

Thirty-three years of the Americans with Disabilities Act: Where are we now? Barriers and facilitators to accessing high-quality healthcare for deaf and blind adults in the US

by

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Submitted to the Graduate Faculty of the
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School of Public Health in partial fulfillment
of the requirements for the degree of
Master of Public Health

University of Pittsburgh

2023

UNIVERSITY OF PITTSBURGH

SCHOOL OF PUBLIC HEALTH

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2023

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Abstract

This literature review explores and highlights the healthcare experiences of people in the United States who have any form of hearing or vision loss. This paper will briefly explore the history of disability advocacy that led to the creation of the Americans with Disabilities Act (ADA), what is outlined in the ADA, and how the frameworks used by contemporary disability scholars can help conceptualize how far disability rights have come, and how much farther they have to go. Twenty-eight articles from Ovid Medline were selected for review, all of which have a public health significance to this population and discuss barriers and facilitators to high-quality healthcare. I categorized the findings presented in these articles into six different themes: patient-provider communication, lack of accommodations, health literacy, transportation and availability, health insurance and out-of-pocket costs, and a source of usual care and emergency department utilization. I then suggest future directions for public health research in the d/Deaf and blind communities.

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Acknowledgments

I would like to start out by thanking my wonderfully kind and thoughtful readers, Doctors Robert Coulter, and Tessa McCarthy. Robert's frequent assurance in my writing ability kept me sane on the days when everything felt overwhelming and impossible to finish. After each meeting with him, I felt lighter and more confident in my ability to write this essay. Tess's attentive and positive comments on my writing made me feel like I was always moving in the right direction and doing meaningful work. The health sciences librarian Helena VonVille was instrumental in helping me conduct my literature search, and without her, I would not have enjoyed the process as much or had such high-quality and extensive sources to review. Helena is truly a database searching wizard and unofficial counselor all wrapped into one. I would also like to thank my academic advisor, Dr. Elizabeth Felter, who helped nudge me along the shockingly fast course of this program and supported me in all my academic endeavors. All four of these people aided me in more ways that I have had the chance to express before, and I appreciate their time and their amazing brains so much.

Additionally, I would like to thank the many wonderful peers and very dear friends I have met through this program, who have deeply inspired me, done many, many hours of homework and bemoaning alongside me, given me stellar public health ideas and guidance, and made me laugh a lot. I have never felt so loved and supported by a group of women that I so admire and cherish. I would never have made it through this program without all of you.

I would like to thank my family for teaching me how to be a better human being in this world every day. My Deaf parents have taught me to advocate for justice, equity, opportunity, access, and empowerment. They have also taught me the importance of knowing when to speak

up for people and when to keep quiet and listen (or watch) closely. Thank you for exposing me to Deaf culture and American Sign Language, which have greatly enriched my life and expanded the way I think about the world.

Lastly, I must thank my partner and our goofy dog, who both have tolerated my near-daily dramatic productions of, “Will she ever stop complaining and finish writing her essay already?” I love you both more than I can say and cannot wait to celebrate this accomplishment with you.

Author Positionality

I would like to acknowledge that I am a hearing child of two Deaf parents, and therefore have more knowledge of the workings of the Deaf community than the blind community. With this being said, I do not live with either low hearing or low vision, so I could never truly understand the daily lived experiences of d/Deaf or blind individuals, nor do I wish to speak on behalf of these very large and diverse communities. Unfortunately, it is beyond the scope of this essay to directly feature the voices and experiences of people with low vision and hearing, beyond what has been collected in the reviewed articles via surveys and interviews. I also acknowledge the many privileges I have been afforded to do this work as a white, cisgender, US-born woman in higher academia. I intend for this essay to focus on the stories existing research tells us about d/Deaf and blind experiences in healthcare settings.

1.0 Introduction

The Centers for Disease Control and Prevention (CDC) reports that there are approximately 61 million adults with disabilities in the United States (US). This is about 26 percent of the adult population. Twenty-five years after the passage of the Americans with Disabilities Act (ADA), how far has the United States come in providing equitable, quality healthcare to this historically marginalized population? While adults with disabilities are a very diverse group, they share many social and health disparities. They are more likely to live with additional health conditions such as heart disease, diabetes, and substance use disorders and they typically face more barriers to healthcare access than their peers without disabilities (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018). Even when people with disabilities live in a setting with excellent healthcare available, they face financial, transportation, mobility, stigma, and discrimination issues. Facing this stigma in healthcare settings negatively impacts relationships with healthcare providers, decreases chances of adhering to medical advice, worsens health outcomes, and causes people to engage with emergency services at higher numbers than their able-bodied peers (James, Miller, et al., 2022). Access to healthcare can be especially problematic for younger adults, who tend to experience more transitions in their healthcare. This can include shifts in provider networks from transferring off their parent's health insurance, getting a new job, moving to a different state, or losing access to school-based care. However, young adults with disabilities are more likely to have public health insurance than their peers without disabilities, who are more likely to have no health insurance at all (Verlenden, Zablotsky, Yeargin-Allsopp, & Peacock, 2022).

This paper will focus specifically on individuals with some level of hearing or vision loss. Communication and language barriers isolate d/Deaf people from the usual media that delivers

public health messaging and often decreases the quality of healthcare communication in healthcare settings. When these factors are combined with the social stigma faced by people with hearing loss or a communication disorder, this puts individuals at high risk for low health literacy (McKee, Paasche-Orlow, et al., 2015). Culturally Deaf individuals also have higher rates of mental health disorders, and about a quarter of them will have complex medical needs in their lifetime (Fellinger, Holzinger, & Pollard, 2012).

Blind adults have reported unique issues with healthcare experiences such as a lack of basic respect from providers, lack of providers believing that they can participate fully in decisions about their own care, and communication and access barriers such as difficulty navigating the physical space or not receiving appropriate reading materials. Many blind adults rate their own health as only “fair” or “poor” (O'Day, Killeen, & Iezzoni, 2004).

Both loss of vision and hearing are issues that increase significantly as people age. With an ever-increasing older segment of the population, the US healthcare system will continue interacting with more patients experiencing problems with their vision and hearing abilities. It is important for the public health system and healthcare providers to understand the unique experiences, barriers, and facilitators to the delivery of high-quality healthcare to these communities. This literature review aims to identify the key factors that influence this healthcare quality in the US.

1.1 A Note on Language

People-First Language (PFL) is a linguistic movement that swelled in popularity among the mainstream in the early 2000s but has its historical roots in the 1970s during the rise of the

self-advocacy wave among people with disabilities in the United States (Wehmeyer, Bersani, & Gagne, 2000). People-First Language is a way of using the most conscientious language possible when referring to people with disabilities. Instead of defining people by their disabilities by naming them first, this language puts the whole individual before their disability by phrasing descriptions such as “person with disability” rather than “disabled person.” Throughout this essay, I will use PFL where I feel it is appropriate. However, exceptions to this rule lie within the Deaf community and are quickly growing among the disability community at large. Some disabled individuals argue that it is more important to align themselves with social models of disability by using identity-first language and reclaim once-stigmatized language (Mander, 2022). Putting someone’s identity first can give support to the idea that disability identities can be and are politicized and is referred to as Identity-First Language (IFL).

The Deaf and blind populations are vast and diverse groups, just like any segment of the population. How anyone—disability or otherwise—chooses to label themselves is a very personal and individual choice. While People-First Language would advise the use of “people with hearing loss” due to its inclusiveness, many people who were born Deaf, or consider themselves to be culturally Deaf do not think of themselves as having “lost” their hearing, nor do they see deafness as a disability that needs to be corrected (Malebranche, Morisod, & Bodenmann, 2020). In addition, many Deaf people feel strongly about their deafness being an important aspect of their identity and even prefer being called a Deaf, deaf, Hard of Hearing, Deaf-Blind, or DeafPlus (Deaf with additional disabilities) person.

The National Association of the Deaf recommends using “deaf” to refer to the condition of not hearing, and “Deaf” when referring to the culture of people who share a language and a set of beliefs and practices, as well as beliefs about their connection to the larger society (“Community

and Culture – Frequently Asked Questions," 2023). The lowercase deaf is also used to distinguish those who lost their hearing later in life or do not identify with the larger Deaf culture. For this reason, I will often use the term d/Deaf. Authors Padden and Humphries (1988) of *Deaf in America* comment that “this knowledge of Deaf people is not simply a camaraderie with others who have a similar physical condition, but is, like many other cultures in the traditional sense of the term, historically created and actively transmitted across generations”.

The term “hearing-impaired” is no longer accepted by much of the Deaf community. It is considered a negative term that focuses on what the individual cannot do and establishes being able to hear perfectly well as the standard or default. Impaired implies that it is something in need of fixing. While most people who use this term rarely intend to convey these sentiments, it can make Deaf folks feel less than. On the other hand, the term “visually impaired” is still widely used in the blind and low vision community, but there have been folks who have proposed the term “visually diverse” to encompass the wide range of vision abilities. I will be using the terms visually diverse, blind, low vision, and limited vision throughout this paper.

For the purposes of this paper and reviewing the current literature, there may be times when I adhere to the same language that the authors of a specific paper used for consistency and transparency. Language is constantly evolving with the culture as we learn and understand more about the world we live in and the people we live with. It is important to use the language preferred by the group of people or the individual whom you are speaking to. Not doing so strips people of their humanity. If you are ever unsure of an individual’s preference, you can and should ask them what they feel comfortable with, whether they are disabled, a sexual or gender minority, or of a different race or ethnicity.

1.2 Essay Objectives

Much of the human subject research conducted in this country is done on the people who hold the most power and privilege. This typically looks like white, cis-gender, heterosexual, able-bodied folks who live in urban areas or near large universities. The purpose of this literature synthesis is to explore the healthcare experiences of d/Deaf and blind adults 33 years after the passing of the Americans with Disabilities Act in 1990. The d/Deaf and blind populations are large and continue to grow as our population lives longer and trends older. Through examining the literature from 2015 to February of 2023, I have identified the most commonly cited barriers and facilitators to receiving high-quality healthcare and how these factors may influence the way that d/Deaf and blind communities interact with the healthcare system.

The rest of this essay will be organized in the following manner: I will first review the background information of what we already know about this population including the prevalence of people with low vision or low hearing in the United States, a brief history of disability advocacy, and theoretical models that are used to understand why these health behaviors occur. The next section will focus on how I conducted the literature search and chose the publications that were included for review. Following this will be an explanation of the characteristics of the selected articles, the type of data that was collected from each one, and the themes that were commonly found regarding barriers and facilitators faced by d/Deaf and blind adults. Finally, I will synthesize the results, discuss the limitations of doing this type of research, and make recommendations for future directions of public health research that includes this population.

2.0 Background

2.1 Definitions and Prevalence of Low Vision and Hearing in the United States

It is unlikely that there is a clear picture of the true prevalence of hearing or vision loss in the in the United States, as this depends on widespread, frequent, and affordable testing. Like nearly any disability, disease, mental condition, or health status, the data that can be found online is very likely an underestimate of the true number of people who are experiencing vision or hearing issues in the US. What is currently estimated is that about one in five people over 12 years old have some form of hearing loss in one ear (unilateral), and one in eight has some form of hearing loss in both ears (bilateral) (F. R. Lin, Niparko, & Ferrucci, 2011). About 37.5 million people 18 years and older report some trouble hearing (Blackwell, Lucas, & Clarke, 2014). In the United States, Deaf and Hard of Hearing sign language users who primarily use American Sign Language make up approximately 250,000 to up to 500,000 people (Mitchell, Young, Bachelda, & Karchmer, 2006). Hearing loss is typically measured by determining someone's auditory threshold in decibels, or how loud a sound must be for someone to hear it. Someone with a full spectrum of hearing is considered to be able to hear any sounds above zero decibels (0 dB). A quiet forest, rustling leaves, or the inside of a quiet home might range from 10-20 dB, while normal conversation may be around 50-60 dB, and a loud rock concert around 120 dB ("Hearing loss and deafness: Normal hearing and impaired hearing," 2008). Hearing loss is tested and determined to be mild (a loss of 20 to 40 dB), moderate (a loss of 41-60 dB), severe (a loss of 61-80 dB), or profound (a loss of more than 81dB) ("Hearing loss and deafness: Normal hearing and impaired hearing," 2008).

There are close to 7.7 million adults in the United States with some form of low vision or blindness, with a large percentage of them being 65 and older ("Blindness Statistics ", 2019). Nine percent of the adult population reported trouble seeing even with glasses or contacts in a 2012 National Health Interview Survey (NHIS) (Blackwell et al., 2014). To compare, a meta-analysis published in JAMA Ophthalmology in 2021 estimates that 6 million Americans have some level of vision loss, and 1 million have blindness (Flaxman et al., 2021). They define vision loss as permanent or uncorrectable loss of vision based on the best vision someone is able to achieve in their best-seeing eye (Flaxman et al., 2021).

Vision is assessed through a measure of visual acuity, or how well one can see and discern letters, shapes, and numbers at different distances. Low vision in this case is being able to see less than or equal to 20/40 vision and blindness as being less than or equal to 20/200 vision. These numbers indicate that one must be as close as 20 feet away from an object to see what a person with “perfect” or “normal” vision could see from 40 feet away or 200 feet away, respectively ("Visual Acuity: What is 20/20 vision?,"). Having 20/20 vision is not necessarily an indicator of having perfect vision, but rather the clarity or sharpness of what one can see from 20 feet away ("How do optometrists measure vision?,").

2.2 A Brief History of Disability Rights and Advocacy

Disability advocacy in the United States has a very long and complex history that spans many decades before the Americans with Disabilities Act (ADA) was passed in 1990. During these decades, people with disabilities and their allies fought for access to a quality education, equal rights, greater job opportunities, physical spaces, and services and accommodations to help them

reach their full potential. In 1817, Thomas Hopkins Gallaudet opened the first American school for the Deaf in Connecticut after learning a manual communication method of instruction from educators in Paris, bringing along a Deaf French educator, Laurent Clerc to assist him ("History & Cogswell Heritage House,"). Gallaudet was inspired to learn more about Deaf education and bring it to America after observing his nine-year-old Deaf neighbor, Alice Cogswell, often playing apart from the other children in the neighborhood. Alice was one of his first students. The Perkins School for the Blind was opened in 1829 in Massachusetts to provide education and job training to individuals with blindness, low vision, and DeafBlindness ("Our History,"). Their mission was to improve literacy and independence for a population that was previously severely undereducated, if at all. Both schools were the first of their kind in the US, where otherwise many people with disabilities often ended up in institutions with deplorable conditions. Of course, only a small percentage of the country's Deaf and blind were able to attend these schools, as well as other specialized schools that were beginning to pop up more and more throughout the 1800s.

As disability advocacy really started to take off in the late 1800s and early 1900s, so too did extremely harmful movements like eugenics and oralism. Eugenics is the inaccurate and immoral theory that humans can, and should, improve the health, social behaviors, intelligence, and genetics of the population through selective breeding ("Eugenics and Scientific Racism," 2022). This idea is rooted in racism, classism, ableism, and colonialism and has persisted throughout history and influenced politics to this day. Scientists and leaders who believed in this theory promoted forced sterilization, segregation, and social exclusion of people deemed unfit to pass on their genes to the next generation. By the 1920s, this had become a global movement. In the US, immigrants, people of color, very poor white families, queer individuals, religious

minorities, and anyone with a disability were the targets of discriminatory policies, forced sterilization, and incarceration.

Oralism has its roots in the late 1800s, becoming the standard of Deaf education by the 1920s. Oralism is the concept that teaching deaf people how to speak would further assimilate them into hearing culture and give them greater opportunities. It was also thought at the time that allowing Deaf people to use sign language would stunt their language development and prevent them from being able to fully integrate into the hearing mainstream (Christensen, 2019). Not only were deaf not allowed to use sign language during this time, but they were largely separated from one another, oralists believing that this would eradicate sign language and “normalize” deaf people. Many deaf teachers were replaced by hearing teachers and sign language came to be viewed as an inferior, almost primitive language. Today, oralism is widely viewed as outdated and highly offensive to the Deaf community, but its legacy lives on, and is still largely debated. Roughly 90 percent of deaf children are born to hearing parents, who do not know sign language and often prefer their child learns how to speak verbally (“Quick Statistics About Hearing,” 2021). Because of this and the persisting influence of oralism, many hearing people treat this language debate with an either/or attitude and believe their child must learn one way of communicating to be successful. Consequently, deaf children miss out on learning an accessible language at a very crucial developmental stage, and experience what is now called language deprivation (Hall, 2017). Hall says, “...a fundamental and irreversible biological impact—on the brain and on healthy development—appears to occur when an accessible language is not provided by a certain early time period in brain development” (2017). This contributes to the commonly seen lower English language literacy in d/Deaf adults.

Over the next several decades, many advocacy organizations began to form and grow in numbers as people with disabilities and their loved ones became increasingly frustrated with their poor quality of education, healthcare, and access to public spaces. The 1973 Rehabilitation Act included several sections that contributed to the advancement of disability rights and kept the fight moving forward. It included language such as requiring the support of people with disabilities in any workplace supported by federal funding and another section that prohibited discrimination against individuals in the workplace ("Disability History: The Disability Rights Movement,"). While many of these regulations were written up by 1973, years passed without anything being implemented and the disability community grew impatient. In 1977 the American Coalition of Citizens with Disabilities (ACCD) protested through a sit-in at the San Francisco Federal Building after many promises to sign the regulations had not been made. Largely inspired by and supported by the Black Civil Rights Movement, this was the longest non-violent occupation of a federal building in US history at 26 days long (Shoot, 2017). Local Black Panthers regularly delivered approximately 120 occupiers food and supplies. Finally, a smaller contingent traveled to Washington, DC to put more pressure on the politicians tasked with signing these sections into law, and on April 28, 1977, they prevailed (Shoot, 2017).

This historic event shifted Americans' viewpoints on people with disabilities, thinking of them now as a minority group whose disadvantages largely stemmed from discrimination and structural issues rather than the disabilities themselves. This paved the way for the Americans with Disabilities Act to come a little more than 10 years later after many iterations and drafts.

2.3 What Does the Americans with Disabilities Act (ADA) Actually Say?

The Americans with Disabilities Act was passed in 1990 chiefly to prohibit any discrimination against people with disabilities in the workplace as well as in day-to-day activities. It is a federal law that covers anyone in the US with a physical or mental impairment that limits a life activity or has a history of such an impairment ("Introduction to the Americans with Disabilities Act,"). This is a broad definition on purpose; this language helps to protect a wide range of disabilities that may or not be explicitly listed in other parts of the regulation. Healthcare-related regulations are primarily housed under the "State and Local Government Services Title II" and "Businesses That Are Open to the Public Title III", which state that all state and local governments, business, and nonprofits serving the public must provide people with disabilities "an equal opportunity to benefit from all of their programs" including, but not limited to, health care, transportation, emergency services, social services, doctors' offices and hospitals, office buildings, and public education ("Introduction to the Americans with Disabilities Act,"). Another portion of the ADA of note as it pertains to healthcare access, appointment making, and receiving healthcare information is Title IV of the ADA, the telecommunications portion, which states the requirement of telephone companies to provide services allowing callers with hearing and speech disabilities to communicate.

The ADA states that businesses, public spaces, government offices, and more must provide "reasonable accommodations" to meet the regulations imposed by the law (Jasper, 2008). This can mean many different things for different people, but for deaf and blind folks it usually looks like providing screen reader software, video phones, sign language interpreters, materials in large print or braille, making the physical space easy and safe to get around, and allowing service animals. Failure to provide these services when they are needed violates federal law and can lead to large

finances and lawsuits. Despite the passing of these important regulations and the abundant healthcare resources and spending in the US, the healthcare system is still far from equitable when it comes to accessibility.

2.4 Theoretical Framework

Public health interventions for people with disabilities have a significant potential to advance the wellbeing and status of people with disabilities and transform lives. However, the field has been criticized for their work on this topic for a few reasons. Methodical rigor and sophistication in capturing the true experiences of living with a disability have been lacking and results in research findings that fail to provide thorough evidence of the unique and diverse experiences associated with various conditions (Berghs, Atkin, Graham, Hatton, & Thomas, 2016). For too many years, people with disabilities have been the objects of study, rather than the holders of great knowledge and expertise. This undermines the core values of public health to promote equity and inclusion. Examining different models of disability and how they have transformed over time can be beneficial in shaping the development and evaluation of public health programs.

Disability used to be viewed more commonly through the lens of the medical model, where it was seen primarily as a medical condition or impairment that needed to be fixed or treated through medical intervention (Berghs et al., 2016). Earlier models also viewed disability through the context of the economy and were concerned with quantifying disability and its cost to the government. Early disability research focused on what parents, medical professionals, teachers, and caregivers had to say about disabilities, especially the “burden” caused by the greater level of care needed placed on caregivers and the medical system. This was especially true for research on

children with disabilities. This practice objectifies and effectively silences the voices of the individuals experiencing the disability (Watson, 2012). Today, there is greater emphasis on uplifting the voices of people with disabilities and seeing them as social change agents for their own life.

In more recent years, more people have adopted the social model of disability, which views disability issues as stemming from socially and environmentally created barriers and attitudes and not from the individual or disability itself (Watson, 2012). It separates the impairment, which can be physical, mental, or sensory, from the disability, which is attributed to societal oppression (Berghs et al., 2016). This highlights the inaccessible and unaccommodating physical environment created by society, which can hold people back more than their disability. For example, many disability advocates hate the term “wheelchair bound,” instead arguing that a wheelchair represents freedom and independence by allowing individuals to navigate physical spaces that they would not otherwise have access to (Fenell, 2015). Wheelchairs enable people. There has also been a shift to thinking in the capabilities framework of development, where the focus is on what people can achieve in terms of being and doing. Capabilities represent true freedoms and the things that people are able to achieve if they so choose, such as getting a good education, travelling, being well-nourished, and more (“The Capability Approach,” 2011). Identifying these capabilities are a way to measure one’s quality of life.

Critical disability theory, sometimes called critical disability studies, is an approach that builds upon the social model and seeks to understand disability as a social construct. It aims to challenge structures of oppression by advocating for social and political change that lead to greater empowerment of people with disabilities. The importance of disability rights, accessibility, advocacy, and social justice are emphasized and encouraged beyond the confines of academia

("Critical Disability Theory," 2019). It is a constantly developing discourse in which some researchers choose not to distinctly define what disability means, preferring to leave open the boundaries of "who counts" and why, arguing that disability is more of a question of politics and power dynamics than a question of medicine and health (Atkins, 2007; Kafer, 2003). Nirmala Erevelles, professor in social and cultural studies and disabilities scholar describes her work in this way: "I have argued that the ideology of disability has been used to justify the racial and gendered division of labor based on heteronormative notions of the family and, in doing so, organizes class relations in a capitalist society" (Erevelles & Kafer, 2010).

It is important to note the influence of the social ecological model (SEM) in conceptualizing the multilevel health factors that influence the utilization of healthcare by low vision and low hearing adults as well as the health outcomes they experience. The SEM recognizes the very complex role played by the context of an individual's life in their health decisions and attempts to identify these factors to guide future interventions (*Principles of community engagement*, 2011). The levels described by the SEM are individual, interpersonal, community, and society. Attention needs to be given to each level to understand the health behaviors of an individual, or a group of individuals. For example, the ADA as a policy was a very positive change at the society level, but one must look at how it is being implemented at the community level to determine its effectiveness and whether communities even have the resources and infrastructure to execute the necessary changes it may require. Similarly, at the individual level, if an adult with disabilities does not have health insurance, they will avoid or delay healthcare regardless of how good the accommodations are at their local doctor's office.

3.0 Methods

3.1 Search Strategy

On February 2nd, 2023, I conducted a literature search with a research librarian through the Ovid Medline database. I limited the search results to peer-reviewed journal articles published from 2015 up to the date of the search. I chose 2015 because that marks the 25-year anniversary that the Americans with Disabilities Act (ADA) was passed, fundamentally changing the civil rights of people with disabilities across the country, and consequentially the larger culture. I wanted to investigate how much has changed and which areas still need attention 25 to now 33 years later.

The exact search terms on Ovid Medline can be viewed in Table 1 of Appendix A. In summary, search terms consisted of phrases related to: adults with low vision or hearing, delivery and quality of healthcare, healthcare satisfaction, barriers and facilitators, and healthcare accessibility. Results were limited to English articles in the United States. All publications were exported to EndNote, publications were assessed for duplicates, and none were found. The article screening process was recorded in an Excel Workbook that was created for single person literature reviews.

3.2 Study Selection

The database search resulted in 366 articles in total. Each title and abstract were reviewed and excluded based on the following criteria: (1) not a US study, (2) focus on visual and auditory care, (3) participants are not low vision or low hearing, (4) not original research (editorial, systematic review, etc.), (5) focus on 18 and younger, (6) not focused on healthcare settings, (7) focus on one condition only, not larger healthcare experience, (8) focus on healthcare provider' experiences, (9) focus on insurance, (10) focus on end-of-life care, (11) not applicable to barriers and facilitators, (12) data collected prior to 2015.

Forty publications went on to full-text review. Each article was included if they had some or all of the following criteria: (1) significance to public health (2) how do adults with low vision and hearing experience healthcare? (3) what are the barriers and facilitators for adults with low vision and hearing receiving high quality healthcare? (4) how do interactions with healthcare providers differ from peers without low vision or hearing? (5) what is the association between low vision or hearing and the satisfaction with received healthcare?

The PRISMA flowchart of study selection can be viewed on the next page, Figure 1.

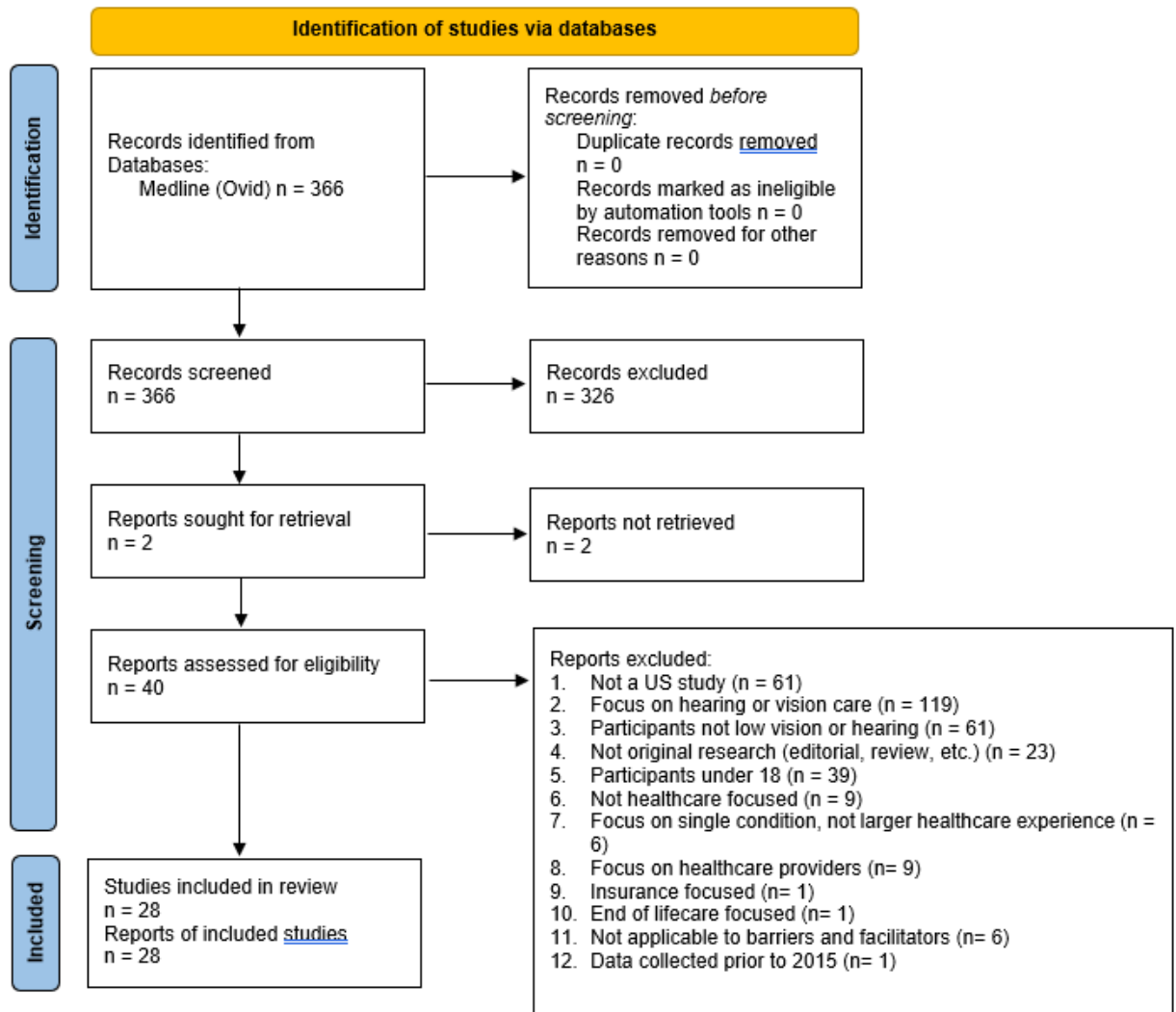


Figure 1: PRISMA Flowchart

3.3 Data Extraction

In total, 40 articles went to full text review, and 28 were selected for final use in the literature synthesis. During the data extraction process, the following was identified from each article: the research question or objective; major conclusions and themes related to barriers, facilitators, and healthcare utilization; sample size; study design; and strengths and limitations. As

I read each paper, I pulled out themes that the authors identified themselves if they chose to do so, or I labeled themes myself according to the results of each study. Table 2 in Appendix C lists the articles selected for review and their characteristics. In the following synthesis of results, the included articles have been grouped together based on the topics they addressed, and which themes they align with.

4.0 Results

Six themes emerged from analyzing the selected articles that help explain the most common barriers and facilitators to high quality healthcare for deaf and blind adults in the US. These themes include patient-provider communication, lack of accommodations, health literacy, transportation and availability, health insurance and out-of-pocket costs, and a source of usual care and emergency department utilization. There are a few significant things to note about the selected publications before explaining the identified themes. Despite the high prevalence of vision loss in the US population, only four studies focused solely on the blind and low vision population. Four studies examined both the deaf and blind populations or looked at a large range of disabilities including deafness and blindness. Twenty of the studies focused on d/Deaf, hard of hearing, or low hearing individuals. Additionally, three studies focused specifically on the period of COVID-19 and one briefly mentioned it. For more on each of the study's characteristics, see Table 2 in Appendix B.

4.1 Patient-Provider Communication and Attitudes

Poor quality patient-provider communication was the most reported theme and barrier among the 28 reviewed articles. It was noted more frequently and as a larger concern in the d/Deaf community than in the low vision population. In one Wisconsin health survey, both patients and providers reported communication breakdowns among patients who had some level of hearing loss (Dillard, Nelson-Bakkum, Walsh, & Schultz, 2023). The patients noted that noisy healthcare

settings make it particularly challenging to effectively communicate with their providers. It was found that in some cases, patients underreported their level of hearing loss or did not mention their hearing loss at all (Dillard et al., 2023). This was the only study that specifically asked about patients' levels of disclosure regarding how much they were able to hear. This could mean that patient self-advocacy and empowerment is a problem in other studies but was not evaluated. It was also noted that the practice of wearing facemasks during COVID-19 severely hindered the ability for deaf or low hearing patients to understand their provider. This was cited as a major concern in two other articles (Panko et al., 2021; Wilson, Crouch, Schuh, Shinn, & Bush, 2021).

Many participants in a survey of ASL interpreters cited provider time constraints as an issue in their client getting all of the information they needed before the end of the appointment (Hommes, Borash, Hartwig, & DeGracia, 2018b). The same study found that patients did not understand provider instructions nearly half of the time and 81 percent of interpreters reported that they never experienced providers using techniques such as “teach back” to ensure understanding. In some cases, patients also chose not to ask doctors to repeat information or explain it in a different way (Hommes et al., 2018b). Deaf women in another study noted that their need to ask more questions and have providers repeat information made them run out of time faster and miss the opportunity for a more thorough appointment (Horner-Johnson, Klein, Campbell, & Guise, 2021)

In a qualitative study that interviewed deaf women who experienced perinatal and pregnancy healthcare, it was expressed that there was a desire for greater provider and healthcare team support in shared decision making for their healthcare plan (Panko et al., 2022). A few facilitators that came out of this study were: providers sharing in-depth knowledge and not making their patients feel rushed, patients feeling “complete” when leaving their healthcare office, and patients feeling like all of their questions were answered (Panko et al., 2022). A survey of Medicare

beneficiaries found that adults with sensory impairments were unsatisfied with clinician attitudes and their doctor's concern for their overall health (Assi, Shakarchi, et al., 2020).

Several papers cited clinicians' misconceptions about their d/Deaf patients' ability to hear or understand them, either while wearing hearing aids, cochlear implants, or lipreading. Participants in one health survey reported that many people wrongly believe that their hearing aids restore their hearing to the level of a person with full hearing capabilities, or that they can hear the same way through their hearing aid(s) that a hearing person does (Dillard et al., 2023). Hearing aid users in this survey did not have statistically significant differences in their healthcare experiences from their deaf peers without any hearing aids. This misconception leads many providers to not be as conscientious about how they are talking to their deaf hearing-aid wearing patients. Another study found that cochlear implant (CI) users reported even greater difficulty communicating with their family and friends than hearing aid users (Wilson et al., 2021). They were also less likely than hearing aid users to seek general healthcare services overall. On the other hand, one article reported that older adults who wore hearing aids had lower odds of limited health literacy (Wells et al., 2020). In this case, it is hard to determine whether these older adults got their hearing aids in the first place because they already had higher health literacy and better resources. No causality was determined here. In the case of lip-reading, ASL interpreters reported in a survey that many providers would say that lip-reading is "good enough" and acceptable when an interpreter is not available (Hommes et al., 2018b). These attitudes and assumptions regarding how well deaf folks can hear and understand their health information without any sort of accommodation are harmful to patients and unethical. It also deprives patients of fully participating in shared decision making if they do not have a full understanding of the information being shared.

One study identified a facilitator to communication specifically for the d/Deaf population. It was found that d/Deaf participants who used social media sites for health related activities were three times more likely to engage with healthcare providers and staff through online platforms and email (Ryan & Kushalnagar, 2018). This positive finding indicates that online platforms for d/Deaf individuals have the potential to increase communication with healthcare providers to facilitate patient engagement in their care, advertise more health promotion activities, encourage early detection screenings, and improve the management of health conditions. This was a large and diverse national sample of Deaf users of ASL but did not include any Deaf who do not use the internet. Overall, the d/Deaf participants with comorbid health conditions or college educations had the highest engagement in e-communication with their providers. The authors suggest that healthcare facilities could also use these online health platforms to post health promotion and informational videos in ASL (Ryan & Kushalnagar, 2018).

4.2 Lack of or Poor Accommodations

There are several noted barriers for d/Deaf and blind communities when it comes to the quality of accommodations provided to them in healthcare settings. One of the biggest issues apparent for d/Deaf folks is getting their healthcare facility to obtain an interpreter for their appointment, and secondarily, one who is qualified enough to do so in medical settings. The first issue for many patients is getting an interpreter. This was stated as a major barrier to getting proper healthcare information in multiple studies (Hommes, Borash, Hartwig, & DeGracia, 2018a; Horner-Johnson et al., 2021; McKee, Winters, Sen, Zazove, & Fiscella, 2015; Panko et al., 2022; Schniedewind, Lindsay, & Snow, 2020; Stevens, Dubno, Wallhagen, & Tucci, 2019). One study

used eight simulated patients (four hearing and four deaf) to make over 1,000 calls to various doctors' offices in Idaho. Simulated hearing patients were twice as likely to get an appointment than simulated deaf patients. For the deaf patients, 80 unsuccessful appointment requests were associated with a request for an ASL interpreter (Schniedewind, Lindsay, & Snow, 2021). Another study reviewed the prior six years of complaints filed regarding interpreter provision for Deaf ASL users in healthcare settings in Idaho (Schniedewind et al., 2020). They found that the biggest complaint was that patients were told an interpreter was not available (nearly half of all complaints). The next biggest complaint was receiving an interpreter who was not qualified. And the third biggest complaint was being promised an interpreter and not having one for the appointment. It was found that patients in more rural areas of Idaho were the least likely have their complaint resolved in any way (Schniedewind et al., 2020). The authors of Schniedewind et al. (2020) found that many clinics were unaware that they could be reimbursed by insurance companies for interpreters, resulting in an unused available resource.

One participant in Panko et al. (2022) mentioned a key facilitator for high-quality healthcare. She discussed that her regular doctor's office knew of her need for an ASL interpreter and always requested one without her needing to ask. If there were none available on the day and time she made the appointment, the office would call her back and have her reschedule, knowing that otherwise it would be a waste of her time and money. In the participant's opinion, this practice made her feel like a valued patient, whose identity and needs were accepted and accommodated for by her healthcare provider without much trouble. Other facilitators pertaining to ASL interpreters were obtaining interpreters that have some medical knowledge, and having an interpreter that is comforting or reassuring (Panko et al., 2022).

Some articles mentioned that there is a lack of high quality ASL interpreters, as some states do not have standardized requirements for ASL interpreters. In one article, a participant mentioned that the medical staff at her doctor's office told her directly to bring a friend or family member to interpret for her (Schniedewind et al., 2021). This does not comply with the ADA, nor is it ethical practice as it compromises the patient's medical privacy. Other studies also cited concerns with privacy and the loss of true independence in cases when patients are forced to rely on someone else to either interpret, read health information out loud, or explain health and drug information out loud (Horner-Johnson et al., 2021; Kim, 2019; Stevens et al., 2019). Participants stated that much of this could be avoided if more materials were available to them in braille, large print, and ASL. In one study, several women with low vision recounted getting large amounts of information about birth control in tiny print (Horner-Johnson, Klein, Campbell, & Guise, 2022). They said this information was "completely unusable" to them. A similar issue came up in a study that focused on older adults with low vision. It was reported that providers did not provide health information in alternative formats, and patients typically did not ask for them either, assuming accessible formats would not be available anyway (Kim, 2019). A lack of information received in accessible formats was also a cited problem discussed in a focus group of women of reproductive age with various disabilities (Horner-Johnson et al., 2022). Deaf women in one study also complained that they are often given info to read in the middle of an appointment, but they struggle to look at the paper and follow the speaking doctor at the same time (Horner-Johnson et al., 2022).

Another issue for deaf folks was having to use the telephone to call offices, make appointments, or receive test results and healthcare information (Stevens et al., 2019). While many doctors' offices today provide patients with the ability to make appointments on their website or through a patient portal, this is not always an option.

4.3 Health Literacy

It was noted in both the d/Deaf and blind populations throughout the selected articles that lower health literacy and issues with gathering health information is a considerable barrier. In a study of how older adults with low vision obtain health information, participants shared their concerns in accessing, understanding, and using health information as well as navigating multimedia technology (Kim, 2019). It was found that older adults do tend to miss a lot of health information due to their unfamiliarity with different forms of media and a lack of materials available in braille and large print. Many older adults in this study were unaware of their protected rights under the ADA to ask for more accessible information. Instead, most relied on friends and family to get most of their health information. This got increasingly difficult with age, as many reported a decrease in socialization as their vision declined and they became less mobile.

Those who had lower health literacy were also found to have lower self-rated health, or to self-rate their health as “poor” (Dillard et al., 2023; Reed, Boss, Lin, Oh, & Willink, 2021). One study found that hearing loss was associated with limited health literacy, and that limited health literacy was associated with higher healthcare costs (Wells et al., 2020). Those with “some aided hearing” (hearing aids or cochlear implants) had slightly lower odds of limited health literacy.

4.4 Transportation and Availability

Several studies cited transportation and availability of healthcare providers as a barrier to healthcare, especially in healthcare situations that are not deemed as “necessary” or “urgent” such as preventative care. Simning, Caprio, Li, and Conwell (2021) found that older adults with hearing

or vision loss are much more likely to have someone drive them to their doctor appointment as well as assist them during their visit. A survey of Medicare beneficiaries found that adults with dual sensory impairment and vision impairment were dissatisfied with their transportation to care appointments and the cost of arranging transportation when that was necessary (Assi, Shakarchi, et al., 2020). Limited transportation was reported as a concern for multiple blind participants in another study that conducted semi structured phone interviews (Kim, 2019). Low vision patients in one survey about COVID-19 reported that they were very concerned about touching public surfaces such as door handles, railings, and seats on public transportation (Nagarajan, Varadaraj, Chanes-Mora, Rosenblum, & Swenor, 2022).

During the COVID-19 pandemic, deaf rural residents reported in a questionnaire that they had greater difficulty accessing general and hearing healthcare and felt less up to date on the latest pandemic information than non-rural residents (Wilson et al., 2021). Deaf adults in rural Kentucky expressed concerns with both a lack of providers and the quality of care in their region (Powell, Jacobs, Noble, Bush, & Snell-Rood, 2019). They cited proximity and accessibility as major barriers to getting hearing healthcare. They reported that many providers in their area were only available during typical working hours, and they could not afford to take time off work.

4.5 Health Insurance and Out-of-Pocket Costs

The high cost of medical care was a huge concern among both blind and deaf communities. Many people under 65 reported not having health insurance at all and those who did report having health insurance cited issues with coverage and high out of pocket expenses. Many of the participants (both deaf and blind) in Horner-Johnson et al. (2021) were on Medicaid and felt they

did not have enough coverage for many of their healthcare needs. In another study, 60 percent of participants (all deaf) were Medicaid insured (Schniedewind et al., 2020). In McKee, Winters, et al. (2015), they also found that d/Deaf participants were more likely to be insured through Medicaid than hearing participants.

Hearing aids are generally not covered by most insurance plans and cost many thousands of dollars out of pocket (Mahmoudi, Zazove, Pleasant, Meeks, & McKee, 2021; Powell et al., 2019). Deaf adults in Horner-Johnson et al. (2021) felt limited by the health insurance they had. They did not have the flexibility to choose disability-friendly doctors and experienced frequent changes of in-network providers. Deaf adults in Powell et al. (2019) expressed that even with insurance, they could not afford specialized hearing healthcare. Several participants stated that they might wait for hearing-related issues to become very severe before seeking hearing care since it is not life-threatening issue, while also acknowledging that it negatively affects their quality of life.

Cheng et al. (2022) found that adults with vision impairment had a lower prevalence of having health insurance coverage and a higher prevalence of reporting costs as a reason for an unmet healthcare need.

4.6 Source of Usual Care and High Emergency Department Utilization

Another cited barrier for both groups of low vision and low hearing was the lack of “a usual health care provider” or “usual source of healthcare” (Cheng et al., 2022; Reed, Assi, et al., 2021; Simning et al., 2021). Cheng et al. (2022) looked at the 2018 Behavioral Risk Factor Surveillance System and determined that adults with visual impairment had a lower prevalence of having a

usual health care provider or a dental visit in the past year. In Simning et al. (2021) near vision loss was associated with decreased odds of having a usual source of care, but distance vision loss and hearing loss were not. Participants in Reed, Assi, et al. (2021) who had trouble hearing were more likely to report that they had not obtained medical care in the past year when they thought it was likely needed. They were also less likely to fill their prescriptions compared to those who reported no trouble hearing.

It has been noted that this population is more likely to avoid and delay healthcare and preventative services than their peers who do not have any trouble seeing or hearing (Assi, Varadaraj, et al., 2020; H. H. Lin et al., 2021; McKee, Winters, et al., 2015; Thai & Megwalu, 2021). H. H. Lin et al. (2021) reported that participants with trouble hearing had a significantly higher risk of avoiding and delaying healthcare than those without trouble hearing. Donald, Rao, Jacobs, MacDonald, and Kushalnagar (2022) reported that d/Deaf women have higher unmet health needs than men, and d/Deaf People of Color have higher unmet health needs than white d/Deaf individuals. Thai and Megwalu (2021) found that increased hearing loss severity was associated with a decrease in perceived access to routine medical visits, an increase in avoidance of routine medical care, and an increase in utilization of emergency department (ED) visits and length of stay. Poor experiences with healthcare encounters due to disability stigma or difficulty understanding and communicating with a healthcare provider may be related to the avoidance or delay of future care, which can in turn lead to more poor outcomes. It was also found that older adults with vision impairments were less likely to report compliance with cancer related preventative screening recommendations (Assi, Varadaraj, et al., 2020)

Avoidance and delay in healthcare is, in part, what can lead to higher ED utilization. Another reason however, is that some d/Deaf participants specifically indicated that they feel they

have more and easier access to ASL interpreters in emergency departments than they do in primary care settings (McKee, Winters, et al., 2015). Hospital systems often have more knowledge of how to obtain an interpreter, and some even employ certain interpreters on the hospital staff depending on the demand in the population. The authors of McKee, Winters, et al. (2015) speculate that this higher ED utilization is also due to lower health literacy, low general health knowledge, and poor patient-provider communication.

5.0 Discussion

The reviewed publications for this literature synthesis form a good foundation for understanding and conceptualizing the most common barriers and facilitators to care for d/Deaf and blind adults in the United States. A number of them even posed solutions and recommendations for improving care. However, 33 years after the ADA was passed, it is clear that even the most well-resourced health care systems have significant barriers for their patients with sensory impairments, with many practices being unaware of the full requirements of the ADA. Medical schools must improve their preparations for students, who will certainly encounter patients with disabilities. It is currently estimated that as many as one in four people in the US has some form of disability ("Disability Impacts All of Us," 2022). In the selected studies, there was very little discussion or analysis on the power dynamics that exist between doctors and their patients, especially those with less education or when the racial or gender identity of the doctor differs from that of the patient. The experiences of the deaf and blind community were overwhelming negative across all studies, regardless of where in the country they took place, and the age and gender of the participant. According to many of these articles, doctors' offices and healthcare facilities are failing to comply with ADA standards very frequently. What happens to these facilities when they fail to comply, and are they facing any consequences? There was no indication in these articles that people with disabilities know who they can complain to regarding failures to provide proper accommodations, or how to do so. Many articles indicated the limited health literacy of this population, which could also contribute to whether they know about their protected rights, or how thoroughly they understand them. The American Medical Association

recommends that all health information is written in a 5th grade to 6th grade reading level, even for folks without any disabilities, but this is so rarely ensured.

Many misconceptions or assumptions made about deaf and blind adults by healthcare providers led to a lot of poor communication outcomes. For example, many providers assumed that their deaf or low-hearing patients could understand them perfectly well if they were wearing a hearing aid or cochlear implants. Some of them even assumed that their low hearing patients understood enough information with lipreading alone. These harmful misconceptions lead to poor-quality communication and leave deaf folks with negative healthcare experiences that may prevent them from returning or may make them feel very anxious to do so. In one study that focused on contraceptive care for women with disabilities, many reported that their doctor assumed they did not want to have children, or even that they were not sexually active at all (Horner-Johnson et al., 2022). A few patients from this study explained that they were made to feel like they should not have children because of their disability, or that they would not make suitable parents.

Another concern was the lack of articles that focused on only blind adults, compared to the number that focused on d/Deaf adults. There could be several reasons for this. During the abstract screening process, many of the articles focused on ophthalmology or audiology care and were removed. The quality of care in these spaces is not always representative of the quality of care in the larger healthcare system. The experiences that patients have in these centers tend to differ slightly from the experiences at regular primary care facilities or in other specialties. These centers are usually more aware of needed accommodations and have more knowledge on how to address them. Another potential reason for the larger focus on the d/Deaf population could be the very strong culture that exists largely due to having a separate language. This culture is especially central at major Deaf universities and the cities they are in, such as the National Technical Institute

for the Deaf in Rochester and Gallaudet University in Washington, DC, where much of the d/Deaf research has taken place. Communication is so central to socialization that many hearing folks have implicit biases about the intelligence and capabilities of Deaf folks based on having a different form of communication, and simultaneously hold a certain fascination with it. Popular phrases in culture such as “Baby Sign Language” only serve to amplify the infantilization of Deaf people and lower regard for ASL as a language. Society does not call a baby learning their first words in English or any other spoken language “Baby English,” but plainly, English, just as babies who know several signs are just using ASL. In addition, the historical marginalization of deaf and blind folks and the practice of withholding equal educational and career opportunities from them has persisted into the present culture. With so many deaf children born to hearing parents who choose not to learn ASL and the persisting legacy of oralism, deaf children frequently become vulnerable to language deprivation in their earliest developmental years which leads to lower literacy in adulthood.

One of the most glaring gaps in the research is how little data there was on race and ethnicity, and how marginalized identities impact deaf and blind of color even more than their white counterparts. A discussion on intersectionality was largely missing, as were discussions on the social model or critical disability theory. What does this say about health researchers’ commitment to equity, inclusion, and justice for the disability community? The field of public health must continue pushing both researchers and health care providers to think about disability through these lenses, rather than strictly medical problems that need to be solved. In order to stay relevant, public health research needs to be able to reflect a diverse range of experiences within the disability community or will otherwise risk producing inaccurate results and using valuable resources inefficiently.

There is a great need for disability advocacy work to continue, and to do so alongside Black, Indigenous, People of Color, LGBTQ+, women, people of lower socioeconomic status, and any groups in the US who face similar marginalization based on their identity and class. The advancement of any one of these groups can only strengthen the rest, and researchers must continue to view these issues through an intersectional lens. There is an immense amount of work that needs to be done to fill the gaps in care received by this population.

5.1 Limitations

While this literature synthesis provides greater insight into some of the healthcare challenges faced by the d/Deaf and blind communities in the US, there are several limitations that exist from doing this type of work. To start, no one literature review can capture the entirety of the data that exists on the subject thus far, nor the diverse range of experiences this population faces on a regular basis. In addition, only one person performed the study selection and data extraction. Without double coding, the potential risk for bias in this selection increases. Only one database (OVID Medline) was searched, potentially missing useful and insightful studies from journals that are not included in this database. The search was also limited to English-only publications since the focus was on the US healthcare system. There could be potentially relevant non-English studies that were conducted and missed by this search, such as the healthcare experiences of Spanish-speaking d/Deaf and blind adults in the US.

There are a few additional limitations regarding the articles chosen for review. First, there was a significant focus on adults 65 years and older. Many of these studies surveyed Medicare beneficiaries or chose this higher age range because it is the age at which more people begin to

experience worsened hearing or vision issues. While it is important to collect data from this age group to understand their experiences, especially as the population is getting older, this takes away an opportunity to learn more about younger d/Deaf and blind adults to then strengthen their relationship with the healthcare system at a much earlier stage in life, which could potentially lead to improved health outcomes in the long run. Focusing only on older adults also fails to capture the experiences of the culturally Deaf and blind, who have lived with their low hearing and vision from a young age and have unique interactions with the healthcare system.

There is the possibility that Deaf people and older people who have lost a significant amount of their hearing may not know just how much health information they are missing out on during appointments. They may overestimate the thoroughness of the information they are receiving and understanding, especially those with lower health literacy. Many people with communication-related disabilities have also reported in these studies that they suspect doctors skip over things that they might otherwise tell patients without disabilities due to the complexity and desire to avoid spending additional time repeating themselves or using an alternative form of communication, such as writing down or drawing the information.

In a majority of the reviewed papers, the focus on barriers is much greater than on facilitators. Now that the field has a better understanding of what is not being done satisfactorily for this population, it is time that researchers and practitioners spend more time and effort examining what improves the patient experience and health outcomes. There were very few studies included in this review that focused on minority racial and ethnic groups, who have intersectional identities that make their healthcare experience even more challenging. Not one of the reviewed studies mentioned Black American Sign Language (BASL) or asked any of the participants about their use of BASL and how this affected their access or understanding of health information.

Because of the very high majority of white participants in many of the reviewed studies, they cannot be considered truly representative of the US population. In addition, many of the studies that focus on culturally Deaf folks have taken place in Rochester, New York and Washington, DC, which have high numbers of Deaf people who are highly educated due to the Deaf universities in those cities. The Deaf population in these cities are not representative of the larger d/Deaf population. Deaf folks in these cities tend to get better care and accommodations and be more health literate than the d/Deaf in other parts of the country, especially those in more rural areas.

Many of the studies chosen relied on data that was previously collected for a larger survey. Because of this, the authors had to rely on using questions that were not necessarily formulated to answer their specific objectives, and therefore were not as thorough or specific as the authors may have made their questions. This also means that most of the studies were cross sectional in design and therefore could not determine causality or temporal trends. Many of the conducted surveys also relied on self-reported data regarding the participants' level of hearing or vision loss. Due to the subjectivity, the data collected on difficulties with seeing or hearing could be either under or overestimating the true experience of sensory loss among the study participants. Several authors listed not having a comparison group as one of their limitations and almost all the articles had significantly more female-identifying participants than male.

5.2 Future Directions

Future research should continue the work done by the publications featured in this review, striving always to go more in-depth and reach more groups of people not typically well-represented in the literature. The d/Deaf and blind communities deserve higher quality healthcare information,

healthcare experiences, and improved quality of life. This has become particularly salient during the challenges of the COVID-19 pandemic. Through evaluating past and current practices, future practices can be improved upon. The field should continue to recognize and empower d/Deaf and blind folks as the experts in their experiences to get a true picture of their attitudes toward the US healthcare system. There is a need for future research to include more in-depth qualitative interviewing with participants in the language they feel most comfortable using. There is a lot of information out there on what blind and d/Deaf folks are experiencing, but a lack of why it is still this way, 33 years later. Blind and d/Deaf folks of every race, gender, class, and geographical location should have the opportunity to elaborate on their healthcare experiences and where they would like to see improvements in order to create higher quality healthcare promotions, interventions, and provider interactions.

Specific attention needs to be given to the experiences of Black, People of Color, Indigenous (BIPOC), and LGBTQ+ d/Deaf and blind people, who's intersectionality presents even greater challenges in the medical system. BIPOC-specific studies were glaringly lacking in this literature search, doing a major disservice to folks that may have very complex health issues due to the systemic oppression that is woven into every facet of life in America. Much like BIPOC-identifying folks, the US healthcare system has a long way to go in terms of gaining the trust of these individuals back through recognizing their past and current faults and constantly striving to do better.

There is a need for more opportunities for healthcare providers to receive regular training on how to best work with and accommodate their d/Deaf and blind patients, or any patient with a disability. These trainings would ideally be developed by, or at least with, the members of this community to ensure their input is heard and incorporated. Beyond formal training however,

healthcare providers need to do a better job of simply asking their patients what they need to best communicate. The distribution of health materials in ASL, braille, large print, accessible and plain language, and visual diagrams is necessary to help more patients in understanding and adhering to their provider's recommendations. This goes for patients who do not have any vision or hearing issues; accessible language and visual diagrams would be beneficial for most of the population.

6.0 Conclusion

Adults with low vision or low hearing make up a substantial and continuously growing segment of the United States population. They often have unique healthcare needs and more than one disability or chronic illness (Stransky, Jensen, & Morris, 2018). They also tend to face a greater number of health disparities than folks without low vision or low hearing (Stransky et al., 2018). This group has been protected by federal legislation put in place in 1990 through the Americans with Disabilities Act (ADA), but this legislation is enforced at varying degrees in different states and municipalities to the great detriment of people with disabilities across the country. This paper examined how far the US has come in terms of access to high-quality healthcare for deaf and blind adults 33 years post the passing of the ADA by reviewing the literature from 2015 to February of 2023.

A total of 28 publications were examined and evaluated for themes. The themes found were: patient-provider communication, lack of accommodations, health literacy, transportation and availability, health insurance and out-of-pocket costs, and a source of usual care and emergency department utilization.

People living with disabilities deserve high quality, accessible, and comfortable healthcare, and the United States has the resources to ensure that. Many providers in this country do not understand the full extent of the accommodations they are legally required to provide for patients visiting their office. Patients themselves are not always aware of their protected rights. Researchers and providers need to listen to their patients, especially those who have been historically marginalized and mistreated by the US healthcare system, and act accordingly. Perhaps the most important theme pulled from all the examined publications is the emphasis placed on patient-

provider communication. This communication can make or break a patient's healthcare experience and continue affecting their healthcare utilization far into the future.

This is a public health issue that is affecting more than the d/Deaf and blind communities. A quarter of the US population has a disability and would benefit from improvements in ADA implementation and enforcement. Additionally, everyone can benefit from an increase in accessibility to healthcare and healthcare information. The ability for the US healthcare system to meet the needs of all its unique users is certainly within reach, but it is a matter of allocating more resources to these areas, properly training medical professionals, and amplifying the voices and stories of people with disabilities to learn from their experiences.

Appendix A OVID Medline Search Strategy

Provider/Interface: Ovid
 Database: Medline
 Date searched: February 2, 2023
 Search developer(s): Helena M. VonVille, Michaela K. Avino
 Limit to English: Yes
 Date Range: 1990-2023

Appendix Table 1: OVID Medline Search

1	persons with hearing impairments/ or visually impaired persons/
2	hearing loss/ or deafness/ or deaf-blind disorders/ or hearing loss, bilateral/ or tinnitus/ or blindness/ or vision, low/
3	((hearing or visual or visually) adj2 (impaired or impairment*)).ti,ab,kf.
4	(blind or blindness or deaf or deafness or (hard adj2 hearing) or ((hearing or vision) adj2 (loss or low))).ti,ab,kf.
5	1 or 2 or 3 or 4
6	"delivery of health care"/ or health services accessibility/ or health equity/ or healthcare disparities/ or practice patterns, pharmacists'/ or practice patterns, dentists'/ or practice patterns, nurses'/ or practice patterns, physicians'/
7	((((health adj1 care) or healthcare) adj3 (access or quality)).ti,ab,kf.
8	6 or 7
9	5 and 8
10	limit 9 to english language
11	10 not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) not (north america/ or exp united states/)
12	cohort studies/ or longitudinal studies/ or follow-up studies/ or prospective studies/ or retrospective studies/ or cohort.ti,ab,kf. or longitudinal.ti,ab,kf. or prospective.ti,ab,kf.
13	Cross-Sectional Studies/ or Prevalence/ or ((association adj2 (studies or study)) or cross-sectional or prevalence or transversal).ti,ab,kf. or (association or associations).ti.
14	focus groups/ or interviews as topic/ or narration/ or qualitative research/ or ((face or f2f or guided or depth or indepth or informal or semistructured or structured or unstructured) adj4 (discussion* or interview* or questionnaire*)).ti,ab,kf. or (ethnograph* or (field adj1 work) or fieldwork or (focus adj1 (group or groups)) or (key adj1 (informant or informants)) or qualitative).ti,ab,kf
15	"surveys and questionnaires"/ or health care surveys/ or patient reported outcome measures/ or health surveys/ or behavioral risk factor surveillance system/ or dental health surveys/ or mass screening/ or nutrition surveys/ or patient health questionnaire/ or self report/
16	(questionnaire* or survey* or (self adj2 (report or reported or reported))).ti,ab,kf.
17	12 or 13 or 14 or 15 or 16
18	11 and 17
19	limit 18 to yr="1990 - 2023"

Appendix Table 1: OVID Medline Search (continued)

1	persons with hearing impairments/ or visually impaired persons/
2	hearing loss/ or deafness/ or deaf-blind disorders/ or hearing loss, bilateral/ or tinnitus/ or blindness/ or vision, low/
3	((hearing or visual or visually) adj2 (impaired or impairment*)).ti,ab,kf.
4	(blind or blindness or deaf or deafness or (hard adj2 hearing) or ((hearing or vision) adj2 (loss or low))).ti,ab,kf.
5	1 or 2 or 3 or 4
6	"delivery of health care"/ or health services accessibility/ or health equity/ or healthcare disparities/ or practice patterns, pharmacists'/ or practice patterns, dentists'/ or practice patterns, nurses'/ or practice patterns, physicians'/
7	((health adj1 care) or healthcare) adj3 (access or quality).ti,ab,kf.
8	6 or 7
9	5 and 8
10	limit 9 to english language
11	10 not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) not (north america/ or exp united states/))
12	cohort studies/ or longitudinal studies/ or follow-up studies/ or prospective studies/ or retrospective studies/ or cohort.ti,ab,kf. or longitudinal.ti,ab,kf. or prospective.ti,ab,kf.
13	Cross-Sectional Studies/ or Prevalence/ or ((association adj2 (studies or study)) or cross-sectional or prevalence or transversal).ti,ab,kf. or (association or associations).ti.
14	focus groups/ or interviews as topic/ or narration/ or qualitative research/ or ((face or f2f or guided or depth or indepth or informal or semistructured or structured or unstructured) adj4 (discussion* or interview* or questionnaire*)).ti,ab,kf. or (ethnograph* or (field adj1 work) or fieldwork or (focus adj1 (group or groups)) or (key adj1 (informant or informants)) or qualitative).ti,ab,kf
15	"surveys and questionnaires"/ or health care surveys/ or patient reported outcome measures/ or health surveys/ or behavioral risk factor surveillance system/ or dental health surveys/ or mass screening/ or nutrition surveys/ or patient health questionnaire/ or self report/
16	(questionnaire* or survey* or (self adj2 (report or reported or reported))).ti,ab,kf.
17	12 or 13 or 14 or 15 or 16
18	11 and 17
19	limit 18 to yr="1990 - 2023"

Appendix B Characteristics of Selected Publications

Appendix Table 2: Characteristics of Selected Publications

Reference	N	Sample	Research Design	Main Findings
Assi, Shakarchi, et al. (2020)	10,783	Medicare beneficiaries	Cross sectional observational study. 2017 Medicare Current Beneficiary Survey (MCBS)	<ul style="list-style-type: none"> • Dual sensory impairment associated with highest odds of dissatisfaction with quality of healthcare. • Any sensory impairment associated with dissatisfaction about information provided. • Hearing impairment and dual sensory impairment more likely to be dissatisfied with doctors' concern for overall health. • Concern with out-of-pocket costs high for all groups. • Worries about transportation.
Assi, Varadaraj, et al. (2020)	Over 1 million	50 and older	Cross sectional using National Health Interview Survey (NHIS) and Behavioral Risk Factor Surveillance System (BRFSS)	<ul style="list-style-type: none"> • Adults with vision impairment less likely to report cancer-related preventative screenings.
Cheng et al. (2022)	437,436	Adults 18 and older	2018 Behavioral Risk Factor Surveillance System (BRFSS)	<ul style="list-style-type: none"> • Low vision folks reported lower access to healthcare. • Lower prevalence of insurance coverage. • Lower usual healthcare provider. • Lower odds of dental visit in past year. • Higher percentage of poor general health.
Dillard et al. (2023)	2,438 total 642 with self-reported hearing loss	Self-reported hearing loss	Self-report household-based examination survey	<ul style="list-style-type: none"> • More likely to rate health as poor. • More likely to have more chronic conditions. • Poor provider communication. • Hearing aids do not help as much as hearing people think. • Difficulty communicating in noisy office environment.

Appendix Table 2: Characteristics of Selected Publications (continued)

Donald et al. (2022)	197	Deaf and Hard of Hearing women	Cross sectional health survey administered in both English and ASL	<ul style="list-style-type: none"> • Deaf with lower education levels have higher unmet dental health needs. • Deaf people of color have higher unmet dental needs than white deaf. • Dental offices more likely to deny appointment to someone who needs an interpreter. • Financial barriers common.
Hommel et al. (2018a)	37	ASL interpreters	Survey of ASL interpreters	<ul style="list-style-type: none"> • Patients do not understand doctors and health information. • Doctors not doing anything extra to improve communication. • Patients not always advocating for themselves and lack of empowerment. • Provider time constraints • Issues with connectivity and quality during video interpretation.
Horner-Johnson et al. (2021)	17	Women of reproductive age with disabilities in Oregon	Multiple-category focus group design	<ul style="list-style-type: none"> • Lack of accessibility and accommodations. • Concerns about privacy. • Clinician attitudes (negative or condescending). • Lack of or poor health insurance. • Many on Medicaid or Medicare. • Doctors do not always know how to obtain ASL interpreter. • Huge variable quality in ASL interpreters. • Appointments too short.
Horner-Johnson et al. (2022)	17	Women of reproductive age with disabilities in Oregon	Multiple-category focus group design	<ul style="list-style-type: none"> • Lack of info in accessible formats. • Incomplete information. • Limited clinician knowledge and research specific to women with disabilities. • Taboos around discussing sexual activity. • Limited opportunities for shared decision-making.
James, McKee, et al. (2022)	92 deaf 12,589 hearing	Deaf ASL users and Hearing English speakers in Florida	2018 Florida Deaf Health Survey and 2018 Florida Behavioral Risk Factor Surveillance System (BRFSS)	<ul style="list-style-type: none"> • Deaf very concerned about mental health above most physical health concerns. • Deaf higher utilization of emergency department. • Lack of communication accommodations for Deaf patients.

Appendix Table 2: Characteristics of Selected Publications (continued)

James, Miller, et al. (2022)	768	Deaf and Hard of Hearing (DHH)	Retrospective chart review	<ul style="list-style-type: none"> Deaf and Hard of Hearing ASL users have longer lengths of stay in the emergency department than hearing English speakers. 10% of encounters were acute revisits that were usually preventable.
Kim (2019)	10	Low vision, 65 and older	Semi structured phone interviews	<ul style="list-style-type: none"> Concerns with accessing, understanding, and using health information, care services, multimedia technologies. Providers did not provide health info in alternative formats. Patients assume health info not available in accessible formats. Poor adherence to medical advice. Difficulty understanding written information. Concerns about privacy. Limited transportation.
H. H. Lin et al. (2021)	12,140	Medicare beneficiaries	2016 Medicare Current Beneficiary Survey (MCBS)	<ul style="list-style-type: none"> Respondents with trouble hearing more likely to avoid and delay healthcare. Trouble hearing also more likely to self-rate health as poor.
Mahmoudi et al. (2021)	1,977 hearing loss 17,399 hearing	Adults 50 and older	National cross-sectional survey	<ul style="list-style-type: none"> Deaf more likely to have many other health conditions. Higher odds of reporting unmet medical needs. Higher unfilled prescriptions. High out-of-pocket costs. Significant communication barriers.
McKee, Winters, et al. (2015)	200 deaf 200 hearing	Deaf ASL users and hearing English speakers	Retrospective cohort study. 400 medical records randomly selected	<ul style="list-style-type: none"> Deaf more likely to have Medicaid. Deaf more likely to use emergency department. Repeated emergency department visits. Higher accessibility to ASL interpreters in hospital.
Nagarajan et al. (2022)	1,921	65% blind 35% low vision	Flatten Inaccessibility Survey	<ul style="list-style-type: none"> Concerns with pharmacy access. Concerns about keeping up with eyecare regimen during COVID-19. Fears of no ventilator access. Perceived higher every day discrimination.

Appendix Table 2: Characteristics of Selected Publications (continued)

Panko et al. (2021)	104 deaf 74 hearing	Deaf and hearing	Data take from Newest Vital Sign (NVS) and ASL-NVS	<ul style="list-style-type: none"> • Linguistic isolation. • Deaf more difficulty accessing info. • More likely to find info scary and to distrust. • Poorer health literacy.
Panko et al. (2022)	45	Female Deaf ASL users 21-50 years old	Semi-structured interviews in ASL	<ul style="list-style-type: none"> • Poor communication. • Lack of healthcare provider support. • Healthcare info not in-depth enough. • Deaf women fewer prenatal appointments. • Women with ASL interpreter had more positive pregnancy and birthing experiences.
Powell et al. (2019)	40	Adults 50-78 rural Kentucky	Semi-structured phone interviews	<ul style="list-style-type: none"> • Lack of providers in rural area. • Lack of trust in providers. • Overwhelming costs.
Reed, Assi, et al. (2021)	10,422	Medicare beneficiaries	2016 Medicare Current Beneficiary Survey (MCBS)	<ul style="list-style-type: none"> • Hearing loss had lower usual source of care. • More trouble obtaining needed medical care. • More likely not to fill a prescription. • Lack of trust in providers.
Reed, Boss, et al. (2021)	11,441	Medicare beneficiaries	2015 Medicare Current Beneficiary Survey (MCBS)	<ul style="list-style-type: none"> • Deaf more dissatisfied with quality of healthcare. • Poorer self-rated health. • Greater number of chronic comorbidities.
Ryan and Kushalnagar (2018)	515	d/Deaf	Survey in ASL video format	<ul style="list-style-type: none"> • Deaf who engaged in social media for health activities were more likely to communicate with healthcare provider through online platform.
Schniedewind et al. (2020)	108 (number of complaints)	d/Deaf in Idaho	Retrospective review of complaints filed regarding interpreter provision in healthcare settings	<ul style="list-style-type: none"> • Most deaf patients told that interpreter was not available. • Next biggest complaint was that interpreter was unqualified. • Interpreter promised but not provided.
Schniedewind et al. (2021)	8	4 d/Deaf and 4 hearing	Cross sectional simulation of patient audit method to request appointments with interpreter	<ul style="list-style-type: none"> • Hearing patients were twice as likely to get appointment than deaf patients. • For deaf, many appointments denied after asking for ASL interpreter.

Appendix Table 2: Characteristics of Selected Publications (continued)

Simning et al. (2021)	7,548	Older adults	2015 National Health and Aging Trends Study (NHATS)	<ul style="list-style-type: none"> • Near vision loss associated with decreased odds of having a usual source of care. • Lack of transportation. • Needing assistance from family and friends during appointments.
Stevens et al. (2019)	1,581	d/Deaf	Anonymous national survey	<ul style="list-style-type: none"> • Poor provider communication. • Issues with using the phone for appointment-making and receiving health info. • Concerns with privacy. • Often no arrangements made to improve communication after disclosing hearing status.
Thai and Megwalu (2021)	7,160	Medicare beneficiaries	2017 Medicare Current Beneficiary Survey (MCBS)	<ul style="list-style-type: none"> • Avoidance of routine medical care. • Increased emergency department visits and increased length of stay.
Wells et al. (2020)	19,223	Adults 65 and older	Cross-sectional health survey	<ul style="list-style-type: none"> • Hearing loss associated with lower health literacy. • Lower health literacy associated with higher healthcare costs.
Wilson et al. (2021)	614	d/Deaf	Prospective cross-sectional questionnaire	<ul style="list-style-type: none"> • Communication challenges. • Challenges with preparedness and information gathering, not feeling up to date on the latest info. • Cochlear Implant users and rural patients reported a lesser quality of life and ability to carry out usual activities. • Lower access to health care.

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