ISSUE BRIEF

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NCIOM

A REPORT FROM THE NCIOM:

ACCESS TO HEALTH SERVICES FOR THE DEAF AND HARD OF HEARING

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, 1.1 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. 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.

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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A copy of the full Access to Health Services for the Deaf and Hard of Hearing report will be available on the North Carolina Institute of Medicine website: www.nciom.org

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