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.