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Health, Human Rights, and Structural Violence: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

Christine A. West
St. Catherine University, westmorgan@cox.net

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Health, Human Rights, and Structural Violence: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

By
Christine A. West

An Action Research Project Submitted in Partial Fulfillment of the

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Master of Arts in Interpreting Studies
and Communication Equity

St. Catherine University
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MAISCE Faculty Advisor: Gloria Nathanson AuD

Committee Members: Erica Alley, PhD, Catherine Bolten, PhD

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ABSTRACT

Deaf American Sign Language (ASL) users possess both human and legal rights to health. Yet, despite these rights, this linguistic minority group continues to experience challenges in accessing health care services. Using a structural violence framework, this study identifies the barriers to healthcare access of Deaf ASL users in one particular state - Rhode Island. More specifically, this study seeks to uncover the structural and social forces that constrain agency of Deaf ASL users in their attempts to access healthcare. Survey methodology is used to obtain both qualitative and quantitative data from 11 community stakeholder groups. Results show that Deaf ASL users in Rhode Island experience numerous structural barriers to accessing health care, including economic, civil, political, and cultural constraints. The structural disempowerment and reduced agency experienced by Deaf ASL users, perpetuated by the state's institutionalized social structures, prevents Deaf ASL users from getting their health needs met. Implications for embodied health risks that result from human needs deprivation, trauma, and social disadvantage are discussed. Recommendations are offered on actions toward transformative justice, which can lead to greater fulfillment of human needs and realization of the inherent dignity, worth, and human rights of Deaf ASL users.

Keywords: structural violence, Deaf ASL users, health care access, human rights

Chapter 1: Introduction

Background: Human Rights

The recognition that all humans are born with certain inalienable rights and fundamental freedoms is a fairly recent phenomenon. According to Flowers (1998), rights were not universally recognized prior to the 20th century and were typically accorded based on membership in a group- a religion, community, tribe, state, or nation, for example. All societies throughout history, regardless of oral or written tradition, have fashioned some system of conduct that has addressed the rights, responsibilities, duties, and welfare of its members. A few examples of this include the Inca and Aztec code of conduct, the Iroquois Constitution, the Bible, and the Hindu Vedas. Over time, these systems of conduct have taken the form of formalized documents that many regard as precursors to the human rights instruments that exist today. The Magna Carta, the French Declaration on the Rights of Man and Citizen, and the US Constitution and Bill of Rights are just a few examples that Flowers notes. While many of the principles expressed in these early documents became codified into law and policy, they still reflected the rights of a few but not all. Women, racial and ethnic minorities, individuals with disabilities, and other marginalized groups were not afforded the same rights, freedoms, and protections that the drafters of these documents enjoyed. Therefore, while these documents may be considered antecedents to present day human rights papers, they fell short of recognizing the universality of all human beings, regardless of age, sex, race, ethnicity, gender, religion, disability, or other defining characteristic (Flowers, 1998).

It wasn’t until the 1940’s that a formal and internationally shared and recognized set of principles articulating the basic human rights of every human being was created. In the aftermath of World War II, governments across the globe committed to establishing an international organization to promote peace, reduce conflict, and uphold the dignity and human rights of all individuals. In 1945, the United Nations (UN) Charter was drafted. Soon after, in 1948, the Universal Declaration of Human Rights (UDHR) was adopted by the UN. A watershed moment in the history of human rights, the UDHR claimed that “the inherent dignity of all members of the human family is the foundation of freedom, justice and peace in the world” (United Nations, 1948, preamble). Since its adoption, the UDHR has been translated into over 500 languages and serves as the exemplar from which numerous human rights treaties and agreements have emanated. It is also recognized as being instrumental to the development of many human rights laws (UN).

Proponents of the UDHR and the human rights resolutions and treaties that have followed it have argued that these documents are necessary to hold governments accountable for human rights violations (Roth, 2014). For if not, human rights abuses and incompetencies could run rampant. Therefore, these documents can be viewed as human rights “yardsticks” against which governments should measure themselves. Although the United States claims to be a champion of global human rights, historically there has been an aversion to ratifying international human rights documents or treaties. This is based, in part, on the presumption that human rights protections are already affirmed in existing domestic law. This attitude of complacency that U.S. citizens already have all of the protections they deserve, fails to recognize the ongoing struggle of women, children, racial and ethnic minorities, people with disabilities, and other oppressed groups. This attitude not only undermines the credibility of the United States as a defender of human rights, but “this superficial participation in the international human rights community reveals its priorities” (Wilken, 2017, para. 9).

Tripartite View of the UDHR: Interdependence, Interrelatedness, and Indivisibility

According to the UN, all rights articulated in the UDHR- political, civil, social, cultural, and economic- comprise an organic and unified whole, viewed in tripartite as interdependent, interrelated, and indivisible. They state:

> Human rights are universal and inalienable; indivisible; interdependent and interrelated…Inalienable because people's rights can never be taken away. Indivisible and interdependent because all rights – political, civil, social, cultural and economic – are equal in importance and none can be fully enjoyed without the others (United Nations Population Fund, 2005, para. 1).

As such, there is no distinction made between the civil and political rights and the social, cultural, and economic rights in the UDHR (UN Office of the High Commissioner, 2021). This has been reflected in the Vienna Declaration and Programme of Action in 1993. However, in the mid-1940's, attempts to implement measures and enforce rights articulated in the UDHR resulted in the adoption of two UN Covenants, separating civil and political rights from economic, social, and cultural rights (UN OHCHR, 2021). While the reasons for drafting separate Covenants at that time have been attributed to heightened Cold War tensions between the East and West and the narrow belief that economic, social, and cultural rights required more human and financial investment than civil and political rights, this separation "has since been abandoned and there has been a return to the original architecture of the Universal Declaration" (para. 1). The lack of formal recognition of the economic, social, and cultural rights of individuals by the United States, as evidenced by the ratification of the International Covenant on Civil and Political Rights (ICCPR) and not the International Covenant on Economic, Social, and Cultural Rights, shows that the U.S. does not fundamentally recognize the rights of individuals outside of what exists in U.S. law. "Our government has only partially and selectively embraced these rights, ignoring international obligations and widening the gap between the United States'...promise and its own current practice" (ACLU, n.d., para. 3). In recognition of this, discussion of human rights in this paper will be viewed holistically to align with the spirit, intention, and original design of the UDHR.

Human Right to Health

Article 25 of the UDHR articulates the fundamental right to health, which acknowledges at its core, the right to survive and the right to live free of preventable suffering. It proclaims that "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services" (United Nations, 1948, art. 25. para. 1). This proclamation implies that the human right to health extends beyond the provision of essential health services. It also encompasses determinants of health, such as nutritious food, safe housing, education and employment opportunities, and other social factors that contribute to health. Included as part of these determinants is language and literacy. In the United States, individuals who are non-fluent or non-native English users experience numerous barriers that impact access to healthcare services, health knowledge, proper medication use, utilization of preventative services, and communication with healthcare providers. These barriers result in adverse health outcomes (Office of Disease Prevention and Health Promotion, n.d.). Despite these inequities, those who are considered members of linguistic minority groups are still equally entitled to "the enjoyment of the highest attainable standard of health" (World Health Organization, 2017, para. 1) regardless of their English language proficiency. This recognition also has been reflected in the adoption of the UN General Assembly's Resolution 47/135, Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, which reaffirms that members of linguistic minority groups have a right to use their language “freely and without interference or any form of discrimination” (1992, art. 2, para. 1). Still, many linguistic minority communities across the United States, including immigrants, refugees, indigenous peoples, and racial and ethnic minorities continue to endure a long history of linguistic segregation and discrimination from healthcare systems. This has resulted in “serious health disparities and unfair differences in health outcomes” (Showstack, Santos, Feuerherm, Jacobson & Martinez, 2019, para. 1). One community in which healthcare access has been particularly challenging is Deaf American Sign Language users.

Deaf American Sign Language (ASL) Users

It is estimated that there are between 500,000 to 1 million Deaf ASL users in the United States (Mitchell, Young, Bachelda, Karchmer, 2006). Deaf ASL users identify as members of a distinct cultural and linguistic group bound together by shared language, norms, values, histories, and experiences that come from navigating the world through visual means. For these individuals, deafness is not measured against a standard of “normalcy”; it is not viewed as a medical or audiological condition. Rather, being Deaf is a cultural identity, a source of pride, and another manifestation of the biocultural diversity and variation of humankind. This view that Deaf is a distinct way of being, which has “cognitive, creative, and cultural” benefits, is reflected in the term *Deaf Gain* (Bauman & Murray, 2014, p. xxiii*).* This term serves as a counter-frame to the more ubiquitous language of *hearing loss,* which may view Deaf people as “lacking” through a hearing normative lens.

While Deaf ASL users share a common language, culture, and experiences of oppression akin to ethnic groups (Ladd & Lane, 2013; Lane, 2005; Lane, Pillard, & Hedberg, 2011), the law defines Deaf people in terms of disability. This is evident in federal civil rights legislation such as Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and Section 1557 of the Patient Protection and Affordable Care Act of 2010, which all apply to healthcare access and prohibit discrimination based on disability. Though some Deaf ASL users may resist the stigmatized label of disability, they recognize that their right to obtain a sign language interpreter or other auxiliary aid or service for meaningful access, rests on the acceptance of this legal designation.

In addition to legal rights documents, human rights papers also include Deaf individuals under the category of disability. This is evident in the Convention on the Rights of Persons with Disabilities (CRPD), an international human rights treaty. Adopted by the United Nations General Assembly in 2006, the purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (art. 1, para. 1). Like its parent document, the UDHR, the CRPD elucidates a number of human rights that are inherent to people with disabilities. In particular, Article 25 states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (para. 1). Therefore, whether viewed from a sociocultural lens as a linguistic minority group or from a disability justice lens as members of a disability group, it is indisputable that Deaf ASL users possess inalienable rights to health. Yet, despite explication of the human rights and the legal rights of Deaf individuals thus far, Deaf ASL users continue to experience challenges in accessing healthcare services.

Statement of the Problem

With the recent COVID-19 pandemic, minority communities have gained increased attention from medical providers, mental and behavioral health clinicians, academics, policymakers, and public health officials. The disproportionate impact of COVID-19 and documented health problems within minority communities have brought to light the important role that social determinants of health play in these health inequities. One community which merits attention is Deaf American Sign Language Users. Due to barriers in communication, this linguistic and cultural minority group has been historically marginalized by the medical community, excluded from health education opportunities (both incidental and directed), understudied by health researchers, underserved by medical providers, and under-represented in public health professions (McKee, Winters, Sen, Zazove, & Fiscella, 2015). Deaf sign language users are also “considered to be the non-English speaking minority group at greatest risk for miscommunication with their health providers” (p. 5).

Despite legal mandates for reasonable accommodations and standards aimed to support the cultural and linguistic needs of all patients (Joint Commission, n.d.; U.S. Department of Health and Human Services, n.d.) access to healthcare remains problematic for many Deaf ASL users. This is due, in part, to the lack of ASL language concordant providers, sign language interpreter shortages, providers’ lack of awareness of legal obligations to provide effective communication, and the negligence of healthcare organizations to develop and implement policies relating to language access and cultural competency (McKee et al, 2015). These systems failures are exacerbated by a long history of distrust of medical providers by Deaf ASL users, who have been subjected to medical experimentation and eugenics practices by doctors, scientists, and others seeking to eradicate deafness throughout history (Biesold, 1999; Burke, 2022; Branson & Miller, 2002; Greenwald, 2006; 2009; Lane, 1992; Proctor, 2002; Renwand, 2012; Ryan, 2002). This confluence of factors, among others, has resulted in marked health disparities amongst members of this community. Increased risk of cardiovascular disease, cancer, adverse pregnancy, fetal, and neonatal outcomes, and mental health conditions, include some of the health disparities noted in the research (Smith, Kushalnagar & Hauser 2015; Sacks, Nakaji, Harry, Oen, Malcarne & Sadler, 2013; Mitra, Akobirshoev, McKee & Iezzoni, 2016; Kushalnagar, Reesman, Holcomb & Ryan 2019). As national data indicates that racial, ethnic, sexual, and gender minority groups experience poorer health outcomes than the general population, Deaf ASL users with additional intersecting identities may be at even greater risk for health disparities than their Deaf, white, straight, cis-gendered counterparts (Mead, Cartwright-Smith, Jones, Ramos, Woods & Siegel, 2008; CDC, 2011; Lefevor, Boyd-Rogers, Sprague & Janis 2019; Perrodin-Njoku, Corbett, Moges-Riedel, Simms & Kushalnagar, 2022; Sanfacon, Leffers, Miller, Stabbe, DeWindt, Wagner & Kushalnagar, 2020).

To begin to understand the nature and extent of suffering experienced by this community and the barriers that prevent access to healthcare, a “geographically broad and historically deep” (Farmer, 2005, p. 42) analysis must be considered. This requires looking beyond identification of healthcare access barriers through narrow one-dimensional analyses. Rather, it requires an “honest assessment of the multilevel interconnected inequalities” (Ryan, 2008, p. 150) that lay hidden in our everyday systems and structures. These inequalities pose constraints on individual agency, assaults on human dignity, and ultimately lead to illness and disease. This necessitates invoking a framework to better understand the pathogenic effects of social and structural inequalities. Therefore, this research seeks to fill a critical gap in academic scholarship by exploring healthcare access barriers of Deaf ASL users from a lens of structural violence.

Structural violence refers to the “multiple ways in which social, economic, and political systems expose particular populations to risks and vulnerabilities leading to increased morbidity and mortality” (Center for Health Equity Research Chicago, 2020, para. 1). The term "structural violence" was first coined by Johan Galtung, a Norwegian sociologist, who introduced this concept in his 1969 article, "Violence, Peace, and Peace Research." However, it is the physician and medical anthropologist, Paul Farmer, who is most widely recognized as having applied this concept to health care. Farmer, Nizeye, Stulac & Kehavjee (2006) write:

> The term "structural violence" is one way of describing social arrangements that put individuals and populations in harm's way. The arrangements are *structural* because they are embedded in the political and economic organization of our social world; they are *violent* because they cause injury to people...neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency (para. 5).

Hence, Farmer's concept of structural violence brings to light the forms of suffering and injustice that are deeply embedded in the patterns, habits, social relations, institutional practices, and policies of our world. It provides a lens for examining how social institutions and organizations cause disproportionate harm to particular groups and communities, preventing them from realizing their potential life expectancy. Moreover, Farmer emphasizes that structural violence impacts quality of life and prevents individuals from achieving their full potential as human beings. Hence, the concept of structural violence provides a useful frame for identifying structural drivers of inequity and devising ways to mitigate harm.

Research Questions

Through an action research approach, this study investigates the healthcare access barriers of Deaf ASL users in one particular state - Rhode Island. More specifically, this study seeks to uncover the subtle, seemingly invisible, structural and social forces that constrain individual agency of Deaf sign language users in their attempts to access healthcare. By employing a structural violence framework to identify healthcare access barriers in this community, strategies can be proposed that address the structural determinants of health inequities, the unequal distribution of power and resources, and the role of state government and community stakeholders in advancing health equity for all. This study also fills a critical research gap by examining healthcare access barriers of this community with a human rights and justice orientation.

Researcher Positionality and Impetus of the Study

Every researcher brings certain beliefs, philosophical assumptions, and worldviews to a study, which reflects their epistemological, ontological, and axiological positioning. Creswell (2003) points out that these assumptions determine what knowledge claims are made by the researcher, including their theoretical perspectives, their strategies of inquiry, and their methods of data collection and analysis. Therefore, to best understand how this study was conceived and the methods used to carry out the investigation, it is important to first acknowledge the history and positionality of the researcher. Adding the concept of positionality "directly incorporates ideas of power and privilege and seeks to describe researcher identity in terms of an insider-outsider perspective, based on the researchers' relationship to the specific research setting and community" (Muhammad, Wallerstein, Sussman, Avila, Belone & Duran, 2015, p. 4).

To start, I am a hearing, cis-gender, straight, able-bodied, and sighted individual. I am also a biracial (Asian/White) woman, daughter of an immigrant, former child language broker, first-generation American, and first-generation college graduate. My worldviews have been shaped by both privilege and oppression, as a person who embodies intersectional identities of race, class, and gender.

Though I do not have Deaf family members, navigating linguistic barriers and confronting institutions of power have been a part of my life growing up. My mother was born and raised in Taiwan and immigrated to the United States when she was 18 years old. Her family had limited financial resources, and consequently, my mother had only an 8th grade education when she arrived in the United States. She faced many challenges in learning English as a second language. As a result, my siblings and I would often function as child language brokers, like many children with immigrant parents do. Whether it was reading mail, explaining letters from school, filling out forms and applications, or ensuring that information was understood at a doctor's appointment, brokering language and making information accessible were important to the survival of the family unit. These early personal experiences were profound for me. They instilled in me a deep appreciation for multilingual spaces and a desire to dismantle the linguistic barriers that prevent *any* individual, regardless of language, from getting their basic human needs met.

In addition, I am a Rhode Islander, born and raised. I have chosen to situate my research within the 37-mile wide and 48-mile long area that comprises the nation's smallest state. It is here that I have worked as a sign language interpreter for more than 20 years. In my professional role, I have worked in a wide variety of community settings- medical, legal, educational, governmental, and more. Over the course of my career, I have been privy to intimate moments in Deaf people's lives. None are more humbling than interpreting for a Deaf couple and the birth of their baby; interpreting for a Deaf patient receiving a terminal illness diagnosis; or interpreting the funeral of a Deaf person's loved one. Some would say that being privy to these private and vulnerable moments in others' lives is just part and parcel of the job of a language interpreter. For me, these everyday experiences of living among the "borderlands" (Anzaldua, 1987; Hunt, 2015; Kreher, 2013), moving between hearing and Deaf worlds, have led to deep connections and lifelong relationships with Deaf community members. My continued engagement in these spaces is not simply reduced to an occupation; it reflects my intentional desire to know, understand, and be with Deaf people.

This perspective as an interpreter has also allowed me to witness the myriad struggles and injustices that Deaf people face in trying to access communication to meet basic human needs. These battles reside in courtrooms, in classrooms, in businesses, and in numerous other venues. However, they are pronounced in healthcare settings, where Deaf people are often denied interpreting services or are provided with accommodations that do not allow them to communicate and be understood effectively.

This reality has been made even more evident in my most recent professional role. In January of 2020, I began working as part of a project team addressing healthcare system transformation under the Rhode Island Commission on the Deaf and Hard of Hearing. In this state agency position, I have worked on a grant-funded project to improve access to healthcare services with Deaf and hard of hearing individuals in Rhode Island. This has included conducting health surveillance activities, developing workforce training for the healthcare provider community, and establishing the state's first interpreter training program with a focus on medical, mental health, and behavioral healthcare interpreting. In working on this project over the past two years, it has become clear that for true healthcare system transformation to be realized, a deeper dive into the structural inequalities that inhibit access to healthcare must be endeavored. Increasing interpreter capacity and training of medical providers alone will not suffice in overcoming problems deeply rooted in political, social, and economic systems of power that reside insidiously within social institutions that routinely neglect Deaf people. More than that, it requires “looking for differences within large-scale social structures – differences of power, wealth, privilege and health that are unjust and unacceptable” and looking for “connections between what might be falsely perceived as separate and distinct social worlds” (Taylor, 2021, para. 11). These “ways of seeing” go beyond the expectations of project goals and grant deliverables. Rather, they require us to critically assess how public health structures and associated systems both include and exclude lives. They implore us to hold institutions accountable for how they utilize their power to decide who receives healthcare, how, and when. This can only be accomplished by critically inspecting “the routines and recipes that have become accepted and commonplace ways of carrying out our professional, organizational, and institutional functions” (Stringer & Aragon, 2021, p. 69). As such, it is from this position as a practitioner-researcher that I conduct this investigation, using my own voice to raise critical consciousness about issues of health equity and confronting notions of power in ways that I have not been able to previously interrogate in my other roles. It is through these efforts that I aim to build upon the work already carried out at the Rhode Island Commission on the Deaf and Hard of Hearing.

Chapter 2: Review of the Literature

To explore this research topic holistically, this literature review draws upon studies from the following disciplines: public health, interpretation and translation, civil rights law, medical ethics, disability and deaf studies, technology, and more. This transdisciplinary review will cover in order the following topics: health disparities and healthcare access barriers of Deaf ASL users, and legal mandates for effective communication in healthcare settings.

Health Disparities of Deaf ASL Users

Despite the fact that Deaf ASL users have been a historically understudied group, there is evidence of health disparities noted in the literature. For purposes of this paper, health disparities are classified into seven categories relating to: health knowledge, screening uptake and adherence, childhood communication experiences, pregnancy, fetal, and neonatal outcomes, mental health, interpersonal violence, and suicide, food insecurity, and COVID-19. Many of the studies included in this section have been conducted in locations where there is a concentrated number of Deaf people. Those locations include Rochester, New York, Chicago, Illinois, and Washington, D.C. Of importance to note also, attempts were made to isolate studies in which data reflected only Deaf ASL users or data was disaggregated from a larger sample of both Deaf and hard of hearing participants. In instances where that was not possible, studies including Deaf, hard of hearing, or those who identify as having hearing loss or a disability were included. Because of this, some studies use capital "D" for "Deaf" to denote Deaf individuals who identify as a linguistic and cultural group; others use small "d" for "deaf" to include those who may or may not identify with the linguistic and cultural marker. Efforts were made to adhere to nomenclature that authors used in their studies.

Health Knowledge

Cardiovascular Disease. Linguistic and informational marginalization and deprivation contribute to gaps in health information and knowledge for Deaf ASL users, which lead to increased risk of health conditions. Margellos-Anast, Estarziau & Kaufman (2006) conducted a study with 203 Deaf adults in Chicago to assess knowledge of cardiovascular disease (CVD) using a comprehensive survey and face-to-face interviews in American Sign Language. Questions included knowledge of heart attack and stroke symptoms, risk factors, and emergency response. Results indicated that 40% of participants were unable to list any symptoms of a heart attack; 60% were unable to list symptoms of a stroke. Furthermore, only 61% reported they would contact 911 in response to acute CVD symptoms. The authors concluded that Deaf ASL users' knowledge of CVD is lower than that of the general population and stressed the importance of developing linguistically accessible educational programs and materials for Deaf ASL users.

Likewise, McKee, Schlehofer, Cuculick, Starr, Smith & Chin (2011) investigated risk perceptions of cardiovascular disease among Deaf ASL users. Four focus groups were conducted in ASL with 22 Deaf participants in Rochester, New York. The majority of participant responses focused on themes related to inaccessible healthcare information, financial constraints, and stress. The authors pointed out that CVD knowledge among participants was inconsistent or misinformed. The importance of providers taking extra measures to ensure Deaf patients understand cardiovascular risk factors was highlighted, along with promotion of accessible health programming.

In 2014, McKee, McKee, Winters, Sutter, & Pearson set out to examine whether educational attainment and/or annual household income were inversely associated with cardiovascular risk in Deaf ASL users. Because educational attainment and annual household income have been associated with increased rates of CVD and worse cardiovascular outcomes in the general population, the authors were interested in seeing whether these associations were true for Deaf ASL users. Using responses from 302 Deaf participants who completed a survey adapted and translated from the Behavioral Risk Factor Surveillance System (BRFSS), the authors concluded that low educational attainment was associated with higher likelihood of reported cardiovascular equivalents, consistent with the general population. However, higher income did not provide any cardiovascular protective effect for Deaf ASL users, which is inconsistent with results reported in the general population.

In addition to adults, Deaf adolescents have also been found to have inconsistent cardiovascular health knowledge. Smith, Kushalnagar & Hauser (2015), conducted a phenomenological study with 20 Deaf ASL-using adolescents in Rochester, New York. The authors sought to capture the lived experiences of deaf adolescents in their quest to access and learn cardiovascular health information. Family, health education teachers, healthcare providers, printed materials and informal sources were identified as people and places to obtain information. Despite demonstrating characteristics that might indicate stronger health literacy, deaf adolescents in the sample described difficulties accessing health information and displayed inconsistent cardiovascular knowledge related particularly to heart attack, stroke, and cholesterol. Consistent with the findings from the Margellos-Anast study (2006) with adults, the authors demonstrated that challenges in accessing health information contributes to inconsistent cardiovascular health knowledge and increases risk. Also, when compared to similarly situated hearing adolescents, Deaf ASL-using adolescents in the sample appeared to have significantly weaker cardiovascular knowledge.

Cancer. Similarly, health disparities due to gaps in knowledge have been found with Deaf ASL users and cancer. Sacks, Nakaji, Harry, Oen, Malcarne & Sadler (2013) created an experimental study which investigated the impact of an educational video on general and testicular cancer knowledge for Deaf and hearing males. The authors used pre-tests to assess baseline knowledge and post- tests to assess knowledge gains after viewing the video. Results showed that Deaf men had lower pre-test general, testicular, and total cancer knowledge compared to hearing men. Knowledge of these cancer domains increased for both Deaf and hearing men after viewing the video, however gains were not found to be equivalent across groups. Hearing men demonstrated greater mean change in knowledge for both testicular and total cancer domains. Finally, Deaf men's post-test scores equaled or exceeded hearing men's pre-test scores after viewing the video. The authors concluded that educational videos like the one used in the study can be effective in improving general and testicular cancer knowledge.

In addition, Spellun, Moreland & Kushalnagar (2018), used secondary data taken from the Health Information National Trends (HINT) survey in ASL administered between the years 2015 and 2018 to examine knowledge of Human Papillomavirus (HPV), HPV vaccine, and HPV-related cancer knowledge. Of the 235 deaf and 115 hearing adults in the sample, results showed that 58% of deaf participants reported knowledge of HPV compared with 84% of hearing participants. The authors concluded that young adults who are deaf ASL users are less likely to know about HPV, virus-related cancer risk, and preventive vaccination.

Screening Adherence and Uptake

Disparities could also be found in screening uptake and adherence for Deaf ASL users. Kushalnagar, Engelman & Simons (2019) used data taken from the HINT survey in ASL from 2017-2018 to analyze adherence to Pap and mammogram screenings. The authors reported that previous data has shown that women with disabilities experience cancer-related health disparities, including decreased likelihood to undergo Pap testing, mammograms, or other screenings to detect cancer. To assess whether these disparities persisted for Deaf women, the investigators compared Pap and mammogram screening adherence of both Deaf women and hearing women. In addition, they assessed whether any racial or ethnic disparities for adherence were found within the sample of Deaf women. Results indicated that for age-eligible Deaf women, disparities were evident in cervical cancer screening (Pap) but not breast cancer screening (mammogram). The sample of Deaf women did not differ by race or ethnicity for Pap screening adherence. Slight differences by race and ethnicity were noted for adherence to mammogram screenings, though the authors suggested using caution in interpreting results due to small sample size. Overall, the authors argued for more targeted programs that promote adherence to cervical cancer screening.

Furthermore, the literature has also shown disparities in HIV screening for Deaf adults. Kushalnagar and Argenyi (2019) investigated both the likelihood of HIV screening uptake among deaf adults and the relationship between social media and HIV screening uptake in deaf ASL users. Using information from the HINT survey in ASL from years 2015-2018, the authors reported that screenings of deaf ASL users fell below universal screening targets with differences among Caucasian, heterosexual, female, or older deaf adults. The authors emphasized that screening outreach attempts may overlook this linguistic minority group due to inaccessibility of technology and language. Despite this finding, social media was discussed as a tool to assist with HIV outreach and screening.

Childhood Communication Experiences

Adverse childhood communication experiences of Deaf ASL users have also been linked to health disparities. A study by Kushalnagar, Moreland, Simons & Holcomb (2018) investigated the link between childhood communication barriers and risk for food insecurity as an adult. Over 600 deaf signing adults across the U.S., ages 18-95 years old, participated in an online survey in ASL. The survey incorporated a screening question from the U.S. Household Food Security Survey Module with additional questions about depression diagnosis and childhood communication experiences. Results showed that those who indicated that they understood little to none of what caregivers communicated during their early years experienced marked risk of food insecurity compared to those who reported understanding some or all of what their caregivers said. The authors concluded with a call to action to stakeholders advocating for change to deaf children's access to communication.

In 2020, Kushalnagar, Ryan, Paludneviciene, Spellun, & Gulati explored how poorer direct child-caregiver communication and lack of access to incidental family communication were associated with acquiring specific medical conditions and mental health disorders. Using patient-reported outcome surveys in both ASL and English, 1,524 deaf and hard of hearing adults comprised the sample. The authors determined that poorer direct child-caregiver communication was significantly associated with increased risk of diagnosis for diabetes, hypertension, and heart disease. Poor indirect family communication increased risks for lung diseases, depression, and anxiety disorders. The authors recommended using a screening measure in pediatric environments to address communication neglect in deaf and hard of hearing patients.

Pregnancy, Fetal, and Neonatal Outcomes

When it comes to women's health, disparities have also been documented in the literature. Mitra, Akobirshoev, McKee, & Iezzoni (2016) conducted a population-based study about pregnancy experiences and outcomes for women with hearing loss. The study used the 2008-2011 Nationwide Inpatient Sample of the Healthcare Cost and Utilization Project to compare birth outcomes (preterm birth and low birth weight) of women with and without hearing loss. Results indicated that women with hearing loss were more likely to have infants with preterm birth and low birth weight. The authors contend that understanding the causes of these disparities and examining the perinatal experiences of women with hearing loss is imperative to improving pregnancy outcomes for this group.

The above findings were supported in a study by Mitra, McKee, Akobirshoev, Valentine, Ritter, Zhang, McKee & Iezzoni in 2020. Using the Massachusetts Pregnancy to Early Life Longitudinal data system, researchers conducted a retrospective study of deaf and hard of hearing (DHH) women to compare pregnancy complications, birth characteristics, and neonatal outcomes with non-DHH women. Results showed that DHH women had increased risk of several chronic medical conditions and pregnancy complications, including pre-existing diabetes, gestational diabetes, pre-eclampsia and eclampsia, and placental abruption. Also, deliveries were associated with adverse birth outcomes, including preterm birth, low birth weight or very low weight, low 1-minute Apgar score or low 5-minute Apgar score. The authors concluded that DHH women are at "a heightened risk for chronic conditions, pregnancy-related complications, and adverse birth outcomes…" (p. 1).

Addressing a broader set of pregnancy and neonatal outcomes, including stillbirth, fetal distress, and size for gestational age, Mitra, McKee, Akobirshoev, Ritter, and Valentine (2021), compared pregnancy complications and neonatal outcomes between deliveries to DHH and non-DHH women. Conducting a retrospective analysis using the 2007–2016 Healthcare Cost and Utilization Project National Inpatient Sample, the researchers confirmed previous study findings and noted additional adverse pregnancy outcomes and chronic medical conditions of DHH women. Outcomes and conditions included: preexisting diabetes, gestational diabetes, chronic hypertension, preeclampsia and eclampsia, placenta previa, placental abruption, labor induction, chorioamnionitis, cesarean delivery, premature rupture of membranes, antepartum hemorrhage, and postpartum hemorrhage. The authors concluded that more awareness is needed within obstetrics and primary care specialties in light of these increased risks for DHH women.

Mental Health, Interpersonal Violence, and Suicide

There has also been evidence of health disparities relating to mental health conditions, interpersonal violence, and suicide among Deaf individuals noted in the literature. Kushalnagar, Reesman, Holcomb, and Ryan (2019) examined the prevalence of self-reported depression and anxiety disorder diagnoses in a sample of 1,704 deaf adults. Data was collected through the HINT Survey in ASL and compared with the self-reported data on depression and anxiety diagnosis taken from the English version of the HINT survey for the general population. Results indicated that rates of diagnosed depression and anxiety disorder were significantly higher and occurred at an earlier age for deaf adults compared to hearing adults. The authors concluded by stressing the importance of proper diagnosis and treatment, and linguistically accessible mental health services.

Considering the intersectional experiences of Deaf ASL users, Kushalnagar & Miller (2019) conducted a study comparing chronic health and mental health conditions of mid-to older deaf LGBTQ adults (45 years or older) to mid-to-older non-deaf LGBTQ adults. Using data from the HINT survey in ASL from 2015 to 2019, researchers noted that deaf LGBTQ participants "reported significantly higher proportions of chronic lung disease/asthma/emphysema/chronic bronchitis, depression/anxiety, and personal cancer history compared with deaf non-LGBTQ participants" (p. 544). The authors noted that these results are consistent with health disparities noted in the general LGBTQ population and concluded by emphasizing the need for culturally and linguistically competent care using an intersectional framework for deaf LGBTQ individuals.

Likewise, for the transgender community, Sanfacon, Leffers, Miller, Stabbe, DeWindt, Wagner, and Kushalnagar (2020) conducted the first U.S.-based descriptive study to identify risks of medical conditions, including depression and anxiety, among Deaf transgender adults.

Using self-reported data from 74 Deaf transgender adults, results indicated that lifetime prevalence for medical conditions in the Deaf transgender sample were: “48.6% for depression/anxiety disorders, 28.8% for hypertension, 20.3% for lung conditions, 16.2% for arthritis/rheumatism, 12.3% for diabetes, 7.0% for cirrhosis/liver, kidney problems, 5.5% for heart conditions, and 2.7% for cancer” (para. 3). Results also showed that a Deaf person’s risk for being diagnosed with depression or anxiety increased by 80% if identifying as non binary compared to identifying as a binary gender. Risk for developing physical and mental health conditions amongst Deaf non binary individuals was discussed.

In addition, health disparities have been noted with interpersonal violence exposure, including intimate partner violence (IPV) and violence myth acceptance. Mason (2010) conducted a study with 226 deaf and hard of hearing Gallaudet University students to assess knowledge and experiences of intimate partner violence (IPV). Results indicated that students knew a great deal about IPV with 16.2% of respondents reporting currently being in an abusive relationship and 26.78% of respondents reporting having been in an abusive relationship previously. Eleven percent of participants who responded to questions about current and past relationships indicated physical abuse by current partners.

Similarly, a study by Anderson and Leigh (2011) was conducted to determine the prevalence and nature of IPV victimization among a sample of 100 Deaf or hard of hearing female college students at Gallaudet University. Using online questionnaires in English, participants were asked to respond to questions about demographics, physical assault, psychological aggression, negotiation, physical injury, and sexual coercion. Results indicated that Deaf female undergraduates in the sample were two times as likely to have experienced victimization in the past year when compared to hearing female undergraduates. The authors concluded by stressing the importance of tailored intervention programs to decrease violence in the Deaf community.

Likewise, Anderson & Pezzarossi (2012) investigated experiences of violence of 97 Deaf and hard of hearing female undergraduate students and strategies for labeling partner violence. Using written English questionnaires to determine prevalence of violent behaviors experienced by participants and strategies and scripts used to label partner violence, the investigators found that 87.5% of the sample reported experiencing psychological aggression, 39.6% reported physical assault, 19.6% reported injury, and 56.7% reported sexual coercion. Furthermore, 50% of the sample chose not to label experiences of psychological aggression, physical assault, and sexual coercion as abuse, "even when these experiences were severe expressions of violence" (p. 282).

In 2012, Schild and Dalenberg gathered data from 79 deaf adults who responded to ASL-translated trauma-related questionnaires, scales, inventories, and checklists to determine prevalence, symptom manifestation, and response characteristics of trauma experienced by deaf adults. Results showed that 21% of men and 38% of women experienced sexual assault and an additional 38% of men and 42% of women had "other unwanted sexual experiences" (p. 123). Using these two categories, the authors reported that 44% of men and 53% of women in the sample reported sexual abuse of some kind.

In 2014, a study by Pollard, Sutter, and Cerulli investigated lifetime and past year experiences of intimate partner violence in two samples of community-dwelling Deaf ASL-using adults in the Rochester, New York area using an online ASL survey. Results were compared to BRFSS data collected for a local, random telephone survey. Results showed that ASL-using Deaf adults experienced higher rates of IPV compared to the general population, with emotional abuse as the most frequently reported form of IPV. The authors also reported that results suggested sexual violence is much more frequently experienced by Deaf individuals. The importance of screenings and assessments for IPV were highlighted in the conclusion.

Additional studies on interpersonal violence have been conducted relating to experiences and perceptions of victimization among Deaf individuals from countries outside the U.S. (Admire & Ramirez, 2021); intimate partner violence victimization in hearing-Deaf and Deaf-Deaf relationships (Anderson & Kobek Pezzarossi, 2014); experiences and resource needs of Deaf women in an IPV program (Ballan, Freyer, Powledge, & Marti, 2017); experiences of crime victims with disabilities and barriers to reporting crime (Child, Oschwald, Curry, Hughes, and Powers, 2011); likelihood of Deaf participants to endorse myths about relationships and sexual violence compared to hearing individuals (Day, Cappetta, & Anderson, 2019); IPV perpetration among DHH individuals (Mastrocinque, Cerulli, Thew, Chin, & Pollard, 2022) Deaf IPV experiences and characteristics of IPV perpetrators with ASL users (Mastrocinque, Thew, Cerulli, Raimondi, Pollard, & Chin, 2017); and sexual assault experienced by Deaf female undergraduates (Smith & Pick, 2015).

Lastly, elevated risk of suicidal-related behavior or ideation has been noted in the literature (Embree, Kinzeler, Fraker, Castle, & Wilson, 2017; O'Hearn & Samar, 2009; Turner, Windfuhr, & Kapur, 2007). In 2011, Barnett, Klein, Pollard, Somar, Schlehofer, Starr, Sutter, Yang, & Pearson conducted a study with 339 Deaf adults in the Rochester, New York area. An ASL accessible health survey was used to estimate the health status and risk of Deaf individuals. Results were compared with data from the local general population. Results showed that past-year suicide attempts in the sample were higher than reported in previous surveillance activities and the authors noted that results confirmed findings of previous studies associating suicide and deafness (Turner et al, 2007). Of importance to mention, prevalence of obesity and intimate partner violence were also indicated in the sample.

In 2017, Embree, Kinzeler, Fraker, & Castle undertook a study to evaluate the relationship between age of language acquisition and suicidal behavior in deaf individuals. In addition, the investigators conducted a second analysis of data collected with 107 deaf adults involved in Substance Use Disorder (SUD) treatment. To evaluate past suicidal ideation and past suicide attempts in the sample of Deaf individuals diagnosed with SUD, the investigators used information gleaned from Government Performance and Results Act (GPRA) instruments and from information gathered during intake at a grant-funded SUD program for deaf individuals in the midwestern region of the U.S. Results indicated that 42% of participants reported having attempted suicide in the past; 50.5% reported past suicidal ideation. The authors concluded that the lifetime prevalence of suicide attempts increases with mental illness and delay of language acquisition for deaf populations.

In 2021, Park, Lee, and McKee explored the association between hearing loss and suicidal ideation in middle-aged and older adults. Using the National Survey on Drug Use and Health from 2015-2018, investigators evaluated responses to a question related to suicidal ideation from those in the sample who indicated they were either deaf or had serious difficulty hearing. The authors pointed out that hearing loss was positively associated with suicidal ideation in the past year for both middle-aged and older adult groups. In addition, the authors stated that compared to those without hearing loss, middle-aged and older adults with hearing loss experience significant health disparities including higher prevalence of chronic diseases, depression, substance use, and suicidal ideation.

In addition to middle-aged and older adults, suicidal behaviors were also investigated among Deaf and hard of hearing college students. In 2020, Fox, James, and Barnett examined the prevalence of suicide ideation and attempts, along with help-seeking attitudes among DHH college students. Using the ACHA-NCHA-IIb survey from 2011-2015, researchers found that DHH college students were more likely to have considered suicide or attempted suicide in their lifetime than hearing college students. The authors also added that in terms of help-seeking behaviors, no differences were noted between DHH and hearing groups.

Food Insecurity and COVID-19

Finally, a review of the literature points to health disparities relating to food insecurity and COVID-19. In 2019, Engelman and Kushalnagar examined the relationships between food insecurity, chronic diseases, and quality of life of 630 Deaf ASL-using adults, aged 18-89 years old. Using measures of the USDA Food Security Module, self-reported diagnoses of chronic diseases, and QoL, the authors found that 22% reported confronting food insecurity, (11% low food security and 11.4% very low food security) which impacted quality of life. The researchers noted that food insecurity was not significantly associated with the presence of chronic diseases, however.

Also, considering increased concerns of food insecurity during COVID-19, Engleman, Paludneviciene, Wagner, Jacobs, & Kushalnagar (2020) collected survey data on Deaf and hard-of-hearing individuals at higher risk for food insecurity and loneliness due to the pandemic. Using an online survey of 537 Deaf and hard of hearing adults, results showed that 42% of respondents experienced a high level of food worry. In addition, concerns about contracting COVID-19 and social isolation and loneliness were noted, especially among those respondents who identified as younger and without a college degree. The authors advocated that additional services be provided so that DHH individuals do not experience additional hardship during the COVID-19 crisis.

Lastly, Moreland, Paludneviciene, Park, McKee, & Kushalnagar (2021) used a national online bilingual ASL/English survey to explore deaf and hard of hearing adults' preferred sources of information for COVID-19 and their perceptions about contracting severe illness from COVID-19. A sample of 474 deaf and hard of hearing adults living in the United States was utilized. The authors noted that potential groups within their sample were at higher risk for underestimating potential health consequences of COVID-19. In addition, the authors stressed that DHH individuals are at a disadvantage when receiving information about COVID-19. Development and deployment of information in both ASL and English across multiple streams was emphasized, especially those that are internet-based.

Healthcare Access Barriers of Deaf ASL Users

The healthcare access barriers experienced by Deaf ASL users are numerous and complex. For purposes of this paper, barriers will be classified into two main categories: linguistic and cultural marginalization; and informational and educational deprivation and marginalization.

Part I. Linguistic and Cultural Marginalization

As American Sign Language and English are two different languages, Deaf ASL users report experiencing language and communication barriers in healthcare settings. The dearth of ASL language concordant providers, a shortage of medically-trained qualified and available sign language interpreters, and the lack of healthcare provider knowledge about Deaf people contribute to the language and cultural divide between healthcare systems and the Deaf community. These factors, combined with "a monolingual bias in public health" (Showstack, 2021, p. 2), puts Deaf ASL users at a severe disadvantage compared to their hearing English-speaking counterparts. In addition to experiencing health disparities as a result of limited access to care, Deaf individuals may also encounter systemic "othering" because of their language and cultural differences. This has implications for how they are socially situated within healthcare contexts. Espinoza and Derrington (2021) state:

> Patients…experience both *distributive injustice*—poor health outcomes as a result of decreased access to care—and *relational injustice*, which involves devaluation of identities. Patients who do not speak English might be seen by some as outsiders or as "other," which makes it dangerously easy to devalue and depersonalize them and to make damaging assumptions about unrelated attributes such as their intelligence, religion, culture, or attitudes towards health and illness (para. 7).

This point is further substantiated by Flores & Rosa (2015), who discuss the ideological practices of language embodiment and social exclusion. They state that language is "the first point of gatekeeping" in healthcare encounters, often becoming a "litmus test for exclusion, an excuse to turn away, to refuse to recognize the other" (p. 64). Hence, language plays a vital role in the construction of identity in healthcare settings. Language-based social differentiation and the lack of identity-affirming medical care that may be experienced by non-English speakers, including Deaf ASL users, can contribute to feelings of social exclusion, identity devaluation, and disenfranchisement from healthcare systems.

In addition, Deaf individuals also encounter stigma based on perceptions of disability by medical professionals (Atcherson, 2002; David & Werner, 2016; Iezzoni, 2016; Wen, 2014). Stigma can be described as a "characterization" or "virtual social identity" that is ascribed to someone based on an "attribute that is discrediting" (Goffman, 2009, p. 3). Stigma may manifest as labeling, stereotyping, exclusion, condescension, discrimination, or other behaviors that reduce the “whole and usual person, to a tainted discounted one” (p. 3). From a historical medical perspective, deafness has been pathologized, viewed as a condition in need of curing. This contradicts a sociocultural view held by Deaf ASL users that deafness is a linguistic and cultural identifier. The pathological view of deafness that has been perpetuated by the medical establishment throughout history has led to distrust of medical spaces by many Deaf ASL users (Baynton, 1996; Burch, 2002; Burch & Joyner, 2007; Lane, 1992; Schmidt, 2016).

Medical Distrust. Differing conceptions of deafness throughout history have coincided with the changing historical, socio-political, and cultural shifts in America and abroad. These varying conceptions have had implications for how Deaf ASL users have been socially situated in healthcare contexts and viewed by the medical establishment. For example, in the late 19th and early 20th centuries, deafness was problematized as a public health concern. Influenced by evolutionary thought, nationalist sentiment, citizenship, and the promise of science, health professionals and scientists sought to normalize Deaf people through the use of eugenics and technology (Bahan, 1989; Burch, 2002; Greenwald & Van Cleve, 2014; Haller, 1963). Deaf historiography is replete with accounts of medical experimentation, forced sterilization, condemnation of intermarriage between Deaf people, and other attempts by medical professionals, scientists, and eugenicists to eradicate a “deaf race” (Bell, 1884; Biesold, 1999; Burke, 2022; Branson & Miller, 2002; Greenwald, 2006; 2009; Lane, 1992; Proctor, 2002; Renwand, 2012; Ryan, 2002). Since the 1900’s, there have been more than 70,000 forced sterilizations of people with disabilities in the United States, many of whom were deaf, blind, and impoverished individuals, and women of color (National Women’s Law Center, 2022; NPR, 2016). Even today, 31 states and Washington, DC still have laws allowing forced sterilization of people with disabilities (NWLC). These state-sanctioned eugenics practices were not unique to the U.S. Looking abroad, Biesold (1999) conducted interviews with over 1,000 deaf survivors of forced sterilization in Nazi era Germany, many of whom still experienced physical pain and psychological trauma from sterilization procedures at the time the interviews were conducted. Even though German sterilization practices slowed in the 1940's, it is believed that 16,000 deaf people were murdered as part of the Nazi "racial hygiene" politics, including children and newborns, who were deemed "unfit to live" (Biesold).

In the late 1800's and early 1900's, fear-based ideologies about Deaf people spilled over into educational domains, resulting in the banning of sign language in schools across Europe and the United States in favor of an oral approach to education (Baynton, 1996; Burch 2002; Gannon, 1981; Lane, 1984). Health professionals and educators sought to normalize Deaf children by teaching them to speak and to become patriotic, law-abiding citizens. The extension of professional boundaries by the medical establishment into areas of education widened the divide with the Deaf community, who viewed these actions akin to linguistic and cultural genocide, donned with a "mask of benevolence" (Lane, 1992). Still, over 200 years later, there are remaining suspicions over present day technologies promoted by the medical establishment that pose existential threats to the language and culture of Deaf people (Hintermair & Albertini, 2005). Many of these technologies have grown into "big business" with markets valued in the billions and growing (Grand View Research, 2020). This has given rise to ethical questions about exploitation and the "commodification of the body and its parts" (Sharp, 2000). This, along with new advances in gene identification and genetic testing, bring to light more questions about reproductive autonomy, genetic engineering, biopolitics, and medical ethics. As long as persistent "negative ontologies" (Campbell, 2005) of deafness held by the medical establishment continues, the deeply rooted distrust of medical spaces by Deaf ASL users remains a valid and justifiable constant.

Language Concordant Providers. Contributing to the linguistic marginalization of Deaf ASL users is the dearth of ASL-language concordant providers (either Deaf or hearing ASL-fluent providers). Language concordant care, in which both the provider and patient share the same language (and sometimes other extra-linguistic characteristics), has been shown to improve health outcomes involving glycemic control, pain management, cancer screening adherence, and COVID-19 contact tracing in spoken language minority communities (Diamond, Izquierdo, Canfield, Matsoukas & Gany, 2019; Eliaz, Blair, Chen, Fernandez, Ernst, Mirjahangir, Celentano, Sachdev, Enanoria & Reid, 2022; Parker, Fernandez, Moffet, Grant, Torreblanca & Karter, 2017). In addition, language concordance has been shown to promote question asking, patient empowerment, trust, (Molina & Kasper, 2019; Villalobos, Bridges, Anastasia, Rodriguez & Gomez, 2016), and increased medication compliance (Kerse, Buetow, Mainous, Young, Coster, & Arroll, 2004).

Studies conducted with Deaf individuals on perceptions of health care communication with language discordant providers have described experiences of frustration, fear, and distrust (Iezzoni, O’Day, Killeen & Harker, 2004; Scheier, 2009). Fears surrounding safety, particularly risk of misdiagnosis, medication errors, or misunderstanding medical instructions have been expressed. Additional concerns noted were lack of patient-centeredness and issues during surgery and anesthesia. Furthermore, health care utilization is impacted by problematic communication with providers. Barnett & Franks (2002) found that Deaf ASL users seek health care less often than those who lose hearing after spoken language is acquired. Therefore, in light of challenges in establishing effective patient-provider communication between Deaf ASL users and non-signing physicians, (Kushalnagar, Engleman, & Sadler, 2018; McKee, Barnett, Block & Pearson, 2011; Shukla, Nieman, Price, Harper, Lin & Reed, 2018) language concordance has emerged as a topic of investigation in Deaf health spaces.

In 1998, Steinberg, Sullivan & Loew investigated Deaf individuals' attitudes and beliefs about mental illness and mental health providers. Through interviews with 54 Deaf people, ages 18-78, results revealed a desirability among participants for direct communication with sign language-fluent mental health professionals. One participant in the study stated, “A deaf counselor knows the language, the culture; knows what deafness means . . . [and] is like me” (para. 11). Additional results from the study revealed that 72% of participants indicated a preference for a Deaf therapist over a hearing one.

Similarly, in 2006, Steinberg, Barnett, Meador, Wiggins, and Zazove conducted a qualitative study with 91 Deaf adults to elicit health care perceptions and experiences. Participants reported positive patient experiences when they communicated with clinicians with sign language skills. As noted in the study, one participant responded, “I was able to explain deeply what was going on with me . . . They asked me questions and I was able to sign back. Having a doctor that signs is a wonderful experience” (p. 262). Though the study reports positive experiences of using ASL language concordant providers, the authors noted that no responses were elicited from the sample regarding a preference for practitioners who use ASL over those who do not.

In 2011, McKee, Barnett, Block & Pearson conducted a study to ascertain whether provider language concordance was associated with improved receipt of preventative services among a sample of Deaf respondents. The authors used the Deaf Health Survey, a version of the BRFSS survey adapted for use with Deaf individuals. Eighty-nine Deaf participants, ages 50-75, comprised the sample. Results showed that having a language concordant provider resulted in a greater number of preventive services for Deaf respondents when compared with those who had a discordant provider (even after adjusting for sociodemographic variables). In unadjusted analyses, the authors reported that respondents who had a language concordant provider were also more likely to receive an influenza vaccination in the past year.

Furthermore, in 2013, Moreland, Latimore, Sen, Arato & Zazove conducted the first study exploring Deaf and hard of hearing physicians and trainees as part of the healthcare workforce. Comprising the sample were 56 respondents, including 25 practicing physicians and 31 trainees. Using a national online survey to assess demographics, accommodations, career satisfaction, and future interest in working with Deaf and hard of hearing patients, the authors reported that 17 of the 25 physicians were in primary care specialties; over 20% of trainees anticipated working with DHH patients in the future. The benefits of using concordant providers were noted by the authors:

> DHoH physicians who have language and hearing concordance with DHoH patients have the potential to improve care for this often underserved population. Anecdotal evidence suggests, for example, that prelingually DHoH physicians are more likely to use signed communication and thus communicate with DHoH patients more effectively (para. 4).

Additional benefits of using Deaf and hard of hearing doctors were noted by McKee, Smith, Barnett & Pearson (2013). In addition to providing concordant care to patients, the authors described how DHH medical school trainees can assist in educating medical school peers and faculty members on communicating with DHH patients and ways to provide more culturally-affirming care. They also pointed out the importance of Deaf physicians serving as role models for younger generations of DHH medical practitioners, providing support and advocating for pipeline programs to increase diversity and to provide care to an underserved population.

While studies indicate the potential benefits of using ASL concordant providers with Deaf patients, the availability of Deaf, hard of hearing, and hearing practitioners who are ASL fluent is still evolving. Barriers such as outdated or narrowly-defined technical standards used by medical schools for admissions and the lack of value placed on recruiting diverse representation among the student body at medical schools has caused delays in the realization of more Deaf, hard of hearing, and hearing ASL concordant providers to meet the linguistic and cultural needs of Deaf patients (Argenyi, 2016; DeLisa & Lindenthal, 2016; Meeks, Herzer & Jain, 2018).

Sign Language Interpreters. Communication between healthcare providers and Deaf patients can also take place through interpreter-mediated exchanges. Sign language interpreters, who are both Deaf and hearing, and who work either in-person or video-based, are another way of bridging the linguistic and cultural divide between healthcare providers and Deaf patients who use ASL[1]. The work of any healthcare interpreter, whether using a signed or spoken language, is complex, multi-layered, and nuanced. Numerous barriers to providing interpreter-mediated healthcare have been noted in the literature, with perspectives shared by patients, providers, and interpreters themselves. For example, Deaf patients have reported that healthcare is the most difficult setting in which to obtain interpreters (Cokely & Winston, 2008). Professional interpreters feel they are least prepared for medical interpreting work and desire additional training. Adding to these barriers is the lack of a specialized credential in the profession. While a set of knowledge domains and core competencies for sign language interpreters who work in

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[1] The author also recognizes the use of Designated Interpreters by Deaf healthcare professionals and recognizes that these professionals have their own perspectives about interpreter-mediated healthcare with deaf and hearing patients. For purposes of this paper, focus will be on interpreter-mediated healthcare between hearing physicians and Deaf patients.

healthcare have been developed, (Swabey, Faber & Malcolm, 2012) and a few specialized training and professional development programs for healthcare interpreters have been created, more work is needed to better prepare practitioners to face the risks, realities, and requirements of interpreting in healthcare environments.

For purposes of this paper, access barriers relating to interpreter-mediated healthcare for Deaf patients will include discussion of interpreter role and decision making, medical discourse and interactions, education and training, costs, shortages, and other considerations.

Role and Decision-Making. Experiences of interpreter role dissonance and conflicting expectations about interpreter role from patients and providers have led to a growing body of literature that speaks to the expansive role of both spoken and sign language interpreters in healthcare settings. In contrast to more traditional views of interpreter role and function, which reduced the interpreter to a mere technician or conduit through which meaning is relayed, researchers have described the more expansive role of the healthcare interpreter to include co-diagnosing (Hsieh, 2007), assessing and decision making (Dean & Pollard, 2001), elaborating (Hsieh, 2013), providing healthcare system navigation or guidance with administrative procedures (Olsen & Swabey, 2017), conversationally redirecting patients (Mirza, Harrison, Chang, Salo & Birman, 2017), determining needs and preferences (Krystallidou, Devisch, Van de Velde & Pype, 2017), providing emotional support (Lara-Otero, Weil, Guerra, Cheng, Youngblom & Joseph, 2018), mediating cultural differences (Rosenbaum, Dineen, Schmitz, Stoll, Hsu & Hodges, 2020), being a bridge for social justice (Messias, Hilfinger, McDowell, Estrada & Dawson, 2009). In relation to this idea, Angelelli (2018) discussed the notion of interpreter role fluidity, where shifts in role occur depending on contextual and interpersonal factors. By using ethnographic and shadowing methods with 10 Spanish/English interpreters in her study, the author showed that interpreters are constantly assessing dynamics in the healthcare environment and utilizing their agency to make decisions that address power differentials among participants, bridge cultural gaps in understanding, and explore conversational dimensions. Viewing interpreters as co-constructors of meaning in healthcare conversations, the author points out that these contextually-dependent decisions and role shifts can impact relationships with providers and patients who have different expectations for the interpreter’s role. This can often lead to conflict among participants in healthcare exchanges.

Likewise, Major & Napier (2019) described healthcare interpreter roles as fluid. The authors employed a case study methodology with Australian Sign Language (Auslan)/English interpreters in their research. Like Angelelli, the authors move away from a traditional view of the interpreter role as merely a discourse manager striving for message equivalence between languages. Rather, they support the notion that interpreters make moment-by-moment decisions based on linguistic and interactional demands in the environment, which may necessitate that they take on a more expansive role. The authors also pointed out the disconnection between what is espoused as interpreter role and what actually happens in healthcare environments in situ. This discrepancy in theory and practice has been reiterated by Angelelli (2020).

Showstack, Santos, Feuerherm, Jacobson & Martinez (2021), also described an expanded role of healthcare interpreters to include “patient advocates, clarifiers, and cultural brokers” (p. 3). Like the previous authors on this subject, they also point out that misunderstandings of interpreter roles within the physician-patient-interpreter triad can lead to the limited ability of interpreters to optimally serve patients. Of importance to note, the authors emphasized that the use of ad hoc interpreters, such as family members, friends, and non-fluent bilingual staff is still a common but detrimental practice used by many healthcare facilities. The authors cited works by Flores, Abreu, Barone, Bachur & Lin (2012) that showed use of ad hoc interpreters is associated with “clinically significant errors in communication and reduced health outcomes for patients with limited proficiency in the dominant language” (p. 3). From an applied linguistics perspective, the authors advocated for additional research that sheds light on both professional and non-professional interpreting practice and how they impact health outcomes for the patient.

Moreover, Marin (2020) conducted a qualitative study with graduates of the Rochester Institute of Technology’s (RIT) Certificate in Healthcare Interpreting (CHI) program. The investigator set out to examine the impact of the professional development program on perceptions of interpreter roles, responsibilities, and decision-making. After completing the certificate program, interpreters reported seeing themselves more in an advocacy role as opposed to a conduit role. They also described utilizing context-based decision making and critical thinking skills more effectively post certificate training.

Finally, Aranda (2021) used a combination of observations, interviews, and questionnaires to better understand the roles of spoken language healthcare interpreters in Spain. Using thematic analyses, the author identified five interpreter roles from the data. These included interpreters as mediators, patient advocates, institutional navigators, healthcare ambassadors, and conversational partners. These findings index the need for increased training for healthcare interpreters that takes into account the realities of constant role shifts and responses to the complex linguistic and interactional demands in healthcare contexts.

Medical Discourse and Interactions. There is also evidence in the literature that investigates linguistic strategies used by interpreters in rendering health-related interpretations. In 2012, Major & Napier examined the notion of “accuracy” in simulated healthcare interactions with sign language interpreters in Australia. Using a role-play activity with paid actors to portray a General Practitioner (GP) and Deaf patient, the authors investigated interpretations made by ten nationally accredited Auslan/English interpreters in Sydney. After videotaped renditions were analyzed, the authors found that interpreters frequently used reduced or expanded strategies in their interpretations based on contextual factors. The authors emphasized that strategic decision making is often employed by interpreters in various contexts and the linguistic decisions that interpreters make as a result do not necessarily constitute miscues. The authors debunk more traditional views of "accuracy" and point out the dynamic and context-dependent nature of interpreter-mediated interactions in healthcare settings.

Nicodemus, Swabey & Moreland (2014) examined the translation of medical instructions from English to American Sign Language by both interpreters (n=3) and Deaf bilingual physicians (n=3). The importance of compliance with medication instructions and protocols have been noted in the literature (Iezzoni et al, 2004; Scheier, 2009; Steinberg et al, 2006). As such, the authors investigated linguistic characteristics used in translations by both groups to identify the use of particular linguistic markers and to better understand how medication instructions are translated in ASL. The authors noted that repetition, emphasis on particular lexical items, and prosody markers were shared among both groups. The authors concluded that the use of these linguistic features in healthcare interpreting and translation can support comprehension and recall of prescription and treatment protocols.

Nicodemus, Swabey & Moreland (2014) conducted a similar study investigating ASL translations of common medical interview questions. Again, using both Deaf physicians (n=3) and experienced ASL interpreters (n=3), the authors identified linguistic markers used by both groups from 18 ASL translations of 3 common medical interview questions. The authors found that contextualization, specification, and contrasting were used in varying degrees by the participants. Again, the authors noted the importance of identifying salient linguistic features used in ASL translations that contribute to better comprehension of medical questions and overall health communication for Deaf patients.

Education and Training of Medical Interpreters. In response to the dearth of training programs and lack of specialized credential for sign language interpreters working in healthcare settings, there have been some discussions about education and training of healthcare interpreters found in the literature (Dean & Pollard, 2012; Nicodemus, Swabey & Witter-Merithew, 2012; Bowen-Bailey, 2012; and Olsen & Swabey, 2013). In 2013, Laurion discussed the need for quality interpreting in healthcare settings in his article, "Improving Healthcare: Specialization for Sign Language Interpreters". He pointed out that the growing demand for ASL interpreters in medical settings has prompted the need for more specialized practice within the profession. While the author acknowledged that gains have been made in improving this area of practice (development of domains and competencies, greater opportunities for reflective practice, case conferencing, mentorship, and collaborating with Deaf experts such as Deaf interpreters and community health workers), there is still need for a specialized credential for healthcare interpreting for sign language interpreters. The author concluded by emphasizing the need for more specialized education and supervised work experiences for interpreters to be effective in bridging communication between patient and provider.

Similarly, Desrosiers (2017) addressed the need for specialized medical certification for sign language interpreters. Conducting a literature review on the topic of healthcare interpreting and then synthesizing findings, the author described the importance of establishing a national interpreting standard for ASL interpreters while at the same time recognizing the challenges involved with doing so. Some of the challenges mentioned included the lack of interpreter preparation programs that provide specialized instruction in healthcare interpreting; the lack of progress on creating a certification test by the Center for the Assessment of Sign Language Interpretation (CASLI), the profession's national testing entity; and barriers involved in legislative adoption of a national standard for states, along with reluctance of medical facilities to adopt hiring practices that align with this standard.

Finally, Plue, Lummer, Gonzales & Ordaz (2018) discussed four key competency areas that community healthcare interpreters must satisfy in order to meet the diverse needs of Deaf consumers. In their chapter "Community Health Care Interpreting" in the text "Deaf Eyes on Interpreting" by editors Holcomb & Smith (2018), the authors emphasized that healthcare literacy, cultural competency, language proficiency, and clarity in communication are necessary. The authors also stressed the importance of interpreters meeting the needs of Deaf individuals from a variety of language and educational backgrounds and using Deaf interpreters when necessary in health settings.

Costs, Shortages, and Other Considerations. Also noted in the literature are other considerations associated with interpreter-mediated healthcare communication with Deaf patients. Those considerations include cost of services, shortages of available practitioners, and occupational hazards.

Cost of interpreter service provision varies depending on whether a healthcare provider or facility employs full-time staff interpreters, contracts with an interpreting agency for services, hires freelance interpreters directly, or uses video-based interpreting services. In addition, some insurance companies pay for the cost of interpreter services depending on the patient's plan and coverage. The cost-paying mechanisms can be complex and healthcare facilities must establish protocols to ensure that provision of interpreting services are in place. Furthermore these protocols must be communicated to all levels of healthcare personnel in response to patients' requests for interpreter services. What is most important to note is that the Deaf patient does not bear the responsibility of paying for interpreting services (or for other auxiliary aids or services). Likewise, providers cannot charge a patient for the costs of providing auxiliary aids and services (DOJ, 2011).

Jacobs, Shepard, Suaya, Stone (2004) assessed the impact of interpreter services on cost and health care utilization of patients identified with the Limited English Proficiency (LEP) marker. Using data from electronic health records from a Massachusetts health maintenance organization (HMO) that provided Spanish and Portuguese interpreting services to patients over the course of two years, the authors calculated direct cost of providing services (salaries, benefits, overhead) as well as costs of net changes in health care utilization (preventive, primary care, and emergency department services) as a result of interpreter service provision. The authors found that providing interpreter services increased delivery of health care to LEP patients. Those patients who used interpreter services showed significant increases in the receipt of preventive services, physician visits, and prescription drugs. The authors concluded that provision of interpreter services can improve patients' access to primary and preventive care for a moderate increase in cost.

In addition to costs, there are other factors that come into play when working with sign language interpreters. Like any other practice professional who works within healthcare settings, sign language interpreters are also susceptible to vicarious trauma, emotional exhaustion, compassion fatigue, burnout, and Post-Traumatic Stress Disorder (PTSD) (Champlin, 2021; Darroch & Dempsey, 2016; Harvey, 2003; Hsieh & Nicodemus, 2015; Knodel, 2018; Lai & Costello, 2021; MacDonald, 2015; and Mehus & Becher, 2016). Likewise, interpreters can experience repetitive stress injuries such as Carpal Tunnel Syndrome (CTS) and tendonitis from overworking (Stedt, 1992, Smith, Kress & Hart, 2000, Gordon, 2017). Moreover, shortages in interpreter availability have been well-documented in both the literature (Schniedewind, Lindsay & Snow, 2020) and in mainstream media (Bleu, 2020; Evelly, 2019; Gil, 2022; Nicolas 2020; Stewart, 2020). While the use of interpreter-mediated communication with Deaf patients is not without its own issues, healthcare facilities should be prepared with robust systems in place to respond to patients who express a preference for interpreters for healthcare encounters.

Video Remote Interpreting (VRI). In addition to the use of in-person, onsite interpreters, more and more healthcare organizations have turned to video-based interpreter service provision. The reliance on VRI services has also been exacerbated by the COVID-19 pandemic. While there are advantages to having these services in place, there is a growing body of literature that shows varying degrees of satisfaction among Deaf patients who use VRI services and varying quality of service provision. In addition, Deaf patients have reported varying opinions about the ability of VRI to enable effective communication between them and healthcare providers.

Kushalnagar, Paludnevicience & Kushalnagar (2019) conducted a nationwide cross-sectional study with 555 Deaf patients to assess Video Remote Interpreting (VRI) satisfaction in healthcare settings. The authors used secondary data collected from the HINT survey from 2016 to 2018, which included information about Deaf patients' experiences with VRI in health settings. The results showed that only 41% of respondents were satisfied with the quality of VRI services. In addition, the authors noted that patients' self-report of VRI interpreter's interference with disclosure of health information resulted in three times greater dissatisfaction with VRI quality.

Similarly, Yabe (2021) conducted a mixed-methods study to identify preferences for in-person interpreting services or VRI services of both healthcare providers and Deaf and hard of hearing patients in both critical and non-critical care settings. The author also investigated whether healthcare providers who worked with patients identified with the “Limited English Proficient” (LEP) marker have differing perspectives about VRI use compared to DHH patients. Sample size consisted of 103 participants, including 36 healthcare providers who worked with LEP patients; 26 providers who worked with DHH patients, and 41 DHH patients. Using a survey and semi-structured 1:1 interviews, the author found that both groups had more positive experiences with in-person interpreting services resulting in better patient-provider communication. Cost and shortage of in-person interpreters were cited as reasons for increased use of VRI in healthcare settings. The author concluded with a general caution for healthcare providers to avoid over-reliance on VRI services exclusively, as there are both advantages and disadvantages to using it.

Likewise, Myers, Annis, Withers, Williamson, & Thomas (2021) conducted a cross-sectional study of ASL users in North Carolina to discern satisfaction and preferences with communication aids and services used in healthcare settings. A total of 189 ASL users responded to an online survey in ASL and English; qualitative interviews were conducted with 54 participants to gather additional information on consumer satisfaction and preferences. Results showed that while ASL users preferred on site, in person sign language interpreters for communication with healthcare providers, most patients were provided with other forms of communication such as VRI or note-writing. The authors stressed the importance of having access to qualified in-person interpreting services to improve patient satisfaction and to meet the needs of patients who use ASL.

Finally, James, Coady, Stacciarini, McKee, Phillips, Maruka & Cheong (2021) investigated the communication experiences of DHH patients in North Central Florida who had used the Emergency Department (past two years). As many Deaf ASL users are denied access when seeking preventive services from primary care providers or may not be aware of appropriate venues to seek preventive services, data shows that many Deaf ASL users have higher Emergency Department (ED) utilization (Foltz & Shank 2020; James, Varnes, Sullivan, Cheong, Pearson, Yurasek, Miller, McKee, 2021; McKee, Winters, Sen, Zazove, Fiscella, 2015). Using a descriptive qualitative methodology, the authors identified five predominant themes from the experiences shared by the 11 participants. One of those themes included experiences of VRI services in the ED. Results showed that none of the 11 participants preferred VRI services in the ED. Several reasons for this were noted in the responses, which included but were not limited to: traumatic experiences with VRI use in the past; technical problems with VRI equipment; waiting for delivery or set-up of equipment; lack of qualified interpreters through VRI; and the provision of VRI services as a perfunctory measure. The authors emphasized that while VRI services are appropriate in some circumstances (triaging and while waiting for an in-person interpreter to arrive on-site), the over reliance on VRI services to provide “access” is performative, and does not always result in meaningful engagement and communication with healthcare providers.

Health Care Provider Cultural Competence and Training. In addition to linguistic and communication barriers, Deaf patients report experiencing cultural marginalization from healthcare providers, who often do not possess required knowledge and understanding of the sociocultural norms of Deaf patients. This topic of provider cultural competence[2] has been

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[2] The author acknowledges the outdated mode and limitations of the term “cultural competence”. However, instead of using more current terms such as “cultural safety” (Papps & Ramsden, 1996), “cultural humility” (Tervalone &

explored in the literature through different perspectives: the perspectives of Deaf patients, the perspectives of providers, and the perspectives of sign language interpreters.

Perspectives of Deaf Patients. There have been some, but albeit limited studies written on the topic of provider cultural competence as observed through the eyes of Deaf patients. Deaf individuals have reported experiences with healthcare providers that include paternalistic attitudes and reduced self-autonomy (Harmer, 1999), perceived prejudice (Witte & Kuzel, 2000), fear and distrust (Iezzoni, 2004; Steinberg, 2006; Scheier, 2009), discomfort and disempowerment (Sirch, Salvador, & Palese, 2017) stress, frustration, and lack of regard for patient privacy (James et al, 2021), among other concerns. More qualitative research is needed in this area to better understand how Deaf patients' perspectives can inform providers' understanding of culturally-affirming care.

In 2011, DeVault, Garden & Schwartz described how story can be a powerful transformative vehicle for teaching healthcare providers on how to be more culturally responsive to Deaf patients. Using an action research project to improve dialogue among Deaf patients, healthcare providers, and sign language interpreters, the authors discussed how creating space for sharing these varied perspectives can foster intercultural understanding among all parties. Of importance to note were the perspectives shared by a Deaf patient in the researchers' article. This person recounted the additional "labor" that is involved in ensuring that his communication needs were met in healthcare settings, an experience that non-Deaf individuals do not have to bear. The authors cited Brunson's (2010) notion of "calculated consumer labor" to describe the time and energy that is expended by Deaf patients in order to gain access to communication to meet fundamental human needs. This additional labor comports with the idea of "negotiation of

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Murray-Garcia, 1998), or "intercultural competence" (Lustig & Koester, 2003), the author has used the term "cultural competence" in the belief that it is most recognizable to the reader.

access" that James et al (2021) speak of in their study. Instead of healthcare organizations bearing the onus and labor of providing communication access to their patients, the perspectives shared in the article showed that the burden is often placed on the patient. This "wearing down" of both energy and faith (in healthcare systems) over time can result in decreased engagement by the Deaf patient and eventually disenfranchisement from healthcare systems.

Deaf patients' experiences and attitudes towards nurses were examined by Gilchrist (2000). Using qualitative interviews with 11 Deaf adults, the author sought to capture the lived experiences of Deaf individuals and to understand the meaning of health from their perspectives. Interview responses revealed that many Deaf people viewed nurses as cold and impersonal. In addition, they noted that nurses were often inpatient and indifferent towards Deaf patients, focusing instead on routines and processes. Additional perspectives included nurses' reluctance to use interpreters despite requests from patients, and a tendency to use note-writing to communicate. The author noted that many Deaf people in the study indicated a desire to learn more about health and health needs, but communication was often curtailed by the lack of an interpreter. Shared decision making, developing relationships to improve therapeutic rapport, opportunities for health education in the moment, and provision of interpreters were wishes expressed by Deaf respondents of nurses in the study.

Finally, Rezende, Guerra & Carvahlo (2021) conducted a study in Brazil with 124 Deaf people, ages 18-70, in order to capture perspectives on health care and ways to improve the healthcare system. Observations and a semi-structured questionnaire were used with responses obtained in writing or in Brazilian Sign Language (Libras). Common experiences that emerged from respondents included needing an interpreter to communicate with healthcare professionals, feeling rushed and wanting more time and attention with providers, wanting more privacy and autonomy, and wanting more accessible health education opportunities. Patients had also expressed that they had been yelled at and had perceived prejudice from providers. Desiring more respect from healthcare professionals was noted.

Perspectives of Providers. Studies could also be found in the literature that have examined provider perspectives of working with Deaf patients. Ebert & Heckerling (1995) conducted one of the first studies to investigate physicians' knowledge, beliefs and practices when communicating with Deaf people who use sign language. Using a survey distributed to doctors at the University of Illinois School of Medicine, the authors determined that while most physicians believed sign language interpreters were the preferred way in which Deaf patients preferred to communicate, very few utilized their services. In addition, the authors noted that physicians overestimated accuracy of speechreading and believed that more time and effort was involved in interactions with Deaf patients.

Ralston, Zazove, & Gorenflo (1996) conducted a comparative study of physicians' attitudes and beliefs about Deaf patients and non-Deaf patients. The authors used questionnaires that were distributed to physicians during medical conferences at the University of Michigan over a three-month period. Sample size consisted of 165 physicians, 94 of whom received a questionnaire assessing attitudes and beliefs of non-Deaf patients and 71 who received a questionnaire assessing attitudes and beliefs about Deaf patients. Results showed that physicians felt that they had experienced greater challenges in understanding Deaf patients and being understood by them compared to non-Deaf patients. They felt Deaf patients trusted them less, became frustrated easily, and were less likely to maintain conversation with them compared to non-Deaf patients. Finally, they felt Deaf patients were less likely to understand diagnosis and treatment recommendations compared to non-Deaf patients. The authors also added that all physicians were unaware of the legal requirements to provide effective communication to Deaf patients.

Perspectives from nursing providers about Deaf patients are noted in the literature. Lieu, Sadler, Fullerton & Stohlmann (2007) discussed the importance of nursing education programs in providing culturally competent care to Deaf patients. The authors suggested that nursing programs should recruit student applicants who have already acquired bilingual competency in ASL. Furthermore, they encouraged incorporating ASL classes in nursing curricula and recommended that healthcare facilities identify funding streams to provide professional development to nurses so that they may acquire linguistic and cultural competence in working with Deaf patients. Similarly, in 2017, Pendergrass, Nemeth, Newman, Jenkins & Jones wrote about nurse practitioners' (NP) perspectives of barriers and facilitators of health care for Deaf ASL users. Using a socio-ecological model and semi-structured interviews, the authors noted several barriers. For example, while NPs preferred the use of a sign language interpreter, they were unsure of interpreters' roles and facility in providing effective communication to patients. In addition, most NPs indicated that gesturing, lip-reading, note-writing, and using family members as interpreters were facilitators to health care and relied on professional interpreters only after other communication methods had been exhausted. The authors noted the importance of educating NPs on ways to improve culturally competent care, including more education on the legal requirements for effective communication with Deaf patients. Recommendations on instituting protocols to obtain professional interpreters at healthcare facilities was also discussed.

In addition to nurses and nurse practitioners, pharmacists have offered perspectives on interactions with DHH customers. Chong, Jacob, Ramadas, Goh & Palanisamy (2021) conducted a study in Malaysia with 297 community pharmacists to assess comfort levels in interacting with

DHH individuals. Results from online and paper surveys showed that pharmacists were “neither extremely comfortable nor averse” (p. 5) when interacting with DHH people. Those who had more contact with DHH customers or had more prescription requests from DHH customers indicated higher comfort levels than those who had infrequent contact. The authors also pointed out that pharmacists preferred note-writing in their communications with DHH customers instead of interpreting services due to resource shortages and costs.

More recently, Agaronnik, Campbell, Ressalam & Iezzoni (2019) conducted a study with 20 physicians in Massachusetts from October 2017 to January 2018 to understand physician perspectives of communication experiences with people with disability. The authors used semi-structured interviews and content analysis to determine common themes in participant responses. Themes that emerged relating to DHH patients included frequent use of communication modalities that did not align with the preferences of the patient. While some physicians had access to ASL interpreters, others used different approaches to communication, including lip-reading, note-writing, or vocal changes. The authors noted that physicians varied in their communication preferences, with some relying on VRI services as opposed to in-person interpreters and citing logistical challenges in securing them.

More personal perspectives of physicians’ beliefs and attitudes towards Deaf patients have been evident in the literature. In 2019, Kittleson wrote a perspective piece in the New England Journal of Medicine, describing personal experiences with caring for a Deaf patient who used ASL. In the piece, the author reflects on the missed opportunity to connect directly with her patient and discusses the complacency that is prevalent among many physicians who prioritize technical expertise and pragmatic processes over developing meaningful relationships with Deaf patients.

Perspectives of Interpreters. Finally, sign language interpreters offer yet another perspective of provider cultural competence in healthcare environments of Deaf patients. Hommes, Borash, Hartwig, DeGracia (2018) conducted a survey of ASL interpreters attending the 2015 National Symposium on Healthcare Interpreting to identify interpreters' perceptions of barriers to healthcare between DHH patients and providers. An online and paper survey was distributed to 146 conference participants. Likert rating scales, multiple choice, and open-ended questions were utilized. In addition to showing that there was a discordance between patient and provider preferences for adequate communication, medication misunderstandings resulted in almost half of the appointments noted. In addition, interpreters observed that providers were less likely to use visual tools for explaining health information (models, diagrams, pictures) and overestimated the efficacy of lip-reading and note-writing for communication. Time constraints were also noted by interpreters, who observed that providers were often in a rush and did not take time to ensure that patients understood diagnoses or medical instructions. Similarly, 81% of interpreters indicated that healthcare providers did not provide teach back education to patients. The authors noted the important role of interpreters in healthcare settings in bridging patient-provider communication and acting as cultural mediators.

Cultural Competency Training and Education. In light of the research that strongly suggests that lack of provider cultural competency hinders patient-provider communication and therapeutic rapport, several studies have focused on interventions and training models to address this issue. For example, Hoang, LaHousse, Nakaji, & Sadler (2010) conducted a study to assess cultural competency of physicians and medical students in working with Deaf patients at the University of California, San Diego, School of Medicine. The authors created and disseminated an anonymous survey to university faculty (n=131), medical students who were a part of a Deaf

Community Training Program (DCT, n=22), a fellowship program which provided ASL immersive experiences and Deaf cultural training), and to medical students who were not part of the DCT program (n=211). The survey explored knowledge of how to work with Deaf patients, interpreters, and overall cultural awareness. Findings suggested that training medical students in areas of culturally competent care can increase their ability to better care for community members and reduce health disparities.

Similarly, in an article by Thew, Smith, Chang, & Starr (2012), the authors described one particular model for training medical students on how to become more culturally competent in working with both Deaf and non-English speaking patients. The Deaf Strong Hospital Program (DSH) at the University of Rochester School of Medicine and Dentistry, which started in 1998, uses hands-on experiences and role-reversal exercises to introduce first-year medical students to working effectively and sensitively with Deaf patients. The article described the curriculum used and provided insights from post-program evaluations. The authors advocate for replication of programs like this in more medical schools and training centers across the country.

Likewise, Lapinski, Colonna, Sexton, & Mariah (2015) conducted a study to see if a workshop on learning basic ASL skills and Deaf culture for first and second year osteopathic medical students resulted in increased knowledge and confidence in interacting with Deaf patients. Thirty-three students participated in a 4-hour workshop with knowledge and standardized patient encounter scores measured using pre- and post-tests. Results showed that medical students reported more confidence interacting with Deaf patients and demonstrated increased knowledge with basic medical signs after participating in the workshop.

Finally, Jacob, Palanisamy, Napier, Verstegen, Dhanoa, & Chong (2022) highlighted health care challenges faced by Deaf ASL users, identified gaps in training of health providers, discussed the importance of culturally competent health care, and suggested steps to take to incorporate cultural competence education within health care curricula. The authors offered recommendations for provider training programs, such as incorporating Deaf individuals in lectures and case discussions, providing explicit instruction on the sociocultural norms of Deaf individuals, and discussing the potential of varying literacy levels of Deaf patients and how this poses risk when relying on medical documents to communicate important information. The authors also suggested the use of role plays in healthcare curricula and inviting representatives from the local Deaf community to share their experiences. The authors noted that Deaf ASL users report more positive experiences when interacting with interpreters with medical training and health care providers who have made efforts to improve communication.

Part II. Informational and Educational Deprivation and Marginalization

In addition to both linguistic and cultural barriers encountered in healthcare systems, many Deaf ASL users also experience difficulty accessing health information both incidentally in the environment and directly through health education opportunities in the community. As this information deprivation typically begins in childhood, there are lifelong implications for health literacy development and health outcomes over the lifespan.

Deaf ASL users have limited access to the auditory environment. Therefore, they differ in how they acquire health information compared to non-Deaf individuals. More than 90% of Deaf children are born to hearing parents (Mitchell & Karchmer, 2004); yet, less than 10% of hearing parents learn to communicate in ASL (Urban Plains, 2018). Therefore, access to family conversations about general health, healthy behaviors, health resources, health values, health protocols, and family medical history are severely limited due to this language barrier. Deprived of this important health information, Deaf children often do not develop the "cultural health capital" (Bordieu, 1986; Mollborn, Rigles, & Pace, 2021) that non-Deaf children acquire. As a result, Deaf children are socially situated in a disadvantaged position, for this lack of information does not allow them to benefit from the "intergenerational processes of advantage" (Mollborn et al, 2020, p. 575) that come with learning specific health behaviors, understanding ways of communicating about health, and embodying performances of health from their families.

Furthermore, Deaf individuals possess varying levels of English proficiency (Traxler, 2000). ASL is a visual language which possesses its own linguistic characteristics that differ from English. In addition, ASL does not have a written form; this makes "translating ASL to written English or vice-versa…a multi-step and inexact process" (DO-IT, 2021, para. 1). As ASL is considered the first language for Deaf ASL users and English is considered a second or non-native language, Deaf individuals face similar challenges in acquiring English proficiency in the same way that other second language learners of English do. Therefore, printed information in English, like pamphlets and brochures that promote health, are often inaccessible to Deaf individuals unless the information can be presented in ASL forms. Moreover, media communications (television, radio, websites, and social media) in spoken or written English that promote health information, including public service announcements or commercials, are inaccessible to most Deaf people without interpreted versions in ASL. Finally, health workshops conducted in spoken English at local clinics, community health centers, and hospitals are not accessible to Deaf individuals unless an ASL interpreter or other preferred accommodation is provided. Overall, these complex dynamics impact the ability of Deaf ASL users to acquire necessary information to make informed decisions about their health.

Health Literacy. The Centers for Disease Control and Prevention (CDC, 2022) view health literacy as two-pronged, consisting of both personal health literacy and organizational health literacy. They define personal health literacy as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (para. 1). This definition emphasizes the ability to not only *understand* information, but to *use* it to make informed decisions. The CDC defines organizational health literacy as “the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (para. 1). This more expanded definition takes into consideration health equity, which recognizes that not all individuals have equal access to health-related information. This also implies that access to health information is a shared responsibility among health care organizations, government agencies, healthcare insurers, and others so that “everyone has the opportunity to be as healthy as possible” (para. 4).

In regards to Deaf ASL users, there have been previous studies in the literature which have focused on health literacy (McKee & Paasche-Orlow, 2012; McKee, Schlehofer, et al., 2011; Pollard & Barnett, 2009; Margellos-Anast, Estarziau, & Kaufman, 2006). In 2015, McKee, Paasche-Orlow, Winters, Fiscella, Zazove, Sen, and Pearson conducted a two-step study to develop a valid health literacy tool in ASL and to assess prevalence of inadequate health literacy among Deaf ASL users and non-Deaf English speakers for comparison. A total of 405 people participated in the study, including 166 Deaf and 230 hearing individuals, ages 40-70 years from the Rochester, New York area. First, the authors adapted and translated an existing health literacy tool called Newest Vital Sign (NVS) and validated its use with Deaf ASL users. Secondly, the researchers assessed the prevalence of inadequate literacy levels among both groups of participants. Results showed that Deaf ASL users were almost 7 times (6.9) more likely to have inadequate health literacy than their hearing peers. The authors emphasized the importance of these findings as there had been no previous validated tools available for assessing health literacy for this population. The authors were also able to validate previous findings regarding the low health literacy of Deaf ASL users.

Similarly, Smith and Samer (2016) used a set of different instruments to assess the health literacy of both DHH and hearing adolescents. Using the Health Literacy Skills Instrument-Short Form (HLSI-SF), Short Form of the Test of Functional Health Literacy (STOFHLA), Comprehensive Heart Disease Knowledge Questionnaire (CHDKQ) and other tools, the researchers assessed 187 DHH and 94 hearing high school students. Results showed that DHH adolescents had weaker health literacy than hearing adolescents according to the instruments used. Results also showed that DHH adolescents had lower cardiovascular health knowledge scores than their hearing counterparts. Authors concluded by emphasizing improved access to health information from a variety of sources, including family, friends, teachers, health providers, and the media.

Finally, in 2018, Kushalnagar, Ryan, Smith, and Kushalnagar explored how critical health literacy (CHL) related to discussions of health information among college Deaf students who use ASL. A total of 38 Deaf and 38 hearing students participated in the study. Researchers first assessed CHL by evaluating responses to a short stimulus involving a health-related scenario. Second, participants were asked two questions to determine how often participants discussed health-related matters with family and friends. Both groups showed a strong relationship between health-related discussions with friends and CHL. While hearing students also demonstrated a relationship between health-related discussions and family, Deaf students did not. As Deaf college students are more likely to engage in health discussions with peers, the authors noted the importance of students receiving health information from trusted sources who are informed and health literate.

Health Education. Pollard, Dean, O'Hearn & Hayes (2009) discussed methods of adapting health education materials for Deaf ASL users so that they are linguistically accessible and culturally relevant. The authors described the first step in their process as identifying legitimate health education material and locating the salient learning points in that source material. Then, they described the next step as creating a film script which incorporated those learning points. The use of dialogue and other features that align with the sociocultural norms and learning preferences of Deaf individuals are then added. Knowledge that may not have been previously acquired on the health topic is also embedded into the script. Afterwards, the script is used by Deaf actors who render the adapted health information in ASL. English subtitles are added to the film, along with spoken English narration. After determining that Deaf audiences found the learning material more engaging and culturally relevant, the authors suggested that similar methods could be used to adapt health education material for Deaf audiences.

Neuhauser, Ivey, Huang, Engelman, Tseng, Dahrouge, Gurung & Kealey (2013) conducted a study to explore the availability and readability of Emergency Preparedness Materials to prepare for public health and other disasters for DHH older and adult populations. The authors collected 40 Emergency Preparedness Materials from 10 community-based organizations and two public health departments in two California counties. In addition, they collected 40 Emergency Preparedness Materials from 14 local and national websites. Reading levels were assessed in a subset of the materials. Results showed that less than half of community-based organizations had materials for their clients. For organizations that did have materials available, all were found to be above recommended reading levels for DHH clients (4th grade). The authors also noted that for organizations that served older adult DHH clients, 91% were above the recommended level for that age population (6th grade). The authors concluded by emphasizing that materials should be available in formats that are accessible to DHH people, including following recommended reading levels, offering materials in ASL, and including DHH people as designers and testers of materials.

In an effort to better understand how DHH people interact with health information, Champlin, Cuculick, Hauser, Wyse & McKee (2021) shared a research protocol used for assessing eye movements and visual behaviors when interacting with health-related content (on websites, for example). The authors contend that by understanding these visual behaviors in both Deaf and hearing people, design and engagement of health-related content could be optimized. Using a multi-site mixed methods approach, the study included 450 deaf participants and 450 hearing participants who took part in sessions using gaze-tracking technology. Interviews were conducted with a subset of the participants. The authors concluded that research protocols using gaze-tracking technology have both advantages and disadvantages. While logistical and procedural limitations were noted using this technology, the authors felt that studies like this can be promising in offering vital information on how visual learners interact with health information.

In regards to COVID-19 health information, Panko, Contreras, Postal, Mussallem, Champlin, Paasche-Orlow, Hill, Plague, Hauser & McKee (2021) compared COVID-19 information access between deaf and hearing people. Using surveys disseminated through a variety of channels with 104 deaf and 74 hearing adults, the authors found that there were no differences in ability to identify symptoms of COVID-19 among groups; however, deaf respondents were almost 5 times (4.7) more likely to report difficulty in accessing information about COVID-19. The authors further stated that deaf respondents were 60% less likely than hearing respondents to stay home or contact a doctor if they suspected they had COVID-19. The authors concluded that public health officials should incorporate ASL-accessible online information about COVID-19, including posting information on social media channels. Additional health education strategies to reach this population should also be considered.

Media. Chad, Massey-Stokes & Lieberth (2012) invoked a call to action for more accessible web-based health information to be available for adolescents, and specifically for female d/Deaf adolescents in their article. The authors noted the scarcity of health education information available in ASL for adolescent females on topics of “body image, physical activity, nutrition, puberty, and relationships” (p. 45). The authors noted the importance of providing accessible health information for this population so that informed decision making could be realized.

Looking internationally, Chininthorn, Glaser, Tucker & Diehl (2016) studied sources of health information and modes of health information distribution in Cape Town, South Africa. Using semi-structured interviews with 23 Deaf people and 10 health professionals, the authors identified four modes of health information distribution: organizations that serve Deaf individuals, health professionals who are hearing, interactions with friends and community, and media communications. The authors noted that respondents had a preference for health information to be delivered in ASL, to incorporate role plays, drama, and other desired learning preferences, and the use of graphics with simple text. The authors concluded that designing a health information app that incorporated preferred learning styles of Deaf individuals has great potential to reach Deaf audiences.

Finally, Ryan & Kushalnagar (2018) explored the potential for eHealth platforms to improve communication with health providers and to provide better access to health information for deaf individuals who use ASL. Using national data from the HINTS-ASL survey, the authors set out to investigate in a sample of 515 deaf people whether deaf individuals who engaged on social media/network sites were more likely to communicate with healthcare providers through the internet or through email. The authors concluded that those respondents who were engaged in social media/network health activity were three times more likely to communicate with health providers through electronic means. The authors noted the potential of using eHealth platforms for increased engagement of health-related information.

Legal Mandates for Effective Communication in Healthcare

In the United States, Deaf individuals and their companions have legislated rights to communication access in healthcare settings. Three federal civil rights laws mandate equal access to and equal participation in health care services for any qualified individual with a disability. Those three anti-discrimination laws are: Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990 (Titles II and III), and Section 1557 of the Patient Portability and Affordable Care Act of 2010.

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 was the first law in the nation to prohibit discrimination based on disability. The law states that “no otherwise qualified individual with a disability in the United States…shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance…” (29 U.S.C. § 794). This law applies to hospitals, nursing homes, mental health centers, human service programs, and other healthcare organizations or employers that receive financial assistance from any federal department or agency, including the U.S Department of Health and Human Services (US HHS, 2006, para. 1-2). This act also applies to medical services received from a Medicare or Medicaid provider, as Medicare is a federally-conducted program and Medicaid is a joint federal-state program.

Americans With Disabilities Act of 1990

The Americans with Disabilities Act of 1990, often referred to as “the ADA” , is another federal civil rights law that prohibits discrimination based on disability in employment (Title I), state and local government services (Title II), and in places of public accommodation (Title III). Health care agencies that are run by state and local governments are covered under Title II; health care organizations that are run by private businesses or non-profit organizations are covered under Title III. Health care agencies include, but are not limited to hospitals (including the emergency room, surgery, inpatient and outpatient services, and more), doctor’s offices, clinics, nursing homes, pharmacies, psychologists’ offices, dentists, and chiropractors. The basic mandate of the ADA is that any person with a qualified disability is entitled to equal services. For healthcare providers, this means effectively communicating with Deaf people. The term “effective communication” is defined legally as communication that is as effective with people who are deaf as communication with those who are hearing (U.S. DOJ, 2014). In other words, when communicating with a Deaf person, messages must be two-way and delivered, received, and understood in order for them to be “effective”. For example, the use of note-writing with a Deaf person who prefers to use a sign language interpreter to discuss complex health matters would not be considered effective; neither would asking a Deaf person to read an Informed Consent form if they did not have the English proficiency to fully comprehend it. Effective communication takes place through the use of auxiliary aids and services, such as a “qualified sign language interpreter, oral interpreter, cued-speech interpreter, or tactile interpreter; real-time captioning; written materials; or a printed script" (para. 5). The law defines "qualified sign language interpreter" as "someone who is able to interpret effectively, accurately, and impartially, both receptively and expressively using any necessary specialized vocabulary" (para. 5). For sign language interpreters working in health care settings, this implies that interpreters should be skilled in the languages of the Deaf patient and the providers and be knowledgeable of setting-specific terminology, processes, and protocols. This includes medical terminology, roles of healthcare providers, healthcare protocols (informed consent, medical interview, etc.), mandated reporting responsibilities and more. Individual states are left to determine how they further define what a "qualified" sign language interpreter means, with some states establishing licensure laws to specify qualifications and/or mandate interpreters to adhere to either organizational or state codes of professional conduct. States that adopt licensure laws for sign language interpreters typically have a governing board or body that regulates the profession on a state level and may take part in grievance procedures if interpreters are suspected to have violated the law.

In addition, auxiliary aids and services can also include technologies, such as captioning, videophones, and VRI services. The Department of Justice (DOJ) specifies performance standards that must be met when using VRI. These include:

> 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 (para. 10).

The DOJ emphasizes that *all* of these performance standards must be met to enable Deaf patients and healthcare providers to communicate effectively via VRI services.

Companions. According to the ADA, when it comes to effective communication, both Deaf patients and their "companions" are covered under the law. The DOJ defines "companion" as "any family member, friend, or associate of a person seeking or receiving an entity's goods or services who is an appropriate person with whom the entity should communicate" (para. 19). This may include the Deaf parent of a hearing child, a Deaf spouse of a patient, or other relative or friend who might accompany the patient. Ineffective communication can occur if the patient *or companion* "experiences a real hindrance, because of her disability, which affects her ability to exchange material medical information with [the] healthcare providers" (para. 20).

Adults and Children as Interpreters. The responsibility for providing effective communication, including interpreters, falls squarely on the shoulders of covered entities (health care providers, agencies, organizations). These covered entities cannot require that a Deaf patient ask a family member, friend, child, or companion to interpret for them. The Department of Justice lists only two situations upon which a covered entity can ask a companion to interpret. They are:

> (1) In an emergency involving an imminent threat to the safety or welfare of an individual or the public, an adult or minor child accompanying a person who uses sign language may be relied upon to interpret or facilitate communication only when a qualified interpreter is not available; (2) in situations ***not*** involving an imminent threat, an adult accompanying someone who uses sign language may be relied upon to interpret or

> facilitate communication when a) the individual requests this, b) the accompanying adult agrees, and c) reliance on the accompanying adult is appropriate under the circumstances. This exception does ***not*** apply to minor children (para. 21).

The DOJ makes it clear that covered entities cannot ask an adult accompanying a patient to interpret if they have reason to believe that the adult lacks impartiality or effectiveness (para. 20). Moreover, reliance on a family member, friend, or other companion to interpret does not guarantee patient privacy or that the patient's personal health information will be protected.

Primary Consideration and Undue Burden. When deciding on auxiliary aids and services, Title II covered entities must give "primary consideration" to the choice of aid or service that is requested by the Deaf person. Title III entities are encouraged to "consult with the person with a disability to discuss what aid or service is appropriate" (para. 23-24). Efforts should be made to honor the patient's choice unless it would result "in a fundamental alteration or in an undue burden" (para. 25). Undue burden as defined by the ADA is "significant difficulty or expense" (para. 25). If it is determined that there is undue burden with a particular aid or service, the health care provider must find another effective aid or service that does not cause undue burden (para. 25). The DOJ acknowledges that undue burden will vary according to entity and circumstance, but written justification must be provided when making a determination of undue burden (para. 25).

Section 1557 of the Patient Portability and Affordable Care Act of 2010

Section 1557 of the Patient Portability and Affordable Care Act of 2010, also known as the "ACA" prohibits discrimination based on "race, color, national origin, sex, age, or disability in health programs or activities that receive Federal financial assistance or are administered by an

Executive agency or any entity established under Title I of the ACA" (U.S. HHS, 2017, para. 5). Consistent with other federal civil rights laws, Section 1557 extends to:

> every health program or activity that receives HHS funding, every health program or activity administered by HHS, such as the Medicare Part D program, and the Health Insurance Marketplaces and all plans offered by issuers that participate in those Marketplaces. Covered entities may include hospitals, health clinics, health insurance issuers, state Medicaid agencies, community health centers, physician's practices and home health care agencies (para. 13).

Section 1557, like the other federal laws mentioned, mandates effective communication for Deaf individuals through the provision of auxiliary aids and services. Also, consistent with the ADA Title II standard of "primary consideration", Section 1557 "must honor" the patient's preferred choice of aid or service "*unless* the covered entity can demonstrate that an equally effective alternative means is available or that the chosen means would fundamentally alter the program or present an undue financial or administrative burden" (HHS, 2016, para. 12).

Chapter 3: Community Profile and State Historical Health Data

Thus far, a broad review of the literature has been presented, including a discussion of the health disparities and healthcare access barriers of Deaf ASL users, and an explanation of the legal rights to effective communication for Deaf individuals in healthcare settings. Now, attention turns narrowly to the research setting- the state of Rhode Island. What follows is a profile of the community. Understanding the history of the problem within its context, having knowledge of organizations and institutions and how they are structured, and understanding relationships between different groups will assist readers in orienting the research problem to its setting. Following the profile, a review of historical health data of the Rhode Island Deaf community is provided, along with a discussion of Rhode Island legal complaints alleging Title III ADA violations.

Community Profile

Rhode Island is the smallest state in the nation (ri.gov, 2021). Despite its diminutive size by area, it is the second-most densely populated state behind New Jersey, with a total population of 1,097,379 according to the U.S. Census (2020). Geographically, Rhode Island comprises one of six states contained within the region known as New England. It borders Massachusetts to the north and east, Connecticut to the west, and the Atlantic Ocean to the south. It also shares a maritime border with New York (ri.gov, 2021). The state is divided into 39 cities and towns amongst five counties. The most populated county is Providence County, which encompasses the state's capital city, followed by Kent, Washington, Newport and Bristol Counties (U.S. Census Bureau, 2020). See Figure 1.

Figure 1

Counties Map of the State of Rhode Island (World Atlas, 2022)

Based on Rhode Island's population of just over 1 million people, about 1 in 5 people or 213,671 individuals are believed to have some degree of hearing loss in at least one ear (RICDHH, 2022a). This figure accounts for about 20% of the state's population. This estimate includes those people who may not ascribe to a cultural view of Deafness and may identify as hard of hearing, deaf-blind, late-Deafened, or other embodied flexible and fluid identity related to hearing loss. For purposes of this investigation, focus will be on a subset of this population, mainly those who use American Sign Language as their primary language of communication and who view their Deafness as a source of cultural identity. These individuals may also possess additional intersecting identities that could include but not be limited to those of gender, race, class, sexual orientation, disability, or other embodied identity.

It is unknown how many individuals in Rhode Island are Deaf ASL users. There is no reliable data source that exists to identify the exact number of people who are Deaf users of sign language in the state. As most communities look to the U.S. Census to determine the number of users of a given language within a particular geographic area, "the U.S. Census Bureau does not recognize ASL as a language, nor sign languages as a language group" (Simmons, 2020, para. 9). In the most recent U.S. Census in 2020, no question items were included to ascertain whether a person was deaf specifically (Daily Moth, 2020) or what the language preferences of deaf people were. The Census Bureau does administer a separate questionnaire called the American Community Survey (ACS), which is randomly sent to three and a half million homes annually (Daily Moth). This survey does include a language and disability question. However, the Census Bureau has been clear that the information collected on language use in the ACS "is not designed to identify ASL users"…and is "not able to provide separate data about ASL use" (Daily Moth, 2020, para. 11). Aside from the Census, any surveillance tools that ask about deafness prevalence alone will not provide reliable data on ASL usage either. Because not all deaf individuals use ASL, “Deafness and ASL usage cannot be conflated” (Mitchell et al, 2006, p. 7).

To add, there is no current data mechanism that accurately and comprehensively captures the geographic location of Deaf ASL users in the state. As many Deaf individuals tend to reside near schools for the Deaf, it is estimated that most Deaf ASL users in Rhode Island live in communities in or around the state’s capital city of Providence. It is within this geographic catchment area that the Rhode Island School for the Deaf is located, along with state agencies and community service providers that primarily serve Deaf individuals. This does not imply that Deaf ASL users live *only* in and around the metro Providence vicinity. Rather, it is hypothesized that many Deaf sign language-using individuals settle near schools for the Deaf as these institutions serve as “cultural hubs”, providing vocational, social, and recreational opportunities beyond graduation. This trend has been shown in numerous other communities across the United States (Moore & Levitan, 2016) and is used here in the absence of any reliable published data.

In addition to the Rhode Island School for the Deaf, the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH) is located in Providence. Established in 1977 and restructured in 1992, RICDHH serves as the principal state agency and central resource for Deaf, Deaf-Blind, hard of hearing, and late-deafened individuals in the state. It is considered an Executive Branch state agency and is one of 11 state commissions or offices serving Deaf individuals in the country that is structured in this way (NASADHH, 2009). The agency is governed by a Board of Commissioners appointed by the Governor. Per state statute, the 11-member Board consists of five individuals who are Deaf and use American Sign Language, one individual who is deaf and does not use sign language, three individuals who are hard of hearing, and two individuals that are hearing. As a self-determining body, the agency represents the needs of Deaf, Deaf-Blind, hard of hearing, and late-Deafened individuals in the state. This includes advocating for improved quality of life, lobbying for legislation, administering a sign language interpreter referral service, and other mandates as charged by the state legislature. Per statutory requirements, the Commission also has four standing committees which focus on education, employment, healthcare, and telecommunications. Finally, as of 2022, the agency employs four full-time staff and four contractors.

Also serving the interests of Deaf and hard of hearing individuals in Rhode Island is the Rhode Island Association of the Deaf (RIAD). This non-profit organization is an affiliate of the National Association of the Deaf (NAD), which is the nation's "premier civil rights organization of, by, and for deaf and hard of hearing individuals in the U.S." (NAD, 2022, para. 1). The organizational objectives of RIAD are to:

> advocate for and facilitate positive change in the quality of life for the Rhode Island Deaf Community by working to improve awareness, conditions, and opportunities for its members in all aspects of life: Civic, Economic, Social, Academic, and Recreational and to represent the Rhode Island Deaf and Hard of Hearing community population at the national level through the National Association of the Deaf (RIAD, 2017, art. 2).

Likewise, the Rhode Island Registry of Interpreters for the Deaf (RI RID) is a non-profit organization which serves as the professional organization for sign language interpreters in the state of RI. As an affiliate chapter of the national Registry of Interpreters for the Deaf (RID), the mission of the organization is to:

> increase the access to communication of the Deaf and Hard-of-Hearing communities by improving the quality and quantity of sign language interpreting services available. RI RID works collaboratively with all like-minded organizations to raise awareness about

> issues important to the Deaf, Hard-of-Hearing, and interpreting communities. RI RID is an organization and is primarily supported by its members. RI RID serves to provide a locally-based network of peer support for its membership and acts as a liaison to the national level for its members (RI RID, n.d., para. 2).

In terms of health, the Executive Office of Health and Human Services (EOHHS) is the executive department state agency responsible for ensuring "access to high quality and cost effective services that foster the health, safety, and independence of all Rhode Islanders" (RI EOHHS, 2021, para. 2). EOHHS is responsible for managing the following departments: the Department of Health (RIDOH), the Department of Human Services (DHS), the Office of Healthy Aging (OHA), the Office of Veteran Services (VETS), Children Youth and Families (DCYF), and Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH), all of which have a role in delivering health services to state residents. The Rhode Island Department of Health is also responsible for the licensing of healthcare facilities and healthcare professionals in the state, through their licensing unit. Included among these professions is sign language interpreting. The profession is governed by a 5-member board (3 certified interpreters, 2 Deaf consumers) charged with carrying out the duties and responsibilities as defined in the state's interpreter licensure law, Rhode Island General Laws, Chapter 5-71. Some of these responsibilities include evaluating qualifications of new interpreter applicants and investigating persons engaging in practices which violate the provisions of the licensure law.

In addition, there are 20 hospitals in Rhode Island, four of which are government hospitals, offering general, medical, and surgical services (OfficialUSA.com, 2022). To the author's knowledge, there are no staff sign language interpreters employed at any of the hospitals in RI. Interpreter service provision is conducted through contracts with private interpreter agencies, direct booking with freelance interpreters, requests to the interpreter referral service at RICDHH for freelance interpreters, or through contracts with Video Remote Interpreting (VRI) providers. RICDHH administers a statewide interpreter referral service that operates during state agency business hours. Of importance to note, the RICDHH interpreter referral service does not have interpreters on staff to deploy to medical or other assignments across the state; rather, the service connects healthcare organizations, insurance companies, or other requesters to independent, freelance interpreters, who use their own discretion to accept or deny requests for their services. This model of interpreter provision differs from private interpreter agencies, who may employ staff interpreters and can deploy them to healthcare facilities when requested and available.

Finally, unlike other states across the country, Rhode Island does not have designated state-employed nor community-based case management professionals with linguistic and cultural expertise to assist Deaf Rhode Islanders with healthcare management issues. Likewise, while several community organizations employ Community Health Workers (CHWs) for other linguistic minority groups (Spanish and Portuguese, for example), RI does not employ any CHWs who can communicate directly with Deaf patients and can assist with health system navigation and health education (Dunklee, 2021). Moreover, RI does not have a dedicated ombudsperson with ASL expertise to assist Deaf Rhode Islanders with healthcare access complaints, understanding insurance plans and options, and learning about healthcare-related rights.

Historical Health Data on Rhode Island’s Deaf Community

An online search of previous studies conducted on the health of Deaf persons in Rhode Island resulted in a handful of peer-reviewed journal articles. Topics of these studies included mental health interventions (Sarti, 1993); access to mental health services and crisis intervention (McEntee, 1993); physician perspectives and practices when working with children with hearing loss (Dorros, Kurtzer-White, Ahlgren, Simon, & Vohr, 2007); and outcomes of the state universal newborn hearing screening program (Vohr, Carty, Moore, & Letourneau, 1998). To the author's knowledge, there have been no published investigations of healthcare access barriers of Deaf ASL users, specifically, in Rhode Island. Hence, this investigation also seeks to fill a gap in the literature on a state level.

In addition to peer-reviewed journals, a search for pre-existing health data was conducted across Deaf consumer and provider organizations in Rhode Island. State agencies, and specifically the Rhode Island Department of Health and the Rhode Island Commission on the Deaf and Hard of Hearing were included. Evidence of eight documents referencing either health surveillance activities, community needs assessments, community learning topics, or poster presentations could be found in the years ranging between 1982 and 2021. Of importance to note is that none of these inquiries explored the healthcare access barriers of Deaf ASL users exclusively. Likewise, while the Rhode Island Department of Health has conducted research over the years relating to healthcare barriers through its Disability and Health Program, many of those studies are unpublished manuscripts that the researcher could not obtain. Moreover, it is unlikely that data on Deaf ASL users would be disaggregated from a larger sample of participants who were considered to have a disability within those studies. Therefore, what follows are the results of the eight investigations mentioned.

1982-2003

The first study, conducted in 1982 by Panarace, consisted of a two-phased assessment determining independent living skills and physical and mental health care access, respectively, of Deaf and hard of hearing people. The second-phase survey found that “one-fifth (N=24) reported problems with health care providers, primarily relating to barriers in communication” (Martell, 2008, p. 6.). Although only 12% (N=13) of respondents reported accessing mental health services, one-third indicated they had a need for individual and/or family counseling. Participants also reported a need for the public to become more knowledgeable about deafness and the needs of Deaf and hard of hearing people (p. 6).

These assessments were followed by a 2003 study of 252 people with “communication impairments” conducted by the Rhode Island Department of Health (Panarace, Kim & Hamel, 2003), which confirmed previous findings. Results of this survey found that “34% of all respondents reported not always understanding their doctor or assistant when they communicate, with 19% reporting that they only sometimes or never understood communications with their doctor” (p. 6).

2004

In 2004, the Healthcare Committee of the Rhode Island Commission on the Deaf and Hard of Hearing initiated a research project “to determine barriers that interfere with consumer access to health and mental health services and issues impacting providers of health and mental health services" (Martell, 2008, p. 1). Key community stakeholders participated in task groups to provide input on the development of two surveys: one to assess consumer need, the other to evaluate provider knowledge and capacity. This project was formalized in 2007, when RICDHH partnered with Rhode Island College (RIC), one of three public institutions of higher education in the state, to carry out the community needs assessments. RIC researchers, Martell & Phillips, “collected data from a sample of 91 Deaf and hard of hearing residents through a written survey that was distributed at Deaf community events, through service providers, and via the mailing list of the Hearing Loss Association of Rhode Island" (2008, p. 6). Initial findings of the consumer survey indicated that while most respondents were generally satisfied with health care services available to them, many indicated that they experienced communication difficulties during healthcare appointments. Deaf respondents indicated less satisfaction with health care services than hard of hearing respondents as "only 32% agreed that they have access to qualified medical interpreters and 20% agreed they have access to qualified mental health interpreters" (p. 7). It was also noted that "more than half of the respondents who use ASL as a preferred method of communication reported that they were not provided with an interpreter" (p. 7). Also, additional qualitative data gleaned from follow-up interviews revealed five general barriers to healthcare access of this population: communication difficulties in making appointments; communication difficulties in accessing interpreters and communicating with healthcare professionals; lack of cultural and linguistic competency of healthcare providers; lack of accessible and culturally affirmative health education programs; and lack of mental health interventions to meet the needs of Deaf and hard of hearing people.

2009-2014

Three additional health-related surveillance activities were conducted by RICDHH between the years of 2009-2014. The first was a short questionnaire in written English disseminated to medical providers at 13 healthcare facilities in Rhode Island in 2009 to assess training needs in working with Deaf and hard of hearing patients. A total of 21 responses were received. Respondents were asked to indicate whether or not they knew how to request sign language interpreting services, had certified interpreters on staff, had live and remote captioning services available, and had assistive listening devices and technologies that serve Deaf and hard of hearing patients. An overwhelming majority of respondents indicated that they required training on Deaf Culture and hearing loss issues, as well as communication strategies with people who are Deaf and hard of hearing. In addition to this medical provider survey, consumer health education needs were assessed with a short survey in 2011. Although the researcher was unable to access findings related to this study, personal communication with former RICDHH staff indicates that "responses were gathered to inform priorities for future health education topics and programming" (S. Florio, December 14, 2021). Finally, in 2014, an online survey was conducted by a former Chairperson of the RICDHH Board of Commissioners and Brown University medical school student to examine the physician-patient relationship of Deaf and hard of hearing people in Rhode Island. Created as part of a medical clerkship project in conjunction with the RI Department of Health, the survey consisted of 16 multiple-choice English questions administered to physicians across the state, with the goal of creating learning resources to improve access and care of Deaf and hard of hearing patients. While sources indicate that 400 responses had been received as of March 2014, no documentation could be accessed by the researcher to discern final results of the surveillance activity (RICDHH, 2022b).

2020

The most recent studies on the health of Deaf and hard of hearing individuals in RI was conducted in 2020 by the Healthcare System Transformation Project (HSTP) under RICDHH. This project, funded by a grant from the RI Executive Office of Health and Human Services, included the development and dissemination of two surveys: one for the Deaf and hard of hearing community to assess health outcomes, satisfaction of healthcare services, and patient-provider relationships; and the other to assess cultural and linguistic competency of healthcare workers across the state. In addition to surveys, the project staff used video testimonials to capture qualitative data from consumers about barriers to healthcare and about ways in which the state's healthcare systems could better serve them.

The first survey, for consumers, was developed in conjunction with the Center for Deaf Health Equity at Gallaudet University and is considered the first-ever comprehensive bilingual (American Sign Language and English) online health survey in the state of Rhode Island. The sample consisted of 105 Deaf and hard of hearing adults, ages 18-86 years old, with a mean age of 49 years. Of the sample, 21% preferred using spoken language, 45% preferred using sign language, and the remaining 34% were bilingual users. While a majority of the respondents reported that the healthcare services received within the 12 months preceding the survey were satisfactory, respondents who preferred using spoken language "rated their physicians as having high patient centered communication care compared to respondents who preferred using sign language or both sign language and spoken language" (RICDHH, 2022c, p.1). Over half of the sample reported "not acceptable PCC experiences" as evidenced by Patient Provider Communication (PCC1) scores, which measure the quality of patient-physician communication. As for health outcomes, 72% of respondents were classified as either obese or overweight based on Body Mass Index (BMI) calculations and several medical conditions[3] were noted in the sample. Among other medical conditions, 43% of respondents indicated having depression or anxiety, 34% hypertension, 35% arthritis, 26% diabetes, 22% lung disease or asthma, and 11% cancer. Within this group, 38% used interpreters and 42% communicated in either sign language or English, while 20% used writing or texting to communicate with healthcare providers (Ibid, 2021). In addition, 41% of the sample indicated they were somewhat confident, a little confident, or not confident at all in filling out medical forms. Furthermore, during the 12 months preceding

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[3] Participants were asked to self-report diagnoses that their healthcare providers had told them.

the survey, 35% of respondents indicated they went to the emergency room or urgent care to receive services. Most respondents in the sample (67%) who use interpreters in health settings prefer on-site interpreting services over Video Remote Interpreting (VRI) services.

The second survey, designed to assess the cultural competency of healthcare workers, consisted of an open and closed-ended 52-question online survey in English, adapted from a pre-existing survey created by Hoang, LaHousse, Nakaji, and Sadler (2010). The sample consisted of 1,559 respondents who were either incumbent and future healthcare workers across the state of RI. Among the professions represented in the sample were: physicians, physician assistants, nurses, nurse practitioners, licensed psychologists, occupational therapists, physical therapists, pharmacists, social workers, respiratory therapists, dental hygienists, hospital administrators, and more. Out of the sample, 78% identified as female, 22% identified as male, and 0.26% identified as non binary. Age of respondents ranged from 18-90+ with the largest number of respondents in the 50-59 age group (484), followed by the 60-69 age group (417) and the 40-49 age group (347). Results of the survey indicated knowledge gaps in several areas: understanding the role and function of sign language interpreters; awareness of legal mandates to provide effective communication to Deaf and hard of hearing patients; and familiarity with basic strategies to communicate with Deaf and hard of hearing patients, among other deficiencies in knowledge (RICDHH, 2022d).

As a final component of the data collection portion of the 2020 RICDHH health project, qualitative data was obtained from video testimonials of Deaf community members. The sample consisted of 9 testimonials (4 females, 5 males), which aimed to capture community perspectives on healthcare access and services in Rhode Island. Using content analysis to determine prominent themes in the digital narratives, the following concerns were noted: providers’ lack of awareness of communication access needs of Deaf patients; lack of systems to notate interpreting needs in electronic medical records; the use of family members to interpret for Deaf individuals in the absence of a qualified interpreter; lack of trust in providers' ability and willingness to secure interpreters or to meet communication access needs of Deaf people; lack of continuity in care with healthcare staff turnover; deferment and delays in response by providers when Deaf individuals seek health care knowledge; evasion of responsibility of providers in securing interpreters; and overall lack of understanding, empathy, and responsibility demonstrated by healthcare providers when considering the communication needs of Deaf patients (RICDHH, 2022e).

2021

Lastly, a community learning project conducted by Bailey (2021), explored parent perspectives on medical interpreter usage for their children's healthcare appointments. As part of the project, a questionnaire was distributed to 58 people resulting in 20 responses. Parents of children, ages 6-18, who attended the Rhode Island School for the Deaf comprised the sample. Results of the questionnaire were as follows: all parent respondents (100%) indicated that their child had a primary care pediatrician; 90% of parent respondents felt that it was very important that their child knows what is happening at a doctor's appointment, while 10% indicated that it was moderately important. Despite the fact that most parents felt that it was important for their child to have communication access during doctor's appointments, 50% of parent respondents indicated that they communicate for their child during healthcare encounters; 15% of parents indicated that there is no communication for their child during appointments; 10% of parents use voice to communicate during doctor's appointments; and 20% use sign and voice to communicate during appointments. When parents were asked whether they knew how to request a sign language interpreter, 45% indicated yes, 25% indicated no, and 30% responded “I don’t know”. The investigator of this community learning project reports that survey results were used to engage parents in collective dialogue about the importance of Deaf children having both linguistic and communication access to healthcare appointments. Strategies for improving access were discussed with parents, along with the sharing of community resources (RICDHH, 2021f).

Rhode Island Legal Complaints: Alleged Title III ADA Violations

In addition to the pre-existing state data on health and healthcare access, an online search of Rhode Island case law pertaining to Deaf individuals and communication access in healthcare settings revealed at least three legal complaints filed between the years of 2007-2022. According to ada.gov, a complaint was filed with the United States Department of Justice (DOJ) against Roger Williams Medical Center in Providence, Rhode Island on alleged ADA Title III violations in 2007. A settlement agreement was reached between parties and remedial actions were ordered. These actions included provision of auxiliary aids and services, establishment of processes to obtain sign language and oral interpreters, making available telecommunications devices for Deaf and hard of hearing patients, publishing and disseminating written policies regarding effective communication with persons who are Deaf or hard of hearing, as well as other remedial actions (DOJ, 2007).

In 2017, a lawsuit was filed by The National Association of the Deaf (NAD), the Rhode Island Disability Law Center, and Eisenberg & Baum, LLP on behalf of the Rhode Island Association of the Deaf and two Deaf Rhode Island residents against a Providence area hospital corporation (National Association of the Deaf, 2017). In the case of Rhode Island Association of the Deaf et al v. Lifespan Corporation et al, the plaintiffs alleged violations of the Americans with Disabilities Act (ADA) and other federal civil rights laws for failing to provide effective communication. Both complainants in the case identified as Deaf ASL users and argued that they were repeatedly deprived of effective communication due to the hospital's failure to provide qualified on-site sign language interpreting services. According to the complaint, hospital staff had asked at least one of the plaintiffs to provide her own interpreter; other times, hospital staff denied interpreting services when requested by plaintiffs due to cost; still other times, staff's failure to provide in-person interpreters was attributed to the lack of interpreters in the area. According to an article in the Providence Journal (Mulvaney, 2017), the lawsuit states that "repeated failure to provide effective communication…is not due to a lack of interpreters in the area. Rather it is due to the hospital's unwillingness to pay interpreters a fair wage, leading many interpreters to refuse to work there" (2017, para. 19). While the lawsuit states that Video Remote Interpreting Services (VRI) were offered on an occasional basis to the complainants, the services were rarely or never effective.

In addition, the lawsuit alleged that the Rhode Island Association of the Deaf (RIAD) and its members had encountered similar struggles in accessing healthcare at Lifespan healthcare facilities. At the time the lawsuit was filed, the acting President of RIAD stated:

> On behalf of the Rhode Island Association of the Deaf, the members of this organization and the Deaf community have experienced tremendous stress and suffered frustration in receiving unclear and unequal communication access from hospitals in Rhode Island. Since the Americans with Disabilities Act (ADA) was passed in 1990, hospitals in Rhode Island have neglected Deaf patients by providing inadequate access to accommodations which infringe on Deaf individual's basic human rights. We expect swift changes to communication access and infrastructure in Rhode Island (NAD, 2017, para. 5)

The most recent legal complaint in RI involving healthcare access and Deaf individuals was in January of 2022. According to the Department of Justice, U.S. Attorney's Office, District of Rhode Island (2022), an investigation began after a complainant alleged that Brown Dermatology, a private medical practice with multiple locations in RI, failed to provide sign language interpreters for her family member who is Deaf. Instead, the complainant alleged that the medical practice forced her to interpret the family member's medical appointments, which she was unqualified to do. Upon further investigation by the DOJ, it was revealed that Brown Dermatology failed to provide the Deaf patient with sign language interpreters for at least 12 other medical appointments between 2018-2021 and had failed to provide at least seven other Deaf patients with sign language interpreters for effective communication during appointments. According to justice.gov (2022), a settlement agreement was reached, remedial actions were ordered, and monetary penalties were incurred by the medical practice.

Chapter 4: Theoretical Framework

Given the state's historical health data and documented legal complaints, it is apparent that healthcare access barriers experienced by Deaf ASL users remain as much of a reality today as they did 40 years ago. In order to arrive at solutions to long-standing problems, new frames must be invoked to examine issues from new perspectives. By using different theoretical frameworks, new meaning and interpretations can be derived from old data, new solutions and strategies can be imagined, and new critical research questions can arise. Ultimately, these will lead to a better understanding of the problem.

Structural Violence

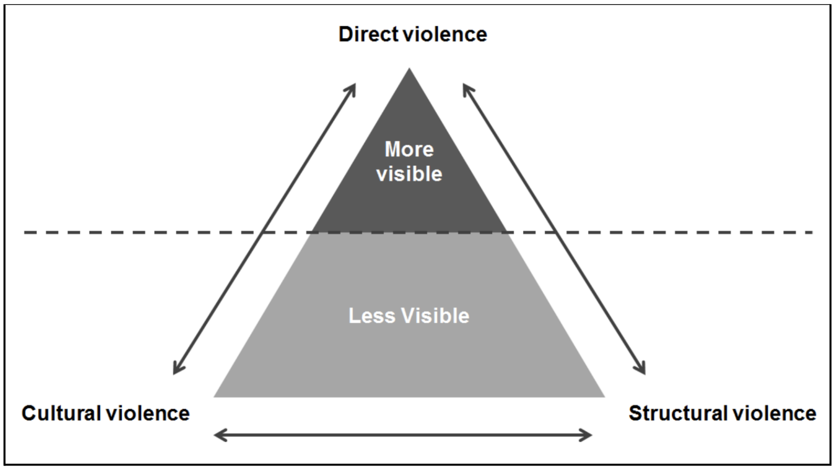
Two main theories undergird this research study. They are human rights theory, which has previously been discussed, and structural violence theory. Structural violence "refers to the multiple ways in which social, economic, and political systems expose particular populations to risks and vulnerabilities leading to increased morbidity and mortality” (Center for Health Equity Research Chicago, 2020, para. 1). Johan Galtung, a Norwegian sociologist and founder of the field of peace and conflict studies, first coined the term “structural violence” in his 1969 article “Violence, Peace, and Peace Research". According to Galtung, violence can be classified in three forms: direct, structural, and cultural. Direct violence is the form that is most often recognized. It involves a perpetrator and a victim, clearly defined actors. Examples of direct violence may include murder, domestic violence, or some form of physical or psychological destruction. On the other hand, structural violence is invisible, unintended, and indirect. It involves structures that prohibit individuals from getting their basic human needs met. Galtung defines basic needs as: “survival (negation: death, mortality); wellness (negation: misery, morbidity); freedom (negation: repression); and identity (negation: alienation)” (Galtung & Fischer, 2013, p. 35-36). Structural violence is embedded in systems and is characterized by unequal power relations which can lead to unequal life chances. This happens when the dominating forces within systems constrain the choices and decision-making ability of less powerful individuals in that system, preventing them from achieving their full life potential. This discrepancy between the potential and the actual lies at the heart of structural violence. Finally, Galtung describes cultural violence as “those aspects of culture, the symbolic sphere of our existence- exemplified by religion and ideology, language and art, empirical science and formal science (logic, mathematics)- that can be used to justify or legitimize direct or structural violence” (p. 41). Cultural violence can take the form of attitudes, prejudices, and symbols, such as flags and military parades, for example. Galtung points out:

> Cultural violence makes direct and structural violence look, even feel right, or at least not wrong. Just as political science is about two problems, the use of power and the legitimization of the use of power, violence studies are about two problems, the use of violence and the legitimation of that use (p. 42).

Hence, these three forms of violence- direct, structural, and cultural, comprise what Galtung describes as the Triangle of Violence. Each of these forms are interdependent and have the power to transfer and influence one another. See Figure 2.

Figure 2

Galtung's Triangle of Violence (Nyman & Provozin, 2019)



Lastly, Galtung explains that violence of any kind- direct, structural, or cultural, inflicts harm on the bodies, minds, and spirits of individuals, leaving "deep wounds, *trauma*, that is difficult to heal" (p. 35). Violence and its resulting trauma have the capacity to perpetuate to the point where "*violence breeds violence* within and among actors, in space and over time" (p. 35).

Galtung's theory of structural violence has been applied widely to the fields of public and global health. Physician and medical anthropologist, Paul Farmer, is most widely known for applying a structural violence lens to his work in these disciplines. In his memoir, "Pathologies of Power: Health, Human Rights, and the New War on the Poor" (2005), Farmer recounts stories of his work in impoverished communities across the globe, including Haiti, Rwanda, Latin America, and Russia, and links these cases to broader analyses of health and human rights. In doing so, he illustrates the pathogenic effects of social inequalities on health and the dynamics of human suffering. For Farmer, structural violence is viewed "as a broad rubric that includes a host of offensives against human dignity like poverty, racism, and other forms of violence...deriving from "historically given and economically driven conditions" (p. 8-9). These assaults on dignity are not haphazard, he argues. Rather, they are determined by underlying matrices of power and domination. He writes:

> Human rights violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm (p. 7).

Hence, Farmer implores us to consider critical issues of health quality and health access and how underlying "pathologies of power " determine their distribution and ultimately lead to differing standards of care.

Finally, using a human rights framework, Farmer intimates that structural violence and its concomitant assaults on dignity constitute structural *violations* of human rights. This view is shared by both Ho (2007) and Rodriguez-Gomez & Russell (2021). Likewise, Farmer's text challenges conventional views on human rights, which have historically prioritized civil and political rights over social and economic rights. He argues, "civil rights cannot really be defended if social and economic rights are not" (p. 9). Aligning with the tripartite view that all human rights are interdependent, interrelated, and indivisible, Farmer claims that violations of social and economic rights *often permit* the violations of civil and political rights. He states:

> Whatever term we use to describe our times, we cannot avoid looking at power and connections if we hope to understand, and thus prevent, human rights abuses. And when we look at and listen to those whose rights are being trampled, we see how political rights are intertwined with social and economic rights, or, rather, how the absence of social and economic power empties political rights of their substance (p. 16-17).

Farmer goes on to state that in order to protect these rights, a robust analytical model is needed to capture the complexity of structural violence and the suffering that accompanies it. Reductionist analyses must be avoided, he argues. Instead, he advocates for an analysis that is "geographically broad and historically deep" (p. 42). This takes into consideration the interconnectedness of actors within systems and how events throughout history have shaped their relations.

In addition to Farmer, several other researchers have applied a structural violence frame to their analyses of health in communities all over the globe. The majority of these studies have been focused on low and middle-income countries in the Global South (Muduredzi, Eide, Braathen, & Stray-Pedersen, 2017; Joseph Jauhula, Arvind & Gadan, 2021; Teixeira & DaSilva, 2019). Macassa, McGrath, Rashid, & Soares (2021) report that there have been eight studies published in Europe between 2010 and 2021 that incorporated a structural violence framework. Studies from the Global North (mainly US and Canada) have focused on immigrants (Page-Reeves, Niforatos, Mishra, Regino, Gingrich, & Bulten, 2013), indigenous communities (Hole, Evans, & Berg, 2015); homeless individuals (Bowen, 2016); elderly people (Banerjee, Daly, Armstrong, Szebehely, Armstrong, & Lafrance, 2012), patients of a community health center (Mead, 2017); and other members of marginalized communities (Saleem, Vaswani, Wheeler, Maroney, Pagan-Ortiz, & Brodt, 2016). Of importance to note is one study from South Africa by Swannack (2018), entitled “Deaf Futures: Challenges in Accessing Health Care Services”. The study, written by a Deaf author, sheds light on the structural violence experienced in accessing health care by six Deaf people in Cape Town, South Africa. To this researcher’s knowledge, Swannack’s investigation is the only study to date that centers on healthcare access of Deaf individuals using a structural violence lens.

Critics have argued that the concept of structural violence is nebulous, complex, and broad, lacking in specificity on how “structure” should be defined. In their article, “As Natural as the Air Around Us: On the Origin and Development of the Concept of Structural Violence in Health Research”, De Maio & Ansell (2018) state, “if structural violence can manifest in so many different ways, it ceases to be a useful explanatory force, becoming instead a “black box” that can be invoked in almost any situation” (p. 754). The authors contend that using structural violence in combination with a larger theoretical framework is the only way to achieve a clear understanding of what “structure” means in a given context. Another criticism that the authors point out is the lack of an existing metric to quantify structural violence. Because of this lack of measurability, the authors presume that “structural violence will likely continue to be invoked in general ways as an explanatory concept rather than a measurable phenomenon” (p. 755). Despite these criticisms, the authors feel that structural violence is an important concept and its use in research on health equity is merited. Compared to the more passive term “social determinants of health”, structural violence has the power to spark moral outrage in its naming of structures as the root cause of health inequities. “By naming structural violence, researchers can push the need to identify the root cause of health inequities and thus channel our efforts to raise awareness of how very different the world could be” (p. 756).

Finally, Galtung's concepts of structural and cultural violence show how a neoliberalist framework contributes to undue suffering and health inequities. Neoliberalism "refers to a body of ideas and practices that emphasize individual responsibility and freedom (to choose); supports deregulation, privatization and fiscal discipline; and assumes that the more allocation of tasks done through markets rather than states, the better" (Biebricher & Johnson, 2012, pp. 202-203). Despite its claims to the contrary, this political and economic framework ignores the fact that "life chances are systematically unevenly distributed, and structural factors loom large as a determinant as to how successful one will be at life in general" (p. 208). Therefore, the assumption that equality is built into the system "is not borne out of reality" (p. 208). More concerning is that this framework has become moralized to the point that it has become a part of the American cultural framework. "Neoliberalism, far from taking the world and individuals as they are, fashions them after its own image—albeit with the complicity of subjects in these processes" (p. 206). This process of "inculcation, subjectification, and internalization" (p. 205) is an example of cultural violence at work.

Chapter 5: Methodology

This study seeks to answer two research questions: what are the healthcare access barriers experienced by Deaf ASL users in Rhode Island? What are the structural barriers that constrain agency of Deaf individuals in their attempts to access healthcare? This chapter describes the methodology used to answer those questions. The chapter begins with an explanation of Action Research. This is followed by a discussion of the study's design, rationale, procedure, data collection, and data analysis methods.

Research Methodology: Action Research

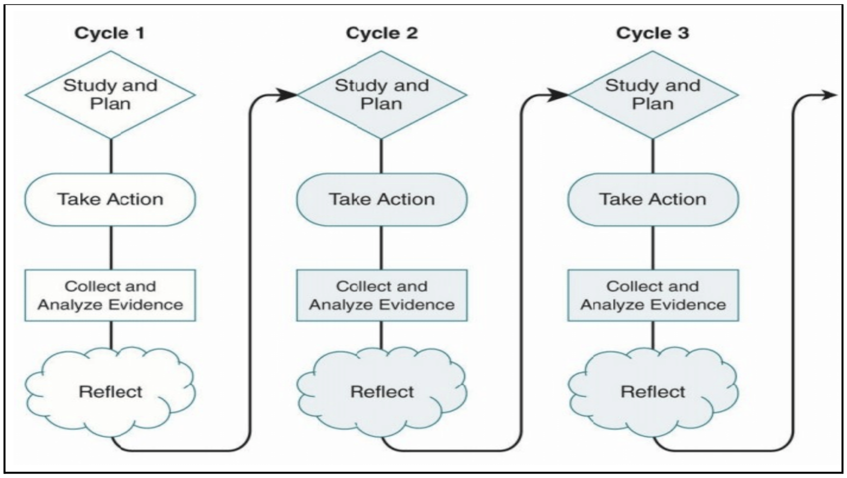
Action Research is an alternative research methodology that is designed to identify problems and develop solutions. This method differs from traditional research in that it seeks outcomes that are actionable and practical as opposed to theoretical and abstract. As Action Research uses the “community as the unit of analysis”, it is well-suited to analyzing this research problem (Ozanne & Anderson, 2010, p. 1).

Social psychologist, Kurt Lewin, has been credited as the originator of Action Research since first coining the term in 1944. Lewin is known for his innumerable contributions to social, organizational and applied psychology, organizational development, and change management, among other fields. In Lewin’s view, research should not be hypothesis driven or done in pursuit of knowledge alone; rather, it should have practical application, be an iterative process, and should be conducted in real world settings (Lewin, 1946). In addition, Lewin postulated that behavior is a function of both the person and the environment. As such, he believed that when trying to understand a problem, the whole system must be taken into account. This includes incorporating multiple stakeholder voices to construct a complete picture of the issue at hand. By engaging in creative inquiry with a variety of stakeholders and examining an issue from multiple angles, solutions to deep-rooted problems can be uncovered. In this way, community members, which include the researcher-practitioner, work collaboratively to arrive at solutions to complex social problems that impact the lives of everyday people.

Action Research can be conceptualized as a series of spiralized steps or cyclical action called “Look-Think-Act” (Stringer & Aragon, 2021). The first step of this research routine involves observing what is happening, gathering relevant information, and describing the situation. The second step involves analyzing and exploring what is happening and why. The final step involves devising a plan based on the analysis of the information, implementing the plan, and assessing the effectiveness of the plan. This process of learning, evaluating, and improving repeats until a problem is resolved. See Figure 3.

Figure 3

The Process of Action Research Adapted from Riel (Mertler, 2017)



This research study serves as the first step in the Action Research cycle. The aim is to gather relevant information about the barriers Deaf ASL users face when attempting to access healthcare in Rhode Island. The next step will involve community-engaged analysis of the research findings to understand what is happening and why. Finally, a community-led plan can be implemented that critically addresses barriers to accessibility and strategically leverages partnerships to confront and overcome the larger structural forces that prevent Deaf individuals from getting their healthcare needs met. This cycle of learning, evaluating, and reflecting continues until the problem has improved.

Study Design and Rationale

This investigation utilized mixed methods in its design, combining both quantitative and qualitative elements with data obtained from the state of Rhode Island. Primary data was obtained through 11 anonymous participant online surveys consisting of both open-ended and closed-ended questions. This design was used to enhance understanding of the research problem and to extend the breadth and depth of inquiry. There is a paucity of data on the topic of healthcare access of Deaf ASL Users at the state or community level. The studies that do exist have rarely included multiple stakeholder perspectives at one given point in time. Moreover, this design coincides with Farmer's notion of a "geographically broad and historically deep" analysis, emphasizing the need to understand the interconnected relations of actors in an environment. Similarly, this design complements a Lewinian view of Action Research, which calls for a methodology that is more participatory in nature and includes multiple stakeholder perspectives.

Data Collection: Surveys

The 11 anonymous participant online surveys were developed using Qualtrics technology and were disseminated to the following stakeholder groups: (1) Deaf ASL users, (2) RI licensed physicians and nurses, (3) RI licensed sign language interpreters, (4) college and university students studying healthcare professions in RI, (5) RI state legislators, (6) RI advocacy professionals, (7) RI interpreter accountability board, (8) RI-serving sign language interpreter agencies or referral service agencies, (9) healthcare administrators at RI hospitals, (10) interpreter service departments at RI hospitals, and (11) patient relations office at RI hospitals. Groups were identified according to ability to inform one or both of the study's research questions. In order to be eligible for participation in the study, all participants were required to be 18 years of age or older and meet additional criteria according to the stakeholder group. Duration of surveys varied from 3-50 minutes, depending on the group surveyed. Data was collected over a three month period from January to March, 2022. No compensation was provided to participants. Of importance to note is that the data collection period coincided with the COVID-19 pandemic, which may have influenced participant responses.

Recruitment

Participants were recruited using a variety of methods. For Deaf ASL Users, a recruitment announcement in both ASL and English was disseminated via RICDHH's electronic mailing list and posted on the agency's social media channels (Facebook, Twitter, and Instagram). Additional Deaf participants were recruited by direct email using publicly available email addresses found on websites of organizations that serve Deaf individuals. Still more Deaf participants were recruited by attending Deaf community organizations. This was done in an effort to capture potential responses from participants who did not have access to technology to complete the online survey. In this case, the Qualtrics survey for Deaf ASL Users was downloaded, printed, copied, and disseminated to consenting Deaf participants at various community organizations with interpretation services available.

Next, licensed physicians and nurses were recruited using a publicly available email list on the RI Department of Health's website. This method of recruitment was also used to request participation from state licensed sign language interpreters and members of the state interpreter accountability board, whose publicly available email addresses also appear on the RI DOH website. In addition, an online announcement in both ASL and English was disseminated via email to members of the RI Registry of Interpreters for the Deaf (RI RID) to solicit additional participation of interpreters. Similarly, state legislators were recruited by using publicly available email addresses listed on the State of Rhode Island General Assembly website. Advocacy professionals were recruited using publicly available email addresses on websites for advocacy organizations that serve Deaf ASL Users in the state. Recruitment of college or university students studying healthcare professions was done by emailing the deans or department heads of healthcare programs across the state requesting that they disseminate the announcement to their students. Additional recruitment of students was done by contacting student activities offices at colleges and universities requesting that an announcement be posted on social media channels. Still more students were recruited by sending an announcement via social media directly to college student health organizations. Finally, recruitment of hospital administrators, hospital patient relations offices, and hospital interpreting service departments or social work offices responsible for the hiring or procurement of interpreter services were recruited using publicly available email addresses on hospital websites. In instances where no public email address could be found, a telephone call was made to the facility to request an email address. Furthermore, for healthcare administrators, emails were sent to the local chapter of the American College of Healthcare Executives (ACHE-RI) to request dissemination of the survey to members and to post on social media channels.

Overall, each stakeholder group was given a period of three weeks to respond to their respective surveys with the exception of Deaf ASL Users. Four weeks was allotted to this group to account for dissemination of paper surveys at community organizations. Each stakeholder group was emailed an initial recruitment announcement followed by scheduled reminders. For recruitment materials, see Appendix B.

Procedure

Upon full review and approval from the Institutional Review Board at St. Catherine University, anonymous participant online surveys were developed using Qualtrics technology. Development of the survey tools for Deaf ASL users and state-licensed sign language interpreters were done with the assistance of a Certified Deaf Interpreter (CDI) so that survey questions and answer options were conveyed in American Sign Language with native or near-native fluency. Surveys were pre-tested before dissemination to avoid any technical issues from arising later that could influence the data collection process.

Due to the large scope of this study, survey dissemination was implemented in three phases. Phase One surveys were disseminated to the healthcare community in early January (RI licensed physicians and nurses, hospital interpreter service departments, hospital patient relations offices, and hospital administrators); Phase Two surveys were disseminated to government entities in mid-January to early February (legislators, advocacy professionals, and state interpreter accountability board); Phase Three surveys were disseminated to college students and Deaf community members in early to mid-February (Deaf ASL Users, licensed sign language interpreters, interpreter agencies and referral service providers, and college and university students). Qualtrics survey response data was stored on a password-protected computer, back-up hard drive, and cloud. All electronic and paper files related to the study were stored in a locked file cabinet in the researcher’s home office and were accessible only to the researcher and her advisors.

Data Analysis

All Qualtrics quantitative and qualitative survey data was collected and exported to Excel for analysis. For quantitative data, Qualtrics was used for descriptive statistics, including demographics, frequency, and percentage. Qualitative data was analyzed using content analysis methods. Patterns and themes were identified in the data, coded, and counted. Both deductive and inductive approaches were used to identify thematic categories. Survey responses were used to inform answers to research questions.

Chapter 6: Results

The aim of this research study is to identify barriers to healthcare access of Deaf ASL users in Rhode Island. This investigation also seeks to uncover the social and structural forces that constrain agency of Deaf ASL users in their attempts to access healthcare. To accomplish these aims, surveys were distributed to several community stakeholder groups to collect perspectives on this topic. The results of each stakeholder survey follow. The chapter is structured so that sociodemographic statistics are presented first in visual form, followed by both quantitative and qualitative responses of survey participants.

Surveys

A total of 556 people responded to surveys from the following stakeholder groups: Deaf ASL Users who seek or receive healthcare services in RI (n= 42); RI licensed physicians and nurses (n= 410); RI licensed sign language interpreters (n= 40); college and university students studying healthcare professions in RI (n= 36); RI state legislators (n= 15); advocacy professionals who work with Deaf ASL Users in RI (n= 6); RI state interpreter accountability board (n= 4); and interpreter agencies or referral service agencies serving RI (n= 3). Surveys were also disseminated to three other stakeholder groups at 16 of the 20 hospitals in RI, but did not return any responses. Those groups were hospital administrators (n= 0), interpreter service departments or social work departments responsible for hiring interpreters (n= 0), and patient relations offices (n= 0).

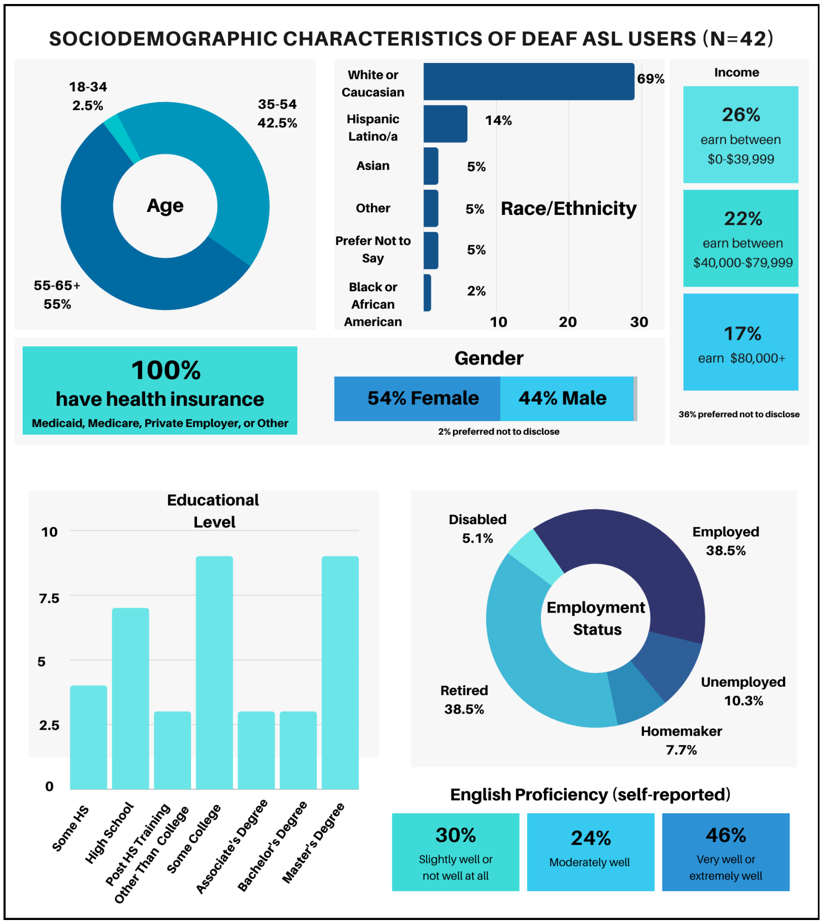
I. *Deaf American Sign Language Users*

Sociodemographic data was collected from 42 Deaf American Sign Language Users, with a mean age of 56 years old, who completed either an online survey in ASL and English or a paper survey in English during the last three weeks of February and the first week of March,

2022. Survey completion rate was 60%. See Figure 4 for a visual breakdown of demographic data.

Figure 4

Sociodemographic Characteristics of Deaf ASL Users



Communication Preferences, Appointment Making and VRS, Non-Emergent and Emergent Healthcare Encounters, VRI, Complaint Processes, and Healthcare Navigation and Perceptions. When respondents were asked how many times they had made an appointment to see a medical provider in-person in the last three years, 36% reported 1-3 times; 31% reported 4-6 times; 5% reported 7-9 times; and 28% reported 10+ times. The type of provider most often seen by respondents was a primary care provider (60%) followed by a specialty provider (30%).

The majority of the sample uses Video Relay Services (VRS) to schedule medical appointments with 57% of respondents reporting that they either sometimes or always experience problems with VRS. The problems most often noted included the receptionist or healthcare provider hanging up or dissatisfaction with interpreters.

Relating to interpreting services, about 93% of survey participants indicated they have sometimes, often, or always requested an in-person sign language interpreter for their healthcare appointments in the last 3 years. However, 73% of respondents said that providers sometimes, rarely, or never agreed to provide an interpreter. When asked why in-person interpreters were not provided, respondents indicated that providers had told them there was no interpreter available (39%), Video Remote Interpreting (VRI) is good enough for them (17%), patient should bring their own interpreter (14%), patient should bring a family member (14%), office cannot afford an interpreter (11%), or patient should pay for the interpreter (6%). About 87% of respondents reported that they have sometimes, often, or always arrived at medical appointments in the last 3 years to find no interpreter there, despite having requested interpreting services. When respondents informed providers that no interpreter was present, responses from providers included (as reported by respondents):

> ***Respondent 1.*** 1) I thought you would bring an interpreter with you 2) I tried to call and they said no interpreter is available 3) sorry no interpreter 4) you would need to reschedule the colonoscopy for the other day (of course I flatly refused).
>
> ***Respondent 2.*** Response varied. "Let me check and get back to you", "I apologize, no interpreter available, we will use VRI", "Hold on, VRI is on its way", etc.
>
> ***Respondent 3.*** I have not heard from the interpreter referral service…

Furthermore, when no interpreter was present for patients' medical appointments over the last three years, 75% of respondents indicated they sometimes, often, or always continued the appointment without an interpreter. Before leaving the providers' office, 75% of respondents said they communicated to the provider that they needed an interpreter for all future appointments. Likewise, 68% of respondents said they told their providers to include information in their electronic medical record about needing an interpreter for future appointments before leaving a provider's office in the past 3 years.

When asked about VRI services, 48% of participants reported that they sometimes, often, or always used remote interpreting services for medical appointments in the past three years. However, 88% of respondents who have used VRI indicated they were somewhat satisfied or not satisfied at all with the services provided. When respondents were asked about reasons for dissatisfaction, 26% reported equipment and technical issues; 26% reported that healthcare staff did not know how to operate equipment; 21% reported difficulty understanding the interpreter. In addition, 69% of respondents said they have expressed to a medical provider that they preferred an in-person interpreter instead of VRI. When respondents have made those preferences known to providers, responses have been (as reported by respondents):

> ***Respondent 1.*** I apologize but it is the office/medical office policy that we provide VRI. I ask you not to discuss this further with us.
>
> ***Respondent 2.*** I'm not sure we can get somebody, it's easier getting a VRI because we already have it set up.
>
> ***Respondent 4.*** We will try but VRI is the better choice for YOU!

For emergent health care needs, 42% of respondents reported they have sometimes, often, or always received health services in the emergency room in the past 3 years. While 54% of respondents indicated they have often or always requested an in-person interpreter for the ER in the past 3 years, an in-person interpreter has rarely or never been provided, according to 73% of respondents. When respondents have communicated their preference for in-person interpreters instead of VRI, 58% of the participants reported that the request has rarely or never been granted.

Overall, 84% of respondents have sometimes, often, or always been dissatisfied with the lack of communication access with medical providers in RI the past three years. Despite this, 61% of respondents say that they are somewhat likely or not at all likely to file a complaint. Over a quarter (27%) of respondents indicated that they do not know where to file a complaint against a medical provider for communication access issues. In addition, over half of respondents (56%) shared that they are either slightly confident or not confident at all navigating the healthcare system in RI. Almost half of participants (49%) feel that RI does not do an effective job in providing communication access to healthcare. Moreover, 58% of respondents have little or no trust at all that the healthcare system in RI meets their communication needs. Finally, 69% of respondents shared that medical providers or receptionists have sometimes, often, or always made them feel humiliated, fearful, insulted, or indignified because of their communication access needs.

To conclude the survey, Deaf ASL Users were offered the opportunity to share any additional comments about healthcare access barriers in RI. After analysis of qualitative responses, the following themes emerged: more education and awareness is needed on behalf of both medical providers and consumers, the need for more interpreting resources, including education on when VRI services are appropriate to use with patients. Responses illustrate:

> ***Respondent 1.*** They [providers] are mostly ignorant about providing communication access. They don't keep up with technologies that we use for

access and they don't invest their resources in improving communication access resources.

Respondent 2. I sometimes feel frustrated, upset, and mad. If an in-person interpreter was not provided when I requested one, I was told by providers to write notes back and forth. Also, I have not been satisfied with VRI services because of equipment/technical issues and healthcare staff did not know how to operate the equipment.

Respondent 3. Even though I have requested interpreters, I have not been provided with interpreting services for my appointments in 3 years. I repeatedly have to ask my doctor if they sent the fax request to RICDHH. There is a lack of communication between provider, consumer and interpreter referral…. I have been repeatedly frustrated. I have had no interpreter for more than 3 years. Receptionists have repeatedly told me to get my own interpreter and pay for it myself. I feel I have had all I can take.

Respondent 4. Barriers experience [sic] usually when a hearing family member is the one in need of medical attention or has a medical appt and I am not able to access or communicate, participate in discussion for the treatment or care for the family memeber [sic].

Respondent 5. We need access, health system to be aware of Deaf HH needs in RI. We cry for help!

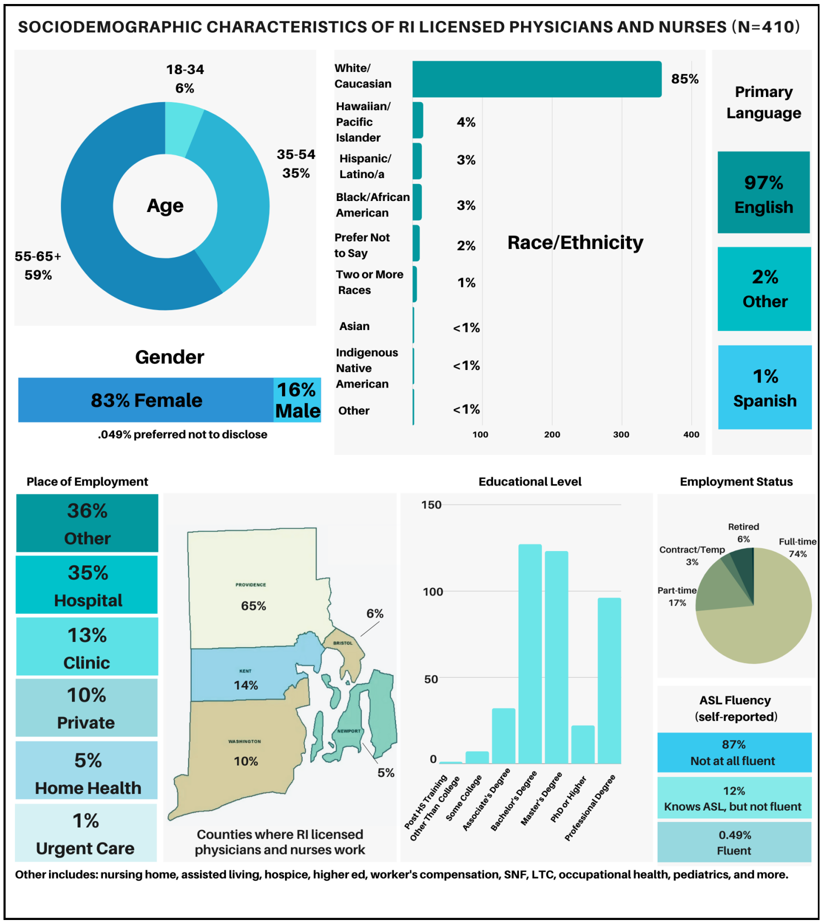
II. *Rhode Island Licensed Physicians and Nurses*

In response to the call for participants, 410 licensed physicians and nurses in Rhode Island completed an online survey in English during the first three weeks of January, 2022.

Survey completion rate was 65%. Mean age of respondents was 50 years old. See Figure 5 for a visual breakdown of demographic data.

Figure 5

Sociodemographic Characteristics of RI Licensed Physicians and Nurses



Communication with Patients, Experience With Interpreters, VRI, Patient-Centered Care, Cultural Competency, Training. When respondents were asked about their familiarity with the communication access needs of Deaf patients in healthcare settings in RI, 68% reported that they were either slightly familiar or not familiar at all. Likewise, almost three-quarters of respondents (74%) said they were either slightly familiar or not at all familiar with the legal requirements for effective communication with Deaf patients. Over half of the respondents

(52%) shared that they were slightly aware or not at all aware that there are Deaf healthcare professionals (doctors, dentists, nurses, and more). When asked if lipreading is a reliable way to communicate with Deaf patients who use sign language, 13% either agreed or strongly agreed; 33% neither agreed nor disagreed. Likewise, when asked if writing back and forth is a reliable way to communicate complex health matters with Deaf patients who use sign language, 14% of respondents either agreed or strongly agreed; 28% neither agreed nor disagreed. Out of those licensed physicians and nurses who have worked with a Deaf patient in the past three years, 67% have never, rarely, or sometimes used teach back methods to confirm if Deaf patients understood them.

When respondents were asked how often they had worked with an in-person sign language interpreter to communicate with Deaf patients over the past three years, 68% of the sample reported that they have rarely or never worked with an in-person interpreter. About 44% of the sample indicated that they were slightly familiar or not at all familiar with the role of a sign language interpreter. Furthermore, when respondents were asked if they knew how to request an in-person sign language interpreter in RI, 65% reported that they were slightly familiar or not familiar at all with how to make such a request. More than half of respondents (56%) replied that they were slightly aware or not at all aware of Video Remote Interpreting (VRI) services. An overwhelming majority of the sample (87%) has never or rarely participated in training to learn more about working with Deaf patients who use sign language. Likewise, 93% of the sample reported that their college or training programs slightly prepared them or did not prepare them at all to work with Deaf patients who use sign language.

To conclude the survey, state licensed physicians and nurses were offered the opportunity to share any additional comments about healthcare access barriers of Deaf ASL users in RI. After analysis of qualitative responses, six main themes emerged: lack of awareness, education, training, and preparation to work with Deaf patients; lack of interpreter capacity and resources; barriers to accessibility and accountability with the onus of access bearing on the consumer; cost of communication access services; use of family members in the absence of qualified interpreters; and use of technology to access interpreter services. Responses illustrate:

> ***Respondent 1.*** Not enough information given or taught to nurses. Extensive education regarding foreign languages, but not enough about sign language.
>
> ***Respondent 2.*** I feel that some facilities might choose not to admit a patient since there would be such a large communication barrier. Informed consent is required yet not knowing how to do that without an interpreter would be impossible. Need to learn about it in adn program. Not really prepared for this scenario.
>
> ***Respondent 3.*** I truly wish that there was a way for the federal government to enforce ADA instead of leaving it up to D/HOH individuals. Many healthcare facilities are clueless that they have an obligation to ensure communication access. It has improved from what I have experienced but it [sic] there is still a learning need. I also find that if insurance does not cover interpreter costs, it can lead to strained relations with the patient. If a third party, like the federal government or insurance, were to pay for interpreting - it would eliminate all of that.
>
> ***Respondent 4.*** I wonder about the appropriateness of making a small PCP office responsible for sign language interpreter [sic] vs the patient's insurance company, especially since an insurance company such as RIBCBS claims PCMH certification!!!

Respondent 5. Working the night shift makes it worse trying to get help with communication/interpreters, inadequate training on scarce equipment and trying to find and use the equipment when it is needed is challenging.

Respondent 6. It's always a struggle with a deaf patient. We end ip usung [sic] a family member most often which is not ideal.

Respondent 7. Cost of hiring interpreter is high for small practices. Insurance does not always cover. Also very hard to get interpreter for sick visits on short notice. Would love to know how to access video relay for urgent visits.

Respondent 8. We consistently have problems schedulling [sic] and accessing both video and in-person ASL interpreters. The only time I have felt we gave good care for a deaf patient who signed was when my one resident who signs was able to provide the care.

Respondent 9. In pediatrics it is often deaf parents who bring in hearing children. The children are the interpreters.

Respondent 10: Biggest obstacle for providing an interpreter is the cost. The cost for an interpreter exceeds the office payment and even more so if they have a two hour minimum bill. The hospital has remote video capability but patients seem to prefer an interpreter present.

Respondent 11: I have a patient who requires a CDI and often I have had both a CDI and ASL interpreter in the room at the same time. We have used video interpreters before using the language line iPad but he does not know ASL well. I am still confused about the differences between CDI and ASL and how to access these.

Respondent 12. Often need to use family members that accompany the deaf pt. [sic] Equipment is lost, not working or just dont [sic] have time to wait for people to look for it. An in person [interpreter] is never available.

Respondent 13. The burden put on deaf clients to educate their caregivers is unacceptable.

Respondent 14. In addition to ASL issues there is very little education on deaf culture limiting culturally competent providers.

Respondent 15. In my experience, providers are completely unaware of their obligations to provide care to the Deaf community according to Section 1557 of PPACA. If obtaining a qualified interpreter us [sic] inconvenient for them, they simply tell the patient they can't see them.

Respondent 16. I learned that it is very difficult to place deaf patients with mental health issues in the community because most providers are not able to communicate with deaf persons. This can delay discharge from the hospital and is unfair to the patient.

Respondent 17. Several hospitals have minimal (mostly nonexistent) services on overnight. In spite of the laws protecting individuals; difficulty in arranging last minute in person sign language interpreter.

Respondent 18. I have never asked a deaf patient if they were satisfied with interpreter services, but I will now.

Respondent 19: Survey was eye opening, wonder how many patients who are hearing impaired may not receive necessary services die to the many barriers!

Respondent 20: Nurses still rely on family members to interpret when they should not.

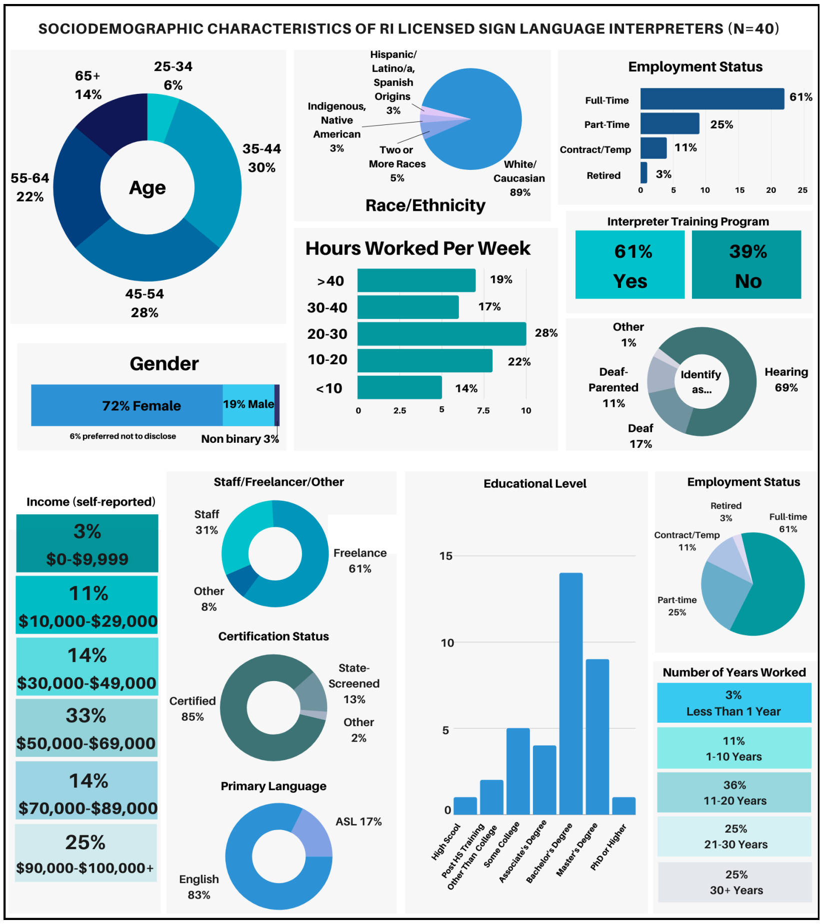
Respondent 21: They are the forgotten patient.

III. Rhode Island Licensed Sign Language Interpreters

Responses were gathered from 40 Rhode Island licensed sign language interpreters who completed an online survey in American Sign Language and English during the last three weeks of February, 2022. Survey completion rate was 85%. Mean age of respondents was 50 years old. See Figure 6 for a visual breakdown of demographic data.

Figure 6

Sociodemographic Characteristics of RI Licensed Sign Language Interpreters



Medical Assignments, Referral, Medical Providers, Payment, COVID-19/Telehealth. More than half (66%) of state licensed sign language interpreters are either somewhat comfortable or extremely comfortable accepting medical assignments in RI. However, when asked how often they had actually interpreted medical assignments over the past three years in RI, 72% of respondents said they sometimes, rarely, or never did. Of those that have provided services, interpreters indicated they worked in the following settings: primary care or physicians office (19%); specialized outpatient care (17%); rehabilitation center (13%), home health care (10%), urgent care (9%); outpatient surgery center (9%); acute care hospital (9%); other (7%); long-term care (4%); and hospice (3%). When asked reasons for not interpreting medical assignments over the past three years, over half of respondents (58%) indicated Other reasons. These included the need for stable hours and a preference to work all day assignments; prior experiences of vicarious trauma; never receiving requests or referrals for assignments; and refusal to work for interpreter agencies that have contracts with hospitals because they feel their practices may be unethical. Of the remaining sample, 23% of respondents reported that they were unavailable to interpret in medical settings; 15% reported delayed payment from providers was a reason they did not accept medical interpreting work; and 4% indicated that medical environments were not a desired work setting.

When asked about qualifications to work in medical settings, 72% feel either very qualified or extremely qualified. Yet, over three-quarters of respondents (77%) reported that they would be interested in additional training. If provided with additional training, over half (53%) said they would accept more work in medical settings. Likewise, 50% of interpreters reported that they would be very likely or extremely likely to accept more work in medical settings if paid more promptly. Similarly, 23% of interpreters indicated they would accept more work in medical settings if more information was provided to them at the time of request. Qualitative responses illustrate:

> ***Respondent 1.*** More information of what I am going there to interpret for. Is it a [sic] initial discussion? Follow up? plan [sic] for a procedure? We get little to no information about the [sic] what the job will entail, which for interpreters, is not a good way to conduct business. The more we know prior to, the more energy we can focus on interpreting and how to translate the information, rather than to understand it and then interpret it. It puts another demand on us in the moment that will hinder our interpretation or create more room for errors, omissions, and more relying on our clozure skills/prediction skills.
>
> ***Respondent 2.*** Access to CDIs and access to information about illnesses, and treatments, a profile of the patients preferred communication.
>
> ***Respondent 3.*** Onboarding into the system, access to a badge and training on codes that opens doors, employee parking.
>
> ***Respondent 4.*** Accurate information, patient name and reason for visit, info about location of appt (which building, which floor, name of practice or unit within a larger system, accurate needs of consumer reflected in a profile of their communication needs and preferences, obtaining a Deaf Interpreter when a hearing interpreter determines a need for one vs making their own assumptions or judgements)…help with navigating hospitals and larger medical systems in RI, providing correct point of contact who is on site and can meet the interpreter and/or provide help in finding a location or connecting with the right departments, correct billing info and following up when interpreters are not paid. Informing

> providers and their responsibility to pay interpreters and making sure to get the correct billing contact.

In addition, respondents were asked to describe the quality of their working relationships with both the state interpreter referral service and private interpreting agencies. Out of those who work with the state interpreter referral service, 29% of respondents described their relationship as good; 25% said acceptable; 17% said very good; 17% said poor; and 12% said very poor. Out of those who work with private interpreting agencies, 42% of respondents described their relationship as very good; 35% said acceptable; 8% said very poor; 7.5% said poor; and 7.5% said good. When interpreters were asked about their work with healthcare providers, 86% of respondents reported that providers sometimes, rarely, or never consider them as part of the healthcare team. Moreover, 79% of respondents felt that the cultural competency of providers serving Deaf ASL users was either somewhat or extremely inadequate. Also, 68% of interpreters reported that they either sometimes, often, or always have had to explain to a medical provider the legal requirements for effective communication for Deaf patients.

When interpreters were asked about COVID-19, 78% of respondents said they sometimes, rarely, or never provided in-person medical interpreting services at healthcare facilities in RI during the pandemic. Out of those interpreters that have provided in-person interpreting services during the pandemic, 65% of respondents said they were rarely or never provided with Personal Protective Equipment (PPE) during their scheduled appointments. Finally, when asked how confident interpreters were that there are enough available in-person interpreters to work in medical settings in RI, 77% felt slightly confident or not confident at all.

To conclude the survey, interpreters were offered the opportunity to share suggestions on how to improve interpreter-related healthcare access barriers of Deaf patients in RI. Two main themes emerged after analysis of qualitative responses: training and dedicated interpreting staff to meet consumer needs. Responses illustrate:

> ***Respondent 1.*** Staff interpreters and CDI's [sic] and emergency interpreters and CDI's [sic] would provide the best coverage, would learn about cases and share pertinent information and strategies. Also staff interpreters can provide information to medical staff on an as-needed basis. Over time relationships would grow and patients could be assured that their needs will be better met.
>
> ***Respondent 2.*** I work for a VRI company. Medical staff must be taught how and WHEN to use VRI.
>
> ***Respondent 3.*** Establishing a dedicated Medical Health Interpreter position and referral might significantly improve availability.
>
> ***Respondent 4.*** More training for consumers about when VRI is appropriate and ideal, and when in person interpreters are better. More transparency about why assignments are unfilled, providing more flex dates and times, and more communication with consumers when they are filled.
>
> ***Respondent 5.*** The state referral service needs more staff. There needs to be a reorganization and additional staff added to really address this problem.
>
> ***Respondent 6.*** I think there needs to be something done at the state level to declare it a health crisis for Deaf/HOH/DB people due to a critical shortage of qualified access providers including interpreters as well as systemic barriers in the medical systems in RI. One result of that could be to look at the laws that allow insurers to dictate how interpreters are obtained and who those interpreters can be and how they are contracted or paid. Insurers should not be making access

decisions, that should be happening between providers and patients. another [sic] result could be to appoint a liaison of some kind to work on health disparities and access for Deaf patients and assess the issues and then establish pathways to connect and fill in the gaps in appropriate access.

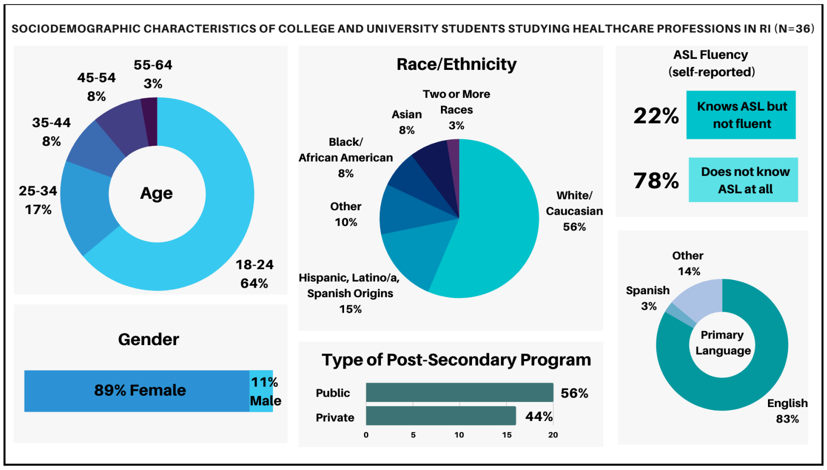
Respondent 7. Have staff interpreter full time at hospital campus during business hours.

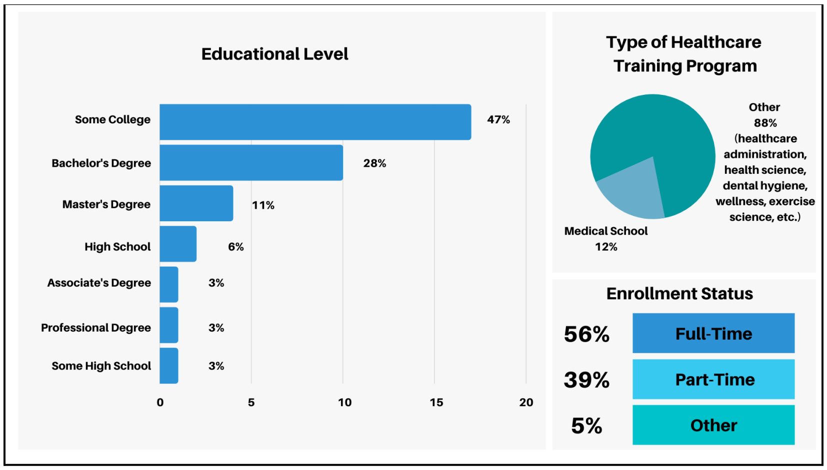
IV. College and University Students Studying Healthcare Professions in Rhode Island

Survey responses were obtained from 36 students enrolled in postsecondary health care programs in Rhode Island. Participants completed an online survey in English during the last week of January and first two weeks of February, 2022. Mean age of respondents was 27 years old. See Figure 7 for a visual breakdown of demographic data.

Figure 7

Sociodemographic Characteristics of College and University Students Studying Healthcare Professions in RI





Experiences With Deaf Community and ASL, Interpreters, Training and Curriculum. The majority of students (81%) indicated that they were either slightly familiar or not at all familiar with the communication access needs of Deaf patients who use sign language in healthcare settings in RI. Over three-quarters of respondents (78%) reported that they have rarely or never interacted with a Deaf person who uses sign language. When asked if there were any Deaf students who use sign language in their healthcare programs, 94% replied no. When students were asked if they would like to see more Deaf students who use sign language in their healthcare programs, 92% replied yes. Of those who replied no, qualitative responses were solicited as to why they would not like to see more Deaf students included in their healthcare programs. One respondent stated:

> A variety of communication barriers exist; I don't need to see them to know that. Having effective tools to aid in communications with all people are essential…I don't see the need to single out one group, other than for this study.

Another respondent cited communication reasons: "I would not know how to communicate with them." Yet another respondent simply stated, "Not interested."

When asked if their college or university program offers sign language classes, over half of respondents indicated that they did not know (53%), while 42% indicated yes and 6% indicated no. Over three-quarters of respondents (78%) said they would be interested in taking a class to learn sign language; 11% said they would not be interested; and 11% said they did not know. Most respondents in the sample (92%) indicated that they have never used a sign language interpreter before. Almost all respondents (97%) are either slightly familiar or not at all familiar with knowing what the requirements are to practice sign language interpreting in the state. In addition, 83% of the sample are either slightly aware or not aware at all of the legal requirements to provide effective communication to Deaf patients who use sign language in RI. Almost all respondents (97%) have received little or no training at all in their healthcare programs on how to work with Deaf patients who use sign language. Likewise, most respondents (97%) have received little or no instruction at all in their healthcare curricula about how to work with Deaf patients who use sign language. Finally, over half of respondents (60%) reported that they would be very interested or extremely interested in learning more about working with Deaf patients who use ASL. Qualitative responses were solicited from students about what they would like to learn about working with Deaf patients who use ASL. Two predominant themes emerged: communication strategies and the learning of ASL. Responses included:

> ***Respondent 1***. How to communicate with them effectively in a way that makes them comfortable and heard.
>
> ***Respondent 2.*** I would like to learn basic communications in ASL to be able to work more closely with our patients who use sign language.
>
> ***Respondent 3***. I think schools should require sign language instead of french [sic] since it is more useful. I would like to learn basic things just to communicate. I do not

have to be fluent but knowing how to say hello and how are you should be basic human knowledge.

Respondent 4. How I can be an ally, communicate effectively and understand their needs.

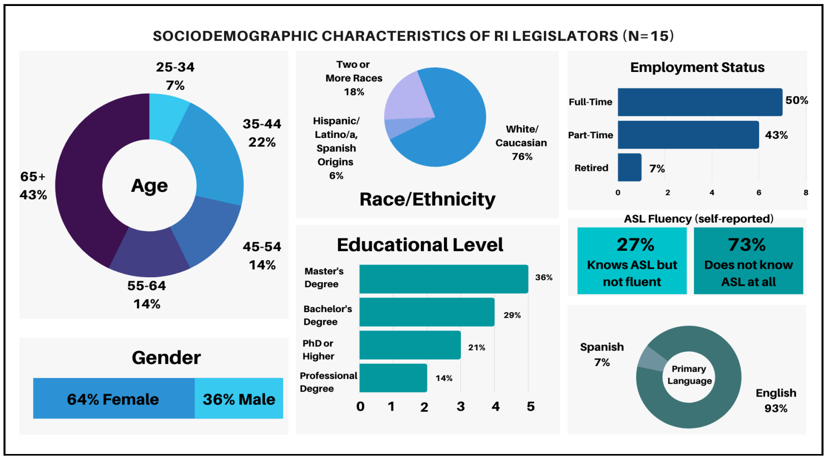
A few respondents indicated they would like to learn more about barriers that Deaf people face, how to obtain interpreter services, what kinds of support are available for Deaf healthcare professionals, and regulatory guidelines and best practices for effective communication.

V. *Rhode Island State Legislators*

Responses were collected from 15 state legislators with a mean age of 56 years old, who completed an online survey in English during the first three weeks of January, 2022. Survey completion rate was 83%. See Figure 8 for a visual breakdown of demographic data.

Figure 8

Sociodemographic Characteristics of RI Legislators



Constituents, Healthcare Access Knowledge, Legislative Support, Training. When respondents were asked about familiarity with the communication access needs of Deaf patients in healthcare settings in RI, 60% replied that they were either slightly familiar or not familiar at all. Over three-quarters of the sample (77%) reported that they have rarely or never met or worked with Deaf constituents who use sign language in their role as a legislator. When legislators were asked how much they knew about the legal obligations of healthcare facilities to provide communication access to Deaf individuals who use sign language, respondents indicated little or some (92%). About 77% of legislators indicated they were either slightly aware or moderately aware of healthcare access barriers of Deaf patients who use ASL in RI. Qualitative responses were solicited from legislators about specific healthcare barriers of which they are aware. Most responses pertained to resource shortages and lack of education and information. Responses included:

> ***Respondent 1.*** The training and licensing systems are not always well funded and there are delays in certifying interpreters.
>
> ***Respondent 2.*** Cost, access, availability and flexibility, understanding of medical staff of appropriate interpreters, lack of trained interpreters for medical appointments, health care literacy for some hearing impaired patients/families, technology to incorporate video interpretation on telehealth, scheduling interpretation.
>
> ***Respondent 3.*** Difficulty obtaining signers.
>
> ***Respondent 4.*** Not enough information for deaf or they [sic] family.
>
> ***Respondent 5.*** Access to interpreters, lack of preparation in healthcare settings for hearing impaired persons.
>
> ***Respondent 6.*** Problems having ASL interpretors [sic] available in ERs and clinics.

One legislator offered this succinct response: “Often, the rights that exist on paper don't happen in reality.”

When legislators were asked how familiar they were in knowing how to request a sign language interpreter to meet with Deaf constituents who use sign language, over three-quarters of the sample (77%) said that they were either slightly or moderately familiar. Most of the legislators in the sample (82%) indicated that they have rarely or never worked with Deaf community members, Deaf organizations, or state agencies that serve Deaf people to introduce or support legislation to improve healthcare access. When asked about support of prior legislation that has addressed Deaf patients’ improved access to healthcare, half of respondents indicated that they have sometimes, rarely, or never supported previous legislation; half indicated they have often or always supported previous legislation. Qualitative responses were solicited from legislators about specific healthcare legislation previously supported. Of those that responded, half could not recall specific bills. Of those that did recall, open captions for movie theaters, interpreter standards, and mandatory coverage for hearing aids were most often noted (none relating to healthcare access was mentioned). Qualitative responses were also solicited about reasons why previous healthcare access legislation was not supported. Responses included:

> ***Respondent 1.*** I will definitely support any legislation to help sign language.
>
> ***Respondent 2.*** I would support any legislation that would improve healthcare access for Deaf patients. I'm not Deaf but have profound hearing loss in one ear. I want to be more proactive in my support and work to improve access for Daef [sic].
>
> ***Respondent 3.*** I support legislation.

Although a bill regarding improved communication access for Deaf patients in healthcare settings had been introduced in the RI legislature in years 2017, 2018, and 2019 (Act Relating to Insurance- Communication Access Services), one legislator responded, “none [bills] have been brought forward.”

Finally, all respondents in the sample (100%) reported that they have rarely or never participated in a training to learn more about working with Deaf constituents who use sign language. Respondents’ interest in training to learn more about working with Deaf constituents showed that 20% were slightly interested, 40% were moderately interested, 20% were very interested, and 20% were extremely interested. To conclude the survey, legislators were offered the opportunity to provide any comments pertaining to healthcare access barriers of Deaf ASL users in RI. Qualitative responses included:

> ***Respondent 1.*** I’ve never seen a training, orientation, or anything like that offered [how to work with Deaf constituents].
>
> ***Respondent 2.*** By participating in this survey I see how I have neglected to do much to work with Deaf residents of Rhode Island. Thank you for raising my awareness.
>
> ***Respondent 3.*** I'd like to understand more about what best practices are in healthcare for hearing impaired and deaf ASL users to better integrate those needs into healthcare legislation and budgeting.

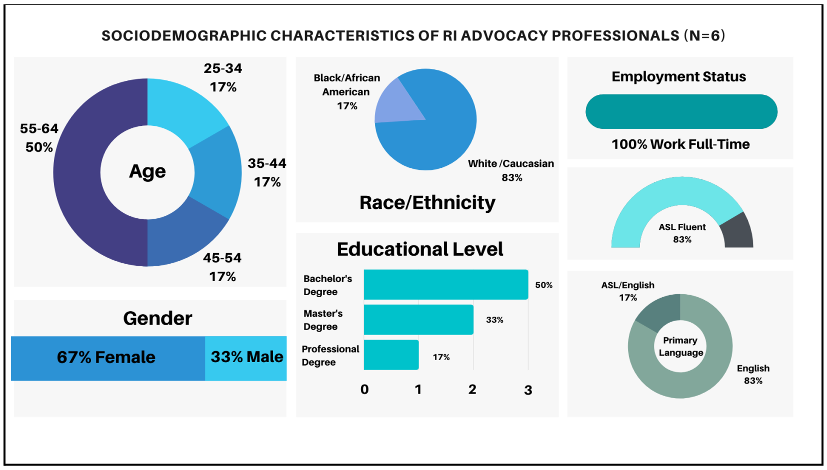
VI. *Rhode Island Advocacy Professionals*

In response to the call for participants, six advocacy professionals completed an online survey in English during the first three weeks in January, 2022. Survey completion rate was 83%.

Mean age of respondents was 49.5 years old. See Figure 9 for a visual breakdown of demographic data.

Figure 9

Sociodemographic Characteristics of RI Advocacy Professionals



Complaints, Communication With Stakeholders, Time and Funding, Pressing Issues. When respondents were asked about familiarity with the communication access needs of Deaf patients in healthcare settings in RI, 83% indicated that they were either very familiar or extremely familiar. Respondents (83%) reported that over the last three years, they have often or always received healthcare access complaints from Deaf ASL users. When asked how often those complaints were resolved, half of respondents said rarely; half said sometimes. Qualitative responses were solicited about the nature of complaints received. One predominant theme emerged from analysis of qualitative responses: lack of primary consideration of the patient's preferred method of communication. The following responses illustrate:

> ***Respondent 1.*** Deaf person's right to request for their first preferred communication mode.

> ***Respondent 2.*** They [providers] refuse to provide ASL Interpreters and only want to use VRI.
>
> ***Respondent 3.*** VRI instead of in person interpreters and refusal to provide.
>
> ***Respondent 4***. Refusal or delay with providing in-person interpreter, use of VRI when in-person was preferred.
>
> ***Respondent 5.*** Use of VRI instead of onsite (live) Interpreters.

A few respondents also attributed complaints to bureaucratic payment processes and providers' lack of awareness of legal obligations to provide effective communication. One respondent summed up their view of the nature of complaints received by stating, "a variety of communication access issues- a never ending cycle!"

When asked how much weekly work time is spent addressing complaints regarding communication access in healthcare settings for Deaf patients who use sign language, half of the sample indicated a little or a moderate amount; half indicated a lot or a great deal. Moreover, all respondents in the sample (100%) felt that organizational funding or staffing often or always precluded them from devoting more time to addressing healthcare access complaints from Deaf ASL users. Respondents also reported that they rarely (67%) have communication with patient advocacy offices, patient relations offices, or risk management offices at healthcare facilities in RI about access barriers of Deaf ASL users. When opinions were solicited on the most pressing issues regarding communication access in healthcare settings for Deaf ASL users, four themes emerged from analysis of qualitative responses: education, consumer choice, advocacy, and resources. Responses include:

> ***Respondent 1.*** Healthcare Offices should be more educated regarding communication access and allow Deaf patients to have a choice with having ASL Interpreters.
>
> ***Respondent 2.*** They [consumers] don't understand their health conditions, treatment plan, medications, and they cannot even advocate for themselves or their children because they don't know what is happening. VRI is not effective for everyone.
>
> ***Respondent 3.*** The community needs guidance on how to file complaints against the medical providers.
>
> ***Respondent 4.*** RI does not have enough interpreters and healthcare professionals may lack information about how to and when to obtain interpreter services.
>
> ***Respondent 5***. Need in person interpreting.

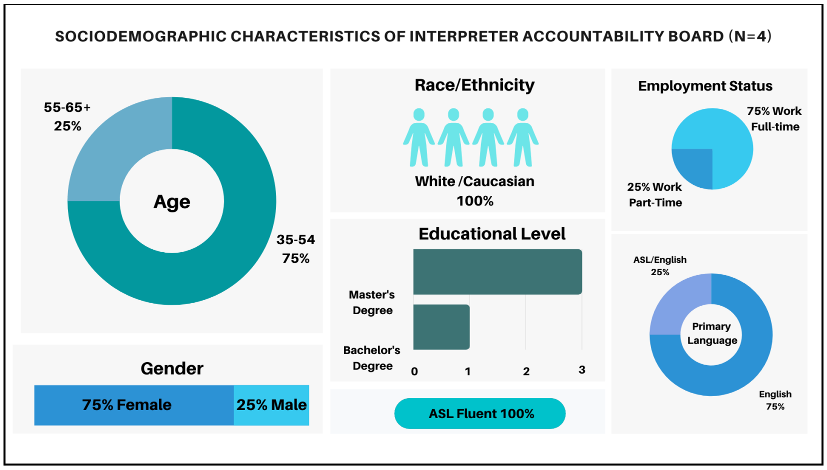
To conclude the survey, advocacy professionals were offered the opportunity to share any additional comments about healthcare access barriers of Deaf ASL users in RI. Qualitative responses indicated that more advocacy is needed on behalf of state agencies that serve Deaf ASL users; hospitals’ decisions to enter into exclusive contracts with private interpreter agencies limit Deaf consumers choice of interpreters; Deaf families who immigrate to RI are often unaware of their communication rights and often do not know how to request an interpreter; linguistic barriers exist for many Deaf ASL users who may not be proficient in English and encounter difficulty in making online requests in English, understanding their illnesses or medications, and reading hospital websites; and advocating for interpreters often falls on the shoulders of the Deaf consumer. One respondent states, “It is a constant challenge for Deaf ASL Users to have to fight to get ASL Interpreters for their medical appointments.”

VII. ***Rhode Island State Interpreter Accountability Board***

Four members of the state sign language interpreter licensure board completed an online survey in English during the first three weeks of January, 2022. Survey completion rate was 75%. Mean age of respondents was 47 years old. See Figure 10 for a visual breakdown of demographic data.

Figure 10

Sociodemographic Characteristics of RI Interpreter Accountability Board



Interpreter Complaints, Roles and Responsibilities, Board Support. All respondents in the sample indicated that they were extremely familiar with the communication access needs of Deaf patients who use sign language in healthcare settings in RI. Moreover, all respondents reported that they either very much understand or extremely understand their roles and responsibilities as members of an accountability board of professionals. Although members who comprise this board are statutorily charged with investigating persons engaging in practices which violate the provisions of the interpreter licensure law, half of the respondents indicated that they are somewhat privy to complaints made against sign language interpreters in RI and half of respondents indicated that they are not really privy to complaints. One respondent offered additional qualitative information pertaining to the complaint process:

> I am made aware by community members, and then I have to follow up with the DOH. They were very clear of their process when we asked: they have a "comittee" [sic] for lack of better words, that reviews the law and the complaint. If the comittee [sic] finds the law to have been violated, it then comes to the board. I have been on the board for over 4 years and have had no complaints come to the board as of yet. I have heard of several community complaints that were submitted. When asked if they cross reference the RID code of professional conduct when reviewing the law. [sic] An assumed no was the answer we recieved [sic].

Furthermore, three-quarters of the sample reported that complaints made against sign language interpreters in RI are never or rarely resolved to the satisfaction of the complainant. In addition, all respondents either disagree or strongly disagree that the governing board of which they are a part effectively carries out its statutory charge. Additional qualitative responses were solicited from respondents on this topic. Predominant themes that emerged from analysis include: lack of political will on behalf of state personnel to conduct meetings according to statute or make recommended changes to legislation or regulations; power dynamics between state personnel and board members; lack of cultural competency of board overseers and state personnel; and lack of transparency, integrity, inclusion, and representation. Responses illustrate:

> ***Respondent 1.*** Department of Health handles the complaint but does not include the license board. We cannot effectively change regulations either because of a lack of political will by the Department of Health.

> ***Respondent 2.*** No, the governing body does not have adequate understanding of the profession of interpreting, the deaf community or the interpreters code of professional conduct.
>
> ***Respondent 3.*** Lack of knowledge and training on issues pertaining to DHOH, hearing people in control of most statutory boards.

One respondent adds:

> Last year, we did not have a meeting although the law requires to meet twice yearly. Covid monetary freeze was cited as they couldn't pay for interpreters while on a COVID monetary hold... There was also a document that was never uploaded following a meeting as there was evidentiary support of oppression that had happened in the meeting prior. Minutes were passed with edits that outlined the oppression that happened at the last meeting in a facutal [sic] way, but were never uploaded to the SOS [Secretary of State's Office]. Regulations passed by the board 3 years ago still sit on someone's desk. The laywer [sic] went through and striked all the conflicting information with the law, however, nothing has happened with it since then. We were asked to help accomidate [sic] their website to become ADA complaint when we had brought up our concerns about the lack of complaints coming to the board and the lack of knowlege [sic] of the field to those who are overseeing the determination process. We stated we were uncomforable [sic] making the website video accessible when the overarching complaint system is weak and ineffective. After we declined their olive branch, this is when our meetings went from 4x a year to the twice mandated. We asked that we please keep quarterly as there is a lot of work to do. The DOH state they decide when an [sic] how

> many times the board meets, we are merely advisory and they continue to emphasis this and act accordingly.

Furthermore, all respondents either somewhat disagree or strongly disagree that they have enough statutory authority to address complaints made against sign language interpreters for alleged ethical violations of conduct. Also, when asked whether the state considers the recommendations made by the respondents in regards to interpreter violations or remedies to interpreter violations, 50% answered rarely and 50% answered never. While 25% of the sample feels that they have support from the state to effectively carry out their statutory charge as a member of an accountability board, the remaining respondents (75%) either somewhat disagree or strongly disagree. Finally, all respondents strongly disagree that state personnel who oversee the board understand the sign language interpreting profession and concerns of Deaf ASL users to make informed decisions.

Qualitative responses were solicited on ways in which the licensure board could be improved, including board composition, duties, functions, or oversight. Respondents suggested the following:

> ***Respondent 1.*** The license board needs to have more statutory authority with more representation from consumers.
>
> ***Respondent 2.*** Statute change through legislation, improved oversight of state agencies, addition of accountability measures and measurable goals, mandatory training for healthcare entities, establishment of a statewide advisory board made up of deaf and interpreters to advise the executive branch.
>
> ***Respondent 3.*** The board makeup is excellent, the board supervisor (a state appointed employee) needs training to understand the profession.

> ***Respondent 4***. We need to be more than advisory. They do not take our advice. They check the boxes for us, 2 meetings a year and a lot of "Ill [sic] get back to you's [sic]" Deaf people are not their priority and they will continue to be low on the priority list.

To conclude the survey, respondents were offered the opportunity to share any general comments about healthcare access barriers of Deaf ASL users in RI. Respondents offered the following:

> ***Respondent 1.*** There's significant consolidation under Lifespan which results in a contract with an agency that may limit consumer choices. Further, there's a significant amount of VRI being used. RI Commission on the Deaf and Hard of Hearing needs more staff interpreters and Deaf interpreters rather than only being an interpreter referral service. Funding mechanisms need to be in place to hire interpreters according to need.
>
> ***Respondent 2.*** Yes, hospitals and/or insurance companies the [sic] have a high volume of deaf consumers should create staff interpreter positions. those [sic] interpreters can use any down time they may have to create educational materials and deliver short trainings to better prepare health care providers to work with deaf people. availability [sic] of freelance interpreters if [sic] unpredictable and unreliable.
>
> ***Respondent 3.*** …people are not getting interpreters for their medical appointments. They are not understanding their medical care and therefore compromising the integrity of the care. RI needs to invest in case management for the deaf. Immigration resources. More community investment. More social

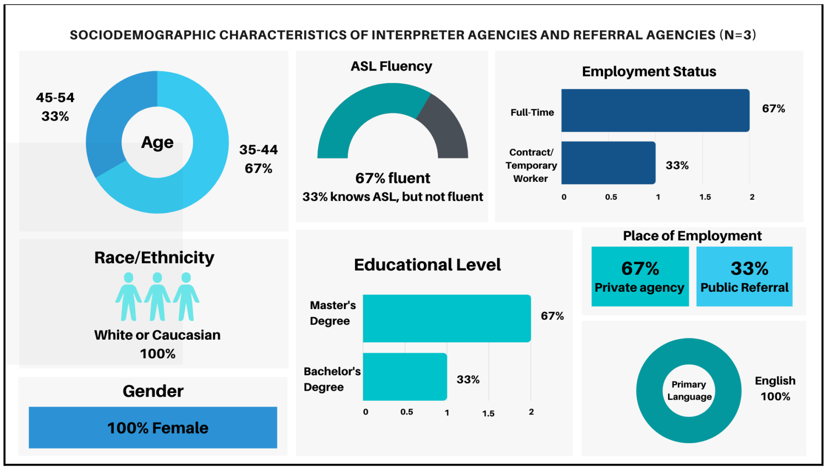
> programs for the deaf. Invest in programs and the community will flourish. They are suffering, and they have been for a long time here in RI.

VIII. *Rhode Island-Serving Sign Language Interpreter Agencies or Referral Service Agencies*

Responses were collected from three sign language interpreter agencies or interpreter referral service agencies, who completed an online survey in English during the last week in January and first two weeks of February, 2022. Survey completion rate was 100%. Mean age of respondents was 43 years old. See Figure 11 for a visual breakdown of demographic data.

Figure 11

Sociodemographic Characteristics of RI-Serving Interpreter Agencies and Referral Service Agencies



Referral Processes, Communication With Stakeholders, Relationship and Support, Technology, and Training. When respondents were asked about familiarity with the communication access needs of Deaf patients in healthcare settings in RI, 100% indicated that they were either very familiar or extremely familiar. When asked about the current pool of sign language interpreters available to accept medical assignments on a regular basis in RI, 33% indicated less than two interpreters; 33% indicated between 2-4 interpreters; 33% indicated between 10-12 interpreters. Based on interpreters that are either provided or referred, respondents were asked how confident they are that there are enough interpreters in RI to respond to medical requests. Of the sample, 100% responded they are not at all confident that there are enough sign language interpreters to respond to medical requests in RI. When asked what the biggest impediment is to filling medical requests, 67% of respondents indicated that there are not enough interpreters in general to fill requests; 33% indicated Other reasons, such as insurance companies' reluctance to contract with some private interpreter agencies for interpreter service provision. All respondents in the sample reported that they have often or always had to explain to a medical provider the legal requirements for effective communication for Deaf patients in healthcare settings over the past three years. One-third of respondents (33%) indicated that they rarely provide training or technical assistance to medical providers about interpreter service provision; two-thirds of respondents (67%) said they sometimes do. When asked how many training sessions had been conducted with medical providers over the past three years, 67% indicated none; 33% indicated one training session. When asked how often respondents coordinate with public interpreter referral services or private interpreter agencies to fill medical requests, all reported that they never do.

Likewise, when asked how often they have meetings (either in-person or virtual) with all interpreting services offices at healthcare facilities in RI on a regular basis, all respondents in the sample said that they rarely or never do. Likewise, all respondents reported that they rarely or sometimes attend the quarterly meetings of the local professional interpreting organization. When asked about their level of knowledge about medical interpreter qualifications, training, and readiness to work in medical settings, 67% indicated they knew a lot; 33% indicated they knew a little. When asked how they would characterize their working relationship with the interpreting community, respondents replied either good (67%) or acceptable (33%). When asked how they would characterize their working relationship with the Deaf community in RI, one-third of the sample (33%) indicated very good; one-third (33%) indicated good; and one-third (33%) indicated acceptable. Likewise, when asked how they would characterize their working relationship with insurance companies in RI, half indicated good while half indicated poor. Moreover, when asked how they would characterize their working relationship with healthcare organizations or providers in RI, all respondents in the sample said acceptable.

In terms of technology, half of the sample indicated they use a computer database to schedule interpreters for medical assignments; half of the sample reported that they never use a computer database for this purpose. All respondents who use database technology feel that their system is efficient. Half of the sample feels that they have received a great deal of training on their database system to optimize its use; half of respondents feel they have received a moderate amount of training. When asked about formal evaluation of the department in which they work, all respondents reported that they are rarely evaluated. If evaluations did take place, respondents reported they were in the form of surveys (33%) or Other (67%), such as direct feedback from the requester or committee review. When asked how often they engaged in professional development opportunities related to their work, responses varied: 33% said rarely; 33% reported sometimes; and 33% reported always. Finally, when respondents were asked how confident they are that they have enough support within their departments to effectively handle medical requests, two-thirds of the sample (67%) responded that they are very confident and one-third (33%) responded that they are slightly confident.

In looking at the data comparatively, there were several differences noted between the responses of private interpreter agencies and public interpreter referral agencies in the sample. In general, responses from private agencies indicated they had ASL-fluent personnel working within their departments; had undergone interpreter training; possessed a greater level of knowledge of medical interpreter qualifications, training, and readiness; had more positive relationships with both Deaf and sign language interpreter communities; had more opportunities for training and professional development; and felt they had overall more support within their departments to handle medical requests. Conversely, responses from public interpreter referral service agencies indicated they have a lack of ASL fluent personnel working within their departments; have not undergone interpreter training; possessed a lesser level of knowledge of medical interpreter qualifications, training, and readiness; had less positive relationships with both Deaf and sign language interpreter communities; had less opportunities for training and professional development; and felt they had less overall support within their departments to handle medical requests.

To conclude the survey, respondents were offered the opportunity to share any additional comments about healthcare access barriers of Deaf ASL users in RI. Respondents offered the following:

> ***Respondent 1.*** Insurance companies are so hard to connect with. I was naive to assume they would jump at the resource despite the low supply of interpreters, they are hesitant or bound for whatever reason.
>
> ***Respondent 2.*** …insurance (non-exclusive) contracts I was told one of 3 things: 1. They have a contract that is exclusive to one agency that they are unable to breach. The resources they are currently using are sufficient. (NHP - who uses RICDHH and PI, was not interested in adding another [sic] resources as they have seized communication. 3. BCBS - best approach. Providers procure, obtain, and

> pay for interpreters then fill out a specific form from BCBS that reimburses the charges (not through insurance billing, but specifically allocated a form for reimbursement).
>
> **Respondent 3.** … there are some insurances and other medical providers that are too corporate. The phone numbers publicly found do not route to representatives aware of where to transfer or how to help re: ASL interpreting provider resources.

One respondent simply added, “Hiring more staff that is dedicated to specific aspects of the referral process.”

Chapter 7: Discussion of the Findings and Conclusion

The purpose of this research study was two-fold: to identify barriers to healthcare access of Deaf ASL users in Rhode Island and to identify the structural and social forces that constrain agency of Deaf ASL users in their attempts to access healthcare. The data suggests that Deaf ASL users in Rhode Island face numerous structural barriers to accessing healthcare, which include economic, civil, political, and cultural constraints.

Economic Constraints

One predominant theme that emerged from responses across stakeholder groups is the scarcity of resources. Borrowing from Knapp, Funk, Curran, Prince, Grigg & McDaid (2006), six sets of economic barriers could be identified in the data: information barriers, resource insufficiency, resource distribution, resource inappropriateness, resource inflexibility, and resource timing.

Information Barriers

Evidence of information barriers were noted in the data across all stakeholder groups. For RI licensed physicians and nurses, college and university students studying healthcare professions, and legislators, informational barriers were evident in the lack of knowledge, awareness, training, and experience in working with Deaf individuals. These findings are consistent with Ebert & Heckerling, 1995; Hommes et al, 2018; Gilchrist, 2008; Pendergrass et al, 2017; Ralston et al, 1996; and Rezende et al, 2021.

For sign language interpreters, the data suggests that barriers exist in acquiring assignment-related information, such as linguistic preferences of Deaf consumers, locations of medical assignments, general health system navigation, and billing contacts and protocols. Interpreters also noted that the current model of interpreter service provision in RI hospitals, one that relies on contracted interpreters as opposed to staff, contributes to information barriers. Respondents state that resident staff interpreters in hospitals can better enable information sharing among interpreters, Deaf patients, and medical providers compared to a “revolving door” of contract interpreters. In addition, having interpreters on staff will likely improve continuity of care, build trust within the Deaf community that in-person interpreting resources are available (which can lead to higher healthcare utilization), better meet the communication preferences of Deaf patients, and provide informal education opportunities for healthcare professionals, interpreters, and Deaf patients to learn from one another. This data supports findings by Jacobs et al, 2004.

From the perspectives of advocacy professionals, the data shows that information barriers exist for healthcare providers (lack of awareness, training, where to obtain interpreter services) and for Deaf community members (unaware of their health conditions, treatment plans, medications, and where to file complaints). The interpreter licensure board indicates barriers to receiving information about Deaf consumer complaints and board processes. Data from interpreter agencies and referral service providers reveal barriers to information about medical interpreter qualifications, training and readiness, use of technology and database systems to schedule interpreters, navigating contracts with health insurance companies, and evaluations of their own work performance. These bureaucratic processes can be viewed as a form of structural violence in that they inhibit or defer the ability of Deaf ASL users to get what they need (in this case, interpreters or complaint resolutions). Finally, for Deaf ASL users, barriers to information were evident in healthcare system navigation, knowledge of where to file complaints (if dissatisfied with communication access services), and the lack of information received after a request for an in-person sign language interpreter has been made (lack of follow-up confirmation).

Of importance to note, the author has departed from prior literature in simply stating that “training needs” are required for particular stakeholder groups, such as healthcare providers, college students studying healthcare professions, and legislators. Framing knowledge gaps as “information barriers” emphasizes the *necessity* of removing obstacles to acquire knowledge and skills to effectively and equally serve the community of Deaf ASL users. Anything less would constitute acute structural violence. Therefore, acquisition of knowledge and skills to serve this population should be viewed as a *prerequisite*, not an add-on. Likewise, including this topic under economic constraints also shows that funding streams must be identified to sustain long-term improvement in this area.

Resource Insufficiency

In addition to information barriers, insufficient resources emerged as a predominant theme in the data. Insufficiencies in both financial resources and human resources were noted. The lack of ASL-concordant providers, the critical shortage of qualified in-person sign language interpreters, the over-reliance on VRI, and the perceived cost burden of hiring interpreters for

Deaf patients were mentioned. These results build on existing evidence by Bleu, 2020; Evelly, 2019, Gil, 2022; Nicolas, 2020; and Stewart, 2020.

From the perspective of sign language interpreters, resource insufficiencies were noted in delayed payment from healthcare providers and lack of PPE provided to them when working in healthcare settings during the pandemic. Interpreter responses also indicate that current models of interpreter service provision offer unpredictable, unreliable, and insufficient coverage. In light of the resource insufficiencies of communication access providers and lack of training programs available to cultivate and replenish the supply of interpreters in RI, service models that offer in-person interpreting services (staff interpreters) can offer increased reliability of preferred communication access services for Deaf ASL users.

For advocacy professionals, resource insufficiencies were noted in the lack of organizational funding that precludes advocates from devoting more time and attention to addressing healthcare access complaints of Deaf ASL users. Likewise, resource insufficiencies were noted by members of the interpreter licensure board, citing a monetary hold on payment for interpreters for board meetings during COVID. Finally, interpreter agencies and referral service providers noted insufficient staff to manage the volume of requests for interpreters throughout the state. All in all, resource insufficiency is one of the biggest concerns to emerge from the data. “The case for a higher level of funding clearly needs to be considered carefully on the grounds of need, cost-effectiveness, equity and human rights” (Knapp et al, 2006, p. 159).

Resource Distribution

Resource distribution also factors into the economic constraints on healthcare access of Deaf ASL users. Like resource insufficiency, resource distribution can be described in terms of both financial and human capital. The expressed preferences for in-person interpreters noted in the data across all groups indicate high demand for services. However, allocation of funds and full-time positions to meet this need have not been realized. Though hospitals throughout RI employ staff interpreters and designated bilingual clinicians for other linguistic minority communities, resources have not been distributed in similar ways for Deaf ASL users. Likewise, while state agencies and community organizations in RI employ community health workers to assist with healthcare navigation and education for members of other linguistic minority groups, no funds to date have been allocated to address this need for Deaf ASL users. Finally, resource distribution can also be viewed in terms of human effort. Data from Deaf ASL users, advocacy professionals, and members of the interpreter licensure board describe the additional “consumer labor” (Brunson, 2010) and “negotiation of access” (James et al, 2021) that Deaf ASL users must shoulder in efforts to access communication in healthcare settings. Distribution of effort must be re-calibrated so that healthcare systems bear the onus for such labor, not the Deaf patient.

Resource Inappropriateness

Resource inappropriateness is most evident in the data through responses from several stakeholder groups regarding the over-reliance on VRI services. “By inappropriateness we mean the situation where the services available do not match the services needed or preferred, quite possibly because those needs and preferences are poorly appreciated” (Knapp et al, 2006, p. 162). While VRI services have advantages, questions remain about the appropriateness of its use and over-reliance with Deaf patients. Responses from stakeholder groups indicate issues in VRI quality and provision (equipment/technical issues, loss of equipment, dissatisfaction with VRI interpreters) and this is consistent in the literature (James et al, 2021; Kushalnagar et al, 2019; Myers et al, 2021; and Yabe, 2021).

Resource Inflexibility

The over-reliance on VRI services with Deaf ASL users can also be viewed from a resource inflexibility perspective. This is “where services are too rigidly organized and resources are not used to treat people in ways that are considered (by them or by others) to be best for them” (p. 163). In addition, there are other ways in which resource inflexibility manifests in the data. Knapp et al state, “Inflexibility can also arise because the services delivered by a range of agencies are poorly coordinated, and because consistent, comprehensive or coherent funding is not provided to meet all of an individual's needs” (p. 164). This is evident in the data where we see siloed systems operating without communication or coordination of efforts to better meet the needs of Deaf patients. Examples of this include: the lack of information provided to interpreters about health assignments; the lack of regular meetings between interpreting services departments at hospitals and interpreter agencies or referral service providers; the lack of communication between advocacy professionals, patient relations offices at hospitals, and community organizations that serve Deaf people; the lack of coordination between health providers, interpreters, referral service providers, and Deaf ASL users to communicate confirmation of interpreting services; and the lack of communication and coordination between state agencies, Deaf community members, and state legislators to work collaboratively to implement changes in health policy.

Resource Timing

Resource timing is also evident in the data. Responses from stakeholder groups indicate delays in several areas and capacity-constrained systems. Sustained long-term education of healthcare providers about the communication needs of Deaf ASL users has gone unrealized in light of constrained funding and capacity. Responses from interpreter agencies and interpreter referral providers have indicated little to no instructional opportunities provided to medical personnel over the past 3 years (about how to work with interpreters). Also, the lack of prioritization given to interpreter workforce development causes delays in the realization of a replenished supply of sign language interpreters available to work in healthcare or other settings. As attrition from the sign language interpreting profession is expected to increase due to retirement and the "aging out" of practitioners from the profession, no state-wide plan has been established to address this workforce shortage. Likewise, college and university programs that do not include curricula and educational opportunities to prepare future health practitioners to work with Deaf ASL users, delay the ability of culturally competent professionals to effectively serve this community.

In sum, several economic factors pose structural constraints on Deaf ASL users in accessing healthcare, with scarcity as the unifying thread. "The common element running through all of the issues discussed…is the multi-levelled, multi-faceted barrier of scarcity: there are not enough resources available in the right places or at the right times, or allocated appropriately" (p. 158).

Civil and Political Constraints

The data also suggests that structural barriers are evident in the form of civil and political constraints. One theme that emerged across all stakeholder groups is the lack of awareness and understanding of the legal obligations to provide communication access services to Deaf patients. These results build on existing evidence by Ralston et al, 1996. Though individuals with disabilities are designated as a protected class with legislated rights to equal health access and services, responses from both incumbent and future healthcare professionals indicate a lack of understanding about these legal obligations. The state's documented history of legal complaints regarding alleged Title III ADA violations puts healthcare facilities at risk for litigation when their healthcare staff do not understand their legal responsibilities in serving Deaf patients. Furthermore, perspectives from Deaf ASL users indicate a lack of understanding on behalf of healthcare professionals about who is responsible for providing and paying for interpreters, and who is qualified to serve as an interpreter. These results build on existing evidence by Gilchrist, 2000 and Pendergrass et al, 2017.

In addition, responses from both Deaf ASL users and licensed physicians and nurses show that provision of communication access services often do not match the needs and preferences of Deaf ASL users. Though the law explicitly provides primary consideration guidance, data suggests that healthcare providers may view “access” as a perfunctory measure, the proverbial “checking off a box” that legal obligations have been met without verification of whether the services provided resulted in “effective” or equal communication for the Deaf patient. This data contributes to a clearer understanding of the literature by Agaronnick et al, 2019; James et al, 2021; Kushalnagar et al, 2019; Myers et al, 2021; and Yabe, 2021. The data may also reveal that healthcare providers may not have adequate tools or processes for assessing and determining the communication preferences of Deaf ASL users.

Furthermore, civil constraints are also evident in the accountability systems that are designed to protect Deaf patients. Responses from Deaf ASL users indicate that 61% are somewhat likely or not at all likely to file a complaint if dissatisfied with communication access services with health providers. However, the reasons for not filing are unknown. Emerging self-advocacy skills and lack of awareness about where to file play a role. However, responses from both advocacy professionals and members of the interpreter licensure board may shed light on additional reasons. Responses from advocacy professionals show that complaints made to them regarding healthcare access from Deaf ASL users were either sometimes or rarely resolved;

responses from members of the interpreter licensure board show that complaints made against sign language interpreters for alleged ethical violations are rarely or never resolved. Additional qualitative responses show that complaint systems are “weak”, “ineffective” and “inaccessible”. While reasons are speculative, it can be inferred from the responses that accountability systems set out to protect Deaf individuals fall short of fulfilling their charge. These shortcomings reduce Deaf ASL users to a disempowered status. Constrained by faulty accountability systems that fail to recognize and uphold both their civil and human rights, it is likely that Deaf ASL users do not file complaints because they believe no change will result from their efforts. Forced to bear the onus for both the negotiation of access in healthcare settings and for the filing of complaints when effective communication is not achieved (often through inaccessible systems that result in little to no fruitful outcomes), adds to the overall stress burden or allostatic load of Deaf ASL users. This undoubtedly impacts health and well-being and may play a contributory role in the health disparities noted in the literature. Moreover, these examples illustrate both structural and cultural violence, with Deaf ASL users being seen as unimportant by the people whose job it is to protect them.

Also, when Deaf ASL users have brought litigation against healthcare systems in RI, there is little evidence observed by this author that those lawsuits have brought a deeper understanding to healthcare providers about the communication needs and preferences of Deaf ASL users. Responses across stakeholder groups support this. In addition, there has been little observational evidence that lawsuits in the state have resulted in a commitment to increased engagement with the Deaf community. Litigation can result in a polarization of the Deaf community and decreased willingness of healthcare systems to engage in meaningful dialogue directly with Deaf community members. In these instances, what is often missing is the notion of "access intimacy". Transformative justice leader and disability justice advocate, Mia Mingus (2017) says, "Access intimacy at once recognizes and understands the relational and human quality of access, while simultaneously deepening the relationships involved. It moves the work of access out of the realm of only logistics and into the realm of relationships and understanding…" (para. 17). Mingus goes on to say that access should work towards liberatory ends. Coining this concept as "liberatory access" she states:

> Liberatory access calls upon us to create different values for accessibility than we have historically had. It demands that the responsibility for access shifts from being an individual responsibility to a collective responsibility. That access shifts from being silencing to freeing; from being isolating to connecting; from hidden and invisible to visible; from burdensome to valuable; from a resentful obligation to an opportunity; from shameful to powerful; from ridged to creative. It's the "good" kind of access, the moments when we are pleasantly surprised and feel seen. It is a way of doing access that transforms both our "today" and our "tomorrow." In this way, Liberatory access both resists against the world we don't want and actively builds the world we *do want* (para. 31).

Therefore, while lawsuits may provide injunctive relief and lead to more equitable policy changes, it is debatable whether those policies are communicated to and upheld by all members of the healthcare system, whether those changes are sustainable, and whether those actions result in the *adoption of values* as expressed by Mingus. This argument builds on existing evidence by Gil, 2022. Hence, while litigation may be a viable tool towards realizing fairer access and treatment, results can often translate to minimal compliance with the law, not necessarily meaningful, liberatory, and equitable healthcare experiences for Deaf people.

Finally, political constraints are also evident in the lack of engagement between legislators and Deaf ASL users. Over three-quarters of legislators who responded to the survey reported having rarely or never met with Deaf constituents who use sign language. Also, 82% indicated they have rarely or never worked with Deaf community members, Deaf organizations, or state agencies that serve Deaf people to introduce or support legislation to improve healthcare access. The ability of Deaf ASL users to participate in the political process to effect change to healthcare policy is severely constrained by this lack of engagement. Deaf ASL users are often deprived of the ability to participate in political life due to information barriers and the lack of ASL accessible political programming. As a result, Deaf ASL users are excluded from decision-making processes that impact their lives and their health. In addition, their ability to make substantive and meaningful changes to these system inequities is severely hindered.

Cultural Constraints

The results indicate that cultural constraints also impede access to healthcare for Deaf ASL users. These cultural barriers take the form of behaviors, attitudes, and interactions that show how Deaf ASL users are socially situated within healthcare contexts and viewed by the medical establishment. Responses across all stakeholder groups indicate a lack of cultural competence displayed by healthcare providers. The lack of primary consideration given to Deaf patients and their preferences for in-person interpreters is evident in the data. Over-reliance on VRI services due to convenience, time constraints, and labor involvement were noted by licensed physicians and nurses, as well as Deaf ASL users. This data is consistent with Agaronnick et al, 2019; James et al, 2021; Myers et al, 2021; and Yabe, 2021.

Moreover, paternalistic attitudes and diminished patient autonomy were noted in survey responses. For example, after making preferences known to a healthcare provider for an in-person interpreter, one Deaf ASL respondent was told, “We will try [to get an interpreter], but VRI is the better choice for YOU!” Likewise, after another Deaf respondent indicated a preference for an in-person interpreter, the individual was told by a provider to “write notes back and forth”. These responses raise questions about the inappropriate use of power and diminished autonomy imposed on Deaf patients. These results build on existing evidence by Harmer, 1999; Sirch et al, 2017; and Witte & Kuzel, 2000.

Furthermore, additional responses from Deaf ASL users reveal dissatisfaction with the lack of communication access with medical providers in the past three years and a lack of trust in RI healthcare systems to meet their communication access needs. More revealing of Deaf ASL users' social positioning within healthcare environments are the assaults on dignity reported by 69% of Deaf respondents. They shared that medical providers or receptionists have sometimes, often, or always made them feel humiliated, fearful, insulted, or indignified because of their communication access needs. These results build on evidence in the literature by Iezzoni, 2004; Steinberg, 2006; and Scheier, 2009 and are examples of cultural violence.

Finally, themes of invisibility of Deaf ASL users are noted in responses across all stakeholder groups. This is evident in the data and noted by the lack of deference to Deaf patient’s preferred communication methods, repeated denials of requests for interpreting services, the lack of resolution on filed complaints, the lack of participation in political processes, the lack of understanding of medical plans and treatments by Deaf ASL users, and the lack of communication from interpreter agencies or referral providers about interpreter confirmations. Additional examples can be found in the data, including qualitative responses from participants. One respondent states, “Deaf people are not their priority and they will continue to be low on the priority list." As one healthcare provider simply points out, "They are the forgotten patient."

Structural Violence

In summary, the data suggests that Deaf ASL users in Rhode Island face numerous structural barriers to accessing healthcare, which include economic, civil, political, and cultural constraints. The "multilevel interconnected inequalities" (Ryan, 2008, p. 150) that reside in the state's public health institutions, government agencies, and associated systems prevent Deaf ASL users from getting their most basic human needs met. Galtung, who conceived the theory of structural violence describes these "insults to basic human needs" as *violence*. Violent structures, according to Galtung, have "exploitation as a centerpiece" (Galtung & Fischer, 2013, p. 45), where some people, or in this case, some communities, do not get as much as others. This results in a discrepancy between the potential (human needs satisfaction) and the actual (human needs deficits). Those who experience human needs deficits, such as lack of access to healthcare, are likely to experience adverse health outcomes, and in some cases, premature loss of life. The health disparities of Deaf ASL users noted in the literature lean toward this. However, these disparities could be avoidable, as they are likely due to structural causes more so than physical ailments.

The question of how structural violence comes to be is also explained by Galtung. Sometimes direct violence is used to establish structural violence. He states, "massive direct violence over centuries quickly seeps down and sediments as massive structural violence…" (p. 47). Indeed, Deaf ASL users have been subjected to horrific acts of direct violence over the course of history, including murder, medical experimentation, sterilization, and social exclusion. This direct violence was enabled and rendered socially desirable by cultural violence. After time, "direct violence is forgotten," says Galtung, and replaced by labels "that are mild enough for public consumption" (p. 47). In the case of Deaf ASL users, those labels may be "discrimination" for massive structural violence and "oppression" for massive cultural violence. As Galtung adds, "such sanitation of language is itself cultural violence" (p. 47). Hence, over time, actors within these violent structures follow established policies and institutional practices that lead to indirect and unintended harm. These unbalanced social relations become normalized as everyday experience.

Finally, as direct, cultural, and structural violence deprive people of needs, trauma results. Galtung states, "When it happens to a group, a collectivity, we have the collective trauma that can sediment into the collective subconscious, and become raw material for major historical processes and events" (p. 47). As such, Galtung cautions that *violence breeds violence*. He states, "Violence is needs deprivation; needs deprivation is *serious*; one reaction to needs deprivation is direct violence" (p. 47). We see evidence of interpersonal violence among Deaf individuals noted in the literature. Equally concerning are the embodied health risks that accompany trauma that are transmitted across generations. Research is now exploring the link between trauma and epigenetics, "where the readability, or expression of genes is modified without changing the DNA code itself" (Henriques, 2019, para. 5). This calls for "an ethical shift toward accounting for how health inequity today is rooted in histories of trauma and violence" (Tao & Clements, 2021, para. 2).

In identifying the structural barriers and constraints on agency that prevent Deaf ASL users from accessing health care, the question that naturally emerges is: how does a community begin to dismantle the structural violence that precludes members from getting their most basic human needs met? According to Galtung, this includes working towards both positive and negative peace. Negative peace is the absence of violence. Galtung offers three tasks to accomplish negative peace: to end the direct violence that causes suffering, to address economic inequities in structures, and to eliminate "cultural themes that justify one or the other" (p. 173). To work towards positive peace, three tasks are also required: to build cooperation into structures, to uphold "reciprocity, equal rights, benefits and dignity" (173), and to build a culture of peace and dialogue into structures. In addition to these tasks, Galtung emphasizes the importance of "conciliation as liberation from trauma" (p. 179). He suggests "3Rs" in which to accomplish this: reconstruction, resolution, and reconciliation. Restoration includes both the un-doing of "non-human" damage (memories, photos, monuments) and human reconstruction, or healing. Resolution involves "seeing the damage done as a symptom of something deeper, to be solved" (p. 179). Finally, reconciliation involves coming to terms with trauma both perpetrated and internalized and working with actors within structures to arrive at creative solutions that will lead to mutual and equal benefit. Taken in totality, these actions toward transformative justice can lead to greater fulfillment of human needs and realization of the inherent dignity, worth, and human rights of Deaf ASL users.

Conclusion

Through an action research approach, this study investigated the healthcare access barriers of Deaf ASL users in one particular state - Rhode Island. More specifically, this study aimed to uncover the subtle, seemingly invisible, structural and social forces that constrain agency of Deaf ASL users in their attempts to access healthcare. Using a "geographically broad and historically deep analysis" this study revealed that Deaf ASL users in Rhode Island face numerous structural barriers to accessing healthcare, which include economic, civil, political, and cultural constraints. This investigation serves as the first step in the action research cycle to improve healthcare access and health outcomes of Deaf ASL users in RI. The next step will involve a community-wide analysis, followed by the development and implementation of a community-led action plan to address the root causes of structural health inequities.

Contributions

This study has a few significant contributions. On the state level, this study fills a gap in academic scholarship by providing a holistic exploration of healthcare access barriers specific to Deaf ASL users in Rhode Island. Second, the study is the first in the state to incorporate numerous stakeholder perspectives in its data collection, offering greater insight into the challenges that Deaf ASL users face when accessing healthcare in RI. On a national level, it is believed that this study is the first in the U.S. to investigate healthcare access barriers of Deaf ASL users using a structural violence framework.

Limitations

This research is also subject to several limitations. First, the scope of the study was ambitious considering the time allotted to collect and report data. Second, the lack of survey responses from three stakeholder groups employed at hospitals- healthcare administrators, patient relations offices, and interpreting service offices, could have informed data on healthcare policies, complaint processes and frequency, coordination of interpreter services with community stakeholders, as well as other vital information. Third, this study examined the healthcare access barriers of Deaf ASL users only and did not include an investigation of barriers for the hard of hearing, deaf-blind, late-deafened, and deaf intersecting communities in Rhode Island. Fourth, because the results of this study are specific to the RI Deaf ASL-using community, findings cannot be generalized to other communities. Fifth, survey results may have been influenced by the COVID-19 pandemic, which coincided with the data collection period. Lastly, as a hearing individual, the potential of researcher bias may exist.

Future Research

There are several research directions to consider in the future. On a local level, additional studies that examine the healthcare access barriers of the hard of hearing, deaf-blind, late-deafened, and intersecting communities in Rhode Island should be considered. More broadly, additional research employing meso- and macro-level analyses of health care access barriers, informed by a multitude of stakeholder perspectives can yield valuable information about structural constraints that present in communities. Research that explores how structural violence perpetuates interpersonal violence can provide important insight on ways to interrupt violent systems. Also, studies that explore new frameworks through which to analyze healthcare access barriers can lead to the formulation of novel solutions. Finally, transdisciplinary collaboration with researchers in fields like medical anthropology, peace and conflict studies, applied linguistics, public health, and justice studies can lead to a greater understanding of the complex causes and effects of health disparities in local communities and beyond.

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Appendix A

IRB Application Form

ST. CATHERINE
UNIVERSITY

ST. CATHERINE UNIVERSITY REQUEST FOR APPROVAL FOR THE USE OF HUMAN SUBJECTS IN RESEARCH APPLICATION

IRB APPLICATION DOCUMENT CHECKLIST

The items listed below are the application, forms and supporting documents to be uploaded to Mentor IRB for your protocol/application submission. Consent forms and additional supporting documents may be uploaded separately; directions for Mentor IRB can be found on www.stkate.edu/irb or https://stkate.box.com/s/iduadmae1guoi4pkrz6hqb7nz9cj31ra.

☒ IRB Application

☒ PI Documentation/CITI Training for Investigator(s)*

☐ PI Documentation/CITI Training for Faculty Adviser (if applicable)*

☒ Informed consent form

☐ Child assent form (if applicable)

☒ Recruiting materials (phone script, fliers, ads, etc)

☒ Survey/questionnaire(s), focus group or interview questions (if applicable)

☐ Conflict of interest/financial interest disclosure (if applicable)

☐ Letter(s) of support (if you are conducting research at another agency, school, etc).

☐ Data management plans meets Data Management Policy (policy below)

***PI Documentation/CITI Training is the completion report received for fulfilling the required Human Subjects Research education requirements in CITI Program. Each person will need to upload their PI Documentation to their individual Mentor IRB account. Directions are located in Mentor IRB.**

IRB RELATED POLICIES:
Listed below as well as throughout the application are St. Catherine policies related to human Subjects research

- IRB Policy: https://stkate.box.com/s/4vxto2w6azt1k9jclim5gc1bqktoe3uv
- Intellectual Property Policy: https://stkate.box.com/s/51my44r6a5no8nurqydhcxpjlj1rwzkm
- Research Misconduct Policy: https://stkate.box.com/s/qzx5oev241s3uw1btpd5fwgickgfzjvx
- Research Data Management Policy: https://stkate.box.com/s/0m4yf9cumy12f2yq5kwo4wlhm9qf86c8

ST. CATHERINE
UNIVERSITY

ST. CATHERINE UNIVERSITY REQUEST FOR APPROVAL FOR THE USE OF HUMAN SUBJECTS IN RESEARCH APPLICATION

Complete the following application in its entirety. You may excerpt material from your thesis or grant proposal, but your application should be relatively concise. Consent forms and additional supporting documents may be uploaded to Mentor IRB separately. For questions, contact the IRB Coordinator at 651-690-6204 or irb@stkate.edu.

Date of application: November 7, 2021

Investigator name(s) and credentials (e.g., PhD, RN, etc.): (*List all co-investigators*)
Christine A. West, MA, CI and CT, SC:L, Ed:K-12

Project Title: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

Department: ASL/Interpreting: Master of Arts in Interpreting Studies and Communication Equity (MAISCE)

Level of Review:
In the Mentor IRB system, you must select the Review Type; selecting Exempt and Expedited will prompt additional questions for you to fill out. For more information on the levels of review, go to the Mentor IRB Info page: Determine the Level of Review.

☐ **Exempt** ☐ **Expedited** ☒ **Full** ☐ **Quality Improvement** ☐ **Not Research**

Will another IRB review this research application?

☒ **No** ☐ **Yes – First reviewed by an External IRB** ☐ **Yes – First reviewed by St. Kate's IRB**

If YES – First reviewed by an External IRB, you may not need to complete a St Kates IRB application and can instead use your external IRB application. Please include a copy of the approved external IRB application and the letter of approval from the external IRB with your Mentor IRB submission.

If YES – First reviewed by St. Kate's IRB, please indicate your plans for review and identify the external IRB:

Note: *Cooperative Research occurs when a research protocol requires approval from outside institutions (e.g., a hospital IRB or other college/university) as well as St. Catherine University. Sometimes it is possible for an IRB to accept an external IRB's review to reduce duplication of review effort. If you have questions about cooperative research and how to determine when only one IRB will need to review your IRB application, contact the IRB coordinator at IRB@stkate.edu or reference the Cooperative Research Policy Addendum.*

1. **RESEARCH SUMMARY:** *Complete each section in clear, easy to read language that can be understood by a person unfamiliar with your research and your field.*

   a. **Purpose of the research:** *Provide a clear, concise statement of your purpose.*

   The goal of my research is to identify barriers to healthcare access of Deaf American Sign Language users in Rhode Island with particular attention to identifying the structural and social forces that constrain agency of Deaf ASL users in their attempts to access healthcare.

   b. **Background:** *Provide a concise summary in 1 - 2 brief paragraphs to explain the importance of the research and how it fits with previous research.*

With the recent COVID-19 pandemic, minority communities have gained increased attention from medical providers, mental and behavioral health clinicians, academics, policymakers, and public health officials (Rimmer, 2020; Stack Whitney & Whitney, 2021; Tai et al, 2021). The disproportionate impact of COVID-19 and a prevalence of documented health problems within these communities show how income, education, employment, race, language access, and other social determinants of health play a role in these health inequities. While there is increased emphasis on understanding the social risk factors and social needs of minority communities, the idea of language as a social determinant of health has received little attention in public health research. However, "unequal treatment related to language access is associated with disparate healthcare access and health outcomes" (Hilfinger Messias et al, 2009). One community in which language access has been particularly challenging is Deaf sign language users. Due to barriers in communication, this linguistic and cultural minority group has been historically marginalized by the medical community, excluded from health education opportunities (both incidental and directed), understudied by health researchers, underserved by medical providers, and under-represented in public health professions (McKee, M. M., Winters, P. C., Sen, A., Zazove, P., & Fiscella, K., 2015). Deaf American Sign Language (ASL) users are also "considered to be the non-English speaking minority group at greatest risk for miscommunication with their health providers" (McKee et al, 2015).

This study investigates the healthcare access barriers of Deaf ASL users in one particular state- Rhode Island. Evidence of healthcare access barriers in this community have been noted in case law (Rhode Island Association of the Deaf et al v. Lifespan Corporation, 2017) and in recent state government healthcare transformation initiatives (Rhode Island Commission on the Deaf and Hard of Hearing, 2021). By identifying and analyzing healthcare access barriers in this community from human rights and structural violence frameworks, strategies can be proposed that address the structural drivers of health inequities, the inequitable distribution of power and resources, and the role of state government in advancing health equity for all. This study would also fill a critical research gap by examining healthcare access barriers of this community with a justice-oriented trajectory.

References

Healthcare System Transformation Project (n.d.), Rhode Island Commission on the Deaf and Hard of Hearing. Retrieved October 3, 2021, from http://www.cdhh.ri.gov/hstp

Hilfinger Messias, D. K., McDowell, L., & Estrada, R. D. (2009). Language interpreting as social justice work: perspectives of formal and informal healthcare interpreters. *ANS. Advances in nursing science*, *32*(2), 128–143.

McKee, M. M., Winters, P. C., Sen, A., Zazove, P., & Fiscella, K. (2015). Emergency Department utilization among Deaf American Sign Language users. Disability and health journal, 8(4), 573–578.

RI Association of the Deaf et al v. Lifespan Corporation et al, 28 U.S.C. § 1331. US District Court for the District of Rhode Island. September 6, 2017.

Rimmer, A. (2020). Covid-19: Disproportionate impact on ethnic minority healthcare workers will be explored by government.

Stack Whitney, K., & Whitney, K. (2021). Inaccessible media during the COVID-19 crisis intersects with the language deprivation crisis for young deaf children in the US. *Journal of Children and Media*, *15*(1), 25-28.

Tai, D. B. G., Shah, A., Doubeni, C. A., Sia, I. G., & Wieland, M. L. (2021). The disproportionate impact of COVID-19 on racial and ethnic minorities in the United States. *Clinical Infectious Diseases*, *72*(4), 703-706.

c. **<u>Research Methods and Questions</u>:** *Give a general description of the study design and specific methods you will use in your investigation. Specify all of your research questions and/or hypotheses. Reviewers will consider whether the information you are gathering is necessary to answer your research question(s), so this should be clear in your application.*

Research Question 1: What are the healthcare access barriers of Deaf ASL users in Rhode Island?

Research Question 2: What are the structural and social forces that constrain agency of Deaf ASL users in their attempts to access healthcare?

(For purposes of this study, healthcare will be explored holistically.)

This will be a mixed-methods study using quantitative and qualitative data obtained from:

1. Analysis of pre-existing publicly available information relating to healthcare access of Deaf sign language users in Rhode Island (websites, social media posts, previous surveys, videos, recorded interviews, policies and procedures, state laws, rules, regulations, and state agency records obtained through public records requests).

2. Anonymous participant online surveys comprised of both open-ended and closed-ended questions which will be disseminated to the following participant groups using Qualtrics technology:

    - Healthcare providers
    - Hospital administrators
    - Patient relations/advocacy offices in healthcare facilities
    - Interpreter services departments at healthcare facilities
    - State legislators
    - State interpreter accountability entity
    - State advocacy professionals
    - College and university students studying healthcare professions
    - Interpreter agencies and interpreter referral service providers
    - State-licensed sign language interpreters
    - Deaf American Sign Language users

For the online surveys, the informed consent language will appear as the first page of the survey, and participants will click either “yes” or “no” to the consent statement. Those who click “yes” will proceed to the survey, those who click “no” will be brought to an exit page.

Development of the survey tools for Deaf ASL users and state-licensed sign language interpreters (hearing and Deaf) will take place with the assistance of a Certified Deaf Interpreter (CDI) to ensure that survey questions and answer options are conveyed with native or near native fluency in American Sign Language (ASL).

All Qualtrics qualitative and quantitative survey data will be collected and exported to Excel. Patterns and themes will be identified in the data, with a focus on using survey responses and pre-existing publicly available information to inform answers to research questions.

d. **Expectations of Participants:** *Give a step by step description of all procedures that you will have participants do. Attach any surveys, tests, instruments, interview questions, data collection forms, etc. that you will use with participants.*

There are 11 different groups of participants that will be surveyed in this study. Participants will respond to their own anonymous online Qualtrics survey that is intended for their group.

See attached surveys (Appendix A).

e. **Estimated Time Commitment for Participants: Survey**

1	**Number of sessions for each participant**
Duration of survey varies from 3-20 minutes, depending on group surveyed.	**Time commitment per session for each participant**
Duration of survey varies from 3-20 minutes, depending on group surveyed.	**Total time commitment for each participant**

f. **Access to Existing Data:** *If you are analyzing existing data, records, or specimens, explain the source and type, means of access, and permission(s) to use them. If not accessing existing data, indicate "NA"*

Data may be collected using the websites below. While some information may be directly accessed using the website, others may require a Public Records Request. No permission needed as all data is publicly available per Rhode Island General Laws 38-2, Access to Public Records.
http://webserver.rilin.state.ri.us/Statutes/TITLE38/38-2/INDEX.HTM

Rhode Island Commission on the Deaf and Hard of Hearing, RICDHH (public website):
www.cdhh.ri.gov

RICDHH Interpreter referral and general statistics, healthcare surveys/projects, health data (public records request):
http://www.cdhh.ri.gov/our-commission/your-commission/request-for-records.php

Meeting minutes (public website):
https://opengov.sos.ri.gov/OpenMeetings

Healthcare System Transformation Project at the RICDHH (public website):
www.cdhh.ri.gov.hstp

Health Survey for Deaf and Hard of Hearing Individuals (public website): http://www.cdhh.ri.gov/hstp/documents/hstp-survey-for-deaf-and-hard-of-hearing-individuals-2020-final.pdf

Healthcare Worker Deaf Cultural Competency Survey (public website):
http://www.cdhh.ri.gov/hstp/documents/hstp-survey-for-healthcare-workers-2020-final.pdf

Video Testimonials of Deaf Community Members (public website):
http://www.cdhh.ri.gov/hstp/testimonials/

Healthcare Committee Meeting- RI School for the Deaf School Nurse Project (public video):
https://youtu.be/bshMHPFYCk0

Healthcare Committee Meetings- 2020-2021 (public videos):
http://www.cdhh.ri.gov/accessible-videos/committee-meetings

Public Health and Equity Sign Language Interpreting Program (public website):
http://www.cdhh.ri.gov/pheslip/

Rhode Island Department of Health (public website):
https://health.ri.gov/

Interpreter Licensure/Board meeting minutes (public website):
https://opengov.sos.ri.gov/OpenMeetings

Rhode Island Executive Office of Health and Human Services (public website):
https://eohhs.ri.gov/

Rhode Island General Assembly (public website):
https://www.rilegislature.gov/Pages/Default.aspx

Disability Rights Rhode Island (public website):
https://drri.org/

Rhode Island General Laws (public website):
http://webserver.rilin.state.ri.us/Statutes/

Publicly available websites/statistics from all healthcare facilities in Rhode Island.

2. SUBJECTS: *Provide your best estimates below.*

a. **Age Range of Subjects Included:** Adults 18 or older

b. **Number:**
(*Indicate a range, or maximum, if exceeded, you will need to submit an amendment)*

560 Total ☒ Not Gender Specific ☐ Female only ☐ Male only

c. **Target Population:** Describe your target population (the group you will be studying; e.g. seniors, children ages 9-12, healthy adults 18 or over, etc.)

Target population includes adults 18 years or older of the following groups:

- Healthcare providers
- Hospital administrators
- Patient relations/advocacy offices in healthcare facilities
- Interpreter services departments at healthcare facilities
- State legislators
- State interpreter accountability entity
- State advocacy professionals
- College and university students studying healthcare professions
- Interpreter agencies and interpreter referral service providers
- State-licensed sign language interpreters
- Deaf American Sign Language users

d. **Specific Exclusions:** *If women and/or minorities are to be excluded from the study, a clear rationale should be provided in section "f" below.*

NA

e. **Special Populations Included:** *Select any special population that will be the focus of your research.* NOTE: *These groups require special consideration by federal regulatory agencies and by the IRB.*

☐ **Minors (under age 18)**
☐ **HIV/AIDS patients**
☐ **St. Catherine Employees**
☐ **People in prison**

☐ **Students**

☐ **Hospital patients or outpatients**

☐ **Elderly/aged persons**

☐ **People who are educationally disadvantaged**

☐ **Individuals with impaired decision-making capacity**

☐ **People who are economically disadvantaged**

☐ **Minority group(s) and/or non-English speakers *(please specify)***

☒ **Other Special Characteristics and Special Populations**

(please specify) Deaf American Sign Language Users

f. **Provide reasons for targeting or excluding any special populations listed above**.

NA

g. **Do you have any conflict of interest (financial, personal, employment, dual-role) that could affect human subject participation or protection?** *Dual-role examples: faculty–student (does not apply to action research projects for education students), medical practitioner-patients, supervisor-direct reports, etc.*

☐ **Yes** ☒ **No**

If Yes, please indicate the steps you will take to minimize any undue influence in your research, recruitment and consent process. You can also reference the university Financial Conflict of Interest policy: https://stkate.box.com/s/ymgyislnxtvn3887om50bzdtu7ezaulu

3. **RECRUITMENT: LOCATION OF SUBJECTS** *(Select all that apply)***:**

☐ **St. Catherine University students**

Research completed within a St. Kate's course must upload a letter of support from the department chair as the research can impact co-course faculty, faculty teaching a related course, or faculty asked to recruit for the study.

☐ **School setting (PreK – 12)**

Requires a letter of support from your institution

☒ **Hospital or clinic** (administrators, workers in patient advocacy office, interpreter service departments, healthcare providers

☒ **Other Institution *(Specify)*:** RI state government agencies, RI institutions of higher education, state accountability entities, state legislature

☒ **None of the above *(Describe location of subjects)*:**

RI Deaf community, RI-licensed sign language interpreters, RI-serving interpreter referral agencies/companies

<u>**NOTE:**</u> *If participants are recruited or research is conducted through an agency or institution other than St. Catherine University, submit either written or electronic documentation of approval and/or cooperation. An electronic version should be sent from the email system of that particular institution. The document should include the name of the PI, Title of the approved study, as well as the name and title of the appropriate administrator sending the approval. You should include an abstract/synopsis of your study when asking for approval from an external institution.*

a. <u>**Recruitment Method**</u>**:** *Describe how you will recruit your subjects? Attach a copy of any advertisement, flyer, letter, or statement that you will use for recruitment purposes.*

Subjects will be recruited using the following methods (see Appendix B):

- For hospital administrators, healthcare providers, hospital patient advocacy offices, hospital interpreter departments, state accountability entities, state legislators, interpreter agencies and referral service providers, and college healthcare programs, an email will be sent to recruit survey participants using publicly available email addresses found online either through the RI Dept of Health licensee database or through organizations' websites.

- For licensed sign language interpreters, an email will be sent to members on the publicly available RI Dept of Health list of licensed interpreters and to the Board of the Registry of Interpreters for the Deaf (RI RID) for dissemination by the organization via email, message boards, and social media (Facebook). Permission has been obtained form RI rID to post and distribute. Please see document under Protocol Advertisement.

- For Deaf ASL users, an email will be sent to the RI Commission on the Deaf and Hard of Hearing (RICDHH) who will disseminate the recruitment announcement to members of their electronic mailing list. Additional participants will be recruited using social media channels of RICDHH (Facebook, Twitter, Instagram). Permission has been obtained form RICDHH to post and distribute. Please see documents under Protocol Advertisement.

b. **Incentives**: *Will the subjects be offered inducements for participation? If yes, explain. Note: Please contact the SPREE office about the use of incentives within your research, as there are important university policies that fall outside of the protection of human subject, SPREE@stkate.edu or x8811 Incentive policy link*: https://stkate.box.com/s/sg18t87402as14xdtc0pppy2rt5w7swp

No

4. RISKS AND BENEFITS OF PARTICIPATION

a. **Select all that apply. Does the research involve:**

☐ **Use of private records (medical or educational records)**

☐ **Possible invasion of privacy of the subjects and/or their family**

☐ **Manipulation of psychological or social variables**

☐ **Probing for personal or sensitive information in surveys or interviews**

☐ **Use of deception**

☐ **Presentation of materials which subjects might consider offensive, threatening or degrading**

☐ **Risk of physical injury to subjects**

☐ **Other risks:**

b. **Risks**: ***Briefly describe the risks of participation in your study, if any. Describe the precautions taken to minimize these risks. Please use "no foreseeable risk" rather than no risks.***

For Deaf ASL users, there is risk of emotional upset form sharing potentially sensitive data about participants' experiences trying to access healthcare. A list of mental health resources will be provided in the Informed Consent section of the survey for Deaf ASL users. Please see list of resources below:

Individual Outpatient Mental Health Resources Serving Deaf Individuals in Rhode Island:

Suzanne Borstein, Ph.D
Clinical Psychologist
http://drborstein.com

Caroline Obrecht, LICSW
Psychotherapy Wayland Psychotherapy
cobrecht@cox.net

Martha Brunzos, LMHC
The Holistic Heart Wellness Center
mbrunzoslmhc@gmail.com

Robert Raphael, Ph.D
Delta Consultants West
bobr@edgenet.net

Rosa Molina, LICSW
Social Sparks, Inc.
socialsparksri@gmail.com

James Simon, LICSW
The Holistic Heart Wellness Center
jsimonlicsw@gmail.com

For all other groups being surveyed, there are no foreseeable risks to participants for completing online surveys. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard-drive will be stored in a locked filing cabinet in my home office. Additionally, all participants will be asked to consent to the online surveys before taking them. Anyone who does not consent, will automatically be exited from the survey.

c. **Benefits**: *List any anticipated direct benefits to your subjects. If none, state that here and in the consent form.*

1. **Direct Benefits:** *List any anticipated direct benefits to your subjects. If none, state that here and in the consent form.*

There are no direct benefits for participation in this research.

2. **Other Benefits:** *List any potential benefits of this research to society, including your field of Study.*

One benefit of participating in this study is that participants will help to inform research on barriers to healthcare access of Deaf ASL users in Rhode Island.

d. **<u>Risk/Benefit Ratio</u>:** *Justify the statement that the potential benefits (including direct and other benefits) of this research study outweigh any probable risks.*

While the direct benefits to participation in this study are minimal, the overall impact on the health of the Deaf ASL-using community in Rhode Island may be great. Access to healthcare is a human right. Identification of access barriers and potential removal or mitigation of those barriers can tremendously affect the quality of life of Deaf individuals in the communities in which we live, work, and play. The risks of this study are minimal as my research advisor and I will be the only viewers of the survey data and all responses will be anonymous.

e. **<u>Deception</u>:** *The use of deception in research poses particular risks and should only be used if necessary to accomplish the research, and when risks are minimized as much as possible. The researcher should not use deception when it would affect the subject's willingness to participate in the study (e.g, physical risks, unpleasant emotional or physical experiences, etc).*

Will you be using deception in your research?

☐ **Yes** ☒ **No**

If yes, justify why the deceptive techniques are necessary in terms of study's scientific, educational or applied value. Explain what other alternatives were considered that do not use deception and why they would not meet the researcher's objective. Attach a copy of a debriefing statement explaining the deception to participants.

5. CONFIDENTIALITY OF DATA

a. **Will your data be anonymous?**

☒ **Yes** ☐ **No**

(*Anonymous data means that the researcher cannot identify subjects from their data, while confidential data means that the researcher can identify a subject's response, but promises not to do so publicly.*)

b. ***How will you maintain anonymity/confidentiality of the information obtained from your subjects?*** *Interview Example: I will assign pseudonyms to each interview participant. I will de-identify the data, and store the key separate from the recordings and transcripts. I will have the transcriptionist sign a confidentiality statement*

Because I am using anonymous online surveys, I will not be able to identify participants form their survey data. For any data obtained from publicly available pre-existing information as listed in Section F, anonymity/confidentiality will not be required as the information is already publicly available.

c. **Data Storage**: ***The IRB expects you to review the Research Data Management Policy (linked at the top of the application) and to make sure your data storage plans meet the St. Kate's policy requirements. For additional guidance see the Research Data Management Guidance document: https://stkate.box.com/s/p73h5om7knkhbcmk84cuanidx4ukhi0b***

Select your Data Level and describe your data storage plans:

☐ **Public** ☒ **Confidential** ☐ **Protected-disclosure could cause harm** ☐ **Restricted-full review only**

Where will the data be kept, and who will have access to it during that time? Examples: I will store audio files and electronic files on a password protected computer or cloud (indicate which; please avoid using flash drives as they are one of the hardest 'tools' to protect and one of the easiest to exploit or lose, it is suggested to encrypt data on the cloud such as using a file password). I will store all paper files in a secure location (a locked filing cabinet) that is accessible only to myself and my advisor.

Qualtrics survey response data will be stored on a password-protected computer or cloud. I will store this data, the back-up hard drive, and all paper files in a locked file cabinet in my home office that is accessible only to myself and my advisors.

d. **Data Destruction***: How long will it be kept? What is the date when original data will be destroyed? (All studies must specify a date when original data that could be linked back to a subject's identity will be destroyed. Data that is stripped of all identifiers may be kept indefinitely). Example: I will destroy all records from the study within six months of the conclusion of the study but no later than June 2017.*

Because I am using anonymous online surveys, data will be stripped of all identifiers. Therefore, data may be kept indefinitely.

e. **Data Transmission/Sharing/Access**: *Will data identifying subjects be made available to anyone other than you or your advisor? If yes, please explain who will receive the data, how it will be transferred/shared and justify the need. Example: The data will only be available to me and my advisor.*

No

f. **Official Records**: *Will the data become a part of the medical or school record? If yes, explain.*

No

6. **INFORMED CONSENT**

a. **How will you gain consent?** *State what you will say to the subjects to explain your research*.

Because I am surveying several different stakeholder groups, each Informed Consent differs slightly, along with criteria to participate. All participants must be at least 18, but depending on the group, they will be asked different questions and there will be different criteria for participating. To see Informed Consent for each of the participant groups, please see Appendix A.

b. **Consent Document:** *Attach the consent or assent form or text of oral statement. A template is available in Mentor IRB. Example: "See attached"*

See Appendix A for consent documents in surveys.

c. **Timing of Consent Process:** *Note: In studies with significant risk or volunteer burden, the IRB may require that subjects be given an interim period of 24 hours or more before agreeing to participate in a study*

NA

d. **Assurance of Participant Understanding:** *How you will assess that the subject understands what they have been asked to do* (Note: *It is not sufficient to simply ask a yes/no question, such as "do you understand what you are being asked to do?"*

Before proceeding with the survey, each participant will attest to the following after reading the Informed Consent: "I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, understand it, and I meet the criteria for this study." Participants will then be asked to select "YES, I CONSENT" or NO, I DO NOT CONSENT".

7. **CITI TRAINING –** Work with your faculty advisor or contact IRB@stkates.edu if you have any questions about whether you should complete additional training modules within CITI. *You can also reference the Mandatory Research Education Policy – Human Subject Research: https://stkate.box.com/s/z3995tyh88e68ap8mmjr07esm9fsqbm2*

c. **Select all the CITI training courses/modules you completed:**

REQUIRED COURSE:

Human Subject Research Training Course – only one course is required

x	**Human Subject Research - Social & Behavioral Research Investigators**

☐ **Human Subject Research - Education Action Research Program**

☐ **Human Subject Research - Biomedical Research Investigators**

OPTIONAL MODULES:

☐ **Financial Conflict of Interest Course (suggested if you answered YES to Section 2 part g)**

☐ **Avoiding Group Harms - U.S. Research Perspectives (suggested if you checked any special populations in Section 2 part e)**

☐ **International Research (suggested for PIs doing research outside of the US that is NOT federally funded)**

☐ **International Studies (suggested for PIs doing research outside of the US that IS federally funded)**

☐ **Cultural Competence in Research (suggested when study related to a marginalized or minoritized population)**

☐ **Internet Based Research (suggested for PIs using internet resources during their research (outside of recruitment) – Skype, survey tools, internet activity monitoring, etc.)**

☐ **Other (prisoners, pregnant women, children):**

8. ASSURANCES

By submitting this application, the researcher certifies that:

- **The information furnished concerning the procedures to be taken for the protection of human subjects is correct.**

- **The investigator has read the IRB policies and to the best of his/her knowledge, is complying with Federal regulations and St. Catherine University IRB Policy governing human subjects in research.**
- **The investigator will seek and obtain prior written approval from the IRB for any substantive modification in the proposal, including, but not limited to changes in cooperating investigators, procedures and subject population.**
- **The investigator will promptly report in writing to the IRB any unexpected or otherwise significant adverse events that occur in the course of the study.**
- **The investigator will promptly report in writing to the IRB and to the subjects any significant findings which develop during the course of the study which may affect the risks and benefits to the subjects who participate in the study.**
- **The research will not be initiated until the IRB provides written approval.**
- **The term of approval will be for one year. To extend the study beyond that term, a new application must be submitted.**
- **The research, once approved, is subject to continuing review and approval by the IRB.**
- **The researcher will comply with all requests from the IRB to report on the status of the study and will maintain records of the research according to IRB guidelines.**
- **If these conditions are not met, approval of this research may be suspended.**

Appendix B

Survey Recruitment Email

ST. CATHERINE
UNIVERSITY

Dear (*Name),

My name is Christine West and I am a degree candidate in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) program at St. Catherine University in St. Paul, Minnesota. For my master's thesis, I am conducting an investigation into healthcare access barriers of Deaf American Sign Language (ASL) users in the state of Rhode Island. As part of my study, I will be surveying various stakeholder groups. You are receiving this email because you are a *______________ and I am inviting you to participate in the study.

If you are interested in participating, please click the link below to access the survey. The survey will take about **_____ minutes to complete. Please note that compensation will not be provided and participation is voluntary. Individuals must be at least 18 or older to participate in the survey. The survey deadline is ***________, 2022.

If you have any questions about this study, you can contact me at cawest745@stkate.edu or you can call me at 401-338-7844 (voice) or 401-648-3170 (VP).

This study has been approved by the St. Catherine University Institutional Review Board (#). You may contact John Schmitt, IRB Chair with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley, who you may also contact at elalley@stkate.edu or call 651-690-6018.

Thank you for your consideration.

Christine A. West, MA, CI and CT, SC:L, Ed:K-12
Graduate Student, Master of Arts in Interpreting Studies and Communication Equity (MAISCE)
St. Catherine University

*Deaf ASL User/ state legislator/ advocacy professional/ patient relations office in healthcare facilities/ interpreter accountability entity/ college students studying healthcare professions/ healthcare administrator/ state licensed sign language interpreter/ interpreter agency or referral service provider/ interpreter services department at healthcare facilities/ healthcare provider

**3 minutes to 20 minutes depending on the survey

***deadline depending on phase 1, phase 2, phase 3 dissemination

Link: varies depending on stakeholder group

Appendix C

Participant Surveys

Default Question Block

St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University, and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 20-50 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old, Deaf, use American Sign Language (ASL), and seek or receive healthcare services in Rhode Island.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

COULD THIS INFORMATION BE USED FOR FUTURE RESEARCH? Yes, it is possible that your data may be used for future research by the same investigator without gaining additional informed consent.

WHAT ARE THE RISKS OF PARTICIPATING IN THIS RESEARCH? There is risk of emotional upset from sharing potentially sensitive data about your experiences trying to access healthcare. A list of mental health resources is provided below in the event counseling services are needed:

Individual Outpatient Mental Health Resources Serving Deaf Individuals in Rhode Island (from public online RICDHH Directory):

Suzanne S. Borstein, Ph.D
Clinical PsychologistClinical Psychologist
ssb@drborstein.com

Caroline Obrecht, LICSW
Psychotherapy Wayland Psychotherapy
COBrecht@cox.net

Martha Brunzos, LMHC
The Holistic Heart Wellness Center
mbrunzoslmhc@gmail.com

Robert Raphael, Ph.D
Delta Consultants West
bobr@edgenet.net

Rose Molina, LICSW
Social Sparks, Inc.
socialsparksri@gmail.com

James Simon, LICSW
The Holistic Heart Wellness Center
jsimonlicsw@gmail.com

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS RESEARCH? There are no direct benefits to you for participation in this research. However, participation in this study may help to inform research on barriers to healthcare access of Deaf American Sign Language users in Rhode Island. This study may also benefit the sign language interpreting profession by identifying interpreter-related healthcare access barriers specifically, and may serve to improve provision of services.

WILL I BE COMPENSATED FOR MY PARTICIPATION? No compensation will be provided for participation in this study.

WHO CAN I CONTACT IF I HAVE QUESTIONS? This study has been approved by the St. Catherine University Institutional Review Board (#1652). You may contact John Schmitt, IRB Chair, with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley who you may also contact at elalley@stkate.edu or call 651-690-6018.

VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**
- **Deaf and use American Sign Language (ASL)**
- **seek or receive healthcare services in Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree

○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current occupational status?

○ Employed
○ Unemployed
○ Homemaker
○ Student
○ Retired
○ Disabled

What is your annual income earned in the past year (excluding family members living in your household)?

○ $0-$9999
○ $10,000-$19,999
○ $20,000-$29,999
○ $30,000-$39,999
○ $40,000-$49,999
○ $50,000-$59,999
○ $60,000-$69,999
○ $70,000-$79,999
○ $80,000-$89,999
○ $90,000-$99,999
○ $100,000+
○ Prefer not to say

How well do you use English?

○ Not well at all
○ Slightly well
○ Moderately well
○ Very well
○ Extremely well

What kind of health insurance do you have?

☐ Medicaid
☐ Medicare
☐ Private employer (self or spouse's/partner's)
☐ ________ Other
☐ I do not have health insurance

Communication Preferences

How do you prefer to communicate with your medical provider?

☐ In-person sign language interpreter
☐ Video Remote Interpreter (VRI)
☐ Use a family member to assist with communication
☐ Speak/lipread
☐ Write back and forth
☐ Text back and forth
☐ Speech to text app
☐ ________ Other

If you do not prefer to use a sign language interpreter for your medical appointments, why not?

☐ Prefer a different accommodation
☐ Protect my privacy and confidentiality
☐ Interpreters often not available
☐ Feel interpreters may not be qualified
☐ ________ Other

Appointment Making and VRS

How do you typically make your medical appointments?

○ Video Relay Services (VRS)
○ Online booking
○ On-site
○ ________ Other

If you use VRS, how often have you experienced problems with VRS while making medical appointments in the last 3 years?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

What problems have you experienced with VRS?

☐ Receptionist/healthcare provider hangs up
☐ Dissatisfied with interpreter
☐ Technical issues
☐ ________ Other

Non-Emergent Healthcare Encounters

How many times did you make an appointment to see a medical provider in-person within the last 3 years?

○ 0 times
○ 1-3 times
○ 4-6 times
○ 7-9 times
○ 10+ times

What kind of provider did you see for these appointments in the last 3 years?

☐ primary care provider (doctor, physician assistant)
☐ nursing care provider (nurse practitioner, midwife, registered nurse, licensed practical nurse)
☐ specialty care provider (cardiologist, OB-GYN, oncologist, psychiatry, dermatology, etc.)
☐ ________ Other

In the last 3 years, how often did you request an in-person interpreter for your appointments?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did you request an in-person interpreter at the same time you made an appointment?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did the doctors or receptionists agree to provide an in-person interpreter when you requested one?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If an in-person interpreter was not provided when you requested one, what were the reasons the doctors or receptionists stated?

☐ No interpreter available
☐ VRI is good enough
☐ Cannot afford one
☐ Told you to bring an interpreter
☐ Told you to ask a family member
☐ Told you to pay for an interpreter
☐ ________ Other

In the last 3 years, how often did a medical provider contact you to let you know whether or not an interpreter was confirmed before your scheduled appointment?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If the provider did not contact you, how often did you follow up with the provider before the appointment to find out if an in-person interpreter was confirmed?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often in the last 3 years did you arrive at a medical appointment but no interpreter was there, even though you requested one?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often were you satisfied with the in-person interpreting services you received?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did you feel the interpreters were qualified to interpret the medical appointments?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

In the last 3 years, how often have you ever requested a Deaf interpreter for a medical appointment?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

In the last 3 years, if an interpreter was not present when you arrived at your medical appointment, how often did you inform the provider?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

If you did inform the provider that no interpreter was present, what was the provider's response?

____

In the last 3 years, in situations where an interpreter was not present for your medical appointment and you requested one, how often did you continue the appointment(s) without an interpreter?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

I last 3 years, did you communicate to the provider that you would need an interpreter for all future appointments before you left the office?

- ○ Yes
- ○ No
- ○ No, because it is already noted in the system

In the last 3 years, did you ask the provider to include information in your electronic medical record about needing an interpreter for your future appointments?

- ○ Yes
- ○ No
- ○ No, because it is already noted in the system

VRI Non-Emergent Healthcare Encounters

At any of your medical appointments in the last 3 years, how often did you use Video Remote Interpreting (VRI) services?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

If you used VRI services at your medical appointments in the last 3 years, how satisfied were you with the services provided?

○ Not at all satisfied
○ Somewhat satisified
○ Very satisfied
○ Extremely satisified

If you were you not satisfied with VRI services at your medical appointments in the last 3 years, why not?
(select all that apply):

☐ Equipment/technical issues (equipment did not operate/frozen screen/pixelated screen)
☐ Did not understand the interpreter/interpreter did not understand me
☐ Interpreter did not display professional behavior
☐ Healthcare staff did not know how to operate equipment
☐ Could not see the screen
☐ ____________ Other

At any of your medical appointments in the last 3 years, how often were you offered Video Remote Interpreting (VRI) services when you requested an in-person interpreter?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often have you expressed to a medical provider in the last 3 years that you preferred an in-person interpreter for your appointment instead of VRI?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If you have expressed to a medical provider that you preferred an in-person interpreter for your appointment instead of VRI, what was the provider's response?

____

Emergent Healthcare Encounters

How often have you gone to the emergency room to receive health services within the last 3 years?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did you request an in-person interpreter in the ER?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often was an in-person interpreter actually provided?

○ Never
○ Rarely

○ Sometimes
○ Often
○ Always

In the last 3 years, on average, how long did you have to wait before an interpreter arrived?

○ 0-15 min.
○ 15-30 min.
○ 30-45 min.
○ 45 min-1 hour
○ Between 1-2 hours
○ Between 2-3 hours
○ 3 hours or more

In the last 3 years, how did you communicate with ER staff while waiting for the interpreter to arrive in the ER?

☐ Write back and forth
☐ Text
☐ White board
☐ Phone app
☐ __________ Other

VRI Emergent Healthcare Encounters

In the last 3 years, how often did you use VRI services in the ER?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often were you satisfied with the VRI services you received?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If you were not satisfied with the VRI services you received, what was the reason? (Select all that apply):

☐ Equipment/technical issues (equipment did not operate/frozen screen/pixelated screen)
☐ Did not understand the interpreter/interpreter did not understand me
☐ Interpreter did not display professional behavior
☐ Could not see the screen
☐ Healthcare staff did not know how to operate equipment
☐ __________ Other

In the last 3 years, if you were not satisfied with the VRI services you received in the ER, how often did you communicate this to ER staff?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If you made a request for an in-person interpreter instead of using VRI in the emergency room, how often was the request granted?

○ Never

○ Rarely
○ Sometimes
○ Often
○ Always

Complaint Processes

In the last 3 years, how often have you been dissatisfied with the lack of communication access with medical providers?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In general, how likely are you to file a complaint against a medical provider because of lack of communication access?

○ Not at all likely
○ Somewhat likely
○ Likely
○ Extremely likely

Where do you file a complaint against a medical provider for communication access issues?

○ RI Commission on the Deaf and Hard of Hearing (RICDHH)
○ Patient relations/advocacy office at the hospital or doctor's office
○ RI Department of Health
○ Disability Rights Rhode Island (Disability Law Center)
○ US Department of Justice
○ I don't know where to file a complaint against a medical provider for communication access issues

In the last 3 years, how often have you filed a complaint against a medical provider related to communication access issues?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If yes, how did you make that/those complaint(s)?

☐ Written English
☐ ASL Video
☐ Through an in-person interpreter
☐ Through a remote interpreter
☐ Through VRS
☐ ________ Other

Healthcare Navigation/Perceptions

In general, how confident do you feel in knowing how to navigate the healthcare system in Rhode Island?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
○ Extremely confident

If you have insurance, how well do you understand your insurance plans and choices?

○ Not at all understand
○ Somewhat understand
○ Understand
○ Completely understand

In general, do you feel healthcare facilities in Rhode Island do an effective job in providing access to healthcare?

○ Yes
○ No

If you use an in-person interpreter for medical appointments, how well do you understand how to request an interpreter from a medical provider?

○ Not at all understand
○ Somewhat understand
○ Understand
○ Completely understand
○ I do not use an interpreter for medical appointments

In general, how much do you trust the healthcare system in Rhode Island in meeting your communication access needs?

○ Not at all
○ A little
○ Some
○ A lot
○ A great deal

How often has a medical provider or receptionist ever made you feel humiliated, fearful, insulted or indignified because of your communication access needs?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often have you felt excluded from the healthcare system in Rhode Island because of your communication access needs?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How confident do you feel about self-advocating for your communication access needs when seeking and receiving medical services?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
○ Extremely confident

If you use an interpreter for health services, do you feel there are enough interpreters in Rhode Island to meet your communication access needs in healthcare settings?

○ Yes
○ No
○ I do not use interpreters

If you have experienced healthcare access barriers in the last 3 years and would like to share any of those experiences in more detail, please share them here:

Default Question Block

St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University, and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 11-15 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and a licensed healthcare worker in Rhode Island.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

COULD THIS INFORMATION BE USED FOR FUTURE RESEARCH? Yes, it is possible that your data may be used for future research by the same investigator without gaining additional informed consent.

WHAT ARE THE RISKS OF PARTICIPATING IN THIS RESEARCH? There are no foreseeable risks to participants for completing online surveys. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. Additionally, all participants will be asked to consent to the online surveys before taking them. Anyone who does not consent will automatically be exited from the survey.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS RESEARCH? There are no direct benefits to you for participation in this research. However, participation in this study may help to inform research on barriers to healthcare access of Deaf American Sign Language users in Rhode Island. This study may also benefit the sign language interpreting profession by identifying interpreter-related healthcare access barriers specifically, and may serve to improve provision of services.

WILL I BE COMPENSATED FOR MY PARTICIPATION? No compensation will be provided for participation in this study.

WHO CAN I CONTACT IF I HAVE QUESTIONS? This study has been approved by the St. Catherine University Institutional Review Board (#1652). You may contact John Schmitt, IRB Chair, with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley who you may also contact at elalley@stkate.edu or call 651-690-6018.

VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**
- **a licensed healthcare worker in Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics Hospital

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ______ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school diploma
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

My primary place of work is in a...

○ Hospital
○ Clinic
○ Urgent Care

○ Home Health
○ Private Practice
○ ☐ Other

In which county do you work?

○ Bristol
○ Kent
○ Newport
○ Providence
○ Washington

What is your primary language?

○ English
○ Spanish
○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Comm/Interpreters

In the last 3 years, how often have you worked with a Deaf patient who uses sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how did you communicate with Deaf patients who use sign language?

○ Through an in-person sign language interpreter
○ Through a remote sign language interpreter on video
○ Write back and forth
○ Lipreading
○ Text
○ Smart phone app
○ ☐ Other

How often did you feel that the communication you used with Deaf patients who use sign language was effective?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often have you worked with an in-person sign language interpreter when communicating with Deaf patients?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, did your facility pay for interpreting services or did an insurance company?

○ My facility paid
○ An insurance company paid
○ I do not know who paid

In the last 3 years, how often have you experienced difficulty in obtaining an in-person sign language interpreter when needed for appointments with Deaf patients?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did you feel that your Deaf patient understood what you were communicating to him/her/them when using an interpreter?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often did you feel that you understood what the Deaf patient was communicating to you when using an interpreter?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How familiar are you with the role of a sign language interpreter?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How familiar are you in knowing how to request an in-person sign language interpreter in Rhode Island?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely famiiar

What are the procedures for requesting a sign language interpreter in your office, department, or facility?

☐

Lipreading is a reliable way to communicate with Deaf patients who use sign language.

○ Strongly agree
○ Agree
○ Neither agree nor disagree
○ Disagree
○ Strongly disagree

Writing back and forth is a reliable way to communicate with Deaf patients about complex health matters.

○ Strongly agree
○ Agree
○ Neither agree nor disagree
○ Disagree
○ Strongly disagree

How familiar are you with the legal requirements for effective communication with Deaf patients?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

VRI

How aware are you of Video Remote Interpreting (VRI) services (accessing a sign language interpreter through a computer or iPad)?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

Does your facility have VRI equipment?

○ Yes
○ No
○ I don't know

How familiar are you with knowing how to use VRI equipment?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How familiar are you with knowing where to find VRI equipment in your facility?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How often have you used VRI services with Deaf patients in the last 3 years?

○ Never
○ Rarely
○ Sometimes

○ Often
○ Always

In the last 3 years, how satisfied were you with the VRI services you received?

○ Not at all satisfied
○ Slightly satisfied
○ Moderately satisfied
○ Very satisfied
○ Completely satisfied

In the last 3 years, how satisfied were the Deaf patients with the VRI services he/she/they received?

○ Not at all satisfied
○ Slightly satisfied
○ Moderately satisfied
○ Very satisfied
○ Completely satisfied
○ I don't know

PCC

In the last 3 years, to what extent did you feel you were able to establish trust with Deaf patients?

○ Not at all
○ Little
○ Somewhat
○ Much
○ A great deal
○ I have not had a Deaf patient who uses sign language in the past 3 years

In the last 3 years, to what extent did you feel you demonstrated effective communication centered behaviors with Deaf patients (e.g. care that is concordant with the patient's values, needs and preferences, and that allows patients to provide input and participate actively in decisions regarding their health and health care)?

○ Not at all
○ Little
○ Somewhat
○ Much
○ A great deal
○ I have not had a Deaf patient who uses sign language in the past 3 years

In the last 3 years, to what extent did you feel that you gave Deaf patients the same level of care as a non-Deaf patient?

○ Not at all
○ Little
○ Somewhat
○ Much
○ A great deal
○ I have not had a Deaf patient who uses sign language in the past 3 years

CC

How aware are you that American Sign Language and English are two completely different languages?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

How aware are you that some Deaf patients may not read or write English well enough to understand informed consent, discharge instructions and other written information?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

In the last 3 years, how often have you used “teach back” methods to confirm if Deaf patients understood you?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always
○ I have not worked with Deaf patients in the last 3 years

How aware are you that there are Deaf healthcare professionals (doctors, nurses, dentists, etc.)?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

Training

How often have you participated in training to learn more about working with Deaf patients who use sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In your college or training programs, to what extent did you feel that you were prepared to work with Deaf patients who use sign language?

○ Not at all prepared
○ Slightly prepared
○ Moderately prepared
○ Very prepared
○ Extremely prepared

Share

Is there anything else you would like to share about healthcare access barriers of Deaf patients who use sign language?

☐

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Default Question Block

St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 14-17 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and a Rhode Island licensed sign language interpreter.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

COULD THIS INFORMATION BE USED FOR FUTURE RESEARCH? Yes, it is possible that your data may be used for future research by the same investigator without gaining additional informed consent.

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WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS RESEARCH? There are no direct benefits to you for participation in this research. However, participation in this study may help to inform research on barriers to healthcare access of Deaf American Sign Language users in Rhode Island. This study may also benefit the sign language interpreting profession by identifying interpreter-related healthcare access barriers specifically, and may serve to improve provision of services.

WILL I BE COMPENSATED FOR MY PARTICIPATION? No compensation will be provided for participation in this study.

WHO CAN I CONTACT IF I HAVE QUESTIONS? This study has been approved by the St. Catherine University Institutional Review Board (#1652). You may contact John Schmitt, IRB Chair, with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley who you may also contact at elalley@stkate.edu or call 651-690-6018.

VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**
- **a Rhode Island licensed sign language interpreter**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ____________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

What is your primary language?

○ American Sign Language
○ English
○ Spanish

○ ☐ Other

Which category describes you?
(Select all that apply):

○ Deaf
○ Deaf-parented (CODA)
○ Hearing
○ ☐ Other

Did you attend an Interpreter Training Program?

○ Yes
○ No

Which category describes you presently?
(Select all that apply):

☐ Nationally certified interpreter (RID, BEI)
☐ State screened interpreter
☐ Interpreter who has undertaken formal training (ITP, RDI), but not yet credentialed
☐ Interpreter who has not undertaken formal training and not yet credentialed
☐ ☐ Other

How many years have you been working as a credentialed interpreter?

○ Less than 1 year
○ 1-5 years
○ 6-10 years
○ 11-15 years
○ 16-20 years
○ 21-25 years
○ 26-30 years
○ 30+ years
○ I have not yet worked as a credentialed interpreter

How many hours on average do you work per week?

○ More than 40 hours
○ 30-40 hours
○ 20-30 hours
○ 10-20 hours
○ Less than 10 hours
○ I do not currently work as an interpreter

Which category best describes you?
(Select all that apply):

○ Staff interpreter
○ Freelance interpreter
○ ITP Student
○ ITP graduate but not yet credentialed
○ Credentialed interpreter, but not yet working
○ ☐ Other

Which interpreting credentials do you hold?
(If none, please indicate none)

☐

What is your annual income earned in the past year (excluding family members living in your household)?

○ $0-$9999
○ $10,000-$19,999

○ $20,000-$29,999
○ $30,000-$39,999
○ $40,000-$49,999
○ $50,000-$59,999
○ $60,000-$69,999
○ $70,000-$79,999
○ $80,000-$89,999
○ $90,000-$99,999
○ $100,000+

Med Assignments

How often have you interpreted medical assignments in the past 3 years in Rhode Island?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years in Rhode Island, in what medical settings have you worked? (Select all that apply):

☐ Primary care physicians office
☐ Home health care
☐ Acute care hospital
☐ Urgent care center
☐ Rehabilitation center
☐ Nursing home or other long-term care facility
☐ Specialized outpatient (podiatry, chemotherapy, hemodialysis, etc.)
☐ Hospice
☐ Outpatient surgery center
☐ ______ Other

If you have not interpreted any medical assignments in the past 3 years in Rhode Island, why not?

○ Not available
○ Not a desired work setting
○ Not qualified to work in medical settings
○ Delayed payment from providers
○ Parking is difficult
○ ______ Other

In general, how comfortable are you in accepting medical assignments?

○ Extremely uncomfortable
○ Somewhat uncomfortable
○ Neither comfortable nor uncomfortable
○ Somewhat comfortable
○ Extremely comfortable

How qualified do you feel to work in medical settings?

○ Not at all qualified
○ Somewhat qualified
○ Moderately qualified
○ Very qualified
○ Extremely qualified

How interested would you be in additional training to work in medical settings?

○ Not at all interested
○ Slightly interested
○ Moderately interested

○ Very interested
○ Extremely interested

If you were provided with additional training, would you accept more work in medical settings?

○ Yes
○ No
○ I don't know

In the last 3 years, how often have you ever been contacted directly by a healthcare facility in Rhode Island to interpret for a medical emergency?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

What would entice you to accept (more) medical interpreting assignments? (select all that apply):

☐ Booked for longer blocks of time
☐ Better rate of pay
☐ More timely payment for services rendered
☐ More training
☐ Easier parking
☐ More support
☐ ________ Other

Referral

How often do you receive referrals for medical assignments in Rhode Island?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how have you received referrals for medical assignments? (Select all that apply):

☐ State referral
☐ Private referral
☐ Direct booking
☐ On-site booking
☐ ________ Other

In the last 3 years, what percentage of medical referrals do you receive from the following:

☐ ________ State referral
☐ ________ Private referral
☐ ________ Direct booking
☐ ________ On-site booking
☐ ________ Other

If you accept medical interpreting assignments through the state referral, how do you feel about the quality of the interpreter referral process/system?

○ Very good
○ Good
○ Acceptable
○ Poor

○ Very poor
○ I do not accept referrals from the state referral

In general, how would you describe the quality of your working relationship with the state interpreter referral service?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor
○ I do not work with the state referral service

In general, how would you describe the quality of your working relationship with private interpreter referral agencies/companies?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor
○ I do not work with any private referral agencies/companies

If you have worked with the state referral service before, what improvements do you suggest for the state referral service when it comes to referring medical assignments?

If you have worked with private referral agencies/companies before, what improvements do you suggest for private referral agencies/companies when it comes to referring medical assignments?

Providers

How often have you engaged in professional development learning opportunities with medical providers?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If you interpret in medical settings in Rhode Island, in general, how much do you feel that medical providers understand your role?

○ None at all
○ A little
○ A moderate amount
○ A lot
○ A great deal
○ I do not interpret in medical settings in RI

In general, how often do you feel that healthcare providers consider you as part of the healthcare team?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

To what extent do you feel that medical providers possess the cultural competency to adequately serve Deaf ASL users?

○ Extremely inadequate
○ Somewhat inadequate
○ Neither adequate nor inadequate
○ Somewhat adequate
○ Extremely adequate

In the last 3 years, what is the longest time you have had to wait for a provider to see a Deaf patient?

○ less than 10 minutes
○ between 10-20 minutes
○ between 20-30 minutes
○ between 30-40 minutes
○ between 40-50 minutes
○ between 50-60 minutes
○ 60+ minutes

In the last 3 years, how many times have you had to explain to a medical provider the legal requirements for effective communication for Deaf patients?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Payment

If you have interpreted in medical settings in Rhode Island in the last 3 years, what percentage of payments for your services are from insurance companies, providers, and private referral companies?

☐ ____________ Insurance companies
☐ ____________ Providers/Hospital/Healthcare facility
☐ ____________ Private referral company
☐ ____________ Other
☐ I have not interpreted in medical settings in RI in the last 3 years

Over the last 3 years, please list in order who pays you most promptly for your services- insurance companies, providers, private referral companies (1=most prompt, 3= least prompt)?

☐ ____________ Insurance companies
☐ ____________ Providers
☐ ____________ Private referral company

If you were paid more promptly for your services, how likely would you accept more interpreting work in medical settings in Rhode Island?

○ Not at all likely
○ Somewhat likely
○ Moderately likely
○ Very likely
○ Extremely likely

COVID/Tele

How often have you provided in-person medical interpreting services to healthcare facilities during the COVID-19 pandemic?

○ Never

○ Rarely
○ Sometimes
○ Often
○ Always

How often did the facility provide you with Personal Protective Equipment (PPE) during your scheduled appointments during the COVID-19 pandemic?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If medical facilities did provide you with PPE, what kind of PPE did they give you? (Select all that apply):

☐ Mask (surgical, KN-95, clear mask, other)
☐ Gloves
☐ Face shield
☐ Gown
☐ ________ Other
☐ The facility did not provide me with PPE

How often have you provided any medical interpreting services for Telehealth appointments over the past 3 years?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often have you provided remote interpreting services for any medical appointments in Rhode Island over the past 3 years (not for a VRI provider/company but as an independent contractor)?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How familiar are you with HIPAA compliant video conferencing platforms for Telehealth?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How confident do you feel that you have sufficient knowledge and skills in providing medical interpreting services via remote means or via Telehealth?

○ Not at all confident
○ Somewhat confident
○ Moderately confident
○ Very confident
○ Extremely confident

Share

How confident are you that there are enough available in-person interpreters to work in medical settings in Rhode Island?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
○ Extremely confident

What suggestions do you have for improved interpreter-related healthcare access for Deaf patients in Rhode Island?

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St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 8-10 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and a student in a post-secondary institution in Rhode Island studying a healthcare profession.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

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- **at least 18 years old**

- **a student in a post-secondary institution in Rhode Island studying a healthcare profession**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your primary language?

○ English
○ Spanish
○ ________ Other

What kind of college or university do you attend?

○ Public (state)
○ Private

What kind of healthcare training program are you enrolled in?

○ Medical school program
○ Nursing school program
○ ________ Other

Are you enrolled full-time, part-time, other?

○ Full-time
○ Part-time
○ ________ Other

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Deaf

How often do you interact with a Deaf person who uses sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Are there any Deaf people who use sign language in your family?

○ Yes
○ No

Are there any Deaf people who use sign language in your social circles?

○ Yes
○ No

Do you know American Sign Language (ASL)?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How did you learn sign language?

○ Family member(s)
○ Community class
○ College class
○ From work
○ ________ Other

Would you be interested in taking a class to learn sign language?

○ Yes
○ No
○ I'm not sure

Do you know any other students who are Deaf and use sign language in your healthcare program?

○ Yes
○ No

Would you like to see more Deaf people who use sign language in your healthcare program?

○ Yes
○ No

If you would not like to see more Deaf people who use sign language in your healthcare program, why not?

☐

Does your college or university offer sign language courses?

○ Yes
○ No
○ I don't know

Interpreters

How often have you used a sign language interpreter before?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How familiar are you with the role of a sign language interpreter?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How familiar are you with knowing how to request a sign language interpreter for a Deaf patient who needs one in Rhode Island?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Where would you make a request for a sign language interpreter in Rhode Island?

☐

How familiar are you with the requirements to practice sign language interpreting in the state of Rhode Island?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How aware are you of the legal requirements to provide effective communication to Deaf patients who use sign language in Rhode Island?

- ○ Not at all aware
- ○ Slightly aware
- ○ Moderately aware
- ○ Very aware
- ○ Extremely aware

Training/Curriculum

In your current healthcare program, how much training have you received in working with Deaf patients who use sign language?

- ○ None at all
- ○ A little
- ○ A moderate amount
- ○ A lot
- ○ A great deal

In your healthcare curriculum, how much instruction is included about working with Deaf patients who use sign language?

- ○ None at all
- ○ A little
- ○ A moderate amount
- ○ A lot
- ○ A great deal

How interested would you be in learning more about working with Deaf patients who use sign language?

- ○ Not at all interested
- ○ Slightly interested
- ○ Moderately interested
- ○ Very interested
- ○ Extremely interested

If you would like to learn more about working with Deaf patients who use sign language, what would you like to learn?

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St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University, and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

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WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 7-10 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and a Rhode Island state legislator.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

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at least 18 years old
a Rhode Island state legislator

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

What is your primary language?

○ English
○ Spanish

○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Constituents

In your role as a Rhode Island legislator, how often have you met or worked with Deaf constituents who use sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How much do you know about the legal obligations of healthcare facilities to provide communication access to Deaf constituents who use sign language?

○ Nothing
○ Little
○ Some
○ Much
○ A great deal

In your role, how familiar are you with knowing how to request interpreting services to meet with Deaf constituents who use sign language?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Healthcare Access

How aware are you of healthcare access barriers for Deaf patients who use sign language in Rhode Island?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

If yes, what barriers are you aware of?

☐

How often have you worked with Deaf community members, Deaf organizations, or state agencies that serve Deaf people to introduce or support legislation to improve healthcare access for Deaf patients who use sign language?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

How often have you been supportive of any legislation that has addressed improved healthcare access for Deaf patients who use sign language?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

If you have been supportive of legislation, which legislation?

If you have not been supportive of any legislation that has addressed improved healthcare access for Deaf patients who use sign language in Rhode Island, why not?

Training

How often have you participated in a training to learn more about working with Deaf constituents who use sign language?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ Always

How interested would you be in participating in training to learn more about working with Deaf constituents who use sign language?

- ○ Not at all interested
- ○ Slightly interested
- ○ Moderately interested
- ○ Very interested
- ○ Extremely interested

Additional Comments

Is there anything you would like to add about working with Deaf constituents or healthcare access barriers of Deaf ASL Users in Rhode Island?

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St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

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WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and an advocacy professional working in the state of Rhode Island.

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WILL I BE COMPENSATED FOR MY PARTICIPATION? No compensation will be provided for participation in this study.

WHO CAN I CONTACT IF I HAVE QUESTIONS? This study has been approved by the St. Catherine University Institutional Review Board (#1652). You may contact John Schmitt, IRB Chair, with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley who you may also contact at elalley@stkate.edu or call 651-690-6018.

VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**
- **advocacy professional working in the state of Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

What is your primary language?

○ English
○ Spanish

○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Complaints

How often have you received healthcare access complaints from Deaf ASL users in the last 3 years?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

What was the general nature of the complaint (e.g., refusal to provide sign language interpreters, use of VRI instead of in-person interpreters, etc.)?

☐

In the last 3 years, how often were those complaints resolved?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Communication

How often do you have regular communication with patient advocacy offices/patient relations offices/risk management offices at healthcare facilities in Rhode Island?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you have regular communication with patient advocacy offices/patient relations offices/risk management offices at healthcare facilities in RI about healthcare access barriers for Deaf ASL users?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you partner with local Deaf organizations, the state Commission on the Deaf, or sign language interpreting organizations to address healthcare access barriers of Deaf

ASL users in Rhode Island?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Time/Funding

How much of your weekly work time is spent addressing complaints regarding communication access in healthcare settings for Deaf patients who use sign language?

○ None at all
○ A little
○ A moderate amount
○ A lot
○ A great deal

How often does organizational funding or staffing preclude you from devoting more time to addressing healthcare access complaints from Deaf ASL users?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Issues

In your opinion, what do you see as the most pressing issues regarding communication access in healthcare settings for Deaf ASL users?

☐

Is there anything else you would like to share about healthcare access barriers of Deaf ASL users in Rhode Island?

☐

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○ No, not at all

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○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Complaints

In your role as an accountability professional/board member, are you privy to complaints made against sign language interpreters who work in the state of Rhode Island?

○ Yes, completely
○ Yes, somewhat
○ No, not really
○ Definitely not

How often do you receive complaints against sign language interpreters?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always
○ ☐ Other

How often do you receive complaints against sign language interpreters working in healthcare settings?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always
○ ☐ Other

To what extent do you feel that complaints made against sign language interpreters in the state of Rhode Island are resolved to the satisfaction of the complainant?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Role, Responsibilities

How well do you feel you understand your role and responsibilities as a member of an accountability/governing board of professionals?

○ Not at all understand
○ Slightly understand
○ Moderately understand
○ Very much understand

○ Extremely understand

I feel the governing body, of which I am a member, has enough statutory authority to address complaints against sign language interpreters for alleged ethical violations of conduct.

○ Strongly disagree
○ Somwhat disagree
○ Neither agree nor disagree
○ Somewhat agree
○ Strongly agree

I feel that the governing body, of which I am a member, effectively carries out its statutory charge.

○ Strongly disagree
○ Disagree
○ Neither agree nor disagree
○ Agree
○ Strongly agree

If you do not feel that the governing body, of which you are a member, effectively carries out its statutory charge, why not?

☐

How often do you feel the state considers the recommendations made by you and the governing body of which you are a member in regards to interpreter violations and/or remedies to violations?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Support

I have support from the state of Rhode Island to effectively carry out my statutory charge as a member of a governing body.

○ Strongly disagree
○ Somewhat disagree
○ Neither agree nor disagree
○ Somewhat agree
○ Strongly agree

State personnel who oversee the governing body of which I am a member understands the sign language interpreter profession and concerns of Deaf ASL users in Rhode Island to make informed decisions.

○ Strongly disagree
○ Somewhat disagree
○ Neither agree nor disagree
○ Somewhat agree
○ Strongly agree

Share

What suggestions do you have to improve accountability/board makeup, functions, duties, and oversight so that access for Deaf individuals, and especially healthcare access, can be improved?

☐

Is there anything else you would like to share about healthcare access barriers of Deaf ASL users in Rhode Island?

☐

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○ 18-24
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(Select all that apply):

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What is the highest grade or level of schooling that you completed?

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○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

My primary place of work is in a...

○ Private referral company
○ Public referral company
○ Prefer not to say

What is your primary language?

○ English
○ Spanish
○ ________ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

Is there anyone in your referral department that is fluent in American Sign Language?

○ Yes
○ No

Have you also undertaken training as a sign language interpreter?

○ Yes
○ No

How many people work in your referral department?

○ 1
○ 2-4
○ 5-7
○ 8+

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Processes

In your best estimation, how many referrals for medical interpreting assignments have you filled in the last 3 years (number of referrals, not number of different interpreters)?

____

In your best estimation, how many interpreters have you referred for medical assignments in the state of Rhode Island over the last 3 years (number of different interpreters, not number of referrals)?

○ between 1-3
○ between 4-6
○ between 7-9
○ between 10-12
○ between 12-14
○ between 15-17
○ between 17-20
○ 20+

In your best estimation, how large is the current pool of available interpreters (under your referral system only) who accept medical assignments on a regular basis in the state of Rhode Island?

○ less than 2

○ between 2-4
○ between 4-6
○ between 7-9
○ between 10-12
○ 12+

Based on the pool of interpreters you refer, how confident are you that there are enough interpreters in Rhode Island to respond to medical requests?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
○ Extremely confident

In your opinion, what is your biggest impediment to filling medical requests in Rhode Island?

○ Not enough interpreters in general
○ Not enough interpreters willing to accept medical assignments
○ Delayed payment to interpreters
○ Inconvenient parking
○ Interpreters are not trained/qualified to work in medical settings
○ ________ Other

How do you make decisions about which interpreters to refer for medical assignments? (Select all that apply):

☐ Availability
☐ Training in medical interpreting
☐ Consumer profile/preferences
☐ ________ Other

What is your level of knowledge about medical interpreter qualifications/training/readiness to work in medical settings?

○ A great deal
○ A lot
○ A moderate amount
○ A little
○ None at all

What do your processes look like when referring interpreters for medical appointments (from start to end)?

____

How many times over the last 3 years have you had to explain to a medical provider the legal requirements for effective communication?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How much time do you spend per week advocating for payment from medical providers either on behalf of an interpreter or on behalf of your agency/company?

○ A great deal
○ A lot
○ A moderate amount
○ A little
○ None at all

How often do you provide training and technical assistance to medical providers about interpreter service provision?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How many trainings have you conducted with medical providers over the last 3 years?

○ 0
○ 1
○ 2
○ 3
○ 4
○ 5
○ 5+

How often do you refer a Deaf-Hearing interpreting team for a medical assignment?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you coordinate with public or private referral companies to fill medical requests?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you feel empowered to make changes to the referral process in order to maximize efficiency and improve consumer, interpreter, and requester satisfaction?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

What changes would you make to your referral process to ensure a more efficient and effective referral system?

☐

Communication

How often do you have meetings (in-person or virtual) with all interpreting services offices at healthcare facilities in Rhode Island on a regular basis?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you attend the quarterly meetings of the local professional interpreter organization?

○ Never

○ Rarely
○ Sometimes
○ Often
○ Always

How often do you have communication with Deaf consumers per week regarding medical interpreter requests, complaints, and confirmation follow-ups?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How do you primarily communicate with Deaf consumers?

○ Video Relay Services
○ Directly via videophone
○ Email
○ In-person
○ ☐ Other

Relationships/Support

In your opinion, how would you characterize your working relationship with the interpreting community in Rhode Island?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor

In your opinion, how would you characterize your relationship with the Deaf community in Rhode Island?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor

In your opinion, how would you characterize your working relationship with the insurance companies in Rhode Island (for medical requests)?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor

In your opinion, how would you characterize your working relationship with healthcare organizations/providers in Rhode Island?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor

How often is there formal evaluation of the referral department in which you work?

○ Never
○ Rarely
○ Sometimes

○ Often
○ Always

What does the formal evaluation process look like?
(Select all that apply):

☐ Surveys
☐ Focus groups
☐ Statistical review
☐ ____________ Other

How often does the formal evaluation take place?

○ Every month
○ Every 3 months
○ Every 6 months
○ One time per year
○ Two times per year
○ ____________ Other

Technology

How often do you use a referral database to refer interpreters for medical appointments in Rhode Island?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

To what extent do you feel your referral database system is efficient?

○ Not at all efficient
○ A little efficient
○ Somewhat efficient
○ Very efficient
○ Extremely efficient

How much training have you had to optimize use of your referral database system?

○ None at all
○ A little
○ A moderate amount
○ A lot
○ A great deal

How often have you provided in-person/virtual training to all interpreters on your referral list on how to use the referral database system?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Training

How often do you engage in professional development opportunities for your referral job?

○ Never
○ Rarely
○ Sometimes
○ Often

○ Always

How confident do you feel that you have enough support within your department to effectively handle medical interpreter requests?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
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Share

Is there anything else you would like to share about healthcare access barriers of Deaf patients who use sign language?

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VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**
- **a healthcare administrator in Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ____________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school diploma
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

My primary place of work is in a...

○ Hospital
○ Clinic

○ ☐ Other

In which county do you work?

○ Bristol
○ Kent
○ Newport
○ Providence
○ Washington

What is your primary language?

○ English
○ Spanish
○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

Policies

Do you have policies and procedures in place in your facility regarding communication access for Deaf patients who use sign language?

○ Yes
○ No

Are your facilities' policies and procedures regarding communication access for Deaf patients publicly available?

○ Yes
○ No

Are your facilities' policies and procedures regarding communication access for Deaf patients available upon request?

○ Yes
○ No

Would you be interested in receiving free technical assistance on updating or creating policies and procedures regarding communication access for Deaf patients? If yes, please provide contact information.

○ ☐ Yes
○ No

Data

Do you have systems and processes in place that capture data regarding the number of Deaf patients served in your facility/facilities per year?

○ Yes
○ No
○ I don't know

Do you have systems and processes in place that capture data regarding the number of requests for sign language interpreters you receive per year?

○ Yes
○ No
○ I don't know

Do you have systems and processes in place that capture data regarding the costs attributed to providing communication access services to Deaf patients per year?

○ Yes
○ No
○ I don't know

If you had to estimate, what costs would you attribute to the provision of sign interpreting services on a yearly basis at your facilities?

☐

Do your facilities include information in patient electronic medical records that indicates primary language preference for a person who is Deaf?

○ Yes
○ No
○ I don't know

How do the staff who work in your facilities assess the communication needs of Deaf patients?

☐

How aware are you of the legal requirements to provide effective communication to Deaf patients?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

Are you aware of any communication access barriers that are currently present in your facilities for Deaf patients who use sign language?

○ Yes
○ No

If you are aware of any communication access barriers that present in your facilities for Deaf patients who use sign language, what are they?

☐

Relationships

How important is your relationship with your interpreting services departments within your facilities?

○ Not at all important
○ Slightly important
○ Moderately important
○ Very important
○ Extremely important

In the last 3 years, how often have you conducted any outreach and/or engaged with the Deaf community for any of your healthcare programs (educational or other)?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

In the last 3 years, how often have your facilities included information in sign language (video clips) for the Deaf community on any of its websites or social media channels?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Training

How often do you mandate annual training for your staff on working with Deaf patients and sign language interpreters?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How interested are you in incorporating free annual training materials about working with Deaf patients and sign language interpreters in your electronic learning platforms for your staff or through either in-person or online workshops?

○ Not at all interested
○ Slightly interested
○ Moderately interested
○ Very interested
○ Extremely interested

Barriers

Is there anything else you would like to share about healthcare access barriers for Deaf patients who use sign language?

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Default Question Block

St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University, and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 7-10 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and a professional working in a patient relations office/patient advocacy office in a healthcare facility in the state of Rhode Island.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

COULD THIS INFORMATION BE USED FOR FUTURE RESEARCH? Yes, it is possible that your data may be used for future research by the same investigator without gaining additional informed consent.

WHAT ARE THE RISKS OF PARTICIPATING IN THIS RESEARCH? There are no foreseeable risks to participants for completing online surveys. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. Additionally, all participants will be asked to consent to the online surveys before taking them. Anyone who does not consent will automatically be exited from the survey.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS RESEARCH? There are no direct benefits to you for participation in this research. However, participation in this study may help to inform research on barriers to healthcare access of Deaf American Sign Language users in Rhode Island. This study may also benefit the sign language interpreting profession by identifying interpreter-related healthcare access barriers specifically, and may serve to improve provision of services.

WILL I BE COMPENSATED FOR MY PARTICIPATION? No compensation will be provided for participation in this study.

WHO CAN I CONTACT IF I HAVE QUESTIONS? This study has been approved by the St. Catherine University Institutional Review Board (#1652). You may contact John Schmitt, IRB Chair, with any questions at jschmitt@stkate.edu or call 651-690-7739. My thesis supervisor is Dr. Erica Alley who you may also contact at elalley@stkate.edu or call 651-690-6018.

VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **at least 18 years old**

- **professional working in a patient relations office/patient advocacy office in a healthcare facility in the state of Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

My primary place of work is in a...

○ Hospital
○ Clinic
○ ☐ Other

In which county do you work?

○ Bristol
○ Kent
○ Newport
○ Providence
○ Washington

What is your primary language?

○ English
○ Spanish
○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

Is there anyone working in your office that is fluent in American Sign Language?

○ Yes
○ No

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

In your current position, how often have you worked with Deaf individuals who use sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Complaints

In your current position how often have you received a healthcare complaint from a Deaf patient who uses sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How did you communicate with the Deaf patient when discussing the complaint?

○ In-person sign language interpreter
○ Remote sign language interpreter through phone or other technology
○ Write back and forth with the patient in-person
○ Email correspondence

○ Mail correspondence
○ ☐ Other

How did the Deaf patient file the complaint?

○ Filled out a complaint form in written English
○ Sent a video in sign language
○ Phoned in a complaint
○ ☐ Other

What was the general nature of the Deaf patient's complaint?

○ Healthcare facility's refusal to provide sign language interpreters
○ Healthcare facility's use of Video Remote Interpreting (VRI) services instead of in-person interpreter
○ Dissatisfaction with sign language interpreter(s)
○ Billing/payment concerns for healthcare services
○ Healthcare facility asked family member/child to interpret for Deaf patient
○ ☐ Other

How often are the complaints typically resolved to the satisfaction of the Deaf patient?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

General

How familiar are you with the legal requirements for effective communication with Deaf patients who use sign language?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

In general, how familiar are you with the communication access needs of Deaf patients who use sign language?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How often have you received training regarding working with Deaf patients who use sign language?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Would you like training on working with Deaf patients who use sign language and learning more about their communication access needs?

○ Definitely yes
○ Probably yes
○ Might or might not
○ Probably not
○ Definitely not

Is there anything else you would like to share about healthcare access barriers for Deaf ASL users in Rhode Island?

Default Question Block

St. Catherine University
Informed Consent to Participate in Research

PROJECT TITLE: Identifying Barriers to Healthcare Access of Deaf American Sign Language Users in Rhode Island

PRINCIPAL INVESTIGATOR: Christine A. West, MA, CI and CT, SC:L, Ed:K-12, Graduate Student in the Master of Arts in Interpreting Studies and Communication Equity (MAISCE) Program, Department of American Sign Language and Interpretation, St. Catherine University, and Project Director of the Healthcare System Transformation Project at the Rhode Island Commission on the Deaf and Hard of Hearing (RICDHH).

WHAT IS THE PURPOSE OF THIS STUDY? The purpose of this survey is to identify healthcare access barriers of Deaf American Sign Language (ASL) users in Rhode Island.

WHAT WILL YOU ASK ME TO DO IF I AGREE TO BE IN THIS STUDY? You will be asked to complete a survey. The survey questions will ask about demographic information and healthcare access barriers for Deaf American Sign Language (ASL) users in Rhode Island. The survey will take about 12-15 minutes to complete. You can decide yourself whether to take the survey or not. It is voluntary. If you decide to start the survey, you can decide later to stop at any time without any consequences. You may also skip questions and may leave the survey at any time.

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY? You are being asked to participate in this study because you are at least 18 years old and work in an interpreting services office/department at a healthcare facility in Rhode Island.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL? If you participate in this online survey, all data will be anonymous. Because this study uses anonymous online surveys, data will be stripped of all identifiers. Only my research advisors and I will have access to the survey responses. All data will be stored on a secure password-protected computer and on a hard drive as a back up. All data, computers, and hard drive will be stored in a locked filing cabinet in my home office. All collected data will be de-identified and may be kept indefinitely.

COULD THIS INFORMATION BE USED FOR FUTURE RESEARCH? Yes, it is possible that your data may be used for future research by the same investigator without gaining additional informed consent.

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WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS RESEARCH? There are no direct benefits to you for participation in this research. However, participation in this study may help to inform research on barriers to healthcare access of Deaf American Sign Language users in Rhode Island. This study may also benefit the sign language interpreting profession by identifying interpreter-related healthcare access barriers specifically, and may serve to improve provision of services.

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VOLUNTARY CONSENT BY PARTICIPANT: Your participation is completely voluntary, and you can withdraw at any time. To take this survey, you must be:

- **be at least 18 years old**

- **work in an interpreting services office/department at a healthcare facility in Rhode Island**

STATEMENT OF CONSENT:
I consent to participate in this study. By selecting the "YES" button below, I acknowledge that I have read this information, I understand it, and I meet the criteria for this study.

○ YES, I CONSENT
○ NO, I DO NOT CONSENT

Demographics

What is your age?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

What is your race/ethnicity?
(Select all that apply):

☐ Indigenous, Aboriginal, Alaskan Native, or Native American
☐ Black or African American
☐ Asian
☐ Native Hawaiian or Pacific Islander
☐ Hispanic, Latino/a, Spanish Origins
☐ White or Caucasian
☐ Two or more races
☐ ________ Other
☐ Prefer not to say

What is the highest grade or level of schooling that you completed?

○ Some high school
○ High school
○ Post high school training other than college
○ Some college
○ Associate's degree
○ Bachelor's degree
○ Master's degree
○ PhD or higher
○ Professional (Medicine, Law, Dentistry, etc.)

Are you currently...

○ Male
○ Female
○ Non binary
○ Prefer not to say

What is your current employment status?

○ Employed full-time
○ Employed part-time
○ Contract or temporary worker
○ Retired
○ Prefer not to say

My primary place of work is in a...

○ Hospital
○ Clinic
○ ☐ Other

In which county do you work?

○ Bristol
○ Kent
○ Newport
○ Providence
○ Washington

What is your primary language?

○ English
○ Spanish
○ ☐ Other

Do you know American Sign Language?

○ Yes, fluently
○ Yes, but not fluently
○ No, not at all

How familiar are you with the communication access needs of Deaf patients who use sign language in healthcare settings in Rhode Island?

○ Not familiar at all
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

General

Do you employ staff interpreters at your facility?

○ Yes
○ No

How many staff interpreters do you employ and which languages do they use (other than English)?

○ ☐ Spanish
○ ☐ Portuguese
○ ☐ American Sign Language
○ ☐ Other

Do the interpreters employed at your facility work full-time, part-time, or on a contract basis?

○ Full-time
○ Part-time
○ Contract staff

If you do not currently employ a staff sign language interpreter at your facility, are you considering employing one in the next two years?

○ Yes
○ No
○ I don't know

If you do not currently employ a staff sign language interpreter at your facility and you are not considering employing one in the next two years, why not?

○ The number of requests do not justify the need
○ Budgetary constraints
○ ☐ Other

In your best estimation, how many requests for in-person sign language interpreters have you received in the past 3 years?

○ 0
○ 1-5
○ 6-10
○ 11-20
○ 21-30
○ 31-40
○ 41-50
○ 51-60
○ 61-70
○ 70+

In your best estimation, what percentage of those requests were filled?

○ 100%
○ 75%
○ 50%
○ 25%
○ 10%
○ 5%
○ 0%

Policy/Data

How familiar are you in assessing a Deaf person's communication preferences in healthcare settings?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How familiar are you with the policies and procedures at your facility for communication access for Deaf patients?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How often do you maintain statistics of communication access requests and service provision for Deaf patients at your facility?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Do the statistics you maintain of all communication access requests and service provision for Deaf patients at your facility include all departments (ER, inpatient, outpatient, etc.) ?

○ Yes
○ No

Interpreters

How familiar are you with knowing who to contact to request an in-person sign language interpreter for your facility?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

How often do you have communication with the state sign language interpreter referral service (RICDHH)?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How would you characterize your relationship with the state sign language interpreter referral service at RICDHH?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor
○ I do not have a relationship with the state referral for sign language interpreters

How often do you have communication with private sign language interpreter referral agencies or companies?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How would you characterize your relationship with private sign language interpreter referral agencies or companies?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor
○ I do not have a relationship with private referral companies for sign language interpreters

How do you determine if a sign language interpreter is qualified to work in your facility?

○ Rely on referral service to make the decision on who is qualified
○ Ask the interpreter if they are qualified
○ I do not know how to determine if a sign language interpreter is qualified to work in my facility
○ ________ Other

Who do you contact if you need a sign language interpreter for emergencies during nights and weekend hours?

○ RICDHH state referral
○ Private referral company
○ Direct contact to interpreters
○ ________ Other

How confident do you feel that you have enough access to sign language interpreters to meet your facility's needs?

○ Not at all confident
○ Slightly confident
○ Moderately confident
○ Very confident
○ Extremely confident

Does your facility have signage that shows where and how to request a sign language interpreter?

○ Yes
○ No

VRI

In your best estimation, how often do you use Video Remote Interpreting (VRI) services with Deaf patients (accessing a remote sign language interpreter via an iPad or computer)?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

Does your facility offer the Deaf patient the option of using an in-person sign language interpreter or only VRI?

○ In-person interpreter is offered as an option
○ Only use VRI

How familiar are you with knowing how to operate VRI equipment?

○ Not at all familiar
○ Slightly familiar
○ Moderately familiar
○ Very familiar
○ Extremely familiar

If your facility has VRI equipment, do you know where it is located?

○ Yes
○ No
○ My facility does not have VRI equipment

How often does your office or facility do regular checks to make sure the VRI equipment is functioning properly?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often does your office or facility offer training to staff on how to use VRI technology?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you follow up with Deaf patients regarding their satisfaction level with either in-person or video remote interpreting services provided at your facility?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often do you provide interpreter services to Deaf patients if they would like to make a complaint (to the patient advocate office or other accountability office within the healthcare facility)?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How often have you ever been asked to provide an interpreter to a Deaf patient so that they could make a complaint to a patient advocacy office/patient relations office in your healthcare facility?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

How aware are you of the legal requirements for effective communication for Deaf patients?

○ Not at all aware
○ Slightly aware
○ Moderately aware
○ Very aware
○ Extremely aware

CC

How would you rate your knowledge and experience of working with Deaf patients who use sign language?

○ Very good
○ Good
○ Acceptable
○ Poor
○ Very poor

How often have you requested training to learn more about how to better serve Deaf patients?

○ Never
○ Rarely
○ Sometimes
○ Often
○ Always

If training was offered about how to better serve Deaf patients, what would you like to learn?
(select all that apply):

☐ How to assess communication preferences of Deaf patients
☐ How to work with sign language interpreters
☐ How to use VRI equipment

- ☐ How to learn sign language
- ☐ To learn about legal obligations for effective communication with Deaf patients
- ☐ To update policies and procedures for effective communication with Deaf patients
- ☐ Other

Share

Is there anything else you would like to share about healthcare access barriers of Deaf patients who use sign language?

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