

The University of Chicago

**“They Don’t Know What it’s Like to be Blind”:  
Assessing Healthcare Access for Visually Impaired New Yorkers**

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## **Abstract**

Disabled individuals at large, and visually impaired individuals in particular, encounter a range of obstacles when attempting to access healthcare in the United States. However, the few studies that have documented the experiences of visually impaired patients as they access healthcare either fail to capture the voices of a diverse range of participants or focus on documenting the opinions of healthcare providers and not of their patients. In this paper, I identify the strengths and weaknesses that visually impaired adults residing in New York State encounter when accessing healthcare. Using Community Based Participatory Action Research (CBPAR) methods, I interviewed 47 visually impaired adults residing in New York State to document strengths/solutions and weaknesses/obstacles they encountered when visiting a healthcare provider. Specifically, I found that visually impaired patients were most impacted by the environmental factors of transportation, design of facilities, and the format of written information, as well as the personal factors of staff's sensitivity toward and familiarity with appropriately assisting disabled individuals. Participants also noted encountering an array of illegal obstacles, ranging from inaccessible buildings to one instance of sexual assault by a physician. Based on these findings, I offer recommendations for both government actors and healthcare providers and argue that both sets of actors must work to improve compliance with existing accessibility legislation. The findings presented here may help guide these actors as they work to develop more comprehensive policies and legislation in the future to ensure improved access to healthcare for visually impaired individuals.

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## **Introduction**

The decision to assign medical meanings to disabilities, also known as the medicalization of disability, has had a wide range of consequences for disabled people. One consequence is that healthcare professionals work to improve the health and quality of life of disabled people, and to find methods by which the onset of disabling conditions can be prevented (Linton, 2006).

However, the medicalization of disability has also meant that healthcare professionals, and society at large, often believe that efforts should be directed toward treating disabling conditions rather than “treating” the aspects of society that restrict disabled individuals’ lives (Linton, 2006). The restrictions that society places on disabled people are far-reaching and permeate into the healthcare spaces where providers want disabled people to seek treatment (Iezzoni et al., 2002, 2003). This discrimination is known to have adverse consequences, such as a reduction in healthcare-seeking behavior among disabled people (Moscoso-Porras & Alvarado, 2018).

Visually impaired people, as a category of disabled individuals, face discrimination when accessing healthcare. However, research regarding this population's experiences while seeking healthcare tend to either restrict the sample to certain subsets of the group, such as visually impaired women (i.e., Sharts-Hopko et al., 2010), or highlight the opinions of healthcare providers rather than of visually impaired people themselves (i.e., Cupples et al., 2012). While such approaches are useful for providing insights into the perspectives of certain groups of underrepresented individuals, they fail to allow the researched to direct the research. This may mean that these approaches result in less accurate results than could a more collaborative approach such as Community-Based Participatory Action Research (CBPAR) (Maiter et al., 2008). Thus, by using CBPAR, this study aims to identify the strengths/solutions and weaknesses/obstacles that visually impaired adults encounter in the healthcare system.

In this paper, I utilize data from surveys and interviews, aligned with CBPAR principles, conducted with 47 legally blind adults residing in New York State. Drawing on Meade's framework of the Model of Healthcare Disparities and Disability (MHDD) (Meade et al., 2014), I categorize my findings about visually impaired individuals' healthcare experiences into the environmental factors of transportation, design of facilities, and the format of written information, as well as the personal factors of staff's sensitivity toward and familiarity with appropriately assisting disabled individuals. Participants further identified 1) how certain healthcare providers had already augmented their attention to these factors, thereby bettering participants' experiences and 2) what deficits in these factors presented as obstacles during their encounters with healthcare providers. Participants also highlighted illegal obstacles ranging from inaccessible facility designs to an instance of sexual assault committed by a physician.

This paper offers two main contributions to the literature. First, the experiences of a diverse range of visually impaired individuals (in age, gender, location of residence, etc.) regarding healthcare access have not previously been documented. I categorize the experiences of a diverse sample of visually impaired adults residing in a geographic area that encompasses urban, suburban, and rural regions with different types of healthcare providers and facilities.

Second, the unique experiences of visually impaired individuals when accessing healthcare have never been contextualized using the Model of Healthcare Disparities and Disability (MHDD). The MHDD allows us to understand how a misalignment between environmental and personal factors may lead to lower healthcare access and quality, which can contribute to a reduction in functioning, activity, and participation among disabled individuals (Meade et al., 2014). To contextualize how the framework can be applied, its application for individuals with spinal cord injuries can be taken as an example. The health status of individuals

with spinal cord injuries, who have higher rates of conditions including heart disease and depression, depends on the characteristics of the individual (such as health literacy and resources) and of their environment (such as social support and access to public transportation). A mismatch between individual and environmental characteristics will worsen the individual's health status. Utilizing this framework enables the use of focused approaches to individually target environmental and personal factors, which can subsequently make healthcare more accessible. Based on my findings, I offer recommendations for potential improvements to current practices that should be universally implemented by government actors and healthcare providers to make healthcare more accessible to visually impaired individuals. Ultimately, this paper argues that improvements must be made to align personal and environmental factors affecting visually impaired adults to improve this population's access to healthcare.

## **Background**

### Contextualizing Disability

Both globally and in the United States specifically, disability is prevalent. 26% of adults in the United States have a disability (CDC, 2019), as compared to 15% globally (McClain-Nhlapo, 2021). Disabled individuals in the United States face significant barriers in accessing healthcare, as evidenced by the fact that 1 in 3 disabled adults do not have a usual healthcare provider, 1 in 3 disabled individuals have unmet healthcare needs due to the cost, and 1 in 4 disabled individuals have not had a routine visit with a healthcare provider in the past year (CDC, 2019). These patterns persist despite efforts to improve conditions for disabled people. For example, the Americans with Disabilities Act was signed into law on July 26, 1990 (Baird & Rosenbaum, 2008). This piece of legislation, which prohibits discrimination against disabled people in several areas of society, is the result of the work of the thousands of individuals/groups/organizations comprising the disability rights movement (Baird &

Rosenbaum, 2008). This powerful movement has concentrated on making the injustices faced by disabled individuals visible to nondisabled Americans, adopting many strategies developed by the civil rights movement to work toward accomplishing a similar goal (Baird & Rosenbaum, 2008).

The key concept in the history of disability rights that linked disabled individuals' struggles with civil rights causes was access (Williamson, 2015). When access is centered, it allows for a move away from a cure for disability on an individual level and toward a series of larger social or legal changes (Williamson, 2015). Access is central to this work, which is centered around increasing access to healthcare.

Further, while the disability rights movement has largely focused on the experiences of White individuals in Northern countries, colonization and colonialism have directly disabled many living in the global South (Meekosha, 2011). As a result, the field of disability studies, which is concerned primarily with the nature and meaning of disability, has begun working to broaden the scope of research conducted to include individuals from various parts of the world and with diverse backgrounds to document the wide range of experiences among disabled individuals (Meekosha, 2011). Disability studies has broadened to analyze the experiences of certain sub-groups, such as disabled women (Fine & Asch, 2009). The field has also begun to work with Critical Race Feminist Theory, expanding the scope of the voices that are amplified in the ongoing movement for disability rights (Erevelles & Minear, 2010). This intersectional approach to disability studies is reflected in recent literature that has been produced by grassroots activists within the disability rights/justice community. For instance, the "10 Principles of Disability Justice," a text that defines the goals around which disability rights/justice activists should aim to center their work, states that collective access and collective liberation necessitate



that the movement amplifies the voices of Brown, Black, and Queer disabled people (Berne & Sins Invalid, 2015).

The changes in the disability rights movement and disability studies have coevolved with changes in the language used to discuss disability. The use of person-first language (i.e., “person with a disability”) allows others to de-center the disability as the defining characteristic of an individual and is based on the ideal that everyone is a person first, regardless of whether they have a disability (Gernsbacher, 2017). This language contrasts with identity-first language (i.e., “disabled person”), which some disability scholars believe can increase equality due to the role it plays in helping disabled individuals embrace their identities (Gernsbacher, 2017). Further, identity-first language has been empirically demonstrated to be linked with improved well-being and self-esteem for many disabled individuals (Gernsbacher, 2017). The use of person-first language in scholarly writing may increase stigma and as a result, some argue that scholarly writing should move toward adopting more identity-first language (Gernsbacher, 2017). Consequently, in this paper, I utilize identity-first language, except when quoting or paraphrasing participants who have used person-first language, in an effort to respect these individuals’ linguistic choices.

The fear and discrimination of disabled bodies is best described by the term “ableism,” which encapsulates the idea that a person’s characteristics are defined by a disability and that disabled individuals are inferior to nondisabled people (Linton, 2006). The rhetoric used to discuss disability underscores the adverse effects of ableism. For instance, individuals often use the phrase “overcome a disability,” which places the responsibility on disabled individuals to “compensate” for their disabilities rather than on society to pass robust civil rights legislation and to remove barriers to disabled people in the environment (Linton, 2006). Such rhetoric conveys

victimization, reinforces stereotypes that disabled individuals are less competent than nondisabled individuals, and implies that disabling conditions should trigger responses of sadness and pity (Linton, 2006). Nevertheless, shifts in disability studies and the rhetoric used to discuss disability have begun to occur. The Americans with Disabilities Act demonstrates that civil rights legislation protecting equal access for disabled individuals can help to combat the notion that disabled individuals should be expected to try harder to adjust to inaccessible spaces (Baird & Rosenbaum, 2008; Linton, 2006).

### Models of Disability

Disabled individuals' interactions with the world have been conceptualized in two main ways. These two models represent theories that aim to explain phenomena we encounter by referencing an abstract system (Llewellyn & Hogan, 2000). Specifically, the two models work to conceptualize disability through differing lenses, thereby defining disability in opposing ways.

The first model, used primarily throughout the late 1800s and early 1900s, is the medical model of disability. This model views disability as a consequence of a physiological impairment that has resulted either from a disease process or damage to a body (Llewellyn & Hogan, 2000). The model arose because health conditions resulting from disabilities have historically been, and continue to be, treated by individuals with medical training (Llewellyn & Hogan, 2000). Subsequently, the model continues to be predominantly used by healthcare providers to conceptualize disabled bodies (Bricher, 2000). However, the use of this model results in healthcare providers believing that disability is a "condition" that requires "treatment" (Llewellyn & Hogan, 2000). The medical model of disability treats disabling conditions as "alterable" and the environment as "unalterable," and as a result, focuses on finding mechanisms that can be used to change disabled bodies to allow them to operate better in the inaccessible environments that society has created (Llewellyn & Hogan, 2000). The medical model of

disability conceptualizes disabled individuals as people who must be changed. As a result, disability scholars have shifted away from the medical model of disability and towards the social model of disability.

The social model of disability emerged in the 1970s in response to the ableism inherent in the medical model of disability (Anderson & Carden-Coyne, 2007). The social model of disability proposes the removal of barriers for disabled people, and advocates for anti-discrimination policy, independent living, and more radical responses to the oppression faced by this community (Shakespeare, 2010). This stands in contrast to the medical model of disability, which aims to change disabled individuals themselves, rather than the environment in which they exist. The social model of disability views civil rights, as opposed to charity or pity, as the mechanism by which the oppression of disabled individuals can be alleviated (Shakespeare, 2010). While much of the disability studies community has shifted to centering their work around the social model of disability, many healthcare providers still utilize the medical model of disability in research and practice, which is thought to contribute to the marginalization of disabled individuals (Bricher, 2000). A critical step in bettering relationships between disabled individuals and healthcare providers, and establishing more dialogue between these two groups, is reducing the medical community's negative perceptions of the social model of disability (Bricher, 2000).

Though the social model of disability offers significant improvements when compared with the medical model of disability, it still has several shortcomings. First, the social model of disability aims to create a barrier-free utopia that simply is not achievable. While environments and services should always be adapted to be more accessible whenever possible, no amount of change could entirely eliminate the barriers that disabled individuals encounter (Shakespeare,

2010). Second, the social model of disability has been used by policy makers to cut the benefits of some disabled individuals in order to give more to individuals who are deemed more “severely impaired” (Oliver, 2013). These policy makers have attempted to justify their slashing of benefits by using the social model of disability to claim that in order to remove barriers, there are only enough resources to focus on giving the most to those who need the most. Third, the social model of disability does little to help explain the complex interaction between individual and environmental factors in disabled people’s lives (Shakespeare, 2010).

In response to the shortcomings in both the medical model of disability and the social model of disability, and because the interactions between disabled individuals and healthcare providers must be addressed to ensure a decrease in the oppression that disabled people face, the Model of Healthcare Disparities and Disability (MHDD) was developed in the context of the medical field (Meade et al., 2014). This model provides a framework for analyzing healthcare disparities that are experienced by disabled individuals (Meade et al., 2014). Healthcare disparities are a type of health disparity that result from differences in healthcare access and quality, and that typically can be deemed the consequence of the healthcare system’s inability to adequately address the needs of certain populations (Meade et al., 2014).

The MHDD theorizes that a “mismatch between personal and environmental factors may result in reduced healthcare access and quality, which in turn may lead to reduced functioning, activity and participation” among disabled individuals (Meade et al., 2014, 1). In this paper, I find that visually impaired individuals’ healthcare experiences are most profoundly impacted by five factors that align with categories delineated by the MHDD. These factors are transportation (environmental factor), design of facilities (environmental factor), format of written information (environmental factor), staff’s sensitivity toward visually impaired patients (personal factor), and

staff's appropriate assistance of visually impaired patients (personal factor). These findings demonstrate the MHDD's utility in providing a framework through which the narratives of disabled individuals can be better analyzed and understood.

Figure 1. Model of Healthcare Disparities and Disability (Meade et al., 2014)

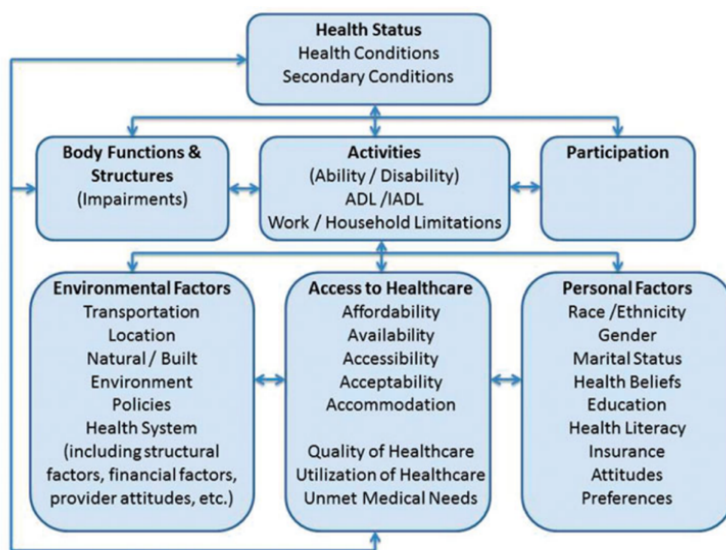


Figure reproduced from Meade et al., 2014

### Healthcare Access for Disabled Individuals

Many disabled individuals are not satisfied with the quality of the healthcare they receive (McCull et al., 2010; Minkler et al., 2008; Mirza et al., 2008; Moscoso-Porras & Alvarado, 2018; Okoro et al., 2018). Disabled individuals generally report dissatisfaction with the information they receive about conditions, the costs of the care they receive, and the ease of visiting a healthcare provider (Iezzoni et al., 2002). Disabled individuals also are more likely than nondisabled individuals to report poor communication with their healthcare providers and a lack of thorough care (Iezzoni et al., 2003). Healthcare providers must recognize that disabled individuals may require extra time during visits because of the potential complexity of their underlying conditions or misalignments between the perceptions and expectations of physicians and patients, particularly about the experience of being a disabled person (Iezzoni et al., 2003).

The sources of the obstacles that disabled individuals in the United States encounter have been delineated into several categories through the CDC's 2016 Behavioral Risk Factor Surveillance System (BRFSS) survey data (Okoro et al., 2018). BRFSS included questions about hearing, vision, cognition, mobility, self-care, and independent living disabilities (Okoro et al., 2018). BRFSS found that within each disability type, the prevalence of having health insurance coverage, having a usual healthcare provider, and going to a check-up during the preceding year increased with increasing age group (Okoro et al., 2018).

Amongst all disabled individuals who responded to BRFSS, young- and middle-aged visually impaired individuals had the lowest rates of health insurance coverage, with 74.9% and 81.3% having coverage, respectively (Okoro et al., 2018). Conditions were found to be worse for those with visual impairments, as opposed to other disabilities; young- and middle-aged visually impaired adults had the lowest prevalence of having a usual healthcare provider, with 64.0% and 92.3% of respondents having a provider, respectively (Okoro et al., 2018). It is evident, therefore, that amongst disabled individuals, visually impaired adults in particular face unique obstacles when accessing healthcare.

In addition to being less satisfied with care, disabled individuals, and visually impaired individuals in particular, encounter a range of obstacles when attempting to obtain high-quality healthcare, especially when compared with nondisabled individuals (Moscoso-Porras & Alvarado, 2018; Okoro et al., 2018). When disabled individuals perceive discrimination in their interactions with healthcare providers, they are less likely to seek care (Moscoso-Porras & Alvarado, 2018). The negative association between perceived discrimination and likelihood of seeking healthcare is strongest for people with communication and physical disabilities, the latter of which includes visually impaired individuals (Moscoso-Porras & Alvarado, 2018).

A limited body of literature has documented the specific obstacles that visually impaired individuals encounter when accessing healthcare. One study documented the experiences of visually impaired women when accessing healthcare, finding that this group encounters particular difficulties with healthcare professionals' awareness of their needs, information access, isolation, the need for self-advocacy, and perception by others at the healthcare office (Sharts-Hopko et al., 2010). Another study used evidence from a conversation between an optometrist, ophthalmologist, and general practitioner to determine how visually impaired people can receive better healthcare (Cupples et al., 2012). Findings suggested that healthcare providers should take steps to be more alert of signs that a patient may be visually impaired, improve their information delivery, assist patients with navigating new environments, and improve communication skills (Cupples et al., 2012). However, this study did not include the voices of any visually impaired individuals. An additional study used National Health Insurance System insurance claims and quantitative methods to analyze healthcare use by visually impaired individuals and found that visually impaired individuals spend more on total healthcare expenditures than non-visually impaired individuals; however, this study also did not include the voices of any visually impaired individuals (Kim et al., 2019). Drawing on these studies and seeking to expand them, my work focuses on centering the voices of visually impaired individuals.

## **Data and Methods**

### Research Methods for Disability Advocacy

Research that aims to advocate for disabled individuals must center the voices of these participants to ensure an accurate analysis. Community-Based Participatory Action Research (CBPAR) is marked by active collaboration between researchers, participants, and other community actors, and thus is one research model that can be used to center the voices of disabled people (Mirza et al., 2014). There are four main principles of CBPAR used with

disabled populations (Buettgen et al., 2012). First, disabled participants must articulate the problem they encounter and must directly participate in defining, understanding, and solving it (Buettgen et al., 2012). Second, disabled individuals must be directly involved in the research process to ensure an authentic depiction of their reality (Buettgen et al., 2012). Third, the research can be used to increase the awareness of disabled individuals of their resources and strengths (Buettgen et al., 2012). Fourth, the goal of the research must be to improve disabled individuals' quality of life (Buettgen et al., 2012).

CBPAR has been utilized to detail the barriers that disabled populations, at large, encounter when accessing healthcare (Minkler et al., 2008; Mirza et al., 2014). CBPAR has also been effectively used to document non-healthcare related obstacles that visually impaired populations encounter. CBPAR has been used with visually impaired populations, for instance, to document obstacles to accessing diabetes education (Williams, 2009), shopping (Yuan et al., 2019), and advocating for equal rights (Jaiswal & Gupta, 2017). However, out of the few studies that have investigated the obstacles that visually impaired individuals specifically encounter when accessing healthcare, none have used CBPAR to amplify these participants' voices (i.e., Cupples et al., 2012; Kim et al., 2019; Sharts-Hopko et al., 2010).

In order to effectively amplify the voices of participants and to focus on the issues that they deem most pertinent, I utilized a modified version of a CBPAR methodology, called Photovoice. Photovoice is a form of CBPAR in which participants capture photographs to record concerns and strengths they encounter (Hergenrather et al., 2009). Photovoice has been used with disabled populations to document the obstacles they encounter in multiple facets of life, including in healthcare-related settings (i.e., Balakrishnan et al., 2017; Cho et al., 2019; Cordova et al., 2015; Grills et al., 2017; Heffron et al., 2018; John et al., 2021; LaVela et al., 2018;



Overmars-Marx et al., 2018; Patka et al., 2020; Payne et al., 2016; Ripat et al., 2020; Shumba & Moodley, 2018). I had initially chosen photography as the medium for this study because I felt it captured parts of the world that non-visually impaired individuals see every day and rarely perceive to be obstacles.

However, after incorporating the feedback of participants, I determined that Photovoice is not an accessible research method to all visually impaired adults. This is consistent with literature that has explained that Photovoice may not be a universally accessible method (Dassah et al., 2017). While some participants enjoyed the challenge of using their smartphones to capture photographs, others felt that this medium was inherently not designed for them. Consequently, I asked participants to choose whether they wanted to use photography or take notes during their participation in the study. This joint decision was made with participants to ensure respect for the opinions of participants and to maintain the principles of CBPAR research.

#### Data Sources

The data in this study come primarily from six months of survey administration and interviews with n=47 visually impaired adults. All of the participants in the study resided in New York State; were over the age of 18 years; were legally blind; and were visiting at least one healthcare provider, either in-person or via telehealth, up to three months after their enrollment in the study. Of enrolled participants, the mean age was 57.3 years. The mean number of years for which enrolled participants had been legally blind was 45.9 years. 27 participants were women, and 20 participants were men. As a result, these data are not representative of the perspectives of legally blind children or young adults, nor are they representative of individuals residing outside of New York State.

Over the course of six months in 2021, participants were recruited through fliers emailed to members of organizations working with visually impaired individuals, and through snowball

sampling (n=58). Participants were screened using eligibility criteria (age over 18 years, residence in New York State, legally blind, and visiting a healthcare provider before the conclusion of the study) and ineligible participants were not enrolled (n=7). All eligible participants were enrolled in the study and verbal consent was obtained (n=51). Enrolled participants were asked to visit a healthcare provider and subsequently completed either a semi-structured individual interview or a focus group discussion (n=47). The 4 participants who were enrolled but who did not complete the study were unable to visit a healthcare provider prior to the completion of the study.

University of Chicago's Institutional Review Board approved the study. Consented and enrolled participants completed a study-specific questionnaire, a modified version of the BRIEF health literacy screening tool (Haun et al., 2012), and the Brief Impact of Vision Impairment Questionnaire (B\_IVI) (Fenwick et al., 2017). While quantitative data were collected using these tools, for the purpose of this paper, I focus mainly on the qualitative data respondents provided.

Participants next visited any healthcare provider of their choice. Participants were asked to document any strengths or solutions that had been implemented to make the space more accessible to them, and any weaknesses or obstacles they encountered by taking photographs using their smartphone cameras, in accordance with Photovoice methodology (Wang & Burris, 1997). However, after several participants voiced their concerns about the inaccessibility of photographs to the visually impaired community, a joint decision with participants was made to make capturing photographs optional (Dassah et al., 2017). Ultimately, this decision was made to center participants' voices by allowing them to direct the research, in accordance with CBPAR principles. All participants were given the choice to take photographs; n=11 participants captured and submitted photographs, while n=36 chose to take notes to document their experiences.

Finally, participants engaged in a semi-structured individual interview or focus group discussion that typically lasted around 30 minutes. During individual interviews, I conversed one-on-one with each participant (n=29). During focus group discussions, I engaged in a conversation with two to six participants (n=18). Participants were able to select the option they preferred. All individual interviews and focus group discussions occurred over Zoom or via telephone. All participants were asked the same set of questions, though different probes were used depending on what interviewees shared in their initial responses.

The main goal of the individual interviews and focus group discussions was to understand the strengths or solutions that visually impaired adults believe should be universally implemented at all facilities to make healthcare more accessible, and the weaknesses or obstacles in the healthcare system that visually impaired adults encounter when accessing healthcare. Broadly, I asked participants to discuss in depth the healthcare provider visit they selected for the study and subsequently asked participants to discuss their past healthcare provider visit experiences more broadly. For participants who chose to take photographs during their healthcare provider visit, the SHOWED discussion guide (Table 1) (Hergenrather et al., 2009) was utilized in conjunction with the interview guide used for all participants (Appendix 1).

Table 1. SHOWED Discussion Guide (Hergenrather et al., 2009)

1.	What do you <i>See</i> here?
2.	What is really <i>Happening</i> here?
3.	How does this relate to <i>Our</i> lives?
4.	<i>Why</i> does this concern, situation, strength exist?
5.	How can we become <i>Empowered</i> through our new understanding?
6.	What can we <i>Do</i> ?

### Data Analysis

Over the course of this study, I produced analytical memos multiple times each month to track significant themes in my data. As a result, data collection and analysis were co-informing

processes (Corbin & Strauss, 1990; Gorski, 2020). All interviews were conducted over Zoom or the telephone, were recorded with permission, and were subsequently transcribed using Otter.ai. Open coding was used during initial rounds to detect possible themes and patterns and focused coding was used in subsequent rounds. Dedoose was also used to analyze transcripts. Participants' responses to survey questions were analyzed using RStudio Version 1.1.463. In order to protect the identities of participants, they are identified only by a pseudonym, their gender, and their age.

### Researcher Positionality

Because I identified myself as a student, many participants were eager to provide me with as much information and as many insights as possible. Though one of my close family members is blind, I did not want participants to assume that I had any prior knowledge or assumptions about their experiences, and I only revealed this information to those participants who chose to ask me why I was conducting this study. When I did reveal this information, participants seemed more invested in the study and expressed that they appreciated my personal stake in ensuring that positive changes are made to the healthcare system. As a result, most participants assumed I had little pre-existing knowledge about or familiarity with visually impaired adults. This allowed participants to speak with me openly and to expand upon details they might otherwise deem unimportant.

### **Findings and Analysis**

The interviews conducted with 47 legally blind adults residing in New York State demonstrated that when encountering healthcare providers, these individuals found strengths/solutions and weaknesses/obstacles within both environmental and personal factors. Participants recognized that different providers approach universal accessibility—conditions that allow any individual to interact with the resource independently and freely—in differing ways.

Nevertheless, participants felt that all healthcare providers should be cognizant of their interactions with transportation, design of facilities, format of written information, staff sensitivity, and staff assistance.

### Environmental Factors

#### *Transportation*

Participants noted that their experiences with transportation to and from healthcare facilities played a large role in the accessibility of their healthcare provider visits. The primary focus of this study is not to analyze the ways in which transportation can be made more accessible to disabled individuals. However, healthcare access for this population cannot be adequately discussed without describing the large role of various modes of transportation in allowing the visually impaired participants in this study to be able to travel to receive healthcare. The role of transportation as an obstacle to participants is consistent with previous studies that have demonstrated that disabled individuals generally report dissatisfaction with the ease of visiting a healthcare provider (Iezzoni et al., 2002).

The modes of transportation that were available to participants were largely dependent on the part of New York State in which they resided. In urban areas, many participants expressed that they were able to use public transportation, such as busses and trains, to independently travel to their healthcare providers' offices. Larry, a 52-year-old man residing in New York City, explained that his mastery of independent use of New York City's public transportation system, run by the Metropolitan Transportation Authority (MTA), allows him to travel to and from his healthcare provider visits. Larry described this as a great source of pride:

And now, in the years ever since I lost my vision, which has been going on about 16 or 17 years now, I've learned how to get on the bus by myself. I've learned how to get on the subway by myself. I get on the Amtrak; I get on the Metro North. You know, I've learned mobility... We strive to be independent. We can do all these things ourselves.

Larry's acknowledgement of the scale of his accomplishment in learning how to independently travel demonstrates that accessible transportation can be very valuable in giving visually impaired individuals a sense of confidence. Yet some elements of the New York City subway system are not as accessible to visually impaired individuals. Eileen, a 29-year-old woman also residing in New York City, took the train to her healthcare provider visit and explained that she could not easily navigate the station:

Another challenge was that I needed to take the subway to a station that I'm not very familiar with. And navigating to get out to street level was a bit hairy. But I, I relied on the help, of just soliciting help from people that were in the station.

Eileen highlighted that there are aspects of the MTA system that are inaccessible to visually impaired individuals. Indeed, several participants described desired changes to New York City's public transit system that they advocate for and that they feel will make the system more accessible to visually impaired individuals. Shanta, a 56-year-old woman also residing in New York City, explained that she is pleased that the "MTA is thinking about using beacons to give you directions on how to walk and find places" in subway stations. She expressed feeling that this could make traveling to and from healthcare providers even easier.

Eileen, who is also involved in initiatives to improve the accessibility of New York City's public transportation, explained that she too believes that some of the MTA's experimental improvements will remove obstacles she's previously encountered when traveling to her healthcare provider visits:

But one thing that I know they've tested at some other stations, and that they're considering rolling out system wide is tactile indications on the floor, that would guide you to different areas. So, I think that would have been helpful. The station where I exited was on the line at 53rd Street. And there's a couple of lines that merge there. And it's a relatively deep subway station. So having those floor guides to kind of help me get to the turnstiles to exit would have been helpful, I think.

Even before visually impaired individuals reach their healthcare providers' offices, they must either navigate a world that is empowering, as demonstrated by Larry's pride in

independently being able to use the MTA, or challenging, as shown by Eileen's suggestions for how the MTA could be bettered. This suggests that urban planners and others involved in developing public transit systems should not only place importance on accessibility during the early stages of their design processes, but also should constantly and actively seek ways they can make existing structures more accessible. This would help to increase the accessibility of healthcare, as well as of other facets of life, to many disabled individuals.

The MTA not only runs public transportation, but also manages transportation services specifically designed for disabled individuals. The most common of these services is Access-a-Ride, which allows passengers to book door-to-door rides on vehicles that transport multiple individuals whose destinations fall along the same route. Participants in this study had a range of opinions on the quality of Access-a-Ride services. Leandra, an 81-year-old woman residing in New York City, expressed satisfaction with the quality of the assistance provided by Access-a-Ride drivers:

I go with the Access-a-Ride. I get Access-a-Ride right to go down there. Access-a-Ride takes me to the door, I go in, there's always a guard or somebody downstairs. And so, they help me upstairs, take me to the correct place. They assist me, sit me down, it's pretty good too.

Leandra expressed that in certain instances, Access-a-Ride drivers have provided her with the service she needs to successfully reach her healthcare provider visits. However, Harry, a 73-year-old man residing in New York City, explained that he has also had some Access-a-Ride drivers whose actions have put him in danger:

Well, I had a driver and he'd left me off like 30 feet from the door of the building. And I turned around and he zipped off. A guy on the block says, "where are you going?" I said, "I'm going up here to the Jewish Guild for the Blind." He says, "oh okay, there it is. It's about 30 feet, you know, in that direction." So, I said "okay." So, then I walked up there. That was about the worst Access-a-Ride experience I've had.

While Harry has had both positive and negative experiences with the service provided by Access-a-Ride drivers, other participants expressed their opinions on Access-a-Ride's policies themselves. Paul, a 51-year-old man residing in a suburb of New York City, felt that Access-a-

Ride is much more difficult to use than private transportation options, such as the car service

Lyft:

The Access-a-Ride system works just right for psychotherapy, but you can't get Access-a-Ride back from a location until you've been there for an hour. Two hours, you have to be there before you can get the ride back. And the two hours ultimately, you're gonna have to sit around and wait for an hour before you get a ride back using Access-a-Ride.

Paul explained that the program is inaccurate in anticipating the needs of users. While some healthcare provider visits, like a psychotherapy appointment, might mean that an individual is in a location for two hours before they need a ride back, other appointments may take much less time. As a result, a disabled individual may be stuck waiting for Access-a-Ride when they should simply be able to take a ride home. A nondisabled individual, on the contrary, would likely be able to use transportation running on a more frequent schedule. This is one example of the unnecessary and additional hurdles that visually impaired individuals must encounter to get to and from their healthcare provider visits. This demonstrates that the time of disabled individuals may not be given equal value to the time of nondisabled individuals.

Access-a-Ride, similar to other MTA services such as the subway system at large, has been working to make improvements to their system in order to address some of the barriers that have been noted by the disabled individuals who use the service. Some participants in the study had been selected to participate in pilot programs that have recently been launched by Access-a-Ride for their users. Shane, a 57-year-old man residing in New York City, had been selected to help test a pilot program for Access-a-Ride users that allows him to hail cabs around New York City. Through the program, he pays a heavily subsidized and standard \$2.50 per taxi ride, regardless of the length of the trip. He explained how beneficial this program has been when compared to the van-share pickup and drop-off service normally offered to Access-a-Ride users:

So, it's very easy. And I have this special service called on-demand service. So, since I don't know what time my appointment is going to be over, after the visit, I come back down to the lobby. And I can call a



cab at that time and then it comes in like four or five minutes. And they pick me up and take me home. It's a pilot program from Access-a-Ride. So that's a very convenient program to be on.

Shane's participation in this pilot program run by Access-a-Ride has vastly improved his ability to commute to and from his healthcare provider appointments and other locations.

However, this program is still not available to all disabled individuals, even if they qualify to use Access-a-Ride. Subsequently, many Access-a-Ride users who participated in this study turned to other, more accessible modes of transportation. Due to his dissatisfaction with Access-a-Ride, Paul, for example, has searched for alternatives. He explained that he had access both to New York City's Access-a-Ride program and to similar programs run by his suburb. As a result, he often opts to use the latter since they present fewer hurdles to him. Nevertheless, these alternatives have associated obstacles. Paul explained that the higher cost of the paratransit systems accessible to him through his suburb is an additional hurdle that nondisabled individuals do not have to face:

The additional downside also is that, and this goes back to your question about who pays with medical transportation around here. Our suburb's equivalent of Access-a-Ride has a fee of \$5 each way so it'd be \$10 extra. So, the cost starts to build up also if you start using the service a lot for that type of purpose.

Once again, Paul clearly articulated the additional burdens that disabled individuals must take on in order to access the same resources, such as transportation, as their nondisabled counterparts. Other participants, too, experienced hurdles when turning to transportation services that are not operated by the MTA.

Thomas, a 60-year-old man residing in New York City, explained that he often turns to private car services to avoid the barriers he has encountered with Access-a-Ride and Eldercare, the transportation service covered by his health insurance company. Thomas has faced discrimination when trying to use private car services because he uses a guide dog:

I let the, you know, the car service know that I'm blind, and that I have a dog because some drivers don't want to take dogs, even though they're supposed to, but some don't. And if they weren't told ahead of time,

they would say, they can say, “well, unfortunately, I’m allergic to dogs. I can’t take you.” So, they can’t adapt?

While certain private car services have not provided Thomas with the accommodations he requires, he has still been able to find other car services that help him to get to and from his healthcare provider appointments. Not all participants residing outside of New York City, however, had access to Access-a-Ride or to other transportation services, which created difficulties for these participants in traveling to and from healthcare provider visits. Francisco, a 33-year-old man who moved from New York City to a suburb, explained that Access-a-Ride is not available in his area and that as a result, he is dependent on his wife for transportation:

For people who are visually impaired or blind, you know, you have less transportation, right? When I first moved up here, I thought that I would have Access-a-Ride. But then, it turned out that the paratransit or Access-a-Ride doesn’t cover the area where I live. I have to get to the train, or, I have to get my wife to drive me. If you live in the suburbs, you have to, you might need to depend on someone to get to the appointment.

Francisco’s frustration in either needing to take inaccessible public transportation or having to depend on others for transportation to access healthcare is shared by other participants. Even if transportation designed for disabled individuals is available, it still may not be fully accessible. Lucille is a 64-year-old woman who is visually impaired and who has mobility-related disabilities. Because she has both vision and mobility-related disabilities, Lucille explained that she faces additional transportation hurdles since she not only needs drivers who are sensitive to her needs, but also vehicles that she can physically enter and exit. Lucille explained that the transportation company she uses often does not have vehicles that are easily accessible for her:

My particular transportation company that I use, they don’t really have small cars. And because of COVID, drivers don’t want to touch you and I don’t always want to be touched. So, if I’m not in a wheelchair, then what’s the accommodation? I have mobility issues but, they don’t require a wheelchair.

Lucille’s story highlights the unmet need for transportation that is designed for a wide range of disabilities and that meets the needs of all disabled individuals, and of individuals who

may not define themselves as disabled. Because of Lucille's struggles when using some transportation companies, she explained that she's worked to find alternatives:

During that visit, because my girlfriend took me and brought me home, there really weren't a lot of issues. A lot of times, I try to stay with the same transportation company, because they understand that I'm blind and I feel safe with them. Like, they get out to help me into the car. You know, they will help me out of the car too.

Like Lucille, other participants also expressed the difficulties that are caused by their need to rely on family members or friends for transportation to and from healthcare provider visits. Miguel, a 24-year-old man residing in a suburb of New York City, explained that he always ensures that he schedules his healthcare provider appointments for times that are convenient not only for him, but that are also convenient for a family member so that he has transportation:

When I schedule the appointment, I try to schedule... Well, we have our own calendars and I schedule it out so whenever the appointment is made, if it's made for three months from now, we schedule, we make sure that someone is available. In the case of my mom, for example, I'll ask her, "are you available for that day?" So, when I'm at the doctor's office, I'm scheduling with the person at the desk not only for me, but also for my family.

While some participants in the study residing in New York City and its suburbs relied on family members or friends to drive them because they didn't have access to transportation they could use independently, this problem was only exacerbated for participants residing in rural parts of New York. Steve, a 63-year-old man living in a rural town, explained the challenge of finding and paying for reliable transportation, such as the paratransit system provided to him through his insurance, Medicare Cap:

My access to transportation is pretty much null and void without paying 30 to 40 bucks each way. The Federal Transit System out here is, Wednesdays they'll pick you up at nine o'clock and they'll bring you back at about four o'clock and that's it. My insurance has Medicare Cap. So, the one healthcare company that I found, the healthcare medical cap is \$32 each way. I got left at my COVID shot for two hours waiting for somebody to pick me back up. Because the company that was supposed to pick me back up had no drivers. So, I stood outside until I finally just got an Uber for myself.

Steve described the predicament of living in a rural part of New York State. He explained that most people in his town drive cars, which is why public transportation is inconvenient and

difficult to use, primarily because it is so underfunded. Since he is legally blind and cannot drive a car, Steve was forced to look for alternate modes of transportation, which were unaffordable and difficult to maneuver. Steve's story demonstrates that the structural barriers disabled individuals may face in finding accessible transportation to commute to and from healthcare provider visits are only heightened for those who live in rural areas.

Some participants have had the ability to work to address these structural barriers. These participants explained that they have chosen to challenge transportation-related obstacles not only by looking for alternative means of transit, but also by working to improve the transit they already use. Nancy, a 77-year-old woman who was a teacher and who enjoys educating people, explained that she works directly with transportation companies to make suggestions about how they can improve their accessibility:

I take out my phone, and I call them. I say, "I am blind, can you come get me?" And they do. And I, you know, I always let people know what I need. And I try to educate them. And I talk to them. And I ask them sometimes, "how many blind consumers do you have?" And most of the time they don't have any. So, I can understand.

Nancy's efforts to educate those around her have allowed her to collaborate with administrators and drivers in order to make improvements to the transportation she uses. Nancy has felt empowered by her efforts. However, not all visually impaired individuals want to be responsible for educating those around them, which is why it may not be reasonable for this to be the expectation.

Indeed, for some visually impaired individuals for whom transportation presents a seemingly insurmountable obstacle, new innovations such as telehealth may prove to be a feasible alternative. Paul explained that his psychiatrist's shift to telehealth as a result of the COVID-19 pandemic has come as a relief to him:

So along with my visual part comes some balance issues. Because of that, getting to her office is not the easiest thing to do. This all comes down to the fact that I'm here in Harrison and there's not really any decent transportation to get to her office. So, the only way for me to get to her office would be, you know,

car service. I mean, yes, it's a walkable distance, a longer walkable distance. Before my vision was deteriorating, I would actually bicycle to her office. But now bicycling is not something I do on my own, either, you know. So, getting to her office is more of a challenge for me because of everything. So that's part of why we've moved to telehealth as the way of doing things.

For Paul, the shift to remote healthcare provider visits necessitated by the pandemic (and dreaded by many) served as a remover of the obstacles he had previously encountered when trying to find transportation to get to his provider's office. It must be noted, nevertheless, that telehealth may not be a feasible alternative for all visually impaired individuals, especially for those who have difficulties using technology, and may not be appropriate for all types of healthcare provider visits.

As demonstrated above, though the accessibility of transportation is not the focus of this study, it greatly shapes visually impaired individuals' experiences when visiting their healthcare providers. Publicly funded transportation must be made more accessible to ensure that all individuals, including visually impaired riders, can use these services to navigate their surroundings and to complete essential tasks, such as going to healthcare provider visits.

### *Design of Facilities*

Once participants arrived at their healthcare provider visits, they were met with a diverse spectrum of facilities. From approaching the building to reaching their healthcare provider's examination room, participants noted difficulties with door access, elevator usage, navigating physical obstacles, and finding visual cues. This is consistent with studies that have suggested that healthcare providers should assist visually impaired patients with navigating new environments (Cupples et al., 2012). Some participants noted features of facilities that they felt would greatly improve their healthcare provider visits, if implemented universally. Others noted features of healthcare facilities, including violations of the Americans with Disabilities Act, that

acted as significant obstacles to their ability to receive accessible care (Baird & Rosenbaum, 2008).

Healthcare providers do not always appear to consider the accessibility of their close surroundings and access pathways. Visually impaired individuals may not feel safe commuting to and entering their healthcare providers' offices if these facilities are not designed to prioritize the safety of all patients. Carolyn, a 33-year-old woman residing in a suburb of New York City, explained that she must walk through a parking lot to get to the entrance of her healthcare provider's facility, which she often feels is dangerous:

As I approached the building, I felt it's not the most, it's not a very pedestrian friendly approach to the building. So, like, you can take the bus there, but then you have to walk down this road, which isn't really a road. It doesn't have sidewalks and it just, it, kind of it makes me feel unsafe, because it's like kind off of a parking lot. And yeah, I think most pedestrian collisions happen in parking lots. So, like, it worries me.

Figure 2. Photograph of an inaccessible “approach to the building” (taken by Carolyn)



Carolyn's experience suggests that there may at times be a mismatch between facilities' accessibility efforts and their most proximate vicinity. Once reaching their healthcare facilities, some participants experienced difficulties entering the buildings in which their providers were

located. Pilar, a 59-year-old woman residing in New York City, explained the difficulties she faced trying to enter the small healthcare facility she visits:

It, it was a nightmare, even walking into the building. Yeah, because it's like in a residential building. And so, you have to find the area of the building where her office was, though I needed sighted assistance to get there. And then, of course, when you get in, and they're not familiar with working with someone who's visually impaired, even though I've gone there like four times. But it's always, they just don't know what to do with me.

Pilar's story demonstrates that even when facilities are difficult to navigate, staff may not be trained on appropriate ways to assist visually impaired patients. Even after navigating innumerable obstacles to enter the doors of healthcare providers' facilities, participants still continued to encounter obstacles.

Further, participants expressed that they often experience difficulties navigating facilities, such that they feel stuck or stranded. Bernice, a 67-year-old woman residing in New York City, explained feeling as though she could not safely exit the facility to enter the Access-a-Ride vehicle she was going to take to get home from her appointment:

The nurse went downstairs with me and showed me a chair to sit in and I waited for Access-a-Ride. Yeah, that was when I went out. It was a little hard because you know, it's kind of recessed in, the building's kind of recessed in. You have to walk up to the street. And that was kind of a little, like, scary for me, because actually, I couldn't tell when I got to the street from the building, I just felt a gate there. And I said, well, maybe you know, this is it. So, I went a little more. And then I heard a car, and it was really close, so I moved back.

Bernice's story demonstrates that for visually impaired individuals, the poorly designed structures of healthcare facilities may not only decrease these patients' independence, but also may diminish their sense of safety. Lorena, a 64-year-old woman residing in New York City, visits a facility part of a large hospital system and explained that she feels extremely overwhelmed when visiting the hospital, and subsequently does not attempt navigating the space alone:

It's such a big hospital and it's just, to get around in it, it's just a maze. But I usually get one of the, I call them red caps, to help me to where I have to get to. Sometimes, I have to ask them to get me a wheelchair and they do have to because it's such a big— *such* a big place.

The experiences of Bernice and Lorena suggest that all healthcare providers must find ways to simplify their facility designs. Healthcare providers may also choose to implement solutions offered by participants including Paul, such as having individuals available to help visually impaired patients navigate spaces and/or having alert systems that patients can interact with to solicit assistance. Healthcare providers may also choose to give patients who need assistance access to “red caps,” a service that Lorena utilizes frequently to navigate the hospital more easily without feeling overwhelmed.

Even if providers are unable to alter the design of their facilities or to implement the solutions suggested by Paul and Lorena, they could work to remove physical objects that may act as obstacles for visually impaired individuals. Thomas explained that he and his guide dog are often unable to maneuver the rope barriers, or stanchions, that are used to help patients form lines in an orderly fashion:

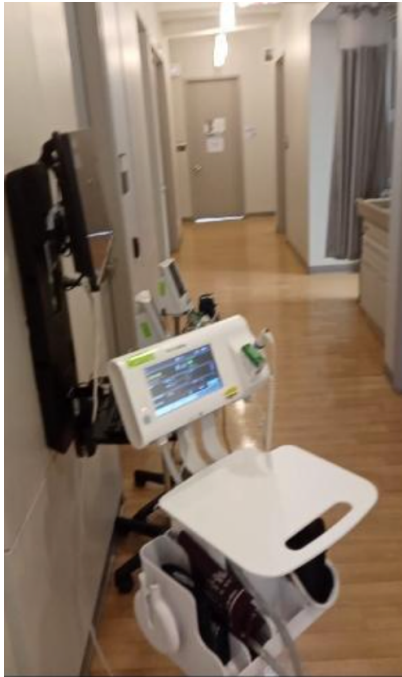
And another thing that was annoying was when I normally go there with my dog, I normally run into those, those, you know where the people that have to line up those, those things. And my dog isn't really even good at, you know, knowing to stop there because he can go under, but I can't.

Figure 3. Photograph of automatic thermometer in an entryway (taken by Cheryl, a 60-year-old woman)





Figure 4. Photograph of a monitor placed in a facility hallway, blocking the pathway (taken by Monica, a 48-year-old woman)



As explained by Thomas and as shown in the photographs captured by Cheryl and Monica, physical obstacles may act as safety hazards to visually impaired patients and make it extremely difficult for these patients to navigate their healthcare providers' facilities unassisted.

Participants also noted that as healthcare facilities have begun incorporating newer technologies, they encounter additional obstacles that were previously non-existent. Michael, a 51-year-old man, explained that while his provider is located in a "big Manhattan office building," he is grateful that his facility still has older-style elevators. Michael explained that older elevators are easier for him to use:

And then I would say the same phenomenon, it's not hard for me to find the buttons in an [old] elevator. So that wasn't too hard to do. And they were old fashioned elevators. So, they didn't have like those fancy interfaces that some of your buildings have now.

Michael's story emphasizes that new technology should be designed with accessibility in mind to ensure that it can be beneficial to all users. Further, healthcare providers may work to ensure that technology is accessible to all patients before incorporating it into their facilities.

Tied more closely to the interior design of facilities than to the structure of facilities, an obstacle that primarily affects some participants with low vision is a lack of color contrast in healthcare facilities. Miguel, who has low vision, explained that the lack of color contrast both within and between the walls and floors of the facility he visits makes it difficult for him to find the examination rooms he needs to go to:

And it's like going left, go right, go left, go right, like, basically a maze more or less, if you're not familiar with it. And for me, personally, if the walls are consistently one color, like a consistent color, I try to use something to be able to see, differentiate, what's the straight wall versus a hallway. Yeah, I mean, for me, it's hard for me to differentiate. So, what I do is to look at the floor, and if it seems the floor has a little corner that's a lot darker or a gray wall versus a brown carpet... And I look at an angle down at the floor. Like, it's not like I'm looking at people, I'm looking for that corner of the floor, following the person saying, "oh, follow me, okay, go left and go right." And I just catch a corner where their foot turns around the angle so I'm like, okay, go that way. And then try to pay attention to if there's any steps of anyone else coming around me. And I try not to bump into people and all those things. So that's, for me, it's like, I want to say a challenge.

Figure 5. Photograph of a corner with little color contrast (taken by Miguel)



Miguel's ability to navigate healthcare facilities is hindered by the lack of color contrast that they often exhibit. Carolyn described in depth some changes that could be made to her healthcare provider facilities to increase their color contrast and accessibility:

Maybe you've seen like, in a place where they have like a handrail that's been painted in a color different from the wall. Sometimes, something like that can be really helpful because you can see where there's a turn, or like, an intersection. So, and I think some places do this on the floor too, like, instead of there just being one color tile or like, laminate, yeah, there's like... There might be a line down the middle.

Carolyn's suggestions take few resources to implement. These suggestions could be implemented before a facility is constructed or even after the facility's construction to increase accessibility to the diverse range of patients who may need to independently navigate the space.

Michael too explained that color contrast, which should be a part of universal design, could make healthcare facilities significantly more accessible to him:

Because I have a lot of, you know, I have a lot of partial vision. So, when things are contrasted, that makes a huge difference. Also, when things are tactile, you know, that makes a huge difference. And, you know, those things can be part of universal design, but, frequently, they're not. But they, you know, they make a huge difference.

In addition to increasing accessibility through color contrast and tactile surfaces, as suggested by Miguel, Carolyn, and Michael, healthcare providers can also ensure that visual cues they add to their facilities have an alternative that can be utilized by visually impaired patients.

While not all visually impaired individuals can read Braille, accurate Braille signage could increase facilities' accessibility, as explained by Paolo, a 43-year-old man:

The signage in the elevator, the Braille signage and the Braille labels were misleading. There was something with a B and a C, and I was trying to figure out what it was. I did one of those things where I went to the wrong floor, but then I figured it out. And then the elevator went back to the right floor when I was leaving. So, it's important to have Braille, you know, decent Braille signage.

Additionally, many participants expressed that regardless of how accessible the facilities themselves are, it is extraordinarily difficult for visually impaired individuals to navigate a space if they aren't given clear and precise directions. Nancy explained that she was not given precise

directions on how to navigate her healthcare provider's facility, which made it difficult for her to locate the office:

When I went to my dentist, I went to go to the second floor. And I found the elevator. What they failed to tell me is that you've got to hit a buzzer to unlock the door to open the door to get to the elevator. Precise directions. The directions must be as precise as it gets. They don't know what it's like to be blind. They don't know what you need. I need them to tell me exactly what I need to do to get in the building. If they couldn't come down and get me, I would have been waiting in that blazing sun for at least an hour before someone... Luckily somebody came along and hit the button for me.

Nancy's story demonstrates that healthcare providers and their staff must learn how to appropriately communicate with visually impaired individuals to best assist these patients in navigating healthcare facilities. The accessibility of facilities, therefore, is in part dependent on the work healthcare providers put in to ensuring that visually impaired individuals understand how they must move through the space. Accessibility, as exemplified by Nancy's story, is hence a combination of environmental and personal factors that affect one another, as supported by the MHDD (Meade et al., 2014).

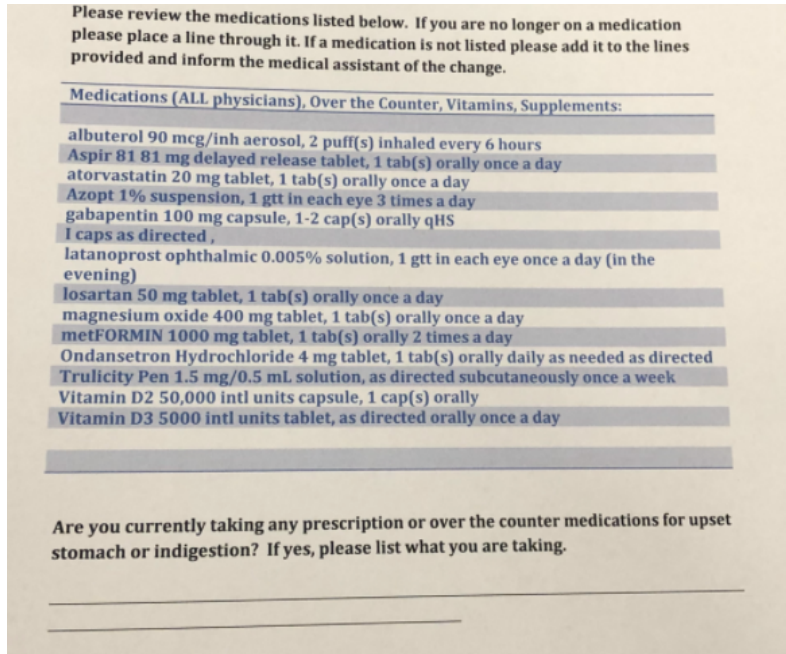
#### *Format of Written Information*

Through the lens of facility design, it is evident that there is a need for more accessible cues, such as Braille signs. Participants in the study expressed that signage is only one of the forms of inaccessible written information that they encounter during healthcare provider visits. Creating accessible alternatives to these forms of written information could help visually impaired individuals to better navigate healthcare facilities and to increase healthcare providers' compliance with the Americans with Disabilities Act (Baird & Rosenbaum, 2008).

Several participants explained that they are often faced with print materials they simply cannot read. Lucille, who has low vision, explained that she needs to wait until her daughter is available to help her before she is able to read the print materials she is given at her healthcare provider's office:

So, my biggest challenge, like I said, is the written material. I got a referral to do some brain therapy, some memory therapy, and some speech therapy. And I can't read it. I have to wait for my daughter to, who is you know, leading her own life and is busy to have the time to read the information to me, because it's not big enough. There's not a chance for me to see that.

Figure 6. Photograph of a medication list with small print (taken by Lucille)



Lucille's difficulty receiving information about her health is consistent with studies demonstrating that disabled individuals generally report dissatisfaction with the information they receive about their conditions (Iezzoni et al., 2002). Further, Lucille's story reinforces the notion that she, and many other visually impaired patients, do not want to be dependent on those around them for tasks such as accessing their personal health information. Lucille explained that for her, and for other low vision patients who can read and write certain print sizes, having the option of receiving written information from healthcare providers in large print would be extremely beneficial:

Um making it large print [would help]. Again, putting it in the record that I'm legally blind. You know, just putting in the records that I'm legally blind and knowing that when you shove a piece of paper at me, there's nothing I can do with it would be helpful.

Lucille explained that she asks her healthcare providers for reasonable accommodations. She asks them to give her written information in large print so that she can read it and also asks them to only have her write in spaces where she can do so in a large font. However, she and others in similar situations are still unable to succeed in convincing their healthcare providers to make these small changes that could exponentially increase the independence of visually impaired patients. Lucille was far from the only participant who expressed her frustration in being unable to receive information in large print. Sam, a 66-year-old woman, explained that the receptionists at her healthcare provider's office said they are simply unable to produce large print forms at their facility:

But I asked the receptionist, I said, "well, do you have these forms in a larger font?" Because I feel that they should be able to accommodate the legally blind. And she said, "no, we don't." She said, "in fact, we don't even print the forms out here, we get them from another company."

Sam explained that even if providers are unable to produce written information in large print, they might be able to provide assistive devices to patients who could benefit from them:

I don't know, I just feel that when you go to these different places, I mean, maybe they can have different things such as maybe I can also bring, you know, a magnifier with me, but maybe they can also have these types of things on hand, perhaps a magnifier and a signature guide. These are not expensive items.

If healthcare providers are truly unable to provide reasonable accommodations that could allow visually impaired patients to independently access written information, these patients may need to rely on staff at their providers' offices for help. Yet participants in the study expressed feeling that their privacy is violated when they are left with no choice but to reveal their personal health information to staff who are non-medical personnel in order to complete their forms. Sometimes, as explained by Steve, staff help visually impaired patients fill out their forms in waiting rooms full of other patients, which means that the privacy of those patients requiring assistance is compromised:

It's like, "Ma'am, I can't read the form you're handing me." Well, they acted like you know, it was a bother for them to fill out the form with me. [And it] was embarrassing because there were people behind me. If

you have to fill forms out in the office, you know, you might just as well stand there and yell to everybody what your problems are.

Steve's story demonstrates three key aspects of the obstacle presented by written information for some visually impaired patients. First, healthcare providers often only provide information and forms in print, which is not accessible to all patients. Second, even if visually impaired patients are willing to fill out forms by working with staff at their healthcare providers' offices, staff members may not provide their assistance. Staff members may also help unwillingly, making patients feel as though they are a burden. Third, the privacy of visually impaired patients may be compromised, since they may not be taken to a private space in their healthcare providers' office where they can verbally provide their answers without other patients hearing their personal health information. Indeed, as reinforced by Alyssa, a 33-year-old woman, this third aspect of the larger obstacle presented by written information is a violation of the Health Insurance Portability and Accountability Act of 1996 (HIPAA):

So, they were helpful for filling out forms and everything. But they were asking questions like, "do you have your period?" So, I mean, I guess somebody's gonna transcribe for me in front of everybody in the waiting room. You know, you may have people who are willing to help you, but you compromise privacy. I mean, think about it medically and legally, think of HIPAA laws, right. You're to be exempt from that law just because you need help filling out a form?

Alyssa's story demonstrates the importance of the shift in disability studies to include principles of Critical Race Feminist Theory (Erevelles & Minear, 2010) and to inspect more closely the experiences of disabled women (Fine & Asch, 2009). Specifically, Alyssa's privacy was infringed in two distinct, but intersectional, ways. First, Alyssa was asked to disclose answers about her personal health information in front of a room of other patients, who are under no legal obligation to maintain the confidentiality of her responses. Second, Alyssa was asked to discuss information about her menstruation, a part of her reproductive system, in front of other patients. It is key to note that not every person who menstruates is a woman and that not all women menstruate. However, the staff at Alyssa's healthcare facility likely assumed that she

menstruates and asked her about her menstruation because she identifies as a woman. The lack of regard demonstrated by the staff at Alyssa's healthcare provider shows a devaluing of both the disabled and female parts of her identity.

The stories narrated both by Steve and Alyssa demonstrate that simply because they require assistance filling out print forms, visually impaired patients may not, in practice, be given the same protection as sighted patients by HIPAA. While some participants described being given assistance in a manner that compromised their privacy, other participants were very pleased with the assistance they've received. Bernice explained that the nurses at her healthcare provider's office bring her to a separate room so she can fill out forms without her privacy being sacrificed:

And then some nurse, I guess it was the nurse who came out, and she was like, "okay, I'm gonna help you fill out these forms." So, we went in the room. And she asked me all these questions and had me sign like, I don't know how many times.

Bernice acknowledged that even though written materials at her healthcare provider's office are not provided to her in a format she can independently access, she greatly appreciates the respect and sensitivity of the nurse who helped her fill out her forms. However, not all participants described needing the same assistance when accessing written materials at their healthcare providers' offices. Like Bernice, who was able to independently sign her forms, Greg, a 48-year-old man, explained that he appreciates when staff at his healthcare provider's office give him the option of helping him sign or of signing on his behalf because he feels that when staff make assumptions about what he is able to do "it's like [they're] taking away my independence."

The experiences shared by Bernice and Greg demonstrate that each visually impaired patient may require and prefer different types of assistance when accessing inherently inaccessible print written information. Nevertheless, many participants agreed that one of the



most frustrating obstacles at a healthcare provider's office can be when staff are unwilling to make such accommodations to help visually impaired patients work through print information.

Linda, a 70-year-old woman, explained that staff at her healthcare provider's office no longer take the time to read written information to her and her blind husband:

You know, they don't read us the papers anymore. If there's something new added to it, they will read it. But in general, they want us to sign really quickly. And one time, my husband asked them to read it for him, since he's also blind, and they wanted to summarize it. I understand it's a busy office. But, you should know what you're signing, of course.

While Linda expressed that she does understand why the staff at her healthcare provider's office chooses to summarize forms instead of reading them aloud in their entirety, she feels that she should know exactly what she is signing. Though Linda wasn't given the assistance she needed to be able to work through inaccessible print materials, she was still fine with receiving written information. Helena, a 75-year-old woman, explained that she prefers receiving information over the phone or through email so that she can refer back to the information. The staff at her healthcare provider's office, however, were unwilling to provide the information in a format other than print:

Could she leave me a phone message? No, she couldn't do that. She could only print out this piece of paper. But this was actually against the Americans with Disabilities Act. The information was not in the accessible format. And this is not like rocket science here. I can't read the print. You can send me an email. You can give me a phone call to leave a message. The only thing you [say you] can do is inaccessible. And that is extremely frustrating.

Regardless of whether reasonable accommodations are made to assist patients, print materials are, by design, inaccessible to many visually impaired individuals. Due primarily to the increased popularity and convenience of electronic materials in all aspects of life, many healthcare providers have transitioned from print to electronic materials. For some visually impaired individuals, such as Helena, the option of receiving written materials electronically may increase independence. Carolyn explained that while electronic written information may not be

accessible to all visually impaired patients, they are far more accessible to her than are print materials:

But don't shove papers at me. The online, like, paperwork and filling out your portal and all that stuff ahead of time can be much more accessible to me than handing me papers that I can't read when I get there. So that's a huge positive. I know that probably doesn't work for other blind people if they've designed it poorly. But as a general matter, for me, it's an improvement.

Carolyn's attention to explaining that electronic materials, especially if poorly designed, may not be accessible to all visually impaired patients is important. For all patients, especially visually impaired ones, having options can greatly help to increase accessibility. Christine, a 70-year-old woman, explained that she would prefer to have all her forms accessible on a computer instead of receiving print forms at her healthcare providers' offices and noted that all forms given to patients by healthcare providers should be compatible with accessibility software, such as JAWS, a screen reader used by many visually impaired individuals. Nancy explained that many times, healthcare providers are unaware of the fact that visually impaired patients may be using screen readers, which leads to incompatibility of their websites with such software:

They need to know what form to send the text in because we have to assume that most of us use screen readers. Yeah. So, they need to have somebody on staff who is aware that a lot of times you get to something, and you click on it, and it can't be read on the screen reader.

It is, therefore, important that healthcare providers are aware of the different ways in which their patients may be interacting with electronic materials. The problem of inaccessible electronic material is only exacerbated when providers opt to use more complicated sites, as described by Cheryl:

Well, when I was trying to make an appointment, I was trying to see what days were good. And it would show me but then like, sometimes other things would pop up. And you don't know what popped up. And so, then I was like, "oh, that wasn't there before, where'd that come from?" And so, it's just constantly swiping and checking and rechecking. And you know, it was kind of disconcerting.

Cheryl was unable to easily navigate her provider's website using the accessibility software built-in to her phone. Her story demonstrates that websites should not only be designed to be compatible with accessibility software, but also should be designed with the goal of being

as simple for users to navigate as possible. As effective as accessibility software can be, especially if websites are designed to be accessible to all users, it is unable to help users troubleshoot all problems. The shortcomings of this software, which healthcare providers cannot fix but should instead be aware of, may serve as an additional obstacle that visually impaired patients face when utilizing electronic healthcare information. Indeed, even if healthcare providers do take all possible steps to ensure that their electronic written materials are accessible, they should always provide the option of human support. Michael explained how beneficial it can be for him to be able to speak with staff at a healthcare provider's office in case he is unable to independently navigate electronic materials:

I'm happy to try it online first and then to be able to call someone. So, then this way, someone just runs through all the forms you need to fill out at the front desk with you over the phone and then they're just done. So, when you arrive, they can present it to you for your signature or something like that. In all honesty I would like that with everything. I use the phone for a lot of things that are available online.

Ultimately, Michael's preferences can be generalized to apply to the community of disabled patients at large. There is no single accommodation that ensures that a service will be accessible to all. Healthcare providers must, therefore, strive to ensure that they can provide a range of accommodations to their patients.

### Personal Factors

#### *Staff Sensitivity*

Participants reported that the sensitivity of staff at their healthcare providers' offices toward their needs played a critical role in the way in which they viewed their overall experience. Staff must ensure that they are sensitive toward visually impaired patients, as there is a negative association between disabled individuals perceiving discrimination in their interactions with healthcare providers and subsequently seeking care (Moscoso-Porrás & Alvarado, 2018). Specifically, participants felt that staff often treated them with a lack of dignity. A key obstacle that participants noted was being spoken to as though their visual impairment was

akin to a cognitive delay. Leandra explained that she wishes her healthcare providers would speak directly to her in the same tone they use with nondisabled patients:

The doctors don't talk to us normally, they talk to us like we're retarded. And we have to remind the doctor or the nurse, that we're not retarded, that they could, they don't have to yell at us or talk loud to us. They should talk to us like they would any other patient.

Leandra explained that she feels as though healthcare providers talk to her, and other visually impaired individuals she knows, as though they are less capable of comprehending information than non-visually impaired individuals. Francisco agreed and explained that he feels this type of behavior stems from a possible lack of empathy:

That's one of the problems that I think with the medical industry, that there is a lack of compassion. You know, you're supposed to have, ideally, people who are caretakers, from the nurses to the doctors, you know, to the medical staff who work in the offices. You would, would hope in an ideal world that they would have compassion, you know.

Francisco attempted to explain the behavior that Leandra and others noticed by presuming that some healthcare providers simply lack the compassion expected from members of the field. Carolyn, on the other hand, explained that she thinks this behavior stems from healthcare providers' uncertainty about how to best interact with visually impaired patients:

I think people just need to be told, just given the script, like so it's in their head. Or, or just be told to say, "I see that you're carrying a white cane. Would you like me to assist in another way?" Or say, "I can come do that for you" or something like that. Just, just acknowledging that we're visually impaired.

Carolyn explained that she appreciates when individuals acknowledge her visual impairment and offer to assist her with anything she needs. Lucille, like Carolyn, said that she appreciates when staff at her healthcare provider's office acknowledge that she is legally blind, assist her, and speak with her as though she is any other patient:

The staff remembers that I'm legally blind. Even like, you know, when you get to reception, they greet you by name, "oh, hi Lucille! What have you done today?" And then when I get into the doctor's office, you know, they ask whether I'm doing good. She always takes out the high points. The nurse knows that I need help getting where we, where you take your weight. So yeah, she will say to me, "now, you know, remember that that's a step up," and she's slow, but she's not grabbing, or she's not rushing me. You know, she allows me to do it the way that she knows that I can do it. They kindly assist you. Where it doesn't necessarily have to be obvious to everybody else. And talk with you like as a person, not just as one big blind eye.

To Lucille, it is important that she be treated “like a person” and not “one big blind eye.” Lucille, like every participant in the study, appreciates when healthcare providers treat her with dignity. Leandra too explained that one of the highest points of her healthcare provider visits is that her provider engages in conversation with her:

And as they're looking at the chart, they asked me, how I've been, how I've been feeling. Do I have any aches or pains and stuff like that? They always do that. They ask me how my family is. They do all of that. They're very kind. They're very kind and they take their time with you. And they do it with all patients. Because sometimes when I'm sitting there, I can hear them talk to other patients.

As highlighted both by Lucille and Leandra, a key manner in which healthcare providers can better treat all patients, including visually impaired patients, with dignity is by engaging in conversation. Doing so fosters a more trusting and intimate provider-patient relationship and can help visually impaired patients feel as though they are not being treated any differently than nondisabled patients.

Indeed, several patients felt as though they received inappropriately intimate treatment simply because of their visual impairment. Linda explained that at one healthcare provider's office, a nurse watched her get changed and the physician subsequently inappropriately guided her and touched her:

The nurse was there with me while I got undressed, and she's taking my clothes and acting like a valet. But you know, they don't do that for everybody. If that were their common practice, okay. But you know, I felt that was weird. Then she left. The doctor came in. And he was talking to me, and he wanted me to get down and come to the scale. And he had no clue how to guide me to the scale. So, so I tried to tell him how, I said, "let me take your arm." And he instead was dragging me by the hand, but I wasn't quite sure where I was going because there was something in my way. And when I did get around it, he slapped my butt, and said, "Oh, my gosh, you have to lose weight." And when I got to the scale, he's going to put my, take my foot and put it on the scale. It's very hard to keep your balance. Of course, I never went back there.

Linda was treated without dignity both by the nurse, who did not respect her privacy while she was naked, and by the doctor, who failed to guide her the way she wanted to be and who touched her without her consent. Indeed, as viewed through the lens of previous work discussing the ways in which disability has a nuanced effect on disabled women's relationships with their bodies, Linda's experience with her agency over her body being violated is even more

significant (Fine & Asch, 2009). Visually impaired patients, like all patients, do not want to be touched by healthcare providers without their consent. However, visually impaired individuals may need to rely on physical contact from healthcare providers to navigate spaces. As a result, providers must be sensitive in communicating with visually impaired patients to determine when they would like physical contact to better navigate spaces. Paolo explained that he appreciates when healthcare providers offer him sighted guide, a way in which a person can help guide a visually impaired person through physical contact:

Once I gave my name, you know, I waited on the side. And then they were actually very helpful because they came and got me and offered me sighted guide. They took me to where they needed to take me to take my blood and to do whatever they needed to do. I mean, I was kind of familiar, but it's always very helpful when somebody offers you an elbow, gives you a guide.

Like Paolo, Hope, a 79-year-old woman, explained that she appreciates when healthcare providers ask her whether and how they can assist her as opposed to grabbing herself, or her mobility aid:

The best thing they did was to ask me if I needed assistance and to ask me how they could help, which I felt was very knowledgeable on their part, rather than just grabbing hold of the walker or, you know, giving me a push or some other kind of odd thing that has been done to me in the past by other people.

Figure 8. Photograph of a nurse guiding a patient by holding her walker (taken by Hope)



Hope explained that she specifically appreciated being asked how she likes to be helped. Jamila, a 48-year-old woman, expressed a similar sentiment, and appreciated that her provider gave her options for how she likes to be guided, as opposed to initiating physical contact without permission:

She asked me, did she want me to hold her arm or would I rather follow behind her. I picked behind her. And she walked at a great pace. So, you know, she didn't walk way ahead of me. She understood.

Participants explained that while they do not like physical contact to be initiated without their consent, they may rely on physical contact to be able to confidently navigate a space. In fact, when physical contact is not possible, it may present challenges for some visually impaired individuals. Paul explained the challenges that arose for him at his healthcare provider's office as a result of the physical distancing guidelines implemented during the COVID-19 pandemic:

The problem was, they weren't touching us, because this was early in the pandemic, they were worried about touching someone who might be positive. So, there was no physical contact allowed. And I understand that, that state of pandemic... But then again, we even, in that sort of situation, we probably should be thinking about what happens when someone does need some physical guidance or someone's unsteady on their feet or whatever the case may be.

As demonstrated by Paul, patients often appreciate when healthcare providers anticipate what assistance they might need due to their visual impairment and, more importantly, when providers communicate with patients directly to ask them if and how they would like to be assisted. Helena explained that during her most recent healthcare provider visit, her sister was visiting her. Helena was appalled by the treatment she received, as it was her first healthcare provider visit during which she was accompanied by someone:

On the main floor that you walk in, there's somebody who checks you and gives you a mask and takes your temperature and does all this stuff. As far as I know, or as far as I felt, they seemed to be only talking to my sister. He actually asked her if it was okay to take my temperature. Usually, they talk to me when I go alone. Who else are they gonna talk to? So that was kind of weird. I would prefer if they talked to me. I mean, frankly, I don't exactly get it. I mean, I know I can't make eye contact. But I'll tell you what, even if my sister comes to visit me again, when I happen to have a doctor's appointment, she's not coming with me.

As Helena explained, she was so offended that the receptionist chose to ignore her and ask her sister to make decisions on her behalf that she will never bring someone to a healthcare

appointment with her in the future. Similarly, Bernice explained feeling as though staff at her healthcare provider's office assume that she is incapable and is often offended when they choose to continue speaking with the person accompanying her, even after she ensures that they're aware of her preferences:

I don't like it if someone else is with me, they try to ask them the questions and not me. And then, you know, like, I've had to tell people, like, if they're going to be with me, like, "don't answer the questions." You know, I'm not stupid, I can answer the questions. You know, sometimes they'll be like, "oh, sorry." And sometimes they'll just, you know, keep on going.

Helena and Bernice both feel as though healthcare providers choose not to speak directly to them because they assume that visually impaired individuals are unable to communicate for themselves. Marie explained that she's even been in situations where healthcare providers assume that her daughter will be making decisions on her behalf:

You're telling my daughter what I need to do. I know what I need to do, okay? But I also know that I'm going to do whatever I have to do, whether it's, you know, however I do it, it's my choice on how I do things. Yeah, you don't live, you don't live in my house, you know, and however I choose to take care of this is going to be because I want to do this in the first place.

Marie explained that some healthcare providers treat her as though she doesn't have autonomy over her health because she is visually impaired. Marie's story is consistent with studies demonstrating that disabled individuals are more likely than nondisabled individuals to report poor communication with their healthcare providers and dissatisfaction about the information they receive about their conditions (Iezzoni et al., 2002, 2003).

Other participants also expressed feeling as though their healthcare providers' behavior indicates that they do not have sufficient exposure to visually impaired patients. A concept that participants believed was difficult for many providers to understand is that a person could be legally blind without being totally blind. Richard, a 63-year-old man, explained how difficult it is for him to get healthcare providers to understand that there are legally blind people who have some sight:



And there are a lot of people that, you know, they only know two things: blind and not being blind. They have a problem with people who are legally blind, but who can see, and they don't understand what their limitations could be.

Lucille, who is also low vision, described how difficult it is for her to explain how she would like to be assisted, given that she is legally blind but not totally blind:

One of my biggest challenges when I get to the doctor's office is reiterating to them that I have, that I'm legally blind, but that I do have some sight. So, I don't need to be led around. And sometimes I think that confuses people. Because either they want you to be led completely around and see nothing, or they don't believe that you're blind.

Richard and Lucille both described having trouble communicating what they need from healthcare providers given that they are not totally blind but still visually impaired. The lack of awareness discussed by Richard and Lucille is consistent with a study demonstrating that visually impaired women encounter difficulties with healthcare professionals' lack of awareness of blindness (Sharts-Hopko et al., 2010). Explaining what assistance is needed can be even more challenging for visually impaired individuals with guide dogs. Pilar explained that it was very difficult for her to communicate to her healthcare provider that she was disorientated and needed the layout of the office to be explained to her. This process was made more difficult because the provider was not only scared of her service dog, but also was unaware of how to help a visually impaired patient:

So, the young lady is like, trying to tell me, "there's a seat." Okay, so, like, "where is there?" But anyway, I was able to sit there. Then, they're petrified of my service dog. So that's another thing. Then you go into this very cramped area. And it's kind of I don't know, I just didn't get the layout of the place in my mind. It's not like anybody's kind of, you know, described it to me. So, they call me in, and, and then she places me in the seat. The dog finds a place. I don't really, like I said, I'm dealing with people that really have no concept of working with someone who doesn't see. You know, they're just, they're very unversed with it.

Pilar was unable to get the assistance she needed because her healthcare provider was afraid of the service dog she relies on to navigate her surroundings. Eileen described having a similar experience with her healthcare provider:

And then, when my physician's nurse came to get me, she was terrified of my guide dog. And that was just, I mean, I've encountered that in many contexts, but it wasn't a great way for us to start the visit. And she didn't understand how to guide me, and I tried to explain, you know, "it would be helpful for me if I could take your elbow, or you can walk in front of me," because I was also trying to be mindful of her fear, but I

needed some assistance. So, we had like, an awkward period where she was trying to grab my arm and pull me. And then in the exam room, once I had my dog settled, and we were, you know, ready to begin the exam, the nurse was still like, completely, distracted is not exactly the word, but she was just thrown off and uneasy about the whole, you know, the dog being there.

Both Pilar and Eileen were discriminated against because of their service dogs, whom they depend on and are legally entitled to have with them when they enter any public space.

Eileen explained that she wishes that providers knew to talk to her, and other visually impaired patients, directly to ask them about their preferences:

You know, every person who's blind, every person with a disability, even people without disabilities, you know, we have our own preferences. Like, providing general awareness and sensitivity training, so that staff are familiar when they are interacting with someone who has a disability, some main things about like treating them as with dignity and respect and understanding some of the common ways that you might guide or provide information to somebody who's blind. I think that those practices can go a long way for interactions being more productive and, you know, maintaining the autonomy of, of the patient and individual.

Like Eileen, Paolo explained that he believes healthcare providers should attempt to better communicate with visually impaired patients. Paolo explained that he thinks healthcare providers should be trained on diversity and disability:

Maybe there should be a class on diversity and disability or something like that. And helping people understand that there could be totally normal, intelligent people who just happen to have a bad pair of eyes. Yeah, everything else works, the eyes don't. So don't assume that I'm any less cognitively able or that I need to have a caretaker or, you know, a nanny with me taking care of me.

As suggested by both Eileen and Paolo, trainings for healthcare providers could increase awareness of and exposure to the needs of visually impaired patients. Ultimately, this could serve to improve healthcare providers' sensitivity when working with visually impaired patients.

### *Staff Assistance*

Most participants agree that many of their memorable interactions, both positive and negative, at healthcare providers' offices occur either when staff provide them with assistance or when they ask staff to assist them. Participants noted that many such experiences occurred when they were attempting to navigate their providers' office. Leandra explained that at her provider's

office, she got lost, but couldn't find any staff members to assist her. As a result, another patient had to assist her:

I went to Manhattan Ear, Nose, and Throat. That's a well-known, prestigious hospital. Now, I always had pretty bad experiences with them. It was difficult to find someone to assist you. When you go in, sometimes, I would have to ask a patient, or somebody I heard walking by if they could help me, cause there was nobody who worked there around.

Leandra's story demonstrates that while visually impaired individuals are often able to voice when they need assistance navigating a space, it is imperative that there are staff present to help when required. Linda, similarly, needed assistance when she was hospitalized, but could not find any staff members willing to assist her:

I was in the hospital for 12 days, and I kept wanting them to help me bathe or shower or something. And they wanted me to go somewhere different. Well, the problem was they told me where it was, but I had had a knee replacement, so it was just too hard to get there. And so, I went for like, 12 days until I took a shower because I couldn't get there.

Linda was denied her cleanliness, and as a result, her dignity, because there were no staff members available during her 12-day hospital stay who were willing to help her find the shower. Nevertheless, several participants did note that the staff members they encountered were very skilled at assisting them as they worked to navigate their providers' offices. Cheryl explained that the physician's assistant at her provider's office did an outstanding job helping her orient herself to the examination room:

The assistant, she does come out, call my name. And she came and got me. So, things like getting on the table, she was saying, you know the tables are on your left, you can stand on the scale, it's right here, you know about three inches away. You know, she was very good at describing what I had to do.

Cheryl's story demonstrates what a profound impact healthcare providers can have if they take the time to provide appropriate navigational assistance to visually impaired patients. Indeed, non-healthcare staff can be valuable in helping patients navigate healthcare facilities. Leandra explained that at the hospital she visits, security guards help her find her provider's office:

Usually, at like St. Luke's, the guards would take me upstairs. Or he'll put me on the elevator, push the button, show me the walk when I get off, make a right. And somebody will assist me. Okay, so I get off, right. If I go in the wrong room, somebody will take me to where I need to go. But at least they'll do something. It's large, and it's hard to navigate for everyone.

Security guards play a unique role in assisting patients as they navigate spaces. They are personable and often, due to the nature of their jobs, are committed to ensuring that visitors are able to successfully arrive at their intended destination. Shane, too, explained that he is able to easily navigate his healthcare provider's office, primarily because of the assistance provided to him by the security guards at the facility:

And I consider my visit as starting from the sidewalk when I get out of an Access-a-Ride vehicle because that's where the guard, you know, introduces themselves and says hi, and they take me into the building, and they check my temperature and whatever else they do—their temperature check and maybe a stick on my finger. And they take me into the elevator, and they press the floor for me.

Shane's positive description of the assistance he has been given by security guards at the healthcare facility he visits suggests that a wide range of staff members can play a pivotal role in improving the experiences that visually impaired patients may have.

The unique support provided to patients by security guards can best be described as “access intimacy” or “that elusive, hard to describe feeling when someone else ‘gets’ your access needs” (Mingus, 2011). Mia Mingus, the writer and disability justice advocate who coined the term, wrote, “some of the people I have experienced the deepest access intimacy with (especially nondisabled people) have had no education or exposure to a political understanding of disability” (Mingus, 2011). As such, it is likely that in certain healthcare settings, security guards—individuals who are likely to be removed from concepts such as the medical model of disability—are best equipped to enable “access intimacy” for visually impaired patients (Llewellyn & Hogan, 2000). This behavior should, subsequently, be encouraged.

As demonstrated, assistance from staff working at healthcare providers' offices can be beneficial to visually impaired patients. This assistance only has its intended effect, however,

when staff listen to the needs of patients. Lucille explained that when she expresses her needs, she's rarely trying to be rude, but she simply wishes healthcare providers would trust her and listen to her:

Hear me, hear what I'm saying to you. If you ask me "do you want me to grab your shoulder or your arm?" And I say "no," realize that I'm not trying to be offensive. I don't want what I don't need. And yeah, hear me, I will tell you what I need. And I think that would make it easier for both of us. I think the biggest thing is that if you hear a person, a person can actually tell you what it is they do and don't need. You just need to hear. So, some things are kind of common sense. Yeah, like if the, the first 10 steps, if you see that I'm still getting up there, you shouldn't be like, turning any corners or anything, I'm still getting up.

Lucille described thinking about what could allow her to best collaborate with staff at her healthcare provider's office. Though Lucille hopes that healthcare providers will trust her enough to listen to her when she expresses her needs, Nancy explained that she takes a different approach and tries to educate staff at her healthcare providers' offices:

So, when I go to the doctor's office, I go by myself. And actually, myself as an educator, I haven't been blind all my life. And a lot of times the mistakes that they've made, it's because they don't know what to do, or what to say. So, a lot of times they say the wrong thing. So, when I go to an appointment, if I'm going to a new doctor, when I call, I tell them I am blind. I have to let people know. If I don't tell them and then they don't do it correctly, then I'm not offended by it.

Nancy explained that she believes that when healthcare providers fail to appropriately provide her with assistance, it is because they simply do not know how to do so. While Nancy likes to pre-emptively educate, Marie explained that she wishes healthcare providers would take initiative and ask her questions about her needs and preferences. She expressed wishing that her providers would have asked her questions about her needs when she was hospitalized, and staff brought her meals:

Yeah, I think, I think if we need assistance eating, we'll ask. The only assistance I need is for you to tell me what that food is that you put on a tray. So, I can reach what I like and reject it when I don't want it, you know? Right? So, I think that's what they need to implement.

Some participants were very pleased with the questions that their healthcare providers asked them about their preferences. Leandra explained that her providers constantly ask her questions and check in to make sure that she is okay:

They always say to me, "Is this okay? How do you want to do it? Take my elbow, or what? How do you want me to assist you?" I said, "I'll take your elbow." So, they never touch me. They always talk to me first. That's important because sometimes somebody will grab you and you jump, but you know. So, they let me know, "okay, okay. I'm putting out my elbow to assist you." They tap on the seat so I can hear. Then whoever comes for me, they say my name and tell me they're going to put me in an exam room. "Is that okay? Is that okay? Is that okay?" "Yes," I say. And they say, "may I assist you" and I say, "thank you." So, I take their elbow and they take me in an exam room.

Though Leandra explained that her healthcare providers are very attentive to her needs and provide only the assistance that she requires, Linda was disappointed that the staff at her healthcare provider's office tried to limit her independence:

When I sat down, the first thing I wanted to do was get some water because they require a urine sample for this visit, right? To test your drugs and stuff. So, I went to get some water and I know where the water is. And I know where the cups are. And I don't ever remember spilling anything major, maybe a few drops, from time to time, but I suspect nothing more than anyone else. But in any event. If they see me over there, they say, "oh, I'll get it. I'll get it." I can be standing right there at the water cooler. And they'll say "oh, I'll get it. I'll get it. Go sit down." So, then I go and sit down.

As Linda explained, she is unable to freely move around her healthcare provider's office because the staff provide her with an excess amount of assistance that she simply does not need. Linda's story demonstrates that healthcare providers must strike a balance between providing visually impaired patients with necessary help while still acknowledging that these patients, too, do not want their independence to be limited.

Some participants, however, explained that they were denied help by staff at their healthcare providers' offices, who instead asked them why they did not bring anyone with them to assist them. Sandy, a 62-year-old man, explained that when he asked for assistance filling out his paperwork, his provider asked him why he did not bring someone with him to help him with such tasks:

If you go to the doctor with me, and somebody is speaking to me and handing me paperwork and explaining things, okay. And I say to you, well, "ma'am, I have a vision problem, so I need some assistance getting paperwork filled out." And you say to me, "is someone with you?" And I say to you, "well, can you help me fill out the paperwork." Well, there's a reason I'm asking you for your assistance.

Sandy was offended by this question. He explained that he does not need anyone to come with him to his appointments, as he independently completes most tasks. He was given

inaccessible forms and as a result, needed the individual who gave him the forms to assist him. Bernice, too, was insulted when she was asked why she did not bring someone with her to her appointment to help her:

And they asked me, “oh, you know, next time you come, you should bring somebody with you so they can take you around and fill out papers and stuff.” I said, “I don't need anyone with me, that's why I have the dog.” You know, they really would rather I didn't come with a dog, I could tell. And they were really not helpful.

The failure of some healthcare providers to give visually impaired patients the assistance they need to navigate situations that are inherently inaccessible to them demonstrates that providers must be more mindful of how they can best meet the needs of their patients.

### **Policy Implications**

As demonstrated above through participants' narratives, existing federal, local, and provider level policies are inadequate for two reasons. First, these policies are not comprehensive in identifying specific areas that healthcare providers must devote resources toward making more accessible. Second, there are no mechanisms to ensure the proper implementation of these policies and to hold healthcare providers accountable to complying with these policies. Existing federal, local, and provider level policies will be discussed in more detail below. Additionally, recommendations that could be implemented to strengthen federal, local, and provider level policies will be offered.

#### Federal Level

Federal level policies mainly impact the environmental factors of design of facilities and format of written information. There are few policies that have been implemented to provide a framework for the provision of equitable healthcare to disabled individuals. The Americans with Disabilities Act, which should eliminate systemic discrimination against disabled individuals, has had little impact on the delivery of healthcare to this population (Baird & Rosenbaum, 2008; National Council on Disability, 2015). The Americans with Disabilities Act has also had little

influence on making healthcare more accessible because healthcare providers continue to have only sparse knowledge about the steps they must take to ensure disabled patients have access to appropriate and competent care (National Council on Disability, 2015).

As demonstrated previously, several participants clearly identified violations of the Americans with Disabilities Act that adversely affected their encounters with healthcare providers. For instance, Jerry explained that his healthcare provider's office does not have Braille signage, making it nearly impossible for him to independently navigate the space. Similarly, Helena explained that the receptionist at her healthcare provider's office refused to provide her with information about her appointment over the telephone or via email, insisting that she could only provide the information in inaccessible print. These experiences demonstrate that while the Americans with Disabilities Act does exist, healthcare providers do not always demonstrate their compliance with this piece of legislation.

A second federal level policy that should help disabled individuals receive better care is Section 504 of the 1973 Rehabilitation Act. Section 504 of the 1973 Rehabilitation Act also prohibits discrimination against disabled individuals (National Council on Disability, 2015). This piece of legislation, in contrast with the Americans with Disabilities Act, specifically monitors entities that receive financial assistance from the Department of Health & Human Services (National Council on Disability, 2015).

These policies are not nearly as effective as they could be because there are few mechanisms by which healthcare providers are held accountable to being compliant with these pieces of legislation in the status quo. For instance, federal agencies such as the Department of Health & Human Services, the Center for Medicare & Medicaid Services, and the Department for Health Resources & Services Administration do not require healthcare providers to submit



information that would reveal the level of their compliance with the Americans with Disabilities Act or with Section 504 of the 1973 Rehabilitation Act (National Council on Disability, 2015). Because healthcare providers do not need to demonstrate that they provide disabled patients with appropriate care in order to receive funds, the responsibility falls on state governments to place nondiscrimination clauses in their “contracts with HMOs, health plans, and health provider organizations” (National Council on Disability, 2015). These entities consequently “pass on the same obligations to [the] health providers” with whom they work (National Council on Disability, 2015). This scheme is intended to ensure cooperation across the three main actors involved in delivering equitable healthcare: government entities, insurance companies, and healthcare providers.

The first recommendation involves healthcare providers submitting information demonstrating their compliance with the Americans with Disabilities Act and Section 504 of the 1973 Rehabilitation Act to federal agencies such as the Department of Health & Human Services, the Center for Medicare & Medicaid Services, and the Department for Health Resources & Services Administration (National Council on Disability, 2015). The inaccessibility of many healthcare offices likely stems from a lack of accountability for healthcare providers. To address this lack of accountability, federal health-related agencies could perform annual inspections of healthcare offices, similar to restaurant and food service inspections that are conducted on an approximately annual basis. These federal agencies could be held accountable to checking for compliance with policies including the Americans with Disabilities Act and of Section 504 of the 1973 Rehabilitation Act. The agencies could inspect facility design (i.e., color contrast; implementation of new technologies, such as elevators) and written information (i.e.,

options for non-print forms; accessibility of electronic portals) to begin with, as these are two major obstacles that were identified by many participants in this study.

The second recommendation builds on the first, but ties healthcare providers' performance during annual inspections to financial incentives. Specifically, a federal level policy could be created requiring healthcare providers to demonstrate that they provide high-quality care to disabled patients in order to receive government funding through channels such as Medicare and Medicaid reimbursements. Similar policies exist in several states (National Council on Disability, 2015), though these policies often do not have their intended effects since there aren't any specific mechanisms by which healthcare providers are asked to demonstrate that they provide appropriate care to disabled individuals. However, the first recommendation would provide the process by which healthcare providers could demonstrate that they provide accessible care, which would allow for the second recommendation to be effective when put in practice at a federal level.

#### Local Level

Local level policies mainly impact the environmental factor of transportation and the personal factors of staff sensitivity and staff assistance. New York City's MTA has demonstrated a commitment to making its transportation system more accessible. It has created the Advisory Committee for Transit Accessibility, or ACTA (MTA Accessibility, n.d.). Several participants in the study, including Shanta and Eileen, mentioned that they have collaborated with ACTA. This committee is comprised of volunteer community members who "represent many forms of disability" and who work with New York City Transit on a wide range of accessibility issues (MTA Accessibility, n.d.). ACTA collects feedback from community members and riders regarding the accessibility of subways, buses, and Access-a-Ride, MTA's paratransit system (MTA Accessibility, n.d.). Further, ACTA develops and promotes accessibility initiatives and

projects to work to make New York City’s public transit more user-friendly for all riders (MTA Accessibility, n.d.). One of these initiatives is the pilot program that Shane described being selected to participate in, which allows him to hail cabs around New York City for \$2.50 per ride. This demonstrates that the programs developed by ACTA are indeed beneficial for disabled riders.

While those participants residing in New York City explained that they are generally satisfied with their transportation options, those residing elsewhere in New York State explained that they often face difficulties finding accessible, affordable, and convenient transportation. The third policy recommendation, therefore, is for accessible public transportation to be expanded throughout New York State. While this is a costly expenditure, it would help greatly disabled and nondisabled residents of these areas live more independently. Until such a large-scale project can be undertaken, local leaders of suburban and rural communities might work to implement programs such as the one Shane benefited from. Such a program would allow visually impaired individuals to take subsidized cabs (or ride-shares, in areas not served by taxi companies) to and from their healthcare providers, increasing the independence of these commuters.

Local level policies also affect personal factors. The New York State Human Rights Law and the New York City Human Rights Law both prohibit discrimination against disabled individuals in spaces including hospitals and health centers (New York State Attorney General, n.d.). Indeed, there are several elements of these pieces of legislation that should address many of the obstacles noted by participants. For instance, the policies state that “allergies and fear of dogs are not valid reasons for denying access or refusing service to people using service animals” (New York State Attorney General, n.d.). Nevertheless, several participants cited negative experiences in which they were provided with inadequate care because staff in

healthcare provider offices were afraid of their guide dogs. The poor implementation of and compliance with state level anti-discrimination policies may be the source of the obstacles that visually impaired participants in this study encountered.

Subsequently, the fourth recommendation is to mandate that all healthcare workers (including non-medical staff, such as receptionists) take annual diversity, equity, and inclusion training. Several participants suggested that the implementation of training for healthcare workers might help these individuals provide disabled patients with more sensitive and informed care. Eileen, who advocated for “providing general awareness and sensitivity training,” felt that this training might help to remind healthcare providers about the importance of providing disabled patients with respect and might also provide providers with insight into the types of questions they can ask disabled patients to best understand if and how they would like to be assisted.

Such patient-centered education, which would include conversations and information about disabled individuals, could help healthcare providers developed informed empathy (Kirschner et al., 2007). This type of education can allow providers to become more effective advocates by better understanding the “physical, social, and communication” needs of disabled individuals (Kirschner et al., 2007). While the implementation of such mandatory training cannot guarantee improvements in sensitivity amongst healthcare workers, it may lead to gradual improvements in the field that could cumulatively result in an improved healthcare experience for disabled individuals.

#### Provider Level

Though the federal level and local level recommendations would allow for the implementation of the most systematic, widespread reform, they would simultaneously require both time and resources to become implementable legislation. Subsequently, there are many

changes that participants recommended that providers should implement. Regarding facility design, Carolyn suggested the incorporation of color contrast, Michael advocated for more tactile surfaces, and Paolo recommended the use of Braille signage. To improve the format of written information, Sam suggested large print alternatives, Nancy recommended that websites be designed to be compatible with screen readers, and Cheryl urged that websites be designed as simply as possible. To better staff assistance, Leandra and Shane noted that non-medical staff, such as security guards, can be major assets for the population of visually impaired patients. As such, these personnel should be trained to maximize the quality of the assistance they provide. Nearly all of the recommendations provided by participants would take few resources to implement and could greatly increase the independence of visually impaired patients.

The main provider level recommendation is the implementation of patient navigator programs. The use of patient navigators has been proven effective in specific health contexts, such as cancer care (Elkin et al., 2012; Meredith, 2013) and primary care (Ferrante et al., 2010) settings. Participants in this study who came into contact with patient navigators expressed how helpful they were in removing obstacles that visually impaired patients may otherwise encounter. Julia, a 68-year-old woman, explained that her hospital has dedicated patient navigators:

Okay, well, I go to Mount Sinai of Queens, that's my hospital. They also have an outpatient clinic and when I got there, the guy told me that you know, he introduced himself to me as a patient navigator. And I asked him, "what do you do?" And he said, "well, I can help you get to where you're going, I can fill out your forms, I can make sure you get back to your Access-a-Ride, etc." I already had the forms filled out. But he was very helpful to show me where the doctor's office was. Then he made sure I got downstairs. And he watched out for the Access-a-Ride for me.

Ultimately, Julia's story demonstrates how helpful it could be if all healthcare providers were to have staff dedicated to providing assistance to those in need of it, including visually impaired patients. Patient navigators would not only be able to help visually impaired/disabled

patients, but also nondisabled patients who may encounter barriers in the healthcare system due to their socioeconomic status, health literacy, etc.

## **Discussion and Conclusions**

This study demonstrates that the healthcare encounters of visually impaired adults are most directly shaped by the environmental factors of transportation, design of facilities, and the format of written information, as well as the personal factors of staff's sensitivity toward and familiarity with appropriately assisting disabled individuals. Previous studies have demonstrated that disabled individuals encounter obstacles while accessing healthcare in the United States. However, these studies either do not capture the voices of a diverse range of participants or focus on documenting the opinions of healthcare providers and not of their patients. In this study, I identify the strengths/solutions and weaknesses/obstacles that visually impaired adults encounter when accessing healthcare. Using CBPAR methods, specifically, a modified version of Photovoice, I interviewed 47 visually impaired adults residing in New York State to document strengths or solutions and weaknesses or obstacles they encountered when visiting a healthcare provider. I found that visually impaired patients are most impacted both by environmental factors and by personal factors, which, according to the MHDD, leads to a reduction in functioning, activity, and participation among disabled individuals (Meade et al., 2014).

As predicted by the MHDD, these impediments to the functioning, activity, and participation of disabled individuals in their navigation of healthcare is evident (Meade et al., 2014). Specifically, and as consistent with previous studies, participants noted that they wished healthcare providers were more aware of their needs, had better access to information and healthcare at large, experienced less isolation while navigating healthcare, and had to rely on self-advocacy (Sharts-Hopko et al., 2010). Also consistent with previous literature, participants

wished that healthcare providers were more aware of signs that a patient is visually impaired, took steps to better deliver information to participants, helped patients navigate new environments, and bettered their communication skills (Cupples et al., 2012). While the findings of this study do not contradict those of previous studies, this study expands upon the documented factors that shape the healthcare experience of visually impaired patients based on the narratives of these patients.

Following these findings, I offer recommendations for government actors and healthcare providers and argue that both must work to improve compliance with existing accessibility legislation. At the federal level, I recommend annual inspections of healthcare practices by federal agencies to ensure providers' compliance with policies guaranteeing equal access to disabled Americans. Additionally, I recommend that federal funding and reimbursements to healthcare providers be contingent upon providers' compliance with accessibility legislation. This could serve to ensure that disabled individuals can access healthcare in practice, specifically by addressing the environmental factors of facility design and accessibility of written information. At a local level, I recommend the expansion of public transit throughout New York State and the implementation of programs through which disabled riders could access subsidized cabs. This would increase the independence of disabled individuals as they travel to and from their healthcare provider visits, thereby addressing the environmental factor of transportation. Additionally, I recommend that New York State mandate annual diversity, equity, and inclusion training for healthcare workers to help educate these individuals and address the personal factors of staff sensitivity and staff assistance. At a provider level, I recommend the implementation of patient navigator programs. The findings and recommendations presented here may help guide governmental and healthcare actors as they work to develop more comprehensive policies and

legislation in the future to ensure improved access to healthcare for visually impaired individuals.

Though this research provides novel findings, it does have limitations. First, while a diverse population of visually impaired adults was recruited, there were limitations to this diversity, specifically in terms of age and location of residence. Of enrolled participants, the mean age was 57.3 years. The mean number of years for which enrolled participants had been legally blind was 45.9 years. As a result, these data are not representative of the perspectives of legally blind children or young adults. Further, since participants residing outside of New York State were not eligible for the study, these data do not represent the perspectives of legally blind adults residing elsewhere in the United States or in other countries. Future research could target younger populations of legally blind individuals to determine the specific access issues they face and could also recruit from a larger geographic area.

Second, while I collaborated heavily with participants during the development of the study and during the collection of data, additional measures could have been taken to adhere to CBPAR principles. Specifically, future research could encourage participants to be more involved in creating policy recommendations and in advocating for the implementation of these recommendations. This could better enable participants to direct every phase of the research, resulting in more accurate conclusions.

This research ultimately elucidates the environmental and personal factors that impact visually impaired adults' access to healthcare. This study is unique in amplifying the voices of a large, diverse sample of visually impaired adults and synthesizing their specific healthcare access needs. Future research is necessary to not only collect the narratives of visually impaired individuals residing outside of New York State, but also to inspect the accessibility of healthcare



to other disabled populations as well. Much work is needed to ensure that more effective policies are developed and implemented to enable healthcare to be as accessible to all disabled individuals as it is to nondisabled individuals in the United States.

Table 2. Participant Demographics

Pseudonym	Age (Years)	Gender	Overall Vision-Specific Quality of Life* (Fenwick et al., 2017)
Shanta	56	Female	1.64285714
Paolo	43	Male	2.15384615
Samantha	51	Female	2.38461538
Nia	47	Female	1.85714286
Maggie	67	Female	2.77777778
Miguel	29	Male	0.78571429
Alyssa	33	Female	0.35714286
Hope	78	Female	2.15384615
Cheryl	60	Female	1.81818182
Carolyn	33	Female	2
Julia	68	Female	1.5
Eileen	29	Female	1.69230769
Steve	63	Male	1.78571429
Francisco	33	Male	2.46153846
Helena	75	Female	2.41666667
Linda	70	Female	1.07142857
Jacob	74	Male	1.92857143
Timothy	55	Male	1.07142857
Lucille	64	Female	0.92857143
Michael	51	Male	1.78571429
Noelle	63	Female	1.28571429
Nancy	77	Female	0.71428571
Harry	73	Male	1.36363636
Paul	51	Male	1.07142857
Leandra	81	Female	2.07692308
Shane	57	Male	1.07692308
Jerry	56	Male	0.75
Pilar	59	Female	0.64285714
Drew	34	Male	2.55555556
Christine	70	Female	2.25
Larry	52	Male	2.5
Maya	65	Female	0.71428571
Wilson	66	Male	2.90909091
Greg	48	Male	1.69230769
Lorena	64	Female	2
Sandy	62	Male	1.42857143
Thomas	60	Male	2.88888889
Luz	36	Female	1
Bernice	67	Female	1.35714286
Frank	69	Male	1.57142857
Richard	63	Male	2.85714286
Sam	66	Female	1.38461538
Marie	64	Female	1.33333333
Monica	48	Female	0.5
Betty	66	Female	2.36363636
Jamila	48	Female	1.57142857
Mo	49	Male	1.85714286

\* Overall Vision-Specific Quality of Life is measured by the B\_IVI score (Fenwick et al., 2017), where a higher score corresponds to a higher vision-specific quality of life. As a loose guide for readers, a score above 2 indicates a high vision related quality of life and a score below 1 indicates a low vision related quality of life.

## Appendix 1. Interview Guide

Thank you for joining us today. Before we begin, I have a few reminders.

- 1) Today, we will be discussing the content of your photographs, what obstacles your photographs speak to, how the content of your photographs relates to your life, why the obstacle your photograph identifies exists, how you can become empowered after identifying these obstacles, and what solutions can be implemented. If you feel uncomfortable sharing any of your thoughts at any point during the interview, please let me know upon the conclusion of the group so we can discuss your thoughts privately.
- 2) An audio recording of the interview will be captured and stored securely so that the researchers can listen to the discussion again to ensure that they haven't missed anything.
- 3) [For focus group only] "Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others."<sup>1</sup>

### Biographical Questions

1. **Please introduce yourself.**  
Probes: What is your name? Where are you from? What is your employment status/where do you work?
2. **Please tell me about your visual impairment.**  
Probes: How is your visual impairment defined clinically? For how long have you been visually impaired?

### Healthcare Experience Questions

1. **Please tell me about a time when you interacted with a healthcare provider whom you could depend on/you couldn't depend on.**  
Probes: What happened in the situation? What about the healthcare provider's behavior made you feel this way?
2. **Please tell me about a time when you were provided with assistance or when you faced an obstacle in accessing healthcare.**  
Probes: What happened in the situation? How did the situation make you feel? What could have made the situation better or worse for you?
3. **Please tell me about the healthcare provider visit you would like to focus on for this study.**  
Probes: What type of healthcare provider did you visit? Where was the provider located? What were some of the best and worst moments of the visit?

### Photovoice SHOWED Discussion Guide (modified)<sup>2</sup>

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<sup>1</sup> <https://www.umass.edu/research/guidance/focus-group-research>

<sup>2</sup> Hergenrather, Kenneth C., et al. "Photovoice as community-based participatory research: A qualitative review." *American journal of health behavior* 33.6 (2009): 686-698.

[For participants who have chosen not to take photographs] Please think of an obstacle you encountered during your visit. Please answer the following questions for each obstacle you would like to share.

[For participants who have chosen to take photographs] Please recall the first photograph you captured of an obstacle you encountered during your visit. Please answer the following questions for each obstacle you captured a photograph of and would like to discuss.

**1. Who/what do you have (See) portrayed here?**

Probes: Why did you choose to capture this person/moment? What is unique about this person/moment? What do you want others to notice about this photo?

**2. What is really Happening here?**

Probes: How did this moment positively or negatively affect you? Have you had a similar experience in the past? If so, please describe that experience and how it made you feel.

**3. How does this experience relate to Our lives?**

Probes: How do you think this experience could benefit or harm another individual?

**4. Why does this concern/situation/strength exist?**

Probes: What structures exist in healthcare, or in society, that gave rise to this concern/situation/strength? What beliefs do individuals hold that gave rise to this concern/situation/strength?

**5. How can we become Empowered through our new understanding?**

Probes: What have you gained by undergoing the experience you captured in your photos? How do you feel after having have participated in this interview?

**6. What can we Do?**

Probes: What steps could we take to improve the situation you captured in your photos? What could healthcare providers do to better your experience? What could society do to better your experience?

Concluding Question

**1. Is there anything else that you think is important or useful for me to know?**

Probes: This project is about the obstacles that visually impaired individuals face when accessing healthcare. Ultimately, we want to learn about how these obstacles affect you and about what policies could be implemented to lessen these barriers.

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