of hospitals, hospices, free standing outpatient surgical facilities, nursing homes, adult care homes, home care agencies, nursing pools, facilities providing mammography/pap smear services, free standing abortion clinics, ambulances and emergency medical services personnel Source: <https://info.ncdhhs.gov/dhsr/nmcac/index.html>

^q All facilities under the purview of the Medical Care commission are subject to the Rule except for Nursing Homes who patient's rights are granted pursuant to G.S. 131E-117.

^r 10A NCAC 13B .3302 (13)

^s 10A NCAC 13B .3302 (14)

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As detailed in earlier chapters, hearing loss is a common health issue that can be associated with a host of conditions and diseases and can affect the quality of life for Hard of Hearing individuals. Despite the prevalence of hearing loss and the potential benefits of timely hearing screenings, especially in the elderly population, hearing loss in health care settings is often inadequately screened. This also holds true in **Long-Term Care Facilities (LTCF)**,¹ which provide a variety of services, including both medical and personal care (bathing, dressing, toileting, etc.), for people who are unable to live independently in their home and community. There are two distinct categories of LTCFs: **Skilled Nursing Facilities (SNFs)**, commonly referred to as nursing homes, and **Adult Care Homes (ACHs)**, also known as assisted living facilities.¹ Although both types of facilities provide services for adults who are no longer able to live independently, the type of services provided to residents depends on the setting. SNFs provide a wide range of medical and personal care services, including nursing care, 24-hour supervision, and assistance with everyday activities. Rehabilitation services such as physical, occupational, and speech therapy are also available in SNFs. SNF residents normally have ongoing physical or mental conditions that require constant care and supervision, so SNFs have licensed health care professionals on staff to provide care. ACHs serve individuals who need personal care assistance and supervision, but do not require the level of medical care provided by SNFs. ACHs usually do not have licensed health care professionals on staff. ACH staff focus on assisting residents with activities of daily living (e.g., feeding, bathing, dressing) and 24-hour supervision. ACH staff can help residents with medication administration, but other levels of medical care, including primary care, are from outside medical providers.^{2,3} Both SNFs and ACHs provide service for adults of all ages, but residents of both types of facilities are on average elderly, with the majority of residents of LTCFs being 65 and older.^{3,4} With the residents of LTCFs tending to be elderly, it is no surprise that incidences of hearing loss in these facilities are high, with varying estimates that 70%-90% of residents of LTCFs are Hard of Hearing.⁵

NEED FOR A STATEWIDE AUDIOLOGY SERVICES PROGRAM IN NORTH CAROLINA

In North Carolina, screening for hearing loss in residents of LTCFs is required by regulations at the state and federal levels. The regulations for LTCFs differ by type. The regulatory requirements for SNFs are under federal authority and set by the Centers for Medicare and Medicaid Services⁶ (CMS) if they participate⁷ in the Medicare and Medicaid Programs.³ CMS sets the requirements, establishes agreements with states, and provides funds to state agencies to regulate SNFs in their state. The North Carolina Department of Health and Human Services, Division of Health Services Regulation (DHSR)⁸ performs the oversight and regulation of SNFs in North Carolina. Per CMS regulations, all SNFs are required to perform an assessment of the physical, cognitive, and psychosocial status of all new residents within 14 days of intake and at discharge.

The standardized form that is used during the required assessment is the Minimum Data Set (MDS)-Nursing Home Resident Assessment. Screening for a hearing loss is required as part of the MDS. A licensed health care

professional, usually a licensed nurse, administers the MDS to residents. When assessing for a hearing loss, the MDS administrator can conduct or coordinate the assessment with another licensed professional who is trained in audiological screenings such as an audiologist or speech-language pathologist. However, this is not required, and neither is the administration of a clinically recommended hearing screening (see **Chapter 3**). All that is required is that the resident is asked about their ability to hear (see **table 5.1**) and usage of a hearing aid or assisted listening device (see **table 5.2**).^{3,6,7}

TABLE 5.1 Steps for Assessment for Ability to Hear

1. Ensure that the resident is using his or her normal hearing appliance if they have one.
Hearing devices may not be as conventional as a hearing aid. Some residents, by choice, may use hearing amplifiers or a microphone and headphones as an alternative to hearing aids.
Ensure the hearing appliance is operational.
2. Interview the resident and ask about hearing function in different situations (e.g., hearing staff members, talking to visitors, using the telephone, watching TV, attending activities).
3. Observe the resident during your verbal interactions and when he or she interacts with others throughout the day
4. Think through how you can best communicate with the resident. For example, you may need to speak more clearly, use a louder tone, speak more slowly, or use gestures. The resident may need to see your face to understand what you are saying, or you may need to take the resident to a quieter area for them to hear you. All of these are cues that there is a hearing problem.
5. Review the medical record.
6. Consult the resident's family, direct care staff, activities personnel, and speech or hearing specialists.

Source: United State Medicare & Medicaid Services Long-Term Care Facility Resident Assessment Instrument 3.0 User's Manual https://downloads.cms.gov/files/mds-3.0-rai-manual-v1.17.1_october_2019.pdf

TABLE 5.2 Steps for Assessment for Hearing Aid and Other Hearing Appliance Used

1. Prior to beginning the hearing assessment, ask the resident if he or she owns a hearing aid or other hearing appliance and, if so, whether it is at the nursing home.
2. If the resident cannot respond, write the question down and allow the resident to read it.
3. If the resident is still unable to respond, check with family and care staff about hearing aids or other hearing appliances.
4. Check the medical record for evidence that the resident had a hearing appliance in place when hearing ability was recorded.
5. Ask staff and significant others whether the resident was using a hearing appliance when they observed hearing ability.

Source: United State Medicare & Medicaid Services Long-Term Care Facility Resident Assessment Instrument 3.0 User's Manual https://downloads.cms.gov/files/mds-3.0-rai-manual-v1.17.1_october_2019.pdf

¹ Throughout this chapter, "Long-Term Care Facilities" is used in an all-inclusive manner for Skilled Nursing Facilities and Adult Care Homes.
² The Centers for Medicare & Medicaid Services (CMS) is a federal agency in the US Department of Health and Human Services (HHS) that administers the Medicare program and works in partnership with state governments to administer Medicaid, the Children's Health Insurance Program (CHIP), and health insurance portability standards.
³ Out of the 438 nursing home facilities in North Carolina, all but nine are certified to receive Medicare and Medicaid funding. The nine that are not certified to receive Medicare and Medicaid funding only accept private pay or payment through private insurance. These nine facilities are only subject to state level regulation.
⁴ Per CMS regulation, DHSR surveys and assesses all SNF in North Carolina annually for regulatory compliance. The assessment of SNF is completed by survey teams composed of nurses, dietary staff, pharmacists, and social workers. Any facilities found to not be compliant could possibly be subject to fines and civil penalties.

Since ACHs are not providers of medical care, and thus do not participate in the Medicare and Medicaid programs, they are not under federal regulatory authority and are completely under the purview of DHSR.^x Per DHSR regulatory requirements, all ACHs must assess all residents' ability to function and need for assistance with daily living. This includes whether a resident has a diagnosed hearing loss, has a hearing aid, and if they do, whether they can maintain the hearing aid. However, the required assessment is not intended to diagnose any condition such as hearing loss. If ACH staff believe a resident may have a medical issue such as a hearing loss, they are directed to raise the issue with the resident's primary provider of medical care.

Regulatory requirements for hearing loss screenings in residents of either type of LTCF does not meet the "gold standard" of hearing screening to diagnose a hearing loss. The lack of a requirement for clinically recommended best practices for the hearing loss screenings in LTCFs is particularly concerning, with the average resident of a LTCF being elderly and, thus, at a higher risk for hearing loss. Like most health care settings, LTCFs can be noisy environments, with sounds from televisions and other electronic devices, intercom sounds, cart transport equipment, and conversations being held. This further complicates the ability of a Hard of Hearing individual to understand and comprehend speech.⁸ In addition, many residents in LTCFs have a decline in cognitive ability, with estimates that 70% of nursing home residents have cognitive impairment⁸ and 40% of residents of ACHs have Alzheimer's or related dementia.³ LTCF residents with a decline in cognitive function may have issues separating speech from background noises and processing speech in noisy environments. This can be further complicated if the LTCF resident suffering from a cognitive decline is Hard of Hearing.⁸

SOCIAL ISOLATION AS A RESULT OF HEARING LOSS – *Ralph's Story*

Ralph is a 72-year-old retired engineer. Last year after a fall, Ralph and his family decided that it would be best if he moved into an assisted living facility. Over the last few years, Ralph's family has noticed that he seems to be having some difficulty following conversations and is socially withdrawn. They have also noticed that he has begun spending most of his time in his room rather than going to the social events and activities that the community hosts. Ralph's doctor has recommended that he be fitted for hearing aids, but his Medicare Advantage plan charges a \$700 co-pay per hearing aid which he cannot afford.

Even though the regulations for the assessment of hearing set forth for North Carolina LTCFs do not meet the clinical standard for hearing screenings (see Chapter 3), the regulatory requirements put no constraints on the ability of LTCFs to do more stringent and clinically proven hearing screenings. Implementing new regulatory requirements would be challenging. Changes to SNF regulations would require changes to CMS standards and guidelines set for SNFs across the United States and would have to be undertaken at the federal level. State-level change of

regulatory requirements of assessments for hearing loss screenings for residents in ACHs would require a change in state regulations and rules, but the lack of licensed health care professionals on staff severely limits what could be done through regulations. However, there is opportunity for improvement and innovation in policies, procedures, and best practices.

While there are various piecemeal strategies that could be used to meet the need for evidence-based services to assess and treat hearing loss among residents of LTCFs, the task force focused on how to create an infrastructure that could bring clinical best practices into LTCFs to improve care for residents who have hearing loss. A statewide system for audiology services in LTCFs could promote and provide hearing screenings as well as consultation and education on hearing screenings, audiological services, and how staff can best meet the needs of residents who are Hard of Hearing. The coordination and development of relationships and partnerships with LTCFs in North Carolina and their respective professional associations will require dedicated staff time at the statewide and regional level. Such a system could be established and housed within the North Carolina Department of Health and Human Services, Division of Services for the Deaf and Hard of Hearing (DSDHH). For such an effort, DSDHH would need increased organizational capacity at its central and regional offices for this undertaking. Full-time staff at the central office would create and implement the efforts of the statewide system for audiology services, and delegate tasks and duties to staff at regional offices as needed.

RECOMMENDATION 5.1:

Improve Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should coordinate, in consultation with appropriate health care facilities associations, the creation and implementation of a statewide audiology service program to increase the care of Deaf and Hard of Hearing patients in long-term care facilities. To effectively staff the program:

- A. DSDHH should submit a budget revision request to the North Carolina Office of State Budget and Management (OSBM) to create up to eight total new positions responsible for creating and implementing a statewide audiology service program for long-term care facilities. These positions should include one North Carolina program coordinator and up to seven regional specialists.
- B. DSDHH should develop job descriptions for the program coordinator and regional specialists. Statewide audiology service program coordinator responsibilities should include completing, and/or delegating to regional specialists, the following:
 - 1. Offer hearing screenings to all residents of long-term care facilities.
 - 2. Act as liaisons to long-term care settings around audiological concerns.

^x The routine monitoring and complaint investigations are by local county Departments of Social Services, while annual and biennial inspections of ACHs are completed by DHSR.

3. Provide recommendations/consultation to these facilities about assistive technology, hearing aids, and communication access.
4. Basic hearing aid care as deemed appropriate by the audiologist.
5. Collaborate with private audiologists already working with residents.
6. Serve as the lead for the long-term care facility capacities assessment (**see Recommendation 5.2**) for quality improvement purposes.
7. Develop and/or locate free training and educational resources for long-term care facilities to use to train their supervisors and/or employees on compliance with communication access laws and cultural sensitivity best practices for delivering care to Deaf and Hard of Hearing individuals.
8. Act as liaison to other organizations that provide training for adult care home providers such as the NC Assisted Living Association, NC Senior Living Association, and Area Agencies on Aging (Ombudsman Programs).

QUALITY IMPROVEMENT AND EVALUATION OF AUDIOLOGICAL SERVICES IN LONG-TERM CARE FACILITIES

As Title III entities under the Americans with Disabilities Act (**see Chapter 2**), LTCFs should have established policies, procedures, or practices for providing interpreting services for Deaf residents. However, like hospitals and health care systems (**see Chapter 4**), data on the quality of interpreting services provided, common practices and procedures for the provision of interpreting services, and complaints from Deaf patients about the quality of the interpreting services provided, or the lack thereof, is not readily available. We can assume that Deaf residents of LTCF facilities face similar barriers to communication access and to interpreting services faced by Deaf individuals in other settings. On the national level, there have been several lawsuits, complaints filed, and allegations of denial of interpretation services toward LTCFs over the past decade.⁹⁻¹⁵ Without concrete data, it is difficult to objectively measure how well LTCFs meet the communication access needs of Deaf and Hard of Hearing individuals and where there is room for improvement. In order to collect data and evaluate the quality of interpreting services, and the interpreting services policies and practices used by North Carolina LTCFs, data should be collected from these facilities with the goal of implementing quality improvement activities to improve services for Deaf and Hard of Hearing residents.

RECOMMENDATION 5.2:

Survey Long-Term Care Facilities on Communication Access Needs of Patients Who are Deaf or Hard of Hearing

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should partner with long-term care facility professional associations to develop a voluntary and uniform self-assessment on how care is provided for Deaf

and Hard of Hearing individuals and their family members to be used by long-term care facilities for quality improvement purposes. In order to do this:

- A. The DSDHH statewide audiology program coordinator should partner with Division of Health Services Regulation (DHSR) and long-term care facility association representatives to identify effective methods to disseminate the voluntary and uniform self-assessment form to facilities. The self-assessment should be designed for long-term care facilities for quality improvement purposes.
- B. Communication should also include information on ADA legal requirements and quality improvement resources, including the availability of technical assistance from DSDHH to help facilities better meet the communications needs of patients and their families.
- C. The DSDHH statewide audiology program coordinator, in conjunction with long-term care facility associations, should collect the results of this assessment and share them with the Coalition and the NC Council for the Deaf and Hard of Hearing.

There is much room for improvement for LTCFs that currently do not adequately screen for hearing loss. In order to ensure that residents who have a hearing loss are identified and receive treatment, LTCFs in North Carolina should consult and partner with DSDHH's Statewide Audiology Program Coordinator to assess and update their procedures and practices related to hearing screenings for their residents, and update them to meet clinical guidelines for hearing screenings as needed.

RECOMMENDATION 5.3:

Update Procedures and Practices Pertaining to the Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities

The Division of Services for the Deaf and Hard of Hearing statewide audiology program coordinator should lead an assessment of:

1. Hearing assessment procedures for the initial resident assessments in long-term care facilities
2. Referral patterns for when a resident is identified as Deaf or Hard of Hearing and what type of periodic review of the resident is being performed
3. Deaf and Hard of Hearing-related regulatory citations in long-term care facilities by gathering data on previous violations committed and their outcomes and evaluating opportunities for educational programs in lieu of penalties when a violation occurs
4. Findings and recommendations to be presented to the NC Council for the Deaf and Hard of Hearing

As detailed in preceding chapters, Deaf and Hard of Hearing individuals have unique needs and communication modalities, and, often, staff in health care settings are not aware of the communication access and cultural/behavior needs of Deaf and Hard of Hearing individuals. To ensure that staff in LTCFs have the requisite knowledge to provide communication accommodations and culturally appropriate care to Deaf

and Hard of Hearing residents in long-term care settings, statewide educational efforts could improve understanding, knowledge, and skills of administrators and staff in LTCFs. Partners in this effort could include DSDHH, long-term care facility professional associations, and the Department of Health and Human Services, Division of Adult and Aging Services' Long-Term Care Ombudsman Program.^z The Long-Term Care Ombudsmen provide a variety of services to LTCF residents and staff (see Table 5.3), including training sessions for LTCF staff on residents' rights and other issues.¹⁶ As a statewide service that already engages and educates LTCF staff, they would be a key partner in these educational efforts.

TABLE 5.3 Services Provided by Long-Term Care Ombudsman

- Answers questions and gives guidance about the long-term care system
- Educates long-term care providers and community groups on residents' rights, restraint use, care planning, activities, and new laws
- Investigates and assesses matters to help families and residents resolve concerns and problems
- Works with appropriate regulatory agencies and refers individuals to such agencies when resolutions of concerns or grievances are not possible through the Ombudsman
- Raises long term care issues of concern to policymakers

Source: <https://www.ncdhhs.gov/assistance/adult-services/long-term-care-ombudsman>

RECOMMENDATION 5.4:

Educate Administrators and Staff in Long-Term Care Settings on Providing Appropriate Services and Care to Deaf and Hard of Hearing Residents

The Division of Services for the Deaf and Hard of Hearing, the Division of Health Services Regulation, and the Division of Aging and Adult Services should collaborate to identify and leverage opportunities to expand and/or strengthen training on communication access and cultural/behavioral sensitivity for direct care and administrative staff in long-term care settings.

y The Division of Aging and Adult Services works to promote the independence and enhance the dignity of North Carolina's older adults, persons with disabilities, and their families through a community-based system of opportunities, services, benefits and protections. The Division of Aging and Adult Services provides monitoring and assessment of aging and services programs in North Carolina and provides training to support adult programs and services. Source: <https://www.ncdhhs.gov/divisions/daas>
z The Long-Term Care Ombudsman Program consists of the Office of the State Long-Term Care Ombudsman and 16 offices of Regional Long-Term Care Ombudsmen housed in Area Agencies on Aging. The Long-Term Care Ombudsmen provide advocacy for LTCF residents, assisting them in exercising their rights and mediating grievances between residents, families, and facilities.

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In the United States, the rights of those with disabilities, including those who are Deaf and Hard of Hearing, have been enshrined in federal law for decades. The rights of the Deaf and Hard of Hearing include access to effective communication while receiving treatment and care in hospitals, inpatient and outpatient clinics, and long-term care facilities. Access to effective communication for the Deaf and Hard of Hearing is key to ensure that they are able to fully participate in their medical care by being able to convey information back and forth with their health care provider and to be fully informed and understand their care. However, when Deaf and Hard of Hearing individuals do not have access to effective communication, they are at increased risk of poor health outcomes, dissatisfaction with their care, increased health care utilization, and higher health care costs. In order to provide and facilitate effective communication for the Deaf and Hard of Hearing, health care providers can use accommodations such as sign language interpretation and personal amplification devices.

Individuals who are Deaf and Hard of Hearing face barriers to receiving communication accommodations in health care settings. These barriers include providers not wanting to absorb the cost of the accommodation and failure to understand federal law or use of effective communication accommodations. To increase access to effective communication in health care settings for the Deaf and Hard of Hearing, the North Carolina Institute of Medicine, in partnership with the North Carolina Department of Health and Human Services Division of Services for the Deaf and Hard of Hearing, convened a seven-month Task Force on Access to Health Services for the Deaf and Hard of Hearing in the spring of 2019. The task force was brought together to study the barriers and limitations to effective communication for the Deaf and Hard of Hearing in health care settings and to identify consensus-based recommendations to increase access to effective communication.

The recommendations of the North Carolina Institute of Medicine Task Force on Access to Health Services for the Deaf and Hard of Hearing call on health care providers, state agencies, advocacy organizations, professional associations, and health care payers to collaborate in educational, self-assessment, and evaluation efforts across health care settings to increase access to effective communication for the Deaf and Hard of Hearing in North Carolina.

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

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.

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

CHAPTER 4: POLICIES, PROCEDURES, AND SYSTEM PRACTICES TO ENSURE APPROPRIATE CARE FOR DEAF AND HARD OF HEARING INDIVIDUALS

RECOMMENDATION 4.1:

Survey Health Care Providers on Methods of Meeting Communication Access Needs of Patients Who are Deaf or Hard of Hearing

- A. The Coalition should develop and disseminate a voluntary and uniform self-assessment form on providing care for Deaf and Hard of Hearing individuals and their family members. The self-assessment should be designed for health systems, facilities, and individual health care providers for quality improvement purposes.
- B. Coalition members, including professional associations and the North Carolina Healthcare Association (NCHA), should distribute the assessment to members and refer them to the toolkit for information on ADA legal requirements and quality improvement resources. Professional associations and the NCHA should also collect completed assessments and share them, without identifying information, with the Coalition.
- C. The Coalition should review collected self-assessments to identify areas where additional education and technical assistance is needed and to inform their annual reports to the NC Council for the Deaf and Hard of Hearing.

While collecting data for quality improvement, it is imperative that data on Deaf and Hard of Hearing patient satisfaction on the provision of interpretation services and other communication accommodations is included. Doing so establishes a baseline to evaluate the effects that any changes or additions to communication access policies may be having on patient satisfaction and outcomes for patients.

RECOMMENDATION 4.2:

Survey Patients Who are Deaf or Hard of Hearing on Their Communication Access Needs

The Division of Services for the Deaf and Hard of Hearing (DSDHH), on behalf of the Coalition, should survey Deaf and Hard of Hearing consumers on how well their communication access needs are met in health care settings. To do this, DSDHH should:

1. Work with the Coalition to develop a consumer survey.
2. Work with Disability Rights North Carolina and other advocacy and consumer agencies/groups to reach Deaf and Hard of Hearing consumers.

RECOMMENDATION 4.3:

Conduct Cost-Benefit Analysis of Insurance Coverage for Hearing Aids

The Coalition, through the Division of Services for the Deaf and Hard of Hearing, should convene representatives of North Carolina’s public and private insurers and prepaid health plans to study and evaluate the potential benefits of providing coverage for hearing aids for members over the age of 21.

RECOMMENDATION 4.4:**Pilot Distributing Personal Amplifiers in Medical Settings**

The North Carolina Healthcare Association should partner with the Coalition/ the Division of Services for the Deaf and Hard of Hearing (DSDHH) to develop a pilot program to distribute personal amplification devices in hospitals or other large medical settings.

RECOMMENDATION 4.5:**Conduct Cost-Benefit Analysis of Publicly Funded Support Service Providers (SSPs):**

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should assess the needs of DeafBlind North Carolinians to see where and how SSPs may play a role in improving health care access. DSDHH should review other states' and cities' SSP programs to determine the costs and benefits of public funding for SSPs. If there is a positive return on investment for publicly funded SSP programs, DSDHH should develop funding recommendations for such a program for the North Carolina General Assembly and/or the Division of Health Benefits.

RECOMMENDATION 4.6:**Include Disability and Access to Sign Language Interpretation in the Minimum Provision of Patient's Bill of Rights**

A. The Coalition, through the Division of Services for the Deaf and Hard of Hearing (DSDHH), should follow and utilize the rulemaking process outlined in North Carolina General Statute Chapter 150B: Administrative Procedures Act to propose a rule update to the North Carolina Medical Care Commission concerning 10A NCAC 13B .3302 MINIMUM PROVISIONS OF PATIENT'S BILL OF RIGHTS. This proposed rule change should include:

- a. A revision of rule 10A NCAC 13B .3302 (13), which states "A patient has the right to medical and nursing services without discrimination based upon race, color, religion, sex, sexual orientation, gender identity, national origin or source of payment," to read "A patient has the right to medical and nursing services without discrimination based upon race, color, religion, sex, sexual orientation, gender identity, national origin, source of payment or disability."
- b. An addition under rule 10A NCAC 13B .3302 (14), which states "A patient who does not speak English shall have access, when possible, to an interpreter," labeled as 10A NCAC 13B .3302 (15), which should read, " A patient who is Deaf or Hard of Hearing shall have access to effective communication accommodations when receiving medical and nursing services."

B. The Medical Care Commission should approve updates to North Carolina Administrative Code 10A NCAC 13B .3302

CHAPTER 5: POLICIES, PROCEDURES AND SYSTEM PRACTICES FOR LONG-TERM CARE FACILITIES**RECOMMENDATION 5.1:****Improve Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities**

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should coordinate, in consultation with appropriate health care facilities associations, the creation and implementation of a statewide audiology service program to increase the care of Deaf and Hard of Hearing patients in long-term care facilities. To effectively staff the program:

- A. DSDHH should submit a budget revision request to the North Carolina Office of State Budget and Management (OSBM) to create up to eight total new positions responsible for creating and implementing a statewide audiology service program for long-term care facilities. These positions should include one North Carolina program coordinator and up to seven regional specialists.
- B. DSDHH should develop job descriptions for the program coordinator and regional specialists. Statewide audiology service program coordinator responsibilities should include completing, and/or delegating to regional specialists, the following:
 1. Offer hearing screenings to all residents of long-term care facilities.
 2. Act as liaisons to long-term care settings around audiological concerns.
 3. Provide recommendations/consultation to these facilities about assistive technology, hearing aids, and communication access.
 4. Basic hearing aid care as deemed appropriate by the audiologist.
 5. Collaborate with private audiologists already working with residents.
 6. Serve as the lead for the long-term care facility capacities assessment (**see Recommendation 5.2**) for quality improvement purposes.
 7. Develop and/or locate free training and educational resources for long-term care facilities to use to train their supervisors and/or employees on compliance with communication access laws and cultural sensitivity best practices for delivering care to Deaf and Hard of Hearing individuals.
 8. Act as liaison to other organizations that provide training for adult care home providers such as the NC Assisted Living Association, NC Senior Living Association, and Area Agencies on Aging (Ombudsman Programs).

RECOMMENDATION 5.2:

Survey Long-Term Care Facilities on Communication Access Needs of Patients Who are Deaf or Hard of Hearing

The Division of Services for the Deaf and Hard of Hearing (DSDHH) should partner with long-term care facility professional associations to develop a voluntary and uniform self-assessment on how care is provided for Deaf and Hard of Hearing individuals and their family members to be used by long-term care facilities for quality improvement purposes. In order to do this:

- A. The DSDHH statewide audiology program coordinator should partner with Division of Health Services Regulation (DHSR) and long-term care facility association representatives to identify effective methods to disseminate the voluntary and uniform self-assessment form to facilities. The self-assessment should be designed for long-term care facilities for quality improvement purposes.
- B. Communication should also include information on ADA legal requirements and quality improvement resources, including the availability of technical assistance from DSDHH to help facilities better meet the communications needs of patients and their families.
- C. The DSDHH statewide audiology program coordinator, in conjunction with long-term care facility associations, should collect the results of this assessment and share them with the Coalition and the NC Council for the Deaf and Hard of Hearing.

RECOMMENDATION 5.3:

Update Procedures and Practices Pertaining to the Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities

The Division of Services for the Deaf and Hard of Hearing statewide audiology program coordinator should lead an assessment of:

- 1. Hearing assessment procedures for the initial resident assessments in long-term care facilities
- 2. Referral patterns for when a resident is identified as Deaf or Hard of Hearing and what type of periodic review of the resident is being performed
- 3. Deaf and Hard of Hearing-related regulatory citations in long-term care facilities by gathering data on previous violations committed and their outcomes and evaluating opportunities for educational programs in lieu of penalties when a violation occurs
- 4. Findings and recommendations to be presented to the NC Council for the Deaf and Hard of Hearing

RECOMMENDATION 5.4:

Educate Administrators and Staff in Long-Term Care Settings on Providing Appropriate Services and Care to Deaf and Hard of Hearing Residents

The Division of Services for the Deaf and Hard of Hearing, the Division of Health Services Regulation, and the Division of Aging and Adult Services should collaborate to identify and leverage opportunities to expand and/or strengthen training on communication access and cultural/behavioral sensitivity for direct care and administrative staff in long-term care settings.

RESPONSIBLE AGENCY/ORGANIZATION

RECOMMENDATIONS	RESPONSIBLE AGENCY/ORGANIZATION								
	North Carolina Department of Health and Human Services (Secretary's Office)	Division of Services for the Deaf and Hard of Hearing	The Coalition	Division of Health Services Regulation	Division of Aging and Adult Services	North Carolina Medicaid	Private Health Insurance Payers	Health Professional and Trade Organizations	Other
Recommendation 3.1: Convene a Coalition to Increase Communication Access in Health Care Settings for Deaf and Hard of Hearing Patients	X	X						X	Area Health Education Centers, Disability Rights North Carolina, Malpractice insurers
Recommendation 3.2: Develop Organizational Infrastructure to Coordinate DSDHH Resources and Partnerships		X							
Recommendation 3.3: Educate Health Care Providers on the Health Benefits of Timely Hearing Screenings		X	X					health care providers professional associations	
Recommendation 3.4: Develop Resources and Educate Deaf and Hard of Hearing Consumers about their Rights		X							Disability Rights North Carolina
Recommendation 4.1: Survey Health Care Providers on Methods of Meeting Communication Access Needs of Patients Who are Deaf or Hard of Hearing			X					NCHA, health care providers professional associations	
Recommendation 4.2: Survey Patients Who are Deaf or Hard of Hearing on Their Communication Access Needs		X	X						
Recommendation 4.3: Conduct Cost-Benefit Analysis of Insurance Coverage for Hearing Aids		X	X			X	X		
Recommendation 4.4: Pilot Distributing Personal Amplifiers in Medical Settings		X	X					NCHA	
Recommendation 4.5: Conduct Cost-Benefit Analysis of Publicly Funded Support Service Providers		X							
Recommendation 4.6: Include Disability and Access to Sign Language Interpretation in the Minimum Provision of Patient's Bill of Rights		X	X						Medical Care Commission
Recommendation 5.1: Improve Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities		X							
Recommendation 5.2: Survey Long-Term Care Facilities on Communication Access Needs of Patients Who are Deaf or Hard of Hearing		X		X				long-term care facility professional associations	
Recommendation 5.3: Update Procedures and Practices Pertaining to the Care of Deaf and Hard of Hearing Residents of Long-Term Care Facilities		X							
Recommendation 5.4: Educate Administrators and Staff in Long-Term Care Settings on Providing Appropriate Services and Care to Deaf and Hard of Hearing Residents			X	X	X				

DEVICE	DEFINITION
HEARING AID	A small electronic device that is worn in or behind the ear. It makes some sounds louder so that a person with hearing loss can listen, communicate, and participate more fully in daily activities. The hearing aid receives sound through a microphone, which converts the sound waves to electrical signals and sends them to an amplifier. The amplifier increases the power of the signals and then sends them to the ear through a speaker.
HEARING AID TELECOIL	The telecoil inside a hearing aid picks up the loop signal and then changes it into an electrical signal that is then processed inside of the hearing aid and eventually delivered to the listener’s ear as sound.
PERSONAL AMPLIFIER (I.E., POCKETALKER)	About the size of a cell phone, these devices increase sound levels and reduce background noise for a listener. Some have directional microphones that can be angled toward a speaker or other source of the sound.
PERSONAL FM SYSTEM (I.E., ROGER PEN)	A wireless microphone that is used in combination with hearing aids or cochlear implants, that helps individuals to hear and understand more speech among noise and over distance.
WIDE AREA LISTENING SYSTEM	A type of listening system that is often set up in auditoriums, conference rooms, dining halls, waiting areas or consultation rooms. These systems utilize a transmitter or a strategically placed hidden copper wire to transmit sound from a performance, presenter or program directly to multiple people with hearing loss. Receivers in the form of body worn devices with headphones/earbuds or hearing aids are the receptors of the sound.
HEARING LOOP (OR INDUCTION LOOP) SYSTEMS	A type of wide area listening system that uses electromagnetic energy to transmit sound. A hearing loop system involves four parts: 1) the sound source, such as a public address system, microphone, or home TV or telephone; 2) an amplifier; 3) a thin loop of wire that encircles a room or branches out beneath carpeting; 4) a receiver worn in the ears or as a headset.
RADIO FREQUENCY (FM) SYSTEMS	A type of wide area listening system that uses radio signals to transmit amplified sounds. They are often used by several people at once in auditorium-like settings. The presenter wears a small microphone connected to a transmitter and the person with hearing loss wears the receiver, which is tuned to a specific frequency or channel. The system can also be used 1:1 during medical provider-patient conversations.
INFRARED SYSTEM	A type of wide area listening system uses infrared light to transmit sound. A transmitter converts sound into a light signal and beams it to a receiver that is worn by a listener. The receiver decodes the infrared signal back to sound.

<p>REQUEST SPECIFIC ACCOMMODATIONS</p>	<ul style="list-style-type: none"> • Be specific about the type of accommodation needed • Make your request for a reasonable accommodation as early as possible • If there is a problem obtaining an accommodation, a written record of what occurred (people talked to and what happened) needs to be maintained to be used as proof if a complaint needs to be filed
<p>KNOW YOUR RIGHTS</p>	<ul style="list-style-type: none"> • Take time to learn your rights— websites of government agencies such as the U.S. Department of Justice, the Equal Employment Opportunity Commission, and other federal agencies provide a wealth of information on the legal rights of individuals with disabilities • If help is needed obtaining information, contact your state’s disability law center or other appropriate state entities • If information or consultation is needed about particular legal rights, contact the National Association of the Deaf Law and Advocacy Center • The National Association of the Deaf website has a host of information on federal disability and civil rights laws • Be aware that different laws apply to similar situations
<p>EDUCATE OTHERS</p>	<ul style="list-style-type: none"> • Do not assume that the places/individuals you are dealing with are familiar with the legal obligations or people who are deaf or hard of hearing • The National Association of the Deaf Law and Advocacy Center has many educational and informative legal documents that can be provided to explain why you need an accommodation
<p>KNOW WHO YOU ARE DEALING WITH</p>	<ul style="list-style-type: none"> • Know the nature of the place you are dealing with because the obligation to provide reasonable accommodations varies based on the nature of the place • Look into whether the place or organization designates a particular person or office to consider requests for reasonable accommodations, so you do not waste time debating with someone who does not have the authority to provide an accommodation • If reasonable accommodations are denied, advance to the next level of authority
<p>FOLLOW PROPER PROCEDURES</p>	<ul style="list-style-type: none"> • Follow any established procedures for requesting a reasonable accommodation or disputing the denial of a reasonable accommodation
<p>BE TACTFUL</p>	<ul style="list-style-type: none"> • The best self-advocates are courteous and tactful • Choose your battles wisely, educate, and persuade • Be consistent and confident when self-advocating • Compromise requires flexibility, so be willing to consider other forms of accommodations if your particular request cannot be granted
<p>COMPROMISE</p>	<ul style="list-style-type: none"> • You should not accept accommodations that do not work for you –compromise does not mean you should settle for less than you deserve • When you have done everything that is within your power, and there is nothing more you can do to obtain your rights to a reasonable accommodation, it may be time to file a complaint or seek legal representation