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 <u>must all</u> 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.[19] [o]

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 Heard 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

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[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 hearings 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

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[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/ncmcc/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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