

bitchmedia

THE ACCESS SERIES



Illustration by [Ananya Rao-Middleton](#)

Introduction

by [Evette Dionne](#) and [Alice Wong](#)

In 2018, we realized there was a void in coverage specifically focused on the impact of chronic illnesses on people from marginalized communities. That led to the creation of [In Sickness](#), a digital series written and illustrated by people with various invisible illnesses. At the time, we promised that we'd continue to publish stories about disability and continue to build a relationship with the disability community—and we've done that. Now, we're taking that commitment to the next level by partnering with the [Disability Visibility Project](#) and [Alice Wong](#) for this digital series all about access, an issue that disabled and chronically ill people are navigating every day.

Though the pandemic has forced U.S. society to grapple with gaping inequalities and everyday “inconveniences,” access is still treated as if it's a privilege, a burden, or a form of special treatment. This digital series explores access through a disabled lens by asking: What does an accessible future look like? How can we build that world right now and trust people with lived experience to guide the process? How does systemic ableism perpetuate inequality and inaccessibility?

We're not giving answers. We're inviting our readers to reflect, learn more, and take action, and our beloved contributors are here to usher in that experience. We have Vilissa Thompson and Keah Brown in conversation about disabled Black girl magic. Anna Hamilton and s.e. smith examine the nuances of anti-ableism and language in online spaces, Diana Cejas shares her story about increasing access during the pandemic as a Black doctor, Julia Métreaux investigates the future of remote work, Jaipreet Virdi and Liz Jackson imagine the potential of accessible design, choreographer and dancer India Harville demonstrates the beauty of access-centered movement and dance, community organizer Teighlor McGee recounts their work providing mutual aid and access in Minneapolis after the summer 2020 uprisings, and podcaster Thomas Reid delves into the importance of culturally accurate audio descriptions in entertainment.

This exploration of access is just the beginning. Access isn't a scarce commodity or something to beg from people in power. *It is an ethos, a whole mood, a vibe.* In a [2018 keynote address](#) for the [Disability & Intersectionality Summit](#), Mia Mingus said,

I don't just want technical and logistical access. I don't just want inclusion, I want liberatory access and [access intimacy](#). I want us to not only be able to be part of spaces, but for us to be able to fully engage in spaces. I don't just want us to get a seat at someone else's table, I want us to be able to build something more magnificent than a table, together with our accomplices. I want us to be able to be understood and to be able to take part in principled struggle together—to be able to be *human* together. Not just placated or politely listened to.

Any movement working toward liberation and justice must be accessible—and that's the conversation we hope this series continues.

Shot Chaser

What Does It Take to Achieve Vaccine Equity?

by [Diana Cejas](#)



Illustration by [Ananya Rao-Middleton](#)

I read the email over and over and over, checking and rechecking it to make sure it was meant for me. Eventually, I called the number and scheduled an appointment for my first dose of the Pfizer COVID-19 vaccine. Any doubts I had about receiving the vaccine had disappeared the moment I received the notification. Getting vaccinated didn't just represent a chance to begin attending concerts, grabbing dinners with friends, or returning to something closer to normalcy. Instead, as a Black Latina physician, it meant that I could help protect my patients and my community. As a high-risk disabled woman, it meant that I finally had the chance to protect myself. The fact that these vaccines have been [developed](#) and [administered to millions](#) so quickly is a testament to [advancements in medical technology](#) and public health campaigns. But the fact that I had access to the vaccine in December 2020, that I am now fully vaccinated when so many Black, Brown, and disabled people like me aren't, highlights just how far these systems have to go when it comes to health equity and justice.

The pandemic revealed some particularly [ugly truths about the U.S. healthcare system](#). During the spring of 2020, we were inundated with messages about how we were “all in this together,” which conflicted with messaging at the time that severe COVID primarily affected older and disabled people. That sentiment—combined with the racist rhetoric and misinformation that our nation’s leaders used to minimize the threat of the disease and actual data on cases and deaths—showed how uninformed we were about the threat we were facing. COVID hit [Black, Latine](#), and [Indigenous](#) communities [hard](#). We’re more likely to be exposed to the virus, less likely to receive appropriate care for it, and more likely to die from it. Public health and healthcare institutions had opportunities to address some of these disparities when the vaccine was introduced by involving marginalized groups in the development of communications campaigns and by prioritizing access in the most vulnerable communities. However, vaccination rates aren’t as high as they could be in communities of color for several reasons: it’s harder to get access to the vaccine in many of these communities and people of color are more likely to distrust the vaccine and government-administered healthcare. That [distrust and hesitancy](#) is warranted.

From the [Tuskegee Study](#) and [forced sterilizations](#) to [J. Marion Sims’s callous experiments on enslaved women](#), the history of medicine in the United States is rife with atrocities committed against people of color. More recent stories of mistreatment by healthcare providers show that racism, ableism, and discrimination in medicine are ongoing problems. Medical racism—along with diversity, equity, and inclusion (DEI) in academic medicine—were hot topics in the summer of 2020, when the twin pandemics of COVID and police violence brought racism and its effects on health to the forefront. The [Association of American Medical Colleges](#), [Accreditation Council for Graduate Medical Education](#), and countless medical schools and hospitals released statements denouncing racism, created DEI strategies, formed anti-racism book clubs, and [announced plans](#) for a host of other DEI programs aimed at addressing the structural inequities in their institutions. The promises to hire and listen to Black and Brown people and address discrimination rang hollow, partly because of the [ongoing disparities in COVID care](#) and [vaccine access](#).

My experiences with medical racism and ableism have influenced me both professionally and personally, including my relationship with COVID and the vaccine. I found a mass in my neck when I was in medical school. After five years of doctor’s appointments and being reassured, disbelieved, or outright dismissed, I was finally diagnosed with cancer. I had surgeries to remove the mass but, unfortunately, had a stroke after one of those procedures. It has been years since my diagnosis and years since I woke up in an ICU connected to a ventilator, the left side of my body completely paralyzed. I’ve reached the point where I can pass for “healthy.” Still, my illness left me with a variety of disabilities and a lot of uncertainty about my body and how it will respond to illness. During the early days of the pandemic, I spent hours watching the news or reading case reports. My anxiety grew as colleagues shared stories about new and

horrifying symptoms. I checked in with my doctors, some of whom reassured me that I'd be okay if I quarantined, but none of them were able to answer questions about my level of risk.

I did as I was told: I stayed home as much as I could and wore a mask whenever I couldn't. I watched the cases rise and restrictions relax at the same time. I watched legislators, commentators, and laypeople alike blame thousands of people of color for their own deaths. They didn't discuss disability unless they were talking about [rationing resources](#). They didn't address race unless they were talking about preexisting conditions, obesity, diabetes, poor hygiene, and "personal responsibility. I watched the reports, felt my heart pound, felt the numbness of my arm, and flashed back to my bed in the ICU. Eventually, I turned off the television, but I kept up with the news about vaccine trials while discussing the virus and vaccination with family and friends.

My white physician colleagues talked about immunizations as if they were miracles and highlighted the science. They knew the difference vaccines could make, as I did, but they had complete faith in our healthcare system and I did not. I knew the science, understood the possibilities, listened to healthcare leaders promise to help hard-hit communities and I tried to believe them. My Black and Brown colleagues talked about their concerns and their fatigue, about how it felt to care for and lose patient after patient who looked like your cousin, your best friend, your auntie. To turn on the television and see the death rate rising, to switch to social media and see anti-masker belligerence, videos of police killings, violence, and brutality on autoplay. We felt conflicted—we were staunch supporters of vaccination but had concerns about the healthcare system, knowing that it failed people of color, sharing that it failed us too.

I had different kinds of conversations with my family. My cousins expressed their doubts, shared stories about doctors who mistreated them, articles about Black people who tried to get help and couldn't, and links to funerals held on Zoom. They told me they didn't know what to believe. I told them to quarantine.

All of this ran through my mind as I read the scheduling email. My thoughts wandered back to the ICU, to my hospital bed. I never want to go back. I made up my mind in an instant. At the same time, I felt as if I was getting away with something. I didn't qualify to get the vaccine because of my finicky airway, my weakened arm, or the cancer that has long been in remission. Nor did I qualify because of the outbreaks that were ravaging my town. I was in the first group to receive the vaccine because I was a physician. I didn't work on a COVID unit, only saw patients in person for a few hours a week. But I felt like I didn't deserve the vaccine, like I had taken something from people sicker or more vulnerable than me. I'm privileged in ways that other disabled people of color aren't. I have the internet required to access the vaccine appointments, a car to get me to a clinic 20 miles away, a flexible schedule, support from my employer, consistent healthcare, and outstanding insurance. All of this on top of access to information about the virus and the vaccine.

If our leaders in medicine and public health mean what they say and want to decrease healthcare disparities and improve outcomes for people of color, they have to start with the basics. Acknowledge the harm that the healthcare system has done and that it continues to do to us. Take concrete steps to address medical racism, ableism, and discrimination. Recognize that health doesn't start and end in the hospital or clinic; that access to housing, transportation, employment, education, food, and other factors impact health too; and that racism and ableism and discrimination affects health too. If they're serious about improving access to the vaccine, then they must address access from a holistic perspective and treat people of color—disabled or abled—as if they deserve that access and that respect.

As of May 2021, every person over the age of 12 in the United States is eligible to get the vaccine. I got both of my shots, posted selfies on social media, and saw other disabled people do the same. I continued to wear my mask and to quarantine despite the loosening restrictions and ever changing guidelines of the spring and early summer. I started watching the news again as the Delta Variant started to spread and case rates again began to rise. I encourage my patients to wear masks and to get vaccinated, especially given how contagious and deadly this new variant is, and I do the same for my family and friends. Despite everything, I hold out hope that our healthcare system will learn something from all of this and start prioritizing the needs of the most marginalized. And that Black, Brown, and disabled people will finally get the kind of healthcare that we deserve.

The Complex Future of Post-Pandemic Work

by [Julia Métraux](#)



Illustration by [Ananya Rao-Middleton](#)

Before the pandemic led many U.S. industries to embrace remote work, Vilissa Thompson, the founder and CEO of the disability-focused organization Ramp Your Voice!, used to travel to attend conferences and give talks. Thompson, who uses a wheelchair and lives in South Carolina, plans to continue working remotely through 2021 because she's found that she's able to attend more events without having to worry about ableism affecting her travels. "It's been nice to not have to deal with airlines," Thompson says. "One time they lost my wheelchair."

For many members of the disability community, the sudden shift to remote work in March 2020 was both a welcome change and a frustrating one. Some disabled people have been fired for seeking accommodations. This includes former Lockheed Martin administrative assistant Donna Kerekes, who asked for permission to use a transcription or recording device to help her do her work. Instead of complying, the company placed Kerekes on disability

leave, then she was fired. They ended up having to [pay her more than \\$100,000](#), and they also had to educate their managers and human resources department about the Americans with Disabilities Act (ADA), which is more than 30 years old. The COVID-19 pandemic has proven that remote work is possible for many industries, but it's unclear what work will look like after the pandemic. The option to use Zoom and other video conferencing platforms that provide hard-of-hearing people, myself included, with the opportunity to lipread, which we cannot do on phone calls, may be eliminated if in-person work is mandated

In many industries, companies will have to decide whether to allow their employees to continue remote work, establish a hybrid model, or require in-person work. Tech companies Google and Apple, for example, are allowing employees to come in only a few days a week, while Facebook is allowing full-time remote work to continue. "Workers appear to want to be the ones choosing where to work, not their employers, and it could very well be a competitive advantage to offer work from home options," [Ron Miller wrote for TechCrunch](#). This is made more complicated by the fact that some disabled people can't get the COVID-19 vaccine due to health reasons, and an [Arizona State University study published in April](#) found that 60 percent of businesses surveyed will require proof of vaccination. Thompson believes that if a boss thinks that in-person work would bring the most money, the needs of disabled workers may be ignored: "People may have to face the harsh truth of capitalism, which is [that] capitalism cares about the money."

Tauhid Chappell, a Philadelphia-based project manager at the media platform *Free Press* who lives with ulcerative colitis, plans to split his time between working from home and participating in in-person engagements, which is a key part of his job. Chappell also recognizes the privilege of being able to work from home during the pandemic, which disabled people with essential jobs weren't able to do. "To be able to have the option to work from home, and not have to physically leave [my] home to still get paid, makes me lucky," he says. But there are disabled people who prefer to work in an office, so it's also crucial that their accessibility needs are still met, says Rebecca Cokley, the disability rights program officer at the Ford Foundation. In her decades as a disability activist, Cokley has seen companies do what they can to skirt the requirements of the ADA. [Kroger](#), [Walmart](#), and [The Hershey Company](#) are just a handful of many companies sued by the U.S. Equal Employment Opportunity Commission for violating the ADA. Cokley is concerned that companies will have the attitude of "let's just have you telework, so we don't have to make our workplaces accessible." Cokley tells *Bitch* that this attitude could lead companies to "enforce segregation" between disabled and non-disabled workers, instead of using financial resources to "comply with a 30-year-old civil rights law."

While being able to work from home is possible for some members of the disability community, remote work isn't an option for all disabled people. That's partly because not everyone has equal access to quality internet. A January 2021 study published in the [World Economic Forum](#) found that internet access can be unreliable and unaffordable in many rural areas and other low-income communities. "There's still a digital divide, a tech divide that

[affects people]who have to be online to work,” Chappell said. “Those with physical disabilities need to be accommodated for, and companies are not creating tech or [other] products that allow them to participate on an even playing field.”

Cokley told Bitch that she’s glad to see the Biden administration’s bipartisan infrastructure bill addressing digital divides. People need stable internet access, just like they would clean water and heating, and she thinks that stable internet is a crucial infrastructure issue. “Because [of] the fact that everybody uses it, it should be thought of [in] the same way as our bridges and our roads,” she said.

Disabled people are often given reasons for why our accommodations can’t be met or why they’re “bad.” For example, [disabled people who need plastic straws](#) are blamed for contributing to climate change. This extends to concerns that a 5G infrastructure may have some effects on the environment, though existing research doesn’t suggest that this would have a substantial impact. Cokley believes that “if we saw accessibility and environmentalism together as a package instead of pitted against each other, which [they] often [are], there’s no telling” what could be accomplished.

Additionally, disabled people shouldn’t have to wait for tech companies to make their products accessible or be charged a fee to access a version that would better accommodate their needs. For instance, Zoom waited nearly a year into the pandemic to announce that it would introduce live captioning—a service that was previously available for a fee—despite the fact that hard-of-hearing and Deaf people, myself included, rely on Zoom for work.

The pandemic will continue to shape society, which includes the disability community, for decades to come. People who contract COVID-19 may experience symptoms for months or, like many members of the chronic-illness community, get sick and have symptoms that never really go away. Chronic-illness symptoms may change what a person can do at work, if they’re even able to work while taking care of their health. María Cristina García, a former seamstress at a performing arts school in New York City, likely contracted COVID-19 while at work. García developed postural orthostatic tachycardia syndrome (POTS) after becoming sick, and like many people who become disabled or chronically ill as adults, García became acutely aware of how inaccessible public transportation is.

“Now, I use a rollator to get around, and I can’t count on the agility and stamina that used to vault me through closing subway doors,” García says. “Service was never great for anyone who needed an elevator, and now I worry that budget cuts will make accessibility even worse.” García hopes to return to work once the students at her school perform again. “Because my job only exists when students are performing in person, I have the time right now to rehab my body and hopefully get my POTS to a more manageable place,” she said.

The pandemic has shown that some accommodations are possible. However, bosses are still going to find ways to take advantage of disabled workers, like justifying paying a person less because they are working remotely. “Capitalism is still going to find a way to exploit workers, whether you’re working in an office, or you work from home, or [you’re] able to come in [only on] certain days of the week,” Thompson says. In order to accommodate disabled people in a post-pandemic world, employers need to realize that meeting our needs is possible, and the rapid switch to virtual work in many industries showed us that. Our accommodation requests are reasonable—ableism isn’t.

Beyond Functional

Unraveling the Long Line of Disability Fashion

by [Liz Jackson](#) and [Jaipreet Virdi](#)



Illustration by [Ananya Rao-Middleton](#)

“To be well dressed is to feel well dressed.”—Helen Cookman

There are no “firsts” in disability fashion, and there can’t be a future for disability fashion without acknowledging its lineage of disabled creators. People have always made clothes for disabled bodies. Whenever possible, we disabled people have modified garments and assistive devices to fit our bodies for style, comfort, and function. In 1948, for example, a British woman named [Gladys Reed was frustrated](#) with her body-worn hearing aid, which placed separate battery packs in a “handbag container” worn over her shoulder. Because the handbag regularly slipped off Reed’s shoulder, she decided to create a better solution: a belt with hip pockets for carrying her instrument and batteries. Her later designs—including bra pockets and linen bags fastened to a suspender belt—improved on the carrier. She even shared her design patterns for others to replicate. Reed’s story fits within a lineage of stories about disabled people who devise their own solutions because mainstream brands don’t often meet our needs.

Designer Helen Cookman also altered her own clothing to accommodate her hearing aid by sewing the battery packs into the waistbands of her skirts and pants. Credited for popularizing the Chesterfield coat in the '30s, Cookman was known for [incorporating masculine styles into womenswear](#) and designing post–World War II industrial uniforms. In 1955, *New York Times* style editor Virginia Pope recommended her for a position at New York University's Institute of Physical Medicine and Rehabilitation, researching the market potential of adaptable clothing. At the institute, Cookman developed a sample collection of “[Functional Fashions](#)”: 17 items created to help disabled people dress themselves independently and tested for “function, utility, and fabric choice.” The garments featured designs such as blouse pleats, double-fabric under arms (to withstand pressure from crutches), Velcro fastening, and wide zippers. Cookman even designed a “wrap-around dress”—nearly 15 years before [Diane von Furstenberg's iconic design](#)—and [patented her trouser modification](#) with full-length side seam zippers.

When the collection debuted in 1959, more than 35,000 people and organizations rushed to place orders. In response to the demand for ready-to-wear apparel, Cookman and Pope established the nonprofit [Clothing Research and Development Foundation](#). The foundation provided space for Cookman to research newer designs, some of which are featured in her coauthored book, [Functional Fashions for the Physically Handicapped](#), to encourage other designers and disabled makers to create their own clothing. In a [2019 article for the Milwaukee Art Museum](#), Natalie Wright, a doctoral student at the University of Wisconsin-Madison, wrote that Cookman's Functional Fashions were popular because of the postwar American notion of “independence that expected citizens to be self-reliant while performing productive, gender-normative roles in the labor force and at home.” These issues became particularly relevant for the large swath of injured and disabled soldiers who returned from World War II and for rising numbers of people disabled by polio, all facing a largely [inaccessible society](#). Recognizing the commercial potential of Cookman's designs, New York designers such as Levi's, Lacoste, and Sears incorporated Functional Fashions into their runway collections. Though Cookman worked on Functional Fashions until her death in 1973, she never secured a mass-market distribution deal.

Thus, few material remnants of this history remain. While many disabled people likely embraced Cookman's zeal for DIY, the runway pieces and brand collaborations are missing or lost in the archives and have yet to be found. Indeed, in 2019 Natalie Wright worked with disabled-design advocate Liz Jackson to track down the collection within Levi's archives. Upon urgings from Wright and Jackson, Levi's historian Tracey Panek located a pair of jeans from the company's Functional Fashions [collaboration](#) with Cookman. For Jackson, and Wright especially, this was deeply validating and beneficial to their research because when Cookman and Pope died, the Functional Fashions line nearly died with them.

At the time, Functional Fashions was one of several companies offering stylish clothing for disabled people. Beginning in the '60s, home economics textbooks, rehabilitation manuals, and newsletters for disabled homemakers presented suggestions for adapting store-bought clothing and

knitting accessible apparel. Chicago-based designer Judy Falk's "adaptive clothing" was [featured](#) in the Sears *Home HealthCare* catalog. The U.S. Department of Agriculture established a [research service](#) to investigate clothing preferences for disabled women, especially those with arthritis, muscular dystrophy, and poliomyelitis. At the same institute where Cookman worked, disabled designer Mrs. Van Davis Odell created [Fashion-Able](#) in the early '60s, a line of accessible garments and accessories for women—likely built on the work of Functional Fashions. Among the most notable products were a bra with Velcro closures and a purse designed to fit on the handrest of a T-shaped cane. Odell eventually sold the business in 1971 after it grew too large for her to manage.

As Cookman's Functional Fashions and Odell's Fashion-Able have been forgotten and gone uncredited in fashion history, "Adaptive clothing" has emerged in their stead: mass-produced garments for disabled people, created by companies promoting disability as [inspiration](#). Adaptive clothing became a marketable trend in 2016 when the Runway of Dreams Foundation partnered with Tommy Hilfiger to create a 22-piece collection of adjustable clothing that encouraged disabled children to dress themselves. Fashion designer Mindy Scheier, who established the foundation, was motivated "to empower people with disabilities through adaptive clothing" after her son Oliver's muscular dystrophy made it challenging for him to manage buttons and zippers on his clothing. In a *Time* [op-ed](#) that corresponded with the Tommy Hilfiger launch, Scheier stated that the goal of Runway of Dreams was to create an "inspiring movement toward inclusivity in the fashion industry."

Target, Nike, and Zappos quickly followed suit with their own adaptive apparel, each motivated by a specific moment that served as inspiration for the line. For [Zappos](#), it was a customer service call that "made a lasting impression on our employee." For Nike, it was a [letter](#) from teenager Matthew Walzer who has cerebral palsy, which stirred CEO Mark Parker. The internal design team for Target's Cat & Jack line included the mother of an autistic child, who was inspired to solve the problem of restrictive garments and sensory-unfriendly fabrics. By inaccurately framing these strategic corporate decisions as tales of epiphany, brands are promoting their products as originals, *firsts*, and innovations, thereby erasing all that existed before them.

In many ways, these decisions reflect what historians Lee Vinsel and Andrew L. Russell describe in their 2020 book, [The Innovation Delusion: How Our Obsession with the New Has Disrupted the Work That Matters Most](#), as "innovation speak," which favors "stories of individual genius to the more complex reality" of how things actually emerge. That is, brands tend to focus more on the *language* of innovation, rather than *actual* innovation. A brand cannot claim to be the "first" at something without erasing past contributions. As scholar Max Liboiron [suggests](#), "Firsting is about the power to discard." Claiming to be the "first" is a proclamation of power deeply rooted in colonialism and capitalism.

We observe this pattern in disability fashion, where claiming to be the first—just as Scheier did when she said that the [Runway of Dreams and Hilfiger collab](#) was the first "to bring adaptive

mainstream clothing directly to consumers”—obscures the legacy of designers such as Reed, Cookman, Odell, and others. The firsting phenomenon is especially striking when looking at the creation of clear face masks. In response to public health mandates, more than a dozen non-disabled people claimed to have invented the first clear mask to make it easier for deaf people to communicate during the pandemic. No credit was given to Anne McIntosh, PhD, a deaf professor who fought for years to bring her “[transparent surgical mask](#)” to market. We’re not assuming that McIntosh was the first to develop this mask, but there is cause for caution here. As with Cookman, McIntosh is a successful deaf woman whose story was erased by the so-called innovations of others.

But things are shifting. A new generation of disabled creators is positioning their fashion as wearable art designed to honor their communities, rather than framing their work as a solution or fix. Several creations launched in 2020 and early 2021: An [ear jewelry collaboration](#) between Chella Man and Private Policy shifted the gaze so that objects historically made to be [discreet](#) are now actually drawing [attention](#) to the ear and to deafness. Sandie Yi of Crip Couture devised a face mask titled “[One of Us](#),” made from material printed with a graphic pattern of Yi’s hands, which she refers to as her “two great hands.” Yi’s design reflected how “the pandemic has uncovered biases around who is deserving of lifesaving treatment.” Sky Cubacub has designed customizable face masks with 11 different attachment styles that embody the brilliant aesthetic of Cubacub’s company Rebirth Garments and uphold their [mission](#) “to resist society’s desire to render us invisible.” By framing these objects within stories of emergence rather than innovation, we gain a deeper understanding and appreciation of disabled creators and the community their work centers. Emergence offers an alternative to erasure—whether that erasure happens as a result of discreteness, eradication, or invisibility. Through this new lens we can begin to imagine a future in which disability fashion will liberate those who have been erased from design, from mainstream disability narratives, and even from within disability communities.

In Living Color

Audio Description Looks Past People of Color

by [Thomas Reid](#)



Illustration by [Ananya Rao-Middleton](#)

Marvel's *Luke Cage* series was a much better experience than *Black Panther*. Perhaps it's an unpopular opinion, but for me it's all about the details: the variety of identities that make up New York City, the urban fashion, and, of course, the mural of the Notorious B.I.G. with a slightly tilted crown, all of which put a big smile on my face. The way the show handled audio description (AD) made me feel at home. At first glance, [audio description](#) sounds simple, providing information about scenes in film, television, live theater, or any other visual medium where there's no dialogue. Consider how much information is conveyed nonverbally in your favorite film, streaming series, live theater performance, or other visual art. There's the back- and foreground scenery, costumes, and landscapes (consider the lush green environment in *The Lord of the Rings* series). Facial expressions, hand gestures, and body language are also used to communicate emotion; onscreen text that provides pertinent

information, such as “A long time ago in a galaxy far, far away...,” in *Star Wars*; and of course, the aesthetic choices filmmakers make consciously and unconsciously that impact viewers’ interpretation of the film.

For the millions of individuals experiencing some form of blindness—from those with “low vision” to those who are totally blind—AD provides access to a variety of visual content. Like retrofitting buildings or other physical spaces where there are real constraints that prevent expansion, AD has its built-in challenges such as space—the amount of description is limited to the time available between dialogue. Assuring pertinent and accurate information is provided often means choosing what’s most important for understanding the plot. Invariably, many details are left behind. When provided, AD is one of the very [last steps in the postproduction process](#) prior to distributing, airing, or streaming a project. But requiring a reduced production window may not allow for quality assurance and incentivizes shortcuts, as we see with the current trend to substitute human narration with synthesized voices. Studios rationalize these choices by noting that it reduces costs and time, but these choices can also reduce the experience for many. Understanding the audience presents another challenge for those writing appropriate descriptions. Those unfamiliar with blindness assume it means never having any sight at all.

Meanwhile, most people who are blind at some point either had some sight or continue to have residual vision even if it’s not especially useful for consuming video content, shadows, or light perception. When considering how to write a description for those who are blind, the question often asked is: How do you describe color to a blind person who has never seen? Most of the answers suggest relating colors to other senses as in equating hot to red. While this will not help conjure an image in the blind person’s mind’s eye, it can be helpful to get an understanding and effectively communicate concepts and ideas. For example, ROYGBIV is an acronym that refers to the colors of a rainbow (red, orange, yellow, green, blue, indigo, violet). While caused by the refraction and dispersion of the sun’s light by rain in the atmosphere, it’s also commonly used to communicate the idea of living together in harmony. Blind people learn the colors of the United States flag and colors that represent our favorite sport teams. We most certainly learn the color of our skin and whether directly or not, the implication that has in society.

Yet, for years the working standard for describing race, ethnicity, or skin color in media has been to only include those things that are deemed applicable to the plot—meaning the film or scene is implicitly about race. When that’s not considered the case, the common practice has been color blindness—a choice to purposefully not include a character’s color or racial identification in the description and assume the default is whiteness. [Color blindness](#) is based on the idea that advancements in society are based on one’s merit. It’s a social construct that completely eliminates race and therefore allows individuals to believe they’re judging others solely by the content of their character. Color blindness

does not see value in a person's race or color and it doesn't leave room for discussing the impact or perpetuation of white supremacy. A color-blind society doesn't see value in difference, meaning it's impossible to ensure justice or fairness. Similarly, the exclusion of color or racial identification from AD continues to limit accessibility for blind people by not producing an experience similar to that of our non-blind peers who casually glean this information. There is no one set of guidelines to aid those producing AD, but if we look at [those published by Netflix](#), it's clear that the company recognizes the importance of inclusion: "When considering whom to describe and in what detail, consider both the needs of the plot and the importance of representation," it reads. "Description should be factual and prioritize an individual's visual attributes to address their most significant identity traits, such as hair texture, skin color, eyes color, build, height, age description (such as late thirties, fifties, teenage, etc.), traits related to visible disabilities, etc. and should be done consistently for all main and relevant supporting characters that are being described (i.e., do not single out a character because of a specific trait, describe everyone equally)."

AD writers have an indication of a character's race, color, or ethnicity. They have multiple ways of ascertaining and communicating that information to the viewer. It should be up to viewers both blind and non-blind to interpret and decide what is relevant, not those producing the AD, and it's the AD writers' responsibility to provide access. In the same way ramps enable wheelchair users to get into a building, what they do when they get in there is their business. As a Black man who became blind as an adult, my experience in the United States means race, color, and ethnicity are always relevant. Focusing on film, the relevancy of race began with the first motion picture, [A Birth of a Nation](#), which includes a racist portrayal of Black people while propagandizing a heroic KKK. Not only did it reinvigorate the Klan's membership, but the film also generated the caricatures seen for years to come. Black stories and characters have been told through a white lens or absent from screen since the inception of filmmaking.

For years, our creative voices have been systematically silenced. While our representation in the media is not yet up to par, there are far more Black and Brown people on screens large and small these days. When it comes to blind viewers, if AD is produced without identifying information, Black representation onscreen is being erased. Blind people want and deserve access to the same information as our non-blind counterparts. AD content must go beyond identifying only BIPOC characters. It must include describing white people as well. It must include BIPOC audio descriptors. Failing to do so assumes that white is the norm and amounts to a perpetuation of white-supremacist ideology. Fortunately, this conversation has been taking place over the past few years and we see signs of change. Much discussion is taking place in the disability arts community with artists such [Alice Sheppard and Laurel Lawson](#) incorporating AD into their art while advancing the technology for consumers, as with their most recent piece [One + One Make Three](#). AD professionals such [Cheryl Green](#) from Portland, Oregon, [Rebecca Singh](#) from Toronto, and others are moving this conversation forward and creating equitable content—helping assure we are all visible—onscreen and off.

Move Your Body

Access-Centered Movement Is Changing Dance from the Inside Out

by [India Harville](#)



Illustration by [Ananya Rao-Middleton](#)

There was a time when I couldn't get out of bed for two years, and all I dreamed about was dancing again. I'd long had chronic health conditions, but I was still dancing and performing six days a week. Suddenly, in 2011, I started having stroke-like symptoms—paralysis on my right side, seizures, and [aphasia](#)—on a daily basis. I was eventually diagnosed with [hemiplegic migraines](#), and seemingly overnight, my whole life came to a screeching halt. It was hard to envision a future outside of the one I was living, and dreaming about dancing was the only thing that kept me going. I would lay in bed and move the left side of my body, then I would imagine moving my right side, trying to coax my body into doing bed choreography. After a year, I got a wheelchair—and the first place I went was a dance class. I felt so exhilarated and free while dancing in my wheelchair, but the rampant ableism in the dance world stifled my exuberance.

[Dance studios and performance venues aren't always accessible](#) to people with disabilities, but that wasn't the only barrier. Often the teachers didn't know how to make the material accessible for disabled bodies, how to deal with fluctuating capacities, or how to use language that wasn't offensive. And my fellow students were terrified of me: People didn't want to partner with me, didn't want to dance next to me, and didn't even want to make eye contact with me. Having control over one's body is something dancers prize, and my body threatened that foundational idea. After encountering so many obstacles, I began studying [mixed-ability dance](#), or dance for people with a variety of disabilities. I was saddened to discover that many of these spaces didn't provide the kind of inclusivity that would welcome my body or the bodies of many other people I knew in the disability community. They were spaces that centered only disabled wheelchair dancers, not people with chronic illnesses, fluctuating capacities, or non-mobility related disabilities, which were all a big part of my reality. Like mainstream dance spaces, many of these mixed-ability spaces perpetrated other harmful behaviors against multiply marginalized disabled people; they were fatphobic, racist, homophobic, and they privileged ballet over other styles of dance. Eventually, I decided to explore choreographing, performing, and teaching dance in ways that could be accessible to a wide array of disabled bodies and minds and that also honored [the principles of disability justice](#).

My students would often cry in class, sharing stories of the number of “accessible” classes they attended that catered only to the needs of those who use mobility aids—excluding people on the autism spectrum, people with multiple chemical sensitivities, people with intellectual disabilities, Blind people, Deaf people, and many other disabled community members. Attendees at my performances remarked on how powerful it was for them to see a fat, Black, disabled, and chronically ill narrative told in my own crip time and told in ways designed to honor my access needs and theirs too. Other multiply marginalized folks exploring similar concepts heard of my work, and we joined together to create the access-centered movement framework. We wanted to fundamentally change how people teach dance in three primary ways: by expanding notions of how to create accessible space in alignment with disability justice standards, by shifting the language teachers use so that it's anti-ableist and trauma informed and accessible, and by tweaking the ways dance moves are demonstrated and taught.

Our work still exists in a very niche realm and isn't fully accepted in mainstream and even in other mixed-ability dance spaces. Getting funding and recognition is still challenging, but having students and audience members share how impactful our classes and performances have been for them makes it all worthwhile. Now my dreams of dance are filled with BIPOC disabled bodies, and no one is trying to force their right foot to do the choreography. We know there's nothing wrong with our bodies—there's something wrong with ableist dance culture. Shifting that culture is the most beautiful choreography we can create.

Language Wars

Callouts Obscure Vital Truths About Disabilities

by [s.e. smith](#) and [Anna Hamilton](#)

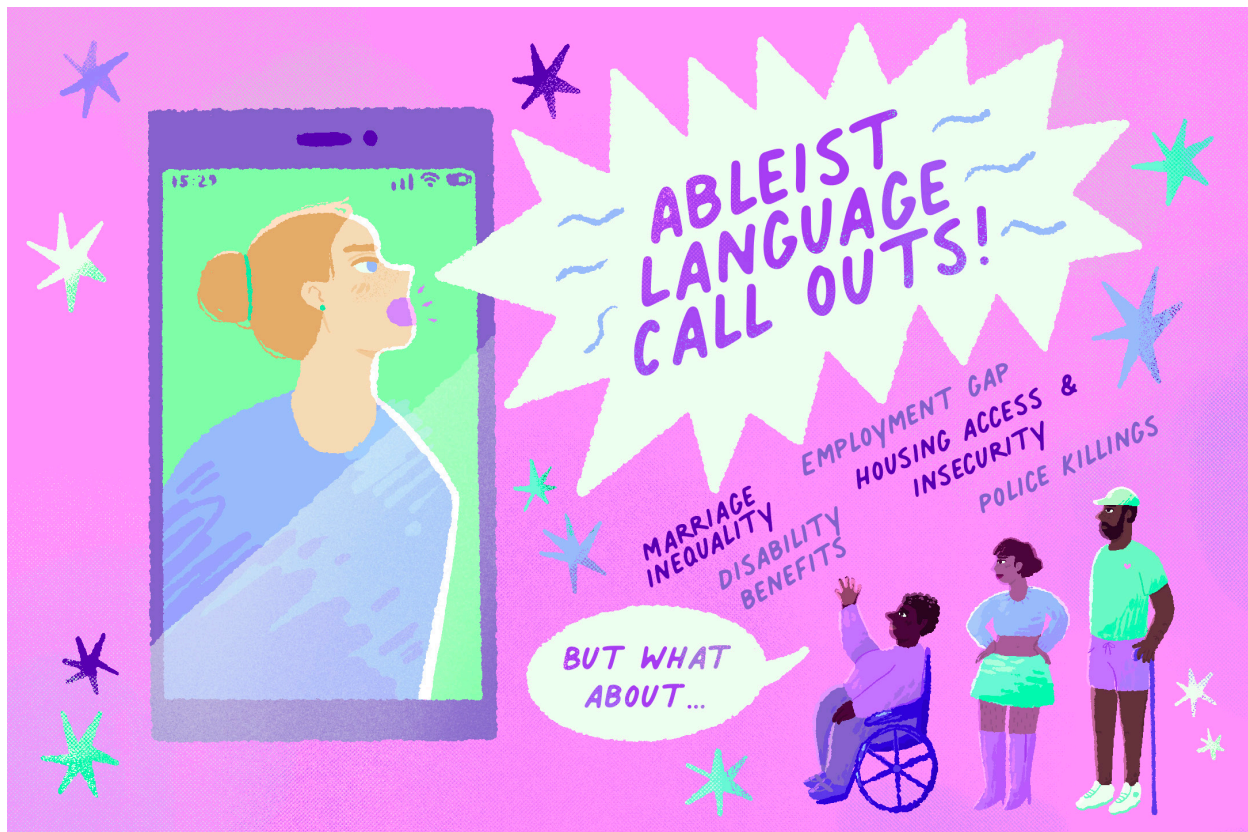


Illustration by [Ananya Rao-Middleton](#)

Editor's note: This article includes ableist language for the purpose of contextual discussion.

Ableist* language callouts have become a fixture of social media, especially in progressive circles: Use a word like “crazy” or “lame” and someone will identify it as disablist. At times, though, the thirst to identify disablist language seems to occur at the exclusion of the deeper and necessary work needed to confront disablism in advocacy, activism, and justice-oriented spaces. Talking about [words and language use](#) matters, especially when ableist or disablist language can enforce harmful beliefs about disability and disabled people, just as [structural racism can appear in language](#). Calling women “insane” for being outspoken, for example, pathologizes [very reasonable responses to sexism](#) and reinforces [stereotypes about mental health and women's experiences](#).

Language use was part of our work at [FWD/Forward: Feminists with Disabilities for a Way Forward](#), a disability feminism collective that ran between 2009-2011. Though our body of work was quite extensive, the component that has stuck in many people's minds is the Ableist Word Profile, a series of posts exploring ableism and language. "We ask you to think about the way in which the language that we use is influenced, both historically and currently, by ableist thought," we wrote, stressing the series was not about "telling people which words they can and cannot use." Most of these posts have since been pulled off the internet because they rapidly turned into tools used for abuse, with people quickly weaponizing them to attack people rather than engage in productive conversation.

The discussion about the words we use took a troubling turn: Instead of being an opportunity to engage deeply with harmful attitudes, people—predominantly white people—are instead focusing on the superficial use of words themselves. They're creating [lists of "bad words" and alternatives](#), and using language in "callouts" that can be extraordinarily malicious. For example, women of color, especially Black women, appear to be targeted more frequently for their word use, sometimes in ways designed specifically to silence them. This mirrors other racist patterns where Black women are held to a higher standard, and one that is often impossible to meet. Similarly, callouts may be used to chill discussion or establish someone as "problematic," undercutting their ability to participate in larger conversations. Language conversations have become highly performative, with a fixation on the words people are using, not *why* they're using them or what they're reaching for when they deploy language like "crazy," "lame," or the r-word.

The language is a metaphor: We call something "insane" because that word carries a specific baggage and burden. But the fact that mental illness is still a shorthand go-to for situations or people that are bad, wild, out of control, chaotic, scary, ridiculous, unbelievable tells us that tremendous social stigma still surrounds mental health conditions. That won't go away by not using former diagnostic terms as insults or yelling at people who do, though we certainly shouldn't use those terms that way. Conversations about language were supposed to be a starting point rather than an end, and one accessible to newcomers curious to learn more about disability. Instead, they have joined the realm of the activism checklist, a performance rather than a praxis. Sometimes criticizing language use actually directly harms the disability community via lateral disablism. It can also be harmful for other marginalized communities by introducing behavioral expectations that don't reflect the realities of their lived experience—for example, piling on to an English language learner for "bad" word use.

The problem of language policing extends to the disability community itself, betraying deep schisms in the way people talk about themselves and others. More online scraps take place when it comes to the use of [person-first language](#) (PFL) versus [identity-first language](#) (IFL).

Both came out of the disability rights movement: IFL (disabled people) affirms disability as its own identity. PFL (people with disabilities) originated in spaces for intellectual and developmentally disabled (IDD) people, and was utilized during the advent of HIV/AIDS activism in the '80s in order to humanize people with those conditions. In the United States, PFL came to be adopted by many disability advocacy groups, people in the deaf/hard-of-hearing community, and professionals outside of those communities as the “correct” way for disabled people to refer to themselves and to be referred to by nondisabled people. Most disabled people have their own preferences when it comes to what type of language they use—some use both, depending on circumstance. While both are marked improvements over outdated, offensive disability euphemisms such as handicapped, differently abled, or special needs, internet spats over which kind of terminology is “correct” still happen.

People with disabilities arguing on social media over which kind of terminology is the right one for *self-identification* is not uncommon—particularly on Twitter, where nuance can be tough to communicate in 280 characters. These arguments add to already thorny questions and debates about language, disability pride, and representation. In March 2021, @WeAreDisabled [tweeted](#), “I know this will spark some debate: identity-first or person-first language? Please be respectful of individual opinions.” Although the responses to the thread were civil, that a disclaimer was included as part of the tweet speaks volumes about the ways in which IFL and PFL have been pitted against each other, to the immense detriment of the disability community.

A solution to the language debate—that is, let disabled people identify themselves in *whatever manner they want to*—seems obvious. This not only applies to IFL/PFL, but also to descriptors such as “crazy”; though some would argue that “crazy” is always ableist, there are people with mental health conditions, particularly in [the Mad Pride movement](#), who choose to identify themselves using a term that is ableist. The trap that some on social media get stuck in, however, is a circular debate about which kind of language is “correct” when referring to people with disabilities, even if that correctness varies from person to person. Additionally, how can the community create both access and flexibility for discussions of language in ways that acknowledge the harm done with ableist language? It is likely that there will always be a contingent of people on social media for whom language-related callouts are the apex of disability activism—particularly if they are new to the disability community—but it is crucial that the community gets beyond internal debates and virtual finger-wags about which terms are “good” and which are “bad.” There are so many disability issues needing focus and action—among them housing access and insecurity, the employment gap, the poverty trap of government-provided disability benefits, police killings, media representation, and marriage inequality—that keeping conversations about disability focused on language correctness can take much-needed energy away from those issues.

The question of language isn't one of finding the right, approved word. It's about fundamentally rethinking the way we view the world, a premise that is much more frightening than swapping "bad" (which may itself have [a transphobic etymology](#)) for "insane." It also requires much more work, including unlearning in addition to undoing. Learned toxic habits like moving quickly and striking hard should become a thing of the past, as should the practice of developing rigid, inflexible attitudes that do not allow for open conversation. Much of this work is interior rather than exterior, requiring us to slow down and sit with our discomfort, listening rather than speaking, reading rather than shouting. In an era when online activism often focuses heavily on 101 education and repeatedly litigating the same arguments, it can be hard to break out of the basic communications that are vital for laying groundwork for more complex conversations, but difficult does not mean "unnecessary."

Editor's Note: We use "ableist" and "disablist" as well as "disabled people" and "people with disabilities" interchangeably throughout. While their meanings are similar, they reflect [different frameworks](#) for thinking about disability and we wanted to acknowledge both.

Let Freedom Reign

A Roundtable About Disabled Black Girl Magic

by [Vilissa Thompson](#) and [Keah Brown](#)



Illustration by [Ananya Rao-Middleton](#)

When CaShawn Thompson created #BlackGirlMagic in 2013, it was meant to be celebratory—to spotlight and honor the Black women often left in the margins, including impoverished Black women, dark-skinned Black women, and disabled Black women. Though the phrase has been both commodified and picked apart over the years, its essence remains. And few people embody the spirit of its message more than Keah Brown and Vilissa Thompson, both writers and disability activists. In this conversation for our Access issue, Brown and Thompson discuss the meaning of disabled Black girl magic and why it's so important to center disability rights in feminism.

What does disabled Black girl magic mean to you?

Keah Brown: Well, for me it means joy, happiness, and the ability to show up as my full self, without apology. Magic is just making sure I'm taking care of myself first and foremost and that I'm not doing something for the comfort of others.

Vilissa Thompson: For me it means just being in my fullness, being my magical and sometimes unmagical self, embracing my identities, embracing my quirkiness and geekiness—these things really matter to me. Disabled Black girl magic is being authentic to who we are, what matters to us, the way we live, the way we represent ourselves, and the way we want society to understand our stories and experiences. [It's also about] how we want the world to see us [in ways] that go beyond the stereotypes. [Disabled Black girl magic] shows our essence, our messiness, our complicatedness, and the diversity of Black womanhood. That's what it means to me: bringing our holistic self forward.

You grew up seeing very few images of disabled Black people in the media. How did that impact the way you viewed yourself as a young disabled Black girl, and does that impact the way you view yourself as a disabled Black woman?

VT: I had a unique childhood. [I grew up] in the Midlands area of South Carolina, and there was a reporter named Susan Audé Fisher, who now goes by Susan Audé, and she was a wheelchair user. She became paralyzed from an accident when she first began her career as a news reporter. She's a white woman, but I [still got to] see her on TV in a wheelchair. I hadn't really thought about her presence on TV until I got older and started doing this work, but it showed me that disabled people can do whatever kind of job we want.

She was everywhere as a local news reporter; she was reporting on major events in the state. When we had the 1996 Olympics in Atlanta, she was [one of the people to carry the torch](#). Her wheelchair had a little prop that they put the torch in, and she just rolled on the path with it. There was no inspirational porn attached to Susan and her visibility. Everybody respected her as a reporter, and she was really good at her job. That mattered to me as a young girl trying to figure out where I fit in. It may have also helped the adults around me to not box me in. No one questioned my desire to go to college. By the end of sophomore year [of high school], I was number one in my class, so college just felt like normal progression. The sky has always been the limit. I've been very blessed. My grandmother in particular really saw my gifts and talents and didn't hinder me based on whatever limitations she may have heard from a doctor. I'm just thankful my grandmother was never one of those people who told me what I couldn't do because I'm disabled.

KB: I didn't have a Susan, so when I saw disabled people growing up, it was [often] in those disgusting, exploitative telethons where [the host would] lean down to [disabled] people, talking for them, and saying, "Give them money. They're suffering." As a child, that made me feel isolated and alone, but I also had a family like yours, who never told me I couldn't do something because I'm disabled. They never made me feel like I was different. My mom was very adamant about making sure I tried whatever my sister and brother tried. If they got skates, I had skates. If they had scooters, I had scooters. They got a bike, and we figured it out.

I'm so grateful for that now because I didn't have somebody telling me, "Oh no, you couldn't possibly do that." But when I turned on the TV, I heard, "All you are is a prop [that we use] to make money. We're not going to let you have a voice in your own telethon." [There were also] those weird late-night holy water infomercials where they would sprinkle "holy water" on disabled people who would then get out of their wheelchair and walk. I spent a lot of my childhood uncomfortable with myself and my disability, but now that I'm a woman and I actually like the person I am, I'm so grateful I had a family that was like, "I'm not going to other you because you're disabled."

VT: When I was in [elementary school], I participated in school plays. Nobody made a big deal about me wanting to do that. I was treated like every other student, except [that sometimes I had to] to leave class to do physical therapy, occupational therapy, or have surgery. We hear a lot of stories about disabled people who were told "no" so much that it made them question what they could do. We're bringing forward stories [about] those of us who were told "yes." That really matters, particularly because Black people are constantly told "no." To [have] lived these childhoods where we received the support we needed gave us confidence. That foundation was instrumental in getting us where we are today—confident, self-sufficient, independent, and also interdependent [in terms of] building community and supporting each other. That matters in so many ways.

KB: I agree. A lot of people I come across in the community don't have the same sort of foundations that we have. It allows me now to feel like I can do whatever I want and [to feel that] I belong in every room I enter. It takes so much longer [to believe that about yourself] when people constantly tell you, "No, you can't do that. You'll never make it."

VT: This may be a little controversial to say, but other folks in the space envy the type of confidence we have. They wish they had that type of confidence because, keep it 100, we have haters. We're confident Black women, confident Black disabled women, and we're queer on top of that. It's like, *where do you get the nerve to be confident, to be brave, to be loud, or to take up space?* There's a lot of tension there from folks who wish they had an ounce of that confidence or who have to belittle you to [feel] that confidence.

KB: Yep. At first it bothered me. I was like why? I didn't even do anything. I'm just trying to show up and do what I want to do. But the more it happens, the more I'm like, *that's a you problem, not a me problem*, and it shows me I'm doing the right things. I'm making the right choices for myself and going after my dreams. If that makes you uncomfortable, then you should examine why that is. You're upset because you want me to be lower than you, but I'm just going to keep going up because I believe in myself.

Disabled Black girlhood is sacred. What would you tell your younger self that you now realize she may have needed to hear or be told?

KB: I desperately needed to know that I was going to be okay. When you're young, everything feels like a big deal, and you feel like the world is ending if some person doesn't talk to you, if you did something embarrassing in front of the teacher, or if somebody said something mean to you. But I wish I would have told myself, *girl, you're going to do things that aren't even in your wildest dreams. The rest of this stuff might be hard, but it doesn't matter. You don't have to be super thin, white, and have long hair to matter. You're going to change minds in so many ways by just being yourself.*

I wish I would've told my younger self that she should relax a little bit. Not everything is as intense as I used to make it. I spent so long trying to figure out how to have a better body or [how to] distract from my disability, and I had no idea that [my disability] would help me get



Keah Brown (Photo credit: Courtesy of the author)

where I am today. I would definitely tell her she's gonna be fine and that all of the things she's thinking about are going to matter. [But] *you're going to love yourself* would be the most important thing. *The love you're seeking comes from within.*

VT: [I would tell my younger self] *the right people are going to see you for you.* I've had more difficulty [forming] good friendships in adulthood than I did in high school. High school wasn't bad. I was a nerd. I studied a lot, which worked in my favor because people wanted help on their homework and papers, so I was the smart cripple. But my disability started to matter in college in certain settings, especially in Black spaces. I'd never encountered that before. I still don't really talk about it publicly because it's

complicated, but it taught me that there are ignorant people out there. It was my first time really dealing with those types of attitudes. I didn't know how to react, so I was very reactionary. I was very angry about the way I was being treated.

It's wild to see some of those very people support my disability activism, which was the thing [they] tried to make me feel bad or self-conscious about. I've realized that my voice does matter, and it's okay to be reactionary sometimes. I wanted to be like my peers, but I now like the fact that I'm different. I've learned to focus on myself and on what makes me feel good. If it's quirky, then it's quirky. If it excites me and nobody else, that's fine. But I'm not worried about fitting in because I wasn't meant to fit in. Those hard experiences taught me to stand in—or wheel in—my truth.

KB: Do the things that make you happy and fulfill you, and stop worrying about whether you're going to look foolish or silly [to other people]. Who cares what they think? You have to put yourself first. Be selfish.

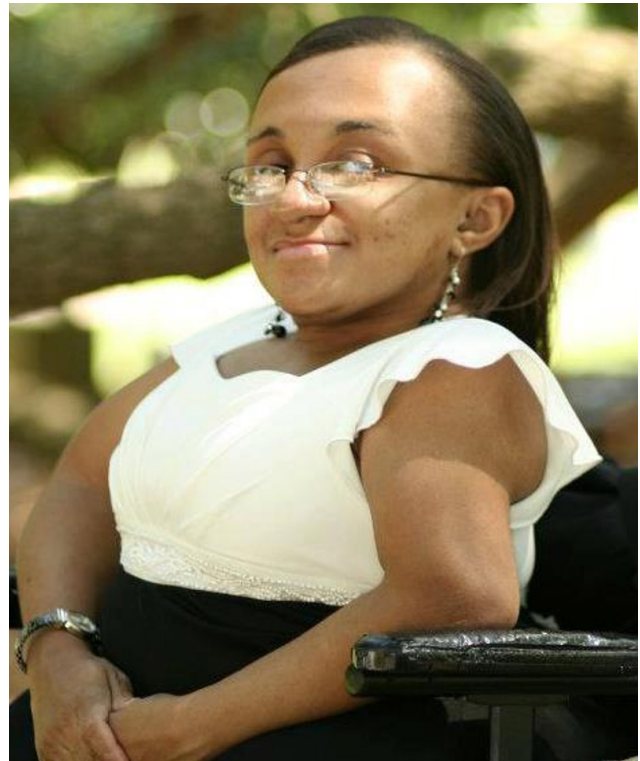
In a world that demands we compartmentalize ourselves and choose which parts of our identities are the most important, what does it mean to resist that and demand to be seen in our fullness?

VT: I want to be seen in my wholeness. Every identity I have has shaped my experiences, my worldview, and my understanding. To ask me to compartmentalize them is unfair because if one of [those identities] didn't exist, I wouldn't be who I am today. I would be a completely different person and have a completely different life. Boxing people in [means] we don't get to see that person's essence. We don't get to see their full experience, and it doesn't allow us to respect their experience. So many of us were so afraid of being different or rocking the boat because we wanted to fit in, but we don't have to. There are billions of people on this planet. Nobody should try to [live up to] standards or expectations that are unrealistic and that 99 percent of people [could never live up to]. In order to respect who I am, you have to respect what I bring forward, which is Black disabled womanhood. I have a full story to tell.

In disability spaces, they want you to center the disability part, and in Black spaces, they want to center the Black part. But if you're going to say that neither community is a monolith, then why are you trying to make it that by just focusing on either the really oppressive part of the identity or shying away from the part you may not understand? You can't have it both ways. If you're uncomfortable with diversity of experience when it comes to Blackness, womanhood, or disability, then that's something for you to handle.

KB: I agree. I'm often told in the disability community, "Don't talk about queerness. Don't talk about Blackness. Don't talk about womanhood. You're just disabled." And it's like, no, that would be disingenuous. It would be a lie to say my experience as a Black disabled queer woman is the same experience as that of a white woman or white man who's disabled. In order for true change to occur, we have to acknowledge the reality of those different experiences. I'm not ever going to stop being Black or a woman or queer or disabled.

I find myself most frustrated with our Black community not being willing to talk about disability. When [my book came out in 2019](#), only two Black publications wanted to [review] it or talk to me about it. Most of the attention I got was from white publications. And the wild thing is that disabled Black people [always] show up for Black movements, but we don't get that same treatment. Instead we're treated like jokes. I understand that we sometimes use jokes to deal with the way the world treats Black people; I get that, but I find myself [feeling] frustrated when the conversation about disability comes up and everything's a joke about a wheelchair or a cane or somebody posts a GIF from [Life](#). So me reclaiming all these identities and saying, "You don't get to put me in a box," is me saying, "Either you take it all, or you leave it because either way I'm going to get done what I need to get done." I'm Black, I'm disabled, and I'm queer; that's what you're going to get.



Vilissa Thompson (Photo credit: Courtesy of Vilissa Thompson)

VT: Exactly. I get more frustrated when it happens in the Black community because I don't expect white people, regardless of disability, to be able to look beyond themselves. I don't expect non-Black people of color to care about Black people because we know anti-Blackness is rampant in every community. It's global. Somebody said that anti-Blackness is the currency of white supremacy—everybody has to subscribe to it because somebody has to be on the bottom, and [no one] wants it to be them. But I do expect Black people to get it because we know what it's like to be oppressed. We know what it looks like to be stripped of our actual personhood. And, as disabled people, we know [what it's like] to not be counted as full people, to be second-class citizens. Black people have been counted as property, so we know what it means to have [our] very existence reduced to nothing.

[It's disappointing] to see Black folks not make the connection that disability is a part of our human experience. Black disabled people have been here, and you have known a disabled person, whether they say the word disabled or not. We all know disabled people in our families, our communities, and our churches. That type of cognitive dissonance and resistance to acknowledging disability frustrates me in a deep way.

In the work we do, some of our harshest and most harmful critics are other disabled Black activists. What does it mean to find and sustain safety in a space where we need each other but can also feel alienated?

KB: This is a wonderful question. Before I ever liked myself, I learned to love you, [Alice Wong](#), and [Rebecca Cokley](#), so I find safety in having a small community, keeping my circles small, and knowing that the people who care about me will get it. At first, I didn't understand why the Black community doesn't talk much about disability and why the disability community refuses to talk about Blackness, queerness, and homophobia. But building communities within the larger community [helped me] see my own worth. I felt like I could fight a little harder knowing that [even] if I have nothing else, I have the three of you who care and understand.

VT: I've known [Heather Watkins](#) for several years now. Heather was one of the first people I met in this space. Getting to know you and Alice Wong has been so important, but having a group of nonactivist friends has been helpful too. A lot of my friends who aren't in this space are also disabled. I know the work I do matters to them. There are people who knew me in college, in grad school, and have seen me at different stages of my life, so their respect for me really matters. I've seen what happens to people who don't have folks who can keep them grounded and make sure they're not out here embarrassing themselves and possibly fumbling opportunities. I don't have to be the "activist friend"; I can just be Vilissa. Honestly, disability activism isn't a safe space for me. If I could do it all over again, there would be a whole lot of people I wouldn't have friended.

KB: I have friends from college and even some from high school who have seen me trip over rolls of toilet paper and do really embarrassing things, and they don't care. It's really nice to have those friends and family who keep me grounded and are like, "Calm down. You're not Oprah [Winfrey]."

What is something outside of disability work that you're dying to do but haven't yet?

VT: I've loosely talked about voice acting and maybe regular acting at some point. I have this idea for a web series that I would either star in or have somebody that has a similar disability [star in]. Voice acting will allow me to do something that's creative and very different from

anything I'm doing now. I like doing things that push the envelope. I wouldn't mind doing some modeling. It's something different that would allow me to express myself [creatively] and use my talents in ways that create representation. So many things we do create representation.

KB: I've been taking acting classes since the start of the pandemic because they've been available via Zoom. That's the thing I've always wanted, but I never thought it was possible. I want to write more books. Fiction is my first love, so I'm working on that. There are a lot of things I want to dive into, but I think the biggest among them is acting and making sure I give it my all. I'm cowriting a musical. I'm just trying to dive into everything I possibly can.

VT: It's about seeing if you can do it and get better with time. We both write. We both can remember the first praise [we received for] something we wrote and that giving us the motivation to keep writing. Sometimes it's just nice to have things that are just for you and aren't about the community or the bigger picture. Modeling, voice acting, and acting are for me. If it's successful in other ways, great, but this is for me. Being good isn't really the point.

A lot of the work we do comes with the inherent assumption that we must teach what we know, but what do you wish people already knew?

KB: [The American with Disabilities Act](#) is 30 years old, but it's still not being enforced the way it needs to be. Disabled people are people, and we deserve the chance to enter the spaces that everybody else gets to enter and have the opportunities that everybody else gets to have. It's not about feeling like you did a good deed by helping out one disabled person; you should want to help us because you're missing out on a whole group of people who have amazing things to offer. When you don't have accessible spaces, you're missing out on those people.

VT: I do a lot of one-on-one trainings, and I [enjoy them] because I love seeing light bulbs go off. I enjoy seeing people disclose that they're disabled, and sometimes you can tell that that's the first time they've spoken it aloud. To be a witness to that is so powerful. When I first got into the Black nerd, a.k.a. Blerd, community five years ago, every once in a while someone might [have said] something about their mental health, anxiety, or chronic illness, but now everybody's talking about it. I love that. I wish people would learn you don't have to be estranged from your disability identity due to stigma, shame, or other people being uncomfortable. You should embrace it. When I [lead] certain trainings or I'm in certain settings, people, especially Black women femmes, start to disclose things. It shows me that being yourself matters in ways that you will never comprehend.

What great TV shows, movies, and artists are you watching and listening to right now?

VT: The Game Show Network is the one channel I have on all evening. It's really funny. I love Steve Harvey on *Family Feud*; his foolishness brings me so much joy. The music from

my adolescence and young adult years really makes me happy. That music takes me back to high school, to college, to just being free. After DMX died, I would listen to “Party Up.” It was lit when that song came on during my middle-school prom. Should any of us have been listening to “Party Up” at 13? Of course not. I shouldn’t have been listening to a lot of music that was marketed to me. Do you ever listen to old Britney Spears and Christina Aguilera songs? I had no business singing those [songs] at 15, but now, at 35, [when I listen to them] I still feel the same joy I did as a teenager. Music is a time capsule. I love Megan Thee Stallion. I love Cardi B. But old school Destiny’s Child, old school Beyoncé—particularly after she [released] her first couple solo albums—really defined a confusing time in my life. Being a teenager and young adult is hard. I would never want to go back, but that music still transports me to a simpler time.

KB: I’m the same way with music. Taylor Swift’s re-recorded *Fearless* album has been in heavy rotation over here. [I’m listening to] a lot of Megan Thee Stallion and some Cardi B—“Up” is so catchy. I’ve started rewatching *The Nanny*. I’ve been watching a lot of stuff on Netflix. A lot of streaming networks have really good stuff right now, but I’m also going back to old stuff and finding joy in that. I’ve been listening to a lot of podcasts lately too. [Brittany Packnett Cunningham’s *Undistracted* podcast](#) is so good. I’m listening to [Roxane Gay and Tressie McMillan Cottom’s podcast, *Hear to Slay*](#), on Luminary.

VT: I’m glad you mentioned the podcasts because if I’m not listening to old-school music or watching *Family Feud*, I’m listening to true crime podcasts like [My Favorite Murder](#), [Wine & Crime](#), [Crime Junkie](#), and [Moms and Murder](#). True crime intrigues me because I have a background in social work and psychology. True crime kind of gives me the ability to learn [about] people’s twisted nature and just how twisted people can get.

How do you foster joy and hope just for yourself and not for the consumption of others?

KB: I do the things I enjoy doing and listen to the music I want to listen to. I’ve really been on an [Aly & AJ](#) kick, who I used to love when I was in middle school. They have new music out. Hayley Williams from Paramore has two albums out that slap so hard. I’m also unapologetic about making sure I take time for myself. I used to constantly work on the weekends, but now I’m at a place where taking days off brings me joy. Taking time away from social media, or even being on social media and not having to post about anything, fosters joy. Whether it’s watching four or five episodes of *The Nanny* in a row or eating pizza, I’m pouring back into myself.

VT: I reduce static. I don’t feel like I always have to be in the mix. I care more about what I want to do versus what everybody else is doing or what people may expect me to do. Hypervisibility and hyperconsumption are draining. You’re expected to perform all the time or be like an ambulance chaser for every critical issue that exists. If you’re not mindful, you’ll lose yourself. I foster joy and hope by being intentional about what I want to do.

I've been doing that [more] during the pandemic. I've taken an astrology class. I'm doing a virtual writing retreat right now. I [recently] took my first wine course. I'm doing whatever the hell I want to do and being unapologetic about it. I'm single and childless; I don't have to answer to anybody. That is freedom.

Being older allows me the freedom of not caring so much. Being more selfish is important to me because I'm a giver. It's important for me not to lose myself in the chaos of whatever drama's going on within the community. None of that is going to matter six months from now. That's the way I think: If it's not going to matter to me a year from now or five years from now, then to hell with it. Peace is so important because we live in a world of chaos. There's always some injustice or some inconceivable nonsense happening in this world, so protecting my peace has been important for me. I've made myself less available, which has been so freeing.

What have you learned about yourself from doing this work and existing in these spaces?

KB: I'm so much more than I ever thought [I was]. When I first started doing disability activism, I was afraid of being pigeonholed. But now I know I can do my work while knowing I'm more than just a disability advocate. I get to be all things at once.

VT: I've learned that no matter what identities people have, they can still be asshats. Don't let the asshats bother you, distract you, or make you feel like you shouldn't be in the space. Knowing that has allowed me to take ownership of my work and who I am. I care about the people that matter to me. I care about the work I do. I care about the issues I fight for and talk about, but the people that are distractions don't mean anything to me. What I'm doing is bigger than what they would ever understand.

People don't have to understand my purpose as long as I understand it. Being in this space and dealing with some of the things I have dealt with has made me very unapologetic about embracing who I am and speaking my truth. I have a background in psychology and social work. I'm a southern Black woman raised by a grandmother who grew up in rural South Carolina under Jim Crow. I bring all of that into my work. When people within these spaces, particularly disability spaces, try to tear me down or make me feel less than, [I have to remember that in] some ways, they're afraid of me. People in this space are afraid of Black disabled women who are unapologetic, bold, and passionate. But there's nothing anyone can say or do to take away my Black disabled joy. The work is bigger than me. I will never allow accolades, connections, or egos to distract me from that reality because I'm leaving behind a legacy. We've had to fight to be in the position we're in.

KB: You're right. It scares people [to see us being] open, bold, and unapologetic because we're not following the status quo. We're [perceived as] a threat. But I don't need the approval or the applause of people who would stab me in the back as soon as I turn. I don't worry about whether my work is palatable for people who don't [understand] my experience. I have people

in my life who will either call me out or call me in, but the rest of it doesn't matter. So many people get upset when one person prospers, but they're upset because they didn't do it first. When I first created [#DisabledAndCute](#), some white disabled people [objected]: "Why would you use that word? It's infantilizing. You're hurting the disability community." My little heart was broken at the time, but now I know that hatred stems from jealousy. It's not my fault you feel that way. If you want to start a movement, do it, but don't harp on somebody else doing something you wish you could have done.

VT: I definitely felt that when I created [#DisabilityTooWhite](#) five years ago. That was the first time I'd ever been called the n-word. It showed me the foulness of the [disability] community and its resistance to talking about the truth. When Black women create innovative things, everybody wants to say, "Listen to Black women; support Black women." But when Black women actually put [themselves] out there, you don't appreciate it.

KB: Right. After I was on the [Today Show](#), this white lady emailed me and said, "I bought your book, and I just want you to know that I burned it." She said I talked too much about what it meant for me to be Black and disabled, and she said, "I thought this was going to be a disability rallying cry, but you made it about race." I didn't respond to her, but I really wish I would have said, "You bought the book, so thanks for the purchase." That's the problem I have with certain white disabled people. They want to be racist in peace. They don't want to talk about things they can't personally relate to, so they want to leave out every other identity.

VT: I'm sorry she had the gall to even reach out to you and tell you that. But those are the kinds of responses that Black women receive. When we share our realities, white people and non-Black people of color fail to understand that there are nuggets in our stories that they can relate to as well. When people have that type of response, we know they were never supportive in the first place. Their support was conditional. Black women aren't safe in online spaces, and [these spaces] don't care enough to ensure we're safe. But when Black women are safe on these platforms, then everybody will be safe.

This conversation has been edited and condensed for clarity and length.

Minneapolis Uses Mutual Aid to Fight for Collective Liberation

by [Teighlor McGee](#)



Illustration by [Ananya Rao-Middleton](#)

Since the pandemic began, communities of color have been witnessing many white people seemingly discovering the concept of mutual aid for the first time. From democratic socialist groups launching mutual-aid initiatives in the communities they colonize to groups working within the nonprofit industrial complex, white people have been actively columbusing mutual-aid ideas and rhetoric under the guise of advancing progressive values. Since Christianity's conception, some white folks have been devout followers of the [Catholic charity model](#), which suggests that it's an individual's responsibility to combat racism, poverty, and other systemic issues. However, there's an inherent performativity that exists at the core of this philosophy—a belief that any singular person can make a significant dent in the unending battle to end oppressive systems. This idea reflects a deep

ignorance regarding the depth of these issues. Being invested in a model that upholds this rampant individualism, similar to the American bootstrap mentality, means caring more about maintaining the appearance of offering public support rather than authentically investing in building the communities necessary to dismantle harmful systems.

Many folks believe that charities and nonprofits are not truly committed to addressing and eradicating harm because if these harmful systems were eradicated there would be no need for them to exist. My father worked for the local ABC News affiliate, so I watched the evening news religiously growing up and witnessed story after story of “well-meaning” white Americans engaging in performative acts of goodwill. News anchors would crawl into tunnels and seek to find homeless people to appear on camera receiving charity. Every food drive organized or hot meal purchased had to be captured for the entire Southeastern Wisconsin area’s 6 p.m. news hour. Most, if not all, of these acts were directed toward the Black community, and they were the complete antithesis of mutual aid. As a concept, mutual aid requires us to consider the collective needs of the communities we live in. This can look like talking to neighbors to organize a rent strike, offering to pick up groceries for elderly people in your building, or shoveling your disabled neighbor’s driveway after a snowstorm. In order to center the needs of the most marginalized in the collective, one has to belong to that collective.

Charity, on the other hand, allows privileged individuals to make monetary donations toward “needy” causes in exchange for a tax writeoff. Charity isn’t a form of justice; it’s completely devoid of community investment because it doesn’t require the donor to be immersed in the community they’re donating to. In direct contrast, mutual aid can appear in many forms, whether through the distribution of funds for communities, donating to help fulfill the needs of an individual in a marginalized community, or organizing and sharing resources for members of said communities. The various forms in which mutual aid exists is why it’s so accessible. Accessibility and dignity are key components of mutual aid when disabled folks have the opportunity to be both the organizers and recipients of mutual aid. [There’s nothing about us without us!](#) Organizing mutual aid in the face of a global pandemic has meant that the majority of this work occurs virtually, which ensures that disabled community members such as myself have a seat at the table. Digital organizing and virtual events work to eliminate many of the accessibility barriers that disabled community members face in traditional movement spaces.

In my own work as the creator of [Black Disability Collective](#), we try to do mutual aid Fridays where we boost fundraisers from community members to our [28,000 followers on Twitter](#) in hopes of helping them meet their individual goals, which range from supporting single mothers, to top surgery fundraisers. When I was a child, I learned about what we now call “solidarity not charity” from my Black church community. Within the walls of my house of worship, I watched folks receive aid organized by their own community with the dignity they deserved. Preserving that dignity is a vital distinction between mutual aid and charity. Providing someone with their unmet needs should never come at the cost of their self-respect. The performativity of charity does not prioritize upholding the dignity and autonomy of our community member’s needs. For Easter, baskets of goodies were made for kids so their parents wouldn’t have to worry. Every summer we fundraised trips to the aquarium and the state fair so the younger children could have something to look forward to. During the winter we collected wish lists from parents so we could help provide their kids with a proper Christmas. The concept of “solidarity not charity” includes the understanding that mutual aid can’t exist without accessibility, dignity, and community care.

Mutual aid isn’t a new concept. Our communities have been organizing calls for mutual aid for generations because it serves as a necessary component of a community care model of engagement. In response to the COVID-19 pandemic, mutual aid has been used in Minneapolis to serve the needs of multiple communities. Resources such as the [Twin Cities Mutual Aid Map](#) serve as an accessible guide for those seeking to donate. Another organization I work for, [Women for Political Change \(WFPC\)](#), launched a mutual-aid program in March 2020 where women, transgender, and nonbinary folks can receive a \$200 stipend, prioritizing Black and Indigenous applicants. WFPC also [created a guide for assisting folks](#) in creating their own mutual-aid pods. Rebel Sidney Black defines a pod as “[a microcosm of “community.”](#) Since it’s more concrete, it’s easier to get organized—to connect, make a plan, and follow through if and when it’s needed.” [Pod mapping](#) was originally developed by Mia Mingus as an accountability tool, but can be adapted in order to help people assess who they can rely on for support. There can be different pods for different circumstances.

Mutual-aid pods are rooted in disability justice, and the innate idea that we will not leave a single one of us behind. Through an adaptation of pod mapping, folks are able to identify who in their community has the resources they need to navigate the COVID-19 pandemic, and beyond. There’s a specific [Trans Disabled Care Fund](#) in the Twin Cities that uses

Patreon, a membership platform for content creators, to work to address the financial needs of disabled trans folks by offering \$100 payments over the course of six months or one lump sum of \$600. Facebook groups have even been created with the sole purpose of organizing mutual aid. In the wake of George Floyd and Daunte Wright's murders at the hands of police, folks in Minneapolis have worked tirelessly to organize mutual aid for the Black community. [More than one-third of individuals killed by the police](#) are disabled, and a number of high-profile cases in recent years have featured Black disabled victims, such as Sandra Bland, Eric Garner, and Freddie Gray.

As a direct result of this, mutual-aid groups are popping up to support people in their communities. For example, as a result of Brooklyn Center residents being tear-gassed by police in their own homes, the [Brooklyn Center Protestor + Resident Safety and Mutual Aid Group](#) was created. This group, made up of people associated with Brooklyn Center, organized volunteers and collected supplies for displaced residents. They put out calls for laundry baskets of items so that the residents who live near where the protests occurred would have access to any items they may need. Other groups such as [Documenting MN](#), a community-led journalism project that revolved around the Derek Chauvin trial, assisted with organizing in Brooklyn Center. Organizing mutual-aid efforts requires community members to unite around common goals and address outstanding needs. In order to have healthy mutual-aid infrastructure within our communities, we must work intentionally to dismantle our egos. In order to position mutual aid as the antithesis of the charity model, we must consistently resist the urge to center ourselves at the detriment of the collective. By dismantling our egos we are doing due diligence to ensure that the needs of those most marginalized remain centered. When we fall into an ego trap, we become unable to fight for the solutions necessary for our overall survival. We are capable of facing our human desires of self importance by recognizing moments where our egos can cause conflict and get in the way of our work.

This recognition will allow us to navigate through conflict, and return our focus back toward fighting to dismantle oppressive systems, and toward advocating for the power of community care through mutual aid. This work isn't rooted in any singular organizer or individual but rather in fighting for the survival of the most marginalized members of the collective. Mutual aid is not a performance; it's a lifelong community practice. Through mutual aid, I can see the ways my community is fighting toward a path of collective liberation, one where chronically ill Black people, myself included, are centered and cared for. Throughout the course of this pandemic, directly in the face of Black death, mutual

aid has helped save my life. I received mutual-aid funds that allowed me to pay my rent while I was out of work during the beginning of the pandemic. The trans and disabled mutual aid fund helped me afford my expensive medications. The mutual aid I received via the Black Disability Collective Twitter helped me purchase new tires that enabled me to safely drive home. Receiving mutual aid has never made me feel as if I had to sacrifice my dignity in exchange for keeping a roof over my head. Mutual aid has never made me feel ashamed and beg people with more class privilege than myself to pay for my groceries. Mutual aid is a complete disruption of the charity model, because it centers the most marginalized while upholding their self-respect. I'm profoundly grateful to live in Minneapolis, a city that's allocating mutual aid to actively fight to free us all.