

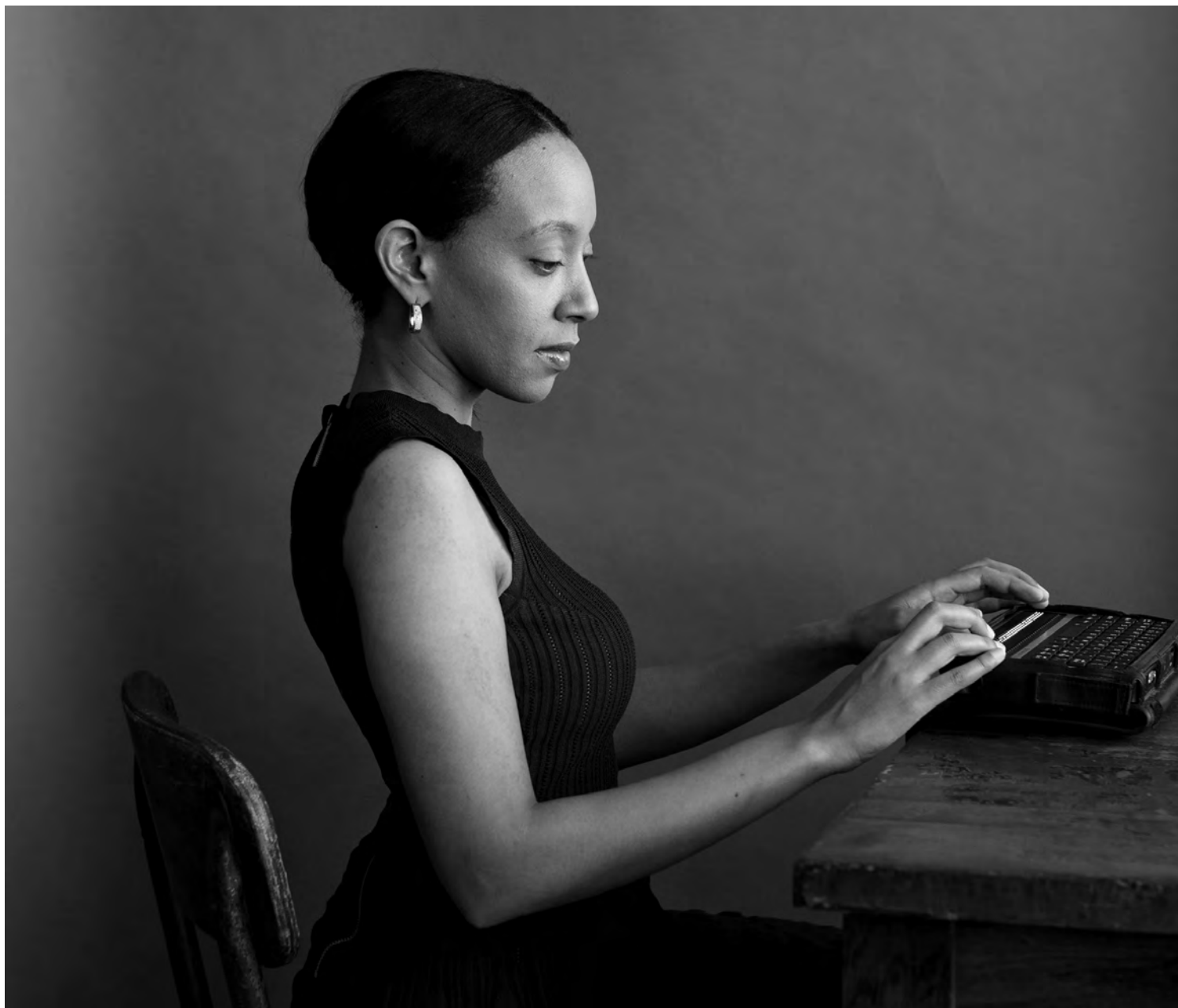
OUR COLUMNISTS

WHO IS “WORTHY”? DEAF-BLIND PEOPLE FEAR THAT DOCTORS WON’T SAVE THEM FROM THE CORONAVIRUS



By Robin Wright

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The lawyer and disability-rights activist Haben Girma, who is deaf-blind, said that she is terrified that “hospitals facing scarce resources will decide not to save our lives.” Photograph by Celeste Sloman /

Redux

Rebecca Alexander volunteered shortly after Governor Andrew Cuomo appealed for mental-health professionals to help counsel first responders traumatized by the COVID-19 crisis. A New York psychotherapist, she has taken calls from a young nurse who had trouble sleeping because she was haunted by the sounds of dying patients gasping for breath. A doctor described getting instructed not to intubate anyone over eighty on the day his mother turned eighty-two. A pediatric nurse who specialized in infant diseases recounted her lack of training after being abruptly transferred to caring for adults in acute respiratory failure. Several confessed their own extreme distress at pushing the

limits of their bodies physically and emotionally. “Constantly being on the front lines is taking a toll on them,” she told me.

What none of the people pouring out their problems to Alexander knew is that she is legally deaf and blind—and has her own deep fears about how the new coronavirus threatens the estimated 2.4 million Americans, and millions more across the globe, who, like her, rely on touch to communicate, navigate, and care for themselves. “When you don’t have vision or hearing or both, you rely heavily on other senses,” she said. “For us, that other sense is touch.” But touch is now the most prevalent means of spreading COVID-19.

The New Yorker’s coronavirus news coverage and analysis are free for all readers.

People who are deaf communicate with sign language, which involves no physical contact with anyone else, but members of the deaf-blind community—the formal term for people with dual sensory impairment of hearing and sight—use tactile sign language, or words pressed by touch into another’s hands. It’s a form of communication made famous by Helen Keller and her tutor, Annie Sullivan. During the pandemic, the new forms of protection—including social distancing, masks, and gloves—only complicate communication. Many deaf-blind people can’t read Braille with gloves on because their hands are desensitized. And many who have residual sight can’t lip-read through masks. “My worry is that the pandemic planning has completely missed this community,” Roberta Cordano, the president of Gallaudet University, in Washington, D.C., told me. Gallaudet is the only university for deaf people in the United States. At least fifteen of its students are deaf-blind. “Unlike hurricanes or other natural disasters, COVID-19 has required physical distance between people. But deaf-blind people rely on fixed physical proximity to communicate with the world around them,” Cordano said. “To be frank, there is no mechanism on a national scale to support the deaf-blind in the current American health-care system.”

The deaf-blind community has been forgotten in the pandemic. When I started reporting this piece, I had no sense of the scope of the issues or the depth of their fears. More than three dozen deaf-blind people from as far away as Australia poured their hearts out in poignant e-mails and calls, some conducted through complex layers of sign interpreters and Braille. People who are deaf-blind don’t

want pity, they told me. Many are exhausted, even in normal times, by simplistic depictions of their heroic survival in a hearing and sighted world.

Alexander, the deaf-blind psychotherapist counselling New York hospital workers, is an extreme athlete who has climbed Mt. Kilimanjaro, gone skydiving, and swum from Alcatraz to shore. She has written a best-selling book—“Not Fade Away: A Memoir of Senses Lost and Found”—that is being made into a movie produced by John Krasinski. She navigates the world with a white cane and a mini goldendoodle named Monkey. She could take calls from New York’s first responders because she has cochlear implants that provide minimal hearing; without them, she hears nothing. “None of the people who speak to me know that, in everyday life, I’d be the last one to turn to for help,” she told me. But deaf-blind people do want a sense that they have a shot at survival.

Several worry that hospitals do not have the policies, bandwidth, or services to help them. They fear becoming victims of Darwinian triage in an overwhelmed health-care system. Haben Girma, an Eritrean-American lawyer, told me that she is terrified that “hospitals facing scarce resources will decide not to save our lives. There is an ableist assumption that causes some people to think it’s better to be dead than disabled.”

In 2013, Girma was the first deaf-blind person to graduate from Harvard Law School. In 2014, she gave a TED Talk that has been viewed more than a quarter of a million times. In 2016, she made Forbes’s 30 Under 30 list. She has been honored by two U.S. Presidents, as well as by a Canadian Prime Minister and a German Chancellor. She has written a best-selling book and travelled the world to give lectures. Now thirty-one, she was scheduled to go on book tour in Australia and New Zealand this month before the COVID-19 outbreak rampaged across the Earth. During the pandemic, she said, hospitals may not allow interpreters who can use tactile sign language to accompany deaf-blind patients—both for the interpreters’ safety and because of limited protective gear. “If I was suffering from coronavirus I would not have the strength to advocate for myself,” she said. “The doctor might look at my health record and say my life is not worth saving. So many doctors undervalue our lives.”

Lisa Ferris, who is deaf-blind, runs an assisted-technology training company for the disabled with her husband, who is blind, in Portland, Oregon. She described the status of the deaf-blind community in the pandemic as “a tragedy waiting to happen. I could communicate by having someone type on a keyboard and I could read it on a Braille display. But will they allow me to keep my Braille display?

Will they be willing to touch my keyboard? Will they have the patience to work something out with me?” she wrote. “The notion that we, as disabled people, could be cast aside in a triage situation is very demoralizing. I do not think my life is worth more than others, but I certainly don’t think it is worth any less.”



Art Roebrig, a former president of the American Association of the Deaf-Blind, works on an art piece.

Photograph by Dawn Watts

There is no central database on how many deaf-blind people have been ill with or tested for COVID-19. But the issue of human worth has been a hurtful undercurrent throughout the pandemic, particularly for the elderly, the homeless, and people with disabilities and preëxisting conditions. For deaf-blind people, an existential issue is just knowing what is going on around them. “We are worried that we would be placed in isolation without access to communication and that we won’t be able to communicate,” Rossana Reis, who is forty-seven and lives in Washington, D.C., told me. A former

counsellor and advocate, Reis uses pro-tactile sign language and a cane. “I worry that, if we ever become sick, our lives will be deemed less worthy of saving than the ones who are more ‘abled’.” Art Roehrig, a former president of the American Association of the Deaf-Blind, posted a video with instructions in sign language on YouTube about how a deaf-blind person should prepare for going to a hospital. “I am now holding a Ziploc bag with some items in it,” he signed. The bag has a paper that says, “I am deaf-blind. Please use your fingertip in printing capital letters on my palm.” The Ziploc bag also had a list of medications and three index cards. One asks for a bathroom, the second for water, and the third provides the name and phone number of his emergency contact, who has the patient’s information, a personal doctor, insurance, and how to get health records.

Deaf-blind people are diverse in their sensory loss and communication skills. “You’ll never find two who are alike,” Pattie McGowan, the president of the National Family Association for Deaf-Blind and the mother of a deaf-blind student, told me. Some are like Helen Keller, who lost all hearing and sight after an illness in infancy. Keller’s autobiography, “The Story of My Life,” published in 1903, was dedicated to Alexander Graham Bell, the American inventor. Bell connected Keller with Annie Sullivan, who taught her a form of communication by touch developed by Louis Braille. In 1918, Braille was adopted as the official language of blind people largely because of Keller’s advocacy.

Some people who are deaf-blind have genetic or degenerative disorders, such as the three types of Usher syndrome that destroy sight and hearing, either from birth or over time. Alexander, the psychotherapist, has Usher syndrome. She currently has little sight and will eventually lose all of it. Girma, the lawyer, has only one per cent of her sight; her older brother Mussie is also deaf-blind. Others are legally deaf-blind because of severe but not total limitations; they may have a bit of hearing with the help of cochlear implants, but still need a guide dog or a cane to navigate and use sign language (by hand gestures) or tactile sign language (by touch) to communicate. Some are well educated and are highly proficient in communication; others have had few educational opportunities and are not. Some are oral; others are not.

Since the pandemic broke out, many people who are deaf-blind have lost access to their two main types of human help: service providers and translators, Sue Ruzenski, the executive director of the Helen Keller National Center, told me. Support service providers are either volunteers or low-paid part-time workers who help members of the deaf-blind community do basic tasks, such as helping

them shop, run errands, or read mail, for a few hours a week. Interpreters, who are highly skilled, certified and well paid, communicate for deaf-blind people using layers of technology. They convert spoken words into Braille or tactile sign language; they also translate the deaf-blind person’s response into speech. (I interviewed Girma through an interpreter named Gordon; she is oral, so she responded without his intervention.) After the pandemic outbreak, Governor Larry Hogan, of Maryland, issued Executive Order No. 20-03-31-02, in March, declaring that service providers and sign-language interpreters should be considered essential workers. But most states do not deem either essential.

“Most, if not all, deafblind persons still need a Deafblind interpreter to help them to get all necessary instructions and information when they do not have family support or where alternative communication methods have failed,” the World Federation of the Deafblind urged this month. “Therefore, it is vital that our unique disability is treated with respect.”

Last month, Gallaudet University cut off access to in-person service providers and interpreters and shut down its Washington campus after the pandemic broke out, even though five deaf-blind students asked to remain in its dorms. Two Gallaudet students—Ashley Jackson and Ali Goldberg, who are both deaf-blind—wrote me a joint e-mail about their frustration, isolation, and vulnerability. Provisions for deaf students to continue learning remotely do not work for them. “We were caught in the same trap of other organizations,” Cordano, the Gallaudet president, countered. “We did not have enough masks or gloves to insure the safety of the providers or the students.”

The pandemic produced other challenges for Terry Dunnigan. As she increasingly lost her sight, Dunnigan moved from her tiny home town in North Carolina to Des Moines because its public-transportation system enabled her, with her guide dog, Bubba, to travel independently. She lost her last bit of vision a year ago. After Bubba died, in October, she enrolled at the Helen Keller National Center to learn how to transcribe Braille on a Braille writer and how to navigate with a cane. The pandemic forced the center, which provides training in independent living, technology, and communication, to shut down, in early March, before she had gained proficiency with either.

“The closest bus is two streets away. I can get to the corner, but I have no sound, so I don’t know where the traffic is coming from,” she told me. “At the Helen Keller center, they give you cards that say ‘I’m deaf-blind. Will you please help me cross the street?’ But you can’t use those signs if you can’t have anyone near you, or touch you, even if they can see the sign. I tried crossing the street with a

cane and almost killed myself.” Dunnigan, who is sixty-six and lives alone, now can’t get into the elevator of her twenty-story apartment building because she can’t see or hear whether there is someone else in it less than six feet away. She is not yet adept at deaf-blind technology and doesn’t have a computer, so she can’t order food deliveries. Last week, she was down to a few canned goods. To communicate, she relies on a Bluetooth connection between her hearing aid and her iPhone. But the Wi-Fi in her building went down recently, so she couldn’t ask Siri to access her phone. For sixteen hours, Dunnigan was alone with no means of communicating in a deaf, dark world. “If this is the new normal, what is it going to be like for deaf-blind people?” she said.

Many deaf-blind people I interviewed said that they were cut off from basic information. The daily White House briefings provide no sign-language translations. Data and statistics about the pandemic, its spread, and its numbers are presented in a visual format in the media, Paul Martz, a fifty-seven-year-old computer specialist in Erie, Colorado, told me. He relies on hearing aids for even marginal hearing, but they made “an unplanned trip through the washing machine” after the pandemic began, he told me. He was never trained in either visual or tactile sign language. “We’ll replace them once we feel it’s worth the risk to venture out into our virus-laden world.”

Since Helen Keller’s days, people who are deaf-blind and their support networks have created institutions to foster their own education, independence, and employment. Anindya Bhattacharyya coordinates technology outreach and training for the Helen Keller National Center. He travels the country helping deaf-blind people connect with technology. He, too, is deaf-blind. Bhattacharyya e-mailed me last week about the case of Dorothy Klein, who turns a hundred and two this month. He set up Klein with a special iPad Pro in 2017. She’s still agile on technology, but her iPad developed a technical problem. He suspects that it needs a software update and that she needs training on its new features. Klein lives in Boca Raton, Florida; Bhattacharyya is in California. “With the stay-at-home order, I am not able to travel and am avoiding contact with others to protect them and myself,” Bhattacharyya said in an e-mail. I checked in with Klein, who lives alone in a senior residence. “Technology is wonderful—until it breaks,” she told me. Her son is unable to help; he is a medical director at a nursing home in Greenfield, Massachusetts, that has been hit hard by COVID-19. When I said that he must worry about his mother’s vulnerability at a hundred and two, she replied, “It goes both ways.”

With social distancing the new normal, shopping for basic necessities has become a huge hurdle. In California, a grocery store told Girma that her guide dog was no longer allowed inside because of the coronavirus. She shot back that the policy violated the Americans with Disabilities Act, which bans discrimination against people with any disability. She prevailed. I heard similar stories from others. In Washington, D.C., Betsy Wohl described being stuck at a Safeway checkout waiting for her grocery bags. Nothing happened. The cashier eventually shoved a card in her face, but Wohl couldn’t read it. Wohl moved her cart closer to the cashier, who thrust the card in her face again. Wohl finally figured out that shoppers are now supposed to bag their own groceries. “Deaf-blindness and social distancing don’t mix,” Bradley Blair, a thirty-seven-year-old graduate student in DeKalb, Illinois, told me. “Some people simply have to break those distancing guidelines if they’re going to get things done, or they have to leave things undone—not a pretty set of choices.”

Sarah McMillen, a thirty-five-year-old San Antonio resident, is worried that her cane—her only means of navigating the world—may expose her to the virus. She uses her dominant hand to hold handrails and open doors, then transfers it to hold the cane. “The handle grip becomes a cesspool of germs,” she wrote. Eduardo Madero, who lives in Powder Springs, Georgia, now washes his entire cane in the bathtub. Using sign language is also problematic, he wrote, because some signs—such as “mom,” “dad,” “sister,” “brother,” “illness,” “serious,” and “fever”—all involve motions that touch the face.

Even for those adept at technology, communication can be slow—sometimes very slow—which complicates shopping online and obtaining delivery times. “I am trying to develop strategies to get those slots, like always having my shopping cart partially full and getting up at 2 A.M. to try and grab slots,” Ferris, the technology trainer, told me. To insure her children get food, they meet the local school bus every morning to get breakfast and lunch provided by her district. “This is not something we would normally do,” she told me. “I have debated getting the local food-bank delivery, but, since we still have an O.K. income, I am loath to take food from a family with no income.” Meanwhile, her pharmacy will provide medication only at its drive-through window. Ferris had to take public transportation to the pharmacy, then stand in line with cars to get a prescription for her kidney disease. “It was very awkward and put me at risk,” she said.

The sense of isolation also runs particularly deep among the deaf-blind community. “I feel like we’re being tossed into a six-by-six-foot cell with no human contact,” Jessica Eggert, a forty-three-year-old

Minnesota resident, told me. Megan Conway said that the rest of the world is learning what life can be like for deaf-blind people. “I feel weirdly more a part of the community than I did before because we share a common experience,” Conway, who is fifty and lives in Healdsburg, California, wrote. But the state’s stay-at-home order has cut her off from other deaf-blind people. “The ability to get together with other Deafblind people to talk and laugh and be unburdened by other people’s perceptions that we are freakish is important to our sanity and well-being.” Francis Casale, a deaf-blind pastor at the Intercommunity Church of God in Covina, California, started posting sermons for his deaf-blind congregants on YouTube and Facebook after his church closed last month. He misses counselling other deaf-blind people, many of whom live alone. Like many of the people I interviewed, Casale wrote me that the thing he misses the most is exchanging hugs, particularly important to deaf-blind people who express friendship through touch.

Vanessa Vlajkovic, a twenty-two-year-old equestrian and graduate student at the University of Queensland, in Australia, complained of unrelenting boredom for deaf-blind people. “It’s not as if I can sit and watch Netflix for hours,” she said. Reading, now her only pastime, has left her with severe repetitive strain injuries in her hands and wrists from overuse of Braille. Girma, the lawyer, appealed to the directors of the new Netflix film “Crip Camp” to provide the script, which she read on a computer that translates into Braille. “I devoured that transcript like a thrilling novel,” she told me. She walks three miles a day with her guide dog, a German shepherd named Mylo, but she can no longer engage in her hobbies, surfing and ballroom dancing. Girma regularly danced at a church in Palo Alto on Wednesday evenings and also when she’s travelled—in India, Costa Rica, and Dubai. She especially likes swing and salsa. “There are many forms of language,” Girma said. “There are physical signals that people know all over the world.” She carried her wireless keyboard so other dancers could communicate by typing words that were relayed in Braille through her mobile device. “I miss talking with the other dancers,” she said. Andre Gray, who is forty and lives in Portland, Oregon, also lamented the absence of sensation without other people around him. “I’ll take a long and extremely hot shower just to experience some exterior touch and sensation for the day,” he wrote.

On March 30th, Nancy Rourke, a well-known deaf painter, launched an online painting event. She posted a YouTube video, in sign language, with instructions, the requisite supplies, and stencils of the theme, which was built around the sign-language symbols for sunrise, unity, and fish swimming freely. Roehrig, the former president of the American Association of the Deaf-Blind, decided to try his first

painting. A friend helped Roehrig guide his hands around the stencil, but as a deaf-blind person he wanted to add different textures—shells, beans, pearls, faux gems, and pipe cleaners—so that he could feel the painting. “I found myself in joy,” he wrote. The result is stunning.

Maricar Marquez, who is deaf-blind, spends most of her day now working remotely as the supervisor of independent living at the Helen Keller National Center. Like many deaf-blind people, she led an extraordinarily active life before the pandemic. “I have completed the New York City Marathon, several triathlons, gone skydiving, rock climbing and zip lining,” she wrote me. I felt shamed; I’ve done none of it. Like many others around the world, she now spends long hours in Zoom meetings. Zoom offers platforms for blind people and those with disabilities to communicate, although people who are deaf-blind often need an interpreter who types what is said or signed; the words show up in Braille. One of Marquez’s interpreters devised a plan to buzz her Fitbit tracker to get her attention to check her text messages in Braille. She also uses Zoom to socialize. “Like many other Americans, I am joining Zoom Happy Hours with friends and enjoying a glass of wine together,” she wrote.

But Marquez hasn’t run, walked her guide dog, Cliff, or been outside her home since New York went into lockdown. Neither she nor her dog can judge if other people are six feet away. “I stand in front of the opened windows feeling the cool air coming in, wondering when we will go back to our normal lives,” she wrote to me. “I want to touch the world again.”

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 - The long crusade of Dr. Anthony Fauci, the infectious-disease expert pinned between Donald Trump and the American people.
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