THE JOURNEY FORWARD

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The Journey Forward: Impact of COVID-19 on Blind, Low Vision, and Deafblind U.S. Adults

AUTHORS:
Carlie R. Rhoads, Ph.D. | Kelly Bleach, M.S. | Sarah Chatfield, M.Ed. Patricia M. Camarillo, M.A.

AFB American Foundation for the Blind

Expanding possibilities for people with vision loss

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INTRODUCTION

In July and August of 2021, the *Journey Forward* survey was conducted to capture the experiences of adults with low vision or blindness during the COVID-19 pandemic. The findings supplement the results of the 2020 *Flatten Inaccessibility* [1] survey that was administered early in the pandemic, in April 2020. Different questions were asked in the two surveys, with *Journey Forward* focusing on issues that had evolved or had been introduced since the earlier survey, such as access to COVID-19 testing and vaccines, healthcare, food and supplies, as well as access to voting in the 2020 elections.

The *Journey Forward* survey was completed by 488 adults in the United States who are blind, have low vision, or are deafblind. Data was gathered through an accessible online survey to aid in understanding the short-term and long-term impact of the pandemic on those with vision loss. Of the 488 participants, 39% reported becoming visually impaired before age 2, 34% between the ages of 2 and 19, 27% in either their 20s, 30s, or 40s, and 4% in their 50s or later. Participants also shared if they identified as someone who is blind (38%), has low vision (52%), or is deafblind (8%); 2% preferred not to answer. Thirty-two percent of participants also identified as having an additional disability. Additional demographic data, including gender and race/ethnicity, are provided in the Appendix.

This report highlights key findings of the *Journey Forward* survey. Specifically, it describes some of the critical challenges encountered by people who are blind, have low vision, or are deafblind, as safe and efficient transportation options became limited in the extreme during the COVID-19 pandemic and as barriers—including digital accessibility problems and poorly executed policies, such as drive-up only protocols—reduced access to necessities, such as healthcare, medical supplies, and food.

While a few data tables are included in the report narrative, a more comprehensive list of data tables is provided in the Appendix, available at www.afb.org/JF.

The *Journey Forward* represents a reflection on experiences during a year and a half of the COVID-19 pandemic, through the Summer of 2021. Although the data gathered from the survey participants revealed challenges specific to COVID-19, it also provided insights into the systemic issues that people with vision loss encounter on a regular basis. The report concludes with recommendations that can be valuable in shaping the experiences of those with vision loss today and in the journey forward.

TRANSPORTATION AND MOVING THROUGH PUBLIC SPACES

When driving is no longer possible, getting to where one wants and needs to go requires navigating a complex patchwork of public and private transportation systems. As described in AFB's white paper on *Improving Transportation Systems for People with Vision Loss* [2]*,* for people with a visual impairment, there are unique challenges such as safely moving through unfamiliar environments. Even in the best of times, lack of transportation can be a major barrier to receiving medical services, maintaining social networks, and obtaining and retaining employment. The COVID-19 pandemic resulted in significant reductions in transportation availability and safety, and the consequences could be dire with regard to access to healthcare or food.

LIMITED OPTIONS FOR NON-DRIVERS

Access to reliable, affordable, and efficient transportation remained a challenge to people who are visually impaired, confirming the concerns expressed in the *Flatten Inaccessibility* study. In particular, traveling to and from testing and vaccination sites, drive-up and waiting policies, safety concerns, and obtaining and retaining employment were key issues that respondents described.

In *Flatten Inaccessibility,* 81% of the respondents agreed or strongly agreed with the statement, "I am concerned that because I do not drive, I will not be able to get myself or a family member to a hospital or healthcare facility if they have severe COVID-19 symptoms," and 79% agreed or strongly disagreed with the statement, "I am concerned that because I do not drive, I will have difficulty getting groceries or other key essentials."

The pandemic caused nationwide logistical problems with transportation, resulting in significant challenges for people with visual impairments. Public transportation routes, often the most cost-effective and reliable means of travel for non-drivers, were reduced or halted, and changes in schedules were difficult to find online. Private rideshare services became less available and more expensive. This resulted in immediate consequences, as described by a participant in the *Journey Forward* study.

> "Restricted bus services and reduced number of Uber/Lyft drivers made transportation to and from work a greater challenge."—*Study participant*

Social systems, such as families and neighbors, were often relied on for driver support, though this often resulted in the anxiety of being exposed or exposing someone to the virus. During the pandemic, 279 participants (59%) traveled to get a COVID-19 test and 343 participants traveled to receive a COVID-19 vaccine. About 40% reported getting a ride from someone they lived with and about 30% went in a car with someone they asked to give them a ride. Others rode a bike, walked, or took public transportation, rideshare, taxi, or non-emergency medical transportation.

When asked about seeking healthcare services without a vehicle (for example, by walking or taking the bus), almost half of the 185 respondents reported that they were asked to wait outside the facility until the medical provider was ready to see them. In some cases, exceptions were made, but too many participants were left outside in unsafe conditions, in which they felt uncomfortable and fearful.

"It was very difficult. Having albinism [and] having to wait in the sun in the desert in 109° is a problem! Frustrated and very concerned."—*Study participant*

"There was no designated safe place or assistance on where to go if you did not have a vehicle, so we just sat on the pavement a few feet down from the door. One place told us we could not sit there and would have to wait in a car. I told them we were walkers and then we got told we cannot sit in front of the building. My daughter took me to a parking spot where we sat on the ground."—*Study participant*

Survey participants described a variety of concerns about the availability and safety of transportation during the pandemic, outlined in Table 1.

TABLE 1:

During the COVID-19 pandemic, have you experienced any of the following related to your use of transportation? Select all that apply. (n=432)

I was concerned for my safety and chose not to travel.	203
There were longer wait times to get a rideshare vehicle or taxi.	131
Bus or train service in my community was restricted.	126
I could not monitor if other riders were following COVID-19 safety precautions.	114
Prices for taxis and/or rideshare services, such as Uber or Lyft, increased in my community.	111
Bus or train service in my community was canceled.	89
Riders were required to board the bus from the back.	89
Availability of paratransit rides was restricted in my community.	77
People outside of my home who previously offered me rides stopped offering rides due to COVID-19 safety concerns.	68
I no longer accepted rides from others outside my home because I had concerns for my safety.	67
Volunteer or paid drivers/services I had used prior to the COVID-19 pandemic were no longer available.	52
I was not allowed to speak to the driver when riding public transportation.	35
Paratransit (door-to-door service for disabled or older people) was no longer available in my community.	33
Other.	44
I prefer not to answer.	10

"I use several forms of transportation, train, bus, rideshare, door-to-door services. The train and bus had many cancelations and ride restrictions. Several route times were canceled, and other ride times were restricted to 50% capacity. The Greyhound bus had canceled my ticket twice due to overbooking past 50%. Ride shares became scarce and limited to the time of day I was traveling. The wait time changed from 5–10 minutes to 25–40 minutes for one ride. The door-to-door services restricted locations to where they would pick me up and take me home."—*Study participant*

"Being a blind person was especially hard on me during the pandemic because of the heightened risk of exposure to COVID-19. When and if I traveled, I relied on my family for transportation because they are the only people I trust when it comes to safety during the pandemic. Whenever I needed to use rideshare services, I always went with my mother because of the need for assistance following social distancing measures and monitoring if others are wearing masks. When I would ride the bus, my mother had to assist with receiving and giving the cash to the driver so that I don't touch anything. I made sure not to touch doorknobs, railings on the bus, and if I did, [I] immediately disinfect my hands. Waiting for the buses took a long time, and the prices of ridesharing services increased depending on the peak hours."—*Study participant*

SAFETY CONCERNS

People generally felt unsafe while traveling through public spaces due to worry over whether they were maintaining social distancing and because they could not see if the people around them were following safety protocols. When asked if they had concerns about maintaining social distancing, 71% of 451 respondents reported that they did. In particular, this concern presented itself in indoor public spaces such as grocery stores or doctor's offices (n=232), when with a family member, friend, or someone they hire to give them a ride who does not live in their home (n=140), and when in outdoor public spaces such as a park (n=121). Actions they took to mitigate safety issues are described in Table 2.

TABLE 2:

Select all of the following you did to address your concerns about maintaining social distance and/or monitoring if others were wearing masks. (n=318)

I washed my hands more frequently.	173
I relied on a sighted person at the location to provide information.	172
I used additional PPE such as gloves or a stronger mask.	137
I used a visual interpreting service such as Aira or Be My Eyes.	70
I did not do anything.	36
Other.	31
I prefer not to answer.	2

"Before the pandemic I was able to take buses and trains and walk everywhere independently. I was able to go to grocery stores on my own and do many errands. During the pandemic, I did not feel safe doing any of these things on my own, so my partner drove me to every appointment and purchased all the groceries, etc. I did not feel safe because of the high number of cases and not being able to see who is distancing or who is wearing masks or trusting others to take things seriously. Public transit also had restricted routes and rideshare was much more expensive. If I did go somewhere on my own, I would not be able to distance safely or not get the same customer service assistance. Because I need more things to be hands-on, more people were more nervous about working with me, and I was nervous about working with them. Staff shortages also meant it would be harder to get the support I needed."—*Study participant*

Non-drivers clearly had difficulty accessing transportation during the COVID-19 pandemic. In addition, they felt unsafe moving through public spaces. This resulted in difficulties in accessing basic needs, such as healthcare, medical supplies, food, and voting.

ACCESS TO BASIC NEEDS

During the COVID-19 pandemic, as in-person access diminished, reliance on web-based information and interfaces grew. Where these services were inaccessible, there were critical barriers to meeting one's basic needs. Risks and consequences to both physical and mental health were reported by study participants. Even where services were sought in person, exclusionary policies and procedures resulted in compromised care and higher anxiety.

RECEIVING CRITICAL INFORMATION

News about the COVID-19 pandemic was generally available; however, there were some frustrating gaps, as a participant describes.

> "I could read statewide tabular data throughout the pandemic, but my state also released a color-coded map and a flowchart indicating precautions to take in each zone. Press releases mentioned how many towns were in the red zone, but since neither the map nor the chart was accessible, I didn't always know when my town was in that zone or how that should affect my behavior."—*Study participant*

Similarly, survey respondents had mixed experiences accessing COVID-19 vaccine information. Of 395 respondents to the query about access to vaccine information, 64% agreed or strongly agreed that they had easy access, 22% disagreed or strongly disagreed, and 14% neither agreed nor disagreed. Participants frequently had someone else schedule their COVID-19 vaccine appointment (47%) while others were able to do so themselves (34%); 19% had no experience scheduling a vaccine or preferred not to answer. Of the 159 participants that reported on the accessibility of scheduling a vaccine themselves, 66% agreed or strongly agreed that the process was accessible, 15% disagreed or strongly disagreed, and 19% neither agreed nor disagreed or preferred not to answer. Often, it was a family member who scheduled the vaccine appointment, as shown in Table 3.

"Many of the county and state websites were completely inaccessible to screen reader users. The online system to sign up for vaccines was so overloaded that it was [even] impossible for nondisabled people to use them to book appointments. The website would time out before any useful information was given and there was not enough time to even schedule an appointment when one was open."—*Study participant*

TABLE 3:

Who scheduled the COVID-19 vaccine appointment for you? (n=217)

A family member	47%
A friend	17%
A healthcare provider	18%
An individual at an agency or organization for the blind	7%
An individual at an agency or organization for older people/senior citizens	1%
Other	10%

"I think it is assumed that someone else is available (friend, family, whoever) to help/look out for us. Some of us have people to do that. Many people do not. I would rather not have to ask someone to help me but sometimes it is just easier/quicker. It doesn't solve the bigger problem."—*Study participant*

CHALLENGES TO MANAGING HEALTHCARE

Survey respondents expressed considerable concern about barriers to obtaining health care and supplies and frustration with protocols that did not take into account patients or customers with a visual impairment. In addition to the aforementioned requirement to wait outside a facility until called, participants found it difficult to complete paperwork, navigate physical spaces on their own, and access telehealth.

"Healthcare is so far from being fully accessible. From inaccessible forms and websites to the lack of accessible buildings and medical equipment, [the lack of accessibility] causes problems with medical care for people with disabilities. You would think the medical field would understand…"—*Study participant*

Of the 202 participants that responded to a question about getting needed healthcare supplies or prescriptions, 43% reported having challenges. Barriers included difficulty getting in touch with the doctor's office or pharmacy, transportation challenges, and inaccessible websites and prescription labels. Fortunately, as a few respondents noted, over time, delivery and mail options expanded and delivery fees were waived by some pharmacies.

In reply to the question "When you, your child, or someone whose healthcare you assist with were receiving medical care, were you allowed to have someone with you who would normally assist you with accessibility issues in a medical setting?" 25% of the 356 respondents indicated that this was not allowed.

"I had to rely more on the medical staff. They didn't understand all of the issues involved in being visually impaired. Some gave me a hard time filling out forms. They were upset that they had to fill them out for me."—*Study participant*

Telehealth became more commonplace during the pandemic. Use of telehealth was attempted by 70% of survey respondents during this period and 57% of those 330 respondents reported having accessibility challenges with telehealth platforms. Table 4 depicts accessibility challenges reported by participants.

"My doctor had to end up using FaceTime to communicate with me because I was not able to communicate with her via the telehealth platform."—*Study participant*

TABLE 4:

Select any of the accessibility challenges you experienced with Telehealth platform(s). (n=188)

I had difficulty navigating the platform to make an appointment.	77
I was not able to independently log in.	60
I was not able to position the camera in a way my healthcare provider needed me to.	59
I was not able to read information provided through the system, e.g., chat.	52
Buttons were not properly labeled to be read by my screen reader.	52
I was not able to privately communicate with healthcare professionals.	49
I was not able to electronically sign documents.	43
The platform was not available on my preferred electronic device.	24
Other.	28
I prefer not to answer.	1

This was identified by some as a problem when relying on telehealth for mental health services. Fifty-seven percent of respondents reported experiencing changes in their mental well-being during the COVID-19 pandemic, and 12% of those 255 respondents reported that they did not have access to the resources necessary to support their challenges with mental well-being.

"I had more anxiety [with] COVID-19, testing, vaccination, and lockdowns. The counseling I received helped me ease my anxiety."—*Study participant*

"[There needed to be] more telehealth appointments, especially for mental health. I live in an area without public transportation of any kind, so travel to appointments can be exceedingly difficult."—*Study participant*

CONCERNS ABOUT OBTAINING FOOD

The *Flatten Inaccessibility* study found that 59% of respondents had concerns about having access to food, meals, and supplies as a result of the COVID-19 pandemic. Many of the respondents used a variety of means, including a friend or family member, local delivery service, or online app, to access these necessities. As COVID-19 progressed, all of these lines of access became compromised, and the results of the *Journey Forward* survey showed that concern was warranted. Almost half (45%) of all survey participants reported that they experienced challenges with having food, groceries, or supplies delivered during the pandemic. Accessibility problems with online ordering apps were reported by more than 40% of survey participants. In addition, a number of other challenges, outlined in Table 5, were experienced.

TABLE 5:

Please check any of the additional challenges that you experienced while having food, groceries, or supplies delivered. (n=204)

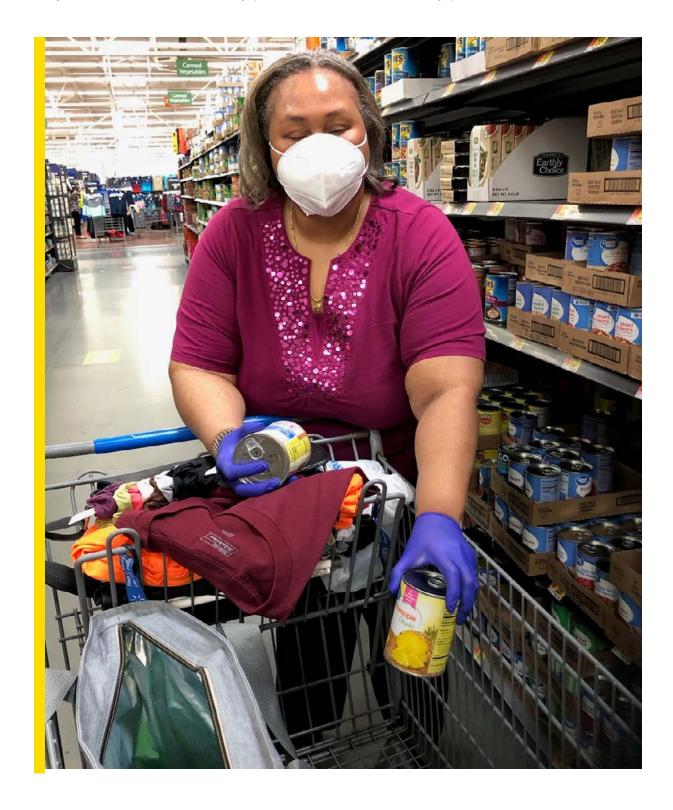|	
All the delivery times were filled.	89
The added cost of delivery meant I had to do without something else to afford the cost of delivery.	70
I was able to place my order but was not notified when my food/groceries arrived.	64
The food/grocery service did not deliver in my area.	42
The company would not accept my SNAP benefits.	41
I could not afford delivery.	14
Other.	10
I prefer not to answer.	4

BARRIERS TO INDEPENDENT VOTING

Eighty-one percent of respondents participated in the November 2020 presidential election and 67% of those voted by mail-in ballot. In the open-narrative question associated with voting experience, 20% of survey participants reported needing to request sighted assistance to complete their ballots, compromising their ability to vote independently and privately.

"Our state government announced an accessible PDF that could be filled out, printed, and returned in an accessible envelope to our local town hall. However, my town hall was not informed of the procedure and refused to accept the PDF I filled out. I found out early enough that I was able to have a friend help me fill out the normal mail-in ballot, but I was disappointed that our secretary of state had not communicated with my town hall to help me vote independently."—Study participant

As the *Journey Forward* study shows, issues identified in *Flatten Inaccessibility* at the start of the COVID-19 pandemic continued unresolved over an extended period, including ongoing problems with transportation, maintaining safety, and access to medical care and supplies, food, and independent voting. As the survey responses illustrate, participants found it frustrating and sometimes unsafe when they encountered accessibility problems and exclusionary processes.

FINAL THOUGHTS

It is evident that the participants in the study experienced vast challenges during the COVID-19 pandemic. At the same time, participants demonstrated a great capacity for resilience. Despite facing isolation, unsafe or uncertain transportation, and compromised access to medical care and meals, study participants also wrote about strategies for carrying on. They shared some unexpected positives, such as enjoying seminars, concerts, and other entertainment via an expanding array of streaming services. Study participants leveraged problem solving and social connections to meet the unique challenges of the pandemic for those who are blind, have low vision, or are deafblind.

"Before COVID, it was pretty isolating being what I am. After COVID, it was extremely isolating! Luckily, I have a core group of friends and we support each other. None of us became ill, and we all managed to get through this together although we don't live close to each other. Although we all have our loved ones and families, being blind and or visually impaired, we had that special edge to what was going on that only we could understand."—*Study participant*

RECOMMENDATIONS

The recommendations in this report are limited to the areas investigated in this study and researchers' understanding of survey responses. Most of the recommendations reflect well-established and widely accepted practices that, nonetheless, have not been fully and broadly implemented, as demonstrated in this report.

TRANSPORTATION ACCESS

• State and local transportation agencies should evaluate routes that were restricted during the pandemic and establish a plan for returning to full and equitable operating capacity that accommodates the needs of non-drivers.

• State and local transportation agencies should evaluate adding on-demand transit options that are fully accessible to people with disabilities to provide additional capacity for serving the needs of non-drivers, especially in areas without easy transit access and during non-peak hours and weekends.

• The federal government should keep the COVID-19 mask mandate for transportation in place until the risk to people with disabilities and other people at high-risk of COVID-19 is significantly lessened. State and local governments should continue to encourage mask wearing and enforce mandates on transportation.

COVID-19 PREVENTION

• State and local governments should continue to encourage mask wearing in high density locations. Healthcare facilities should require masking as long as the pandemic lasts, so that at-risk individuals feel comfortable seeking medical care.

• The federal government should continue to make high-quality N-95 masks available to individuals, including blind and low vision people who may need to continue wearing masks in high-touch situations or when they cannot see whether other people are taking precautions against COVID-19.

• The federal government should fund research and development into fully accessible at-home rapid COVID-19 testing and require testing providers to make their tests accessible to people with disabilities.

- Websites and applications providing information about COVID-19 should be fully accessible to people who are blind or have low vision. Charts, maps, and graphs should be accessible and/or include additional text that provides full access to users who cannot visually access the information. Videos should include audio descriptions and captioning. The Web Content Accessibility Guidelines (WCAG) provides recommendations for internationally recognized standards for developing accessible websites.

- States and local governments should continue to provide easy access to COVID-19 testing, including options for in-home testing as long as COVID-19 presents a public health risk.

- Vaccination and testing facilities must be accessible to non-drivers accessing facilities by foot, bus, rideshare, bike, or other modes. Information about using non-car transportation modes, especially when the individual is symptomatic, should be made widely available.

- Vaccination and testing appointment websites must be fully accessible, so that individuals can access information about the vaccine and independently book a vaccine appointment. Information about available transportation options should be provided before or during booking. The Web Content Accessibility Guidelines (WCAG) provides recommendations for internationally recognized standards for developing accessible websites.

- Public health agencies should incorporate lessons learned from the COVID-19 pandemic to prepare for future pandemics and other emergencies by incorporating the needs of blind and low vision people into planning from the outset.

HEALTHCARE ACCESS

- Healthcare facilities must accommodate and plan for non-drivers. Allowing individuals who cannot drive or arrive by car to wait indoors while wearing a mask or following other COVID-19 prevention measures or providing a bench protected from the weather is likely a reasonable accommodation that removes barriers and supports the needs of people with disabilities who cannot drive. Federal civil rights laws covering healthcare remain in effect, even during emergencies such as the COVID-19 pandemic.

- Healthcare facilities should be physically accessible, and users need access to fully accessible patient forms, post-visit instructions, and other forms of communication. Medical staff from the front desk receptionist to the surgeon should be trained to interact effectively with people with disabilities. AFB has developed *Best Practices Guide for Hospitals Interacting with People Who Are Blind or Visually Impaired* [3].

- In some cases, people with disabilities need a support person while in the doctor's office or hospital to provide communication and access support. The Office of Civil Rights at the Department of Health and Human Services has clarified provider responsibilities for ensuring people with disabilities have access to a support person either in person or remotely.

- Healthcare websites, telehealth, and electronic health records must be fully accessible. Patients who are blind or have low vision should be able to independently navigate the platform, log in, use chat and email features, read clinical information, complete forms, and activate buttons. The Web Content Accessibility Guidelines (WCAG) provides recommendations for internationally recognized standards for developing accessible websites, serving as a starting point for accessible digital health websites and applications.

ACCESS TO FOOD AND SUPPLIES

- Grocers should work with state agencies to accept SNAP (Supplemental Nutrition Assistance Program) benefits for online ordering and delivery.

- Grocers and pharmacies should make online ordering accessible to people who are blind or have low vision. The Web Content Accessibility Guidelines (WCAG) provides recommendations for internationally recognized standards for developing accessible websites.

- Grocers may consider implementing a delivery-scheduling preference for people with disabilities, older adults, and other non-drivers for whom delivery is not merely a convenience but a means of access to food and other necessary supplies.

VOTING ACCESS

- States should ensure that voters with disabilities have access to accessible ballots and ballot-marking devices that are fully functional and operational at every polling station. Additionally, states should implement and coordinate with local election boards to provide fully accessible electronic absentee voting for people with disabilities.

- State election agencies must coordinate with local election officials to fully implement accessible voting policies and practices.

When study participants were asked for recommendations, there were many, but summing it up, one replied:

"I really don't know [what advice to give authorities], as this would mean they have to be thinking about the needs and concerns of minority groups before something like this happens. When vaccines opened up to senior citizens, it was so obvious that no one thought ahead to the unique challenges they might have trying to sign up due to lack of tech experience, transportation, and other factors. The same is true of [people with disabilities]. Our needs are often not thought about."—*Study participant*

APPENDIX: DATA TABLES

An extensive set of survey data tables is available at www.afb.org/JF

REFERENCES

[1] Rosenblum, L. P., Chanes-Mora, P., McBride, C. R., Flewellen, J., Nagarajan, N., Nave Stawaz, R., & Swenor, B. (2020). *Flatten Inaccessibility: Impact of COVID-19 on Adults Who Are Blind or Have Low Vision in the United States.* American Foundation for the Blind. www.afb.org/Flatten

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[3] American Foundation for the Blind. (2022). *Best Practices Guide for Hospitals Interacting with People Who Are Blind or Visually Impaired.* www.afb.org/Healthcare

For more information on this report, please visit: afb.org/JF