



INCLUDE

November 2021

Disability in the new workplace:

What companies need to know and do

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It wasn't a me problem, it was the system that was set up against people like myself.

MARYAM AJAYI

More than one in four adults in the United States is disabled,¹

and disabled people are a big part of our workforce. Disability affects all of us. As we age, disability becomes more common; 2 in 5 people age 65 or above are disabled.² As we try to manage health impacts from Covid-19, racism, and climate change, our disabled population is growing; more than 23% of people who had Covid had lingering health issues.³ Disability and its likelihood are a significant part of our community and workplaces.

So is [ableism](#) (prejudice and systemic discrimination against disabled people). We surveyed almost 3,000 people across the globe and 1,964 people (70%) identified with at least one or more disabilities.⁴ We've analyzed those responses as a follow up to our [initial report](#) (on how Covid has impacted harm in our workplaces) to provide a fuller understanding of how ableism creates problems in our workplaces and what we should do to identify it and intervene in it. We learned a lot of this information for the first time thanks to disabled people who took our survey, disability activists who granted us interviews, and the disability justice

movement as a whole, but ableism is not new to our workplaces or to the disability community.⁵

Our focus for research was on harm in the workplace and a desire to ensure all people, especially people from marginalized identities, are treated fairly at work. In creating our survey and analyzing its findings, we used an [intersectional](#) lens, as defined by Professor Kimberlé Crenshaw, and centered the people who experienced disproportionate harm. In our first report, we found that disabled people were more likely to have experienced an increase in anxiety since the pandemic. We also found that people who are neurodivergent or have multiple mental health conditions are three times as likely as others to strongly agree that there's more pressure to be online. We wanted to share these and other workplace experiences on a more disaggregated level and to encourage companies to acknowledge and reduce these harms.

Disabled people often experience problems with environments most, and solving problems for them often solves problems for many. Another way of thinking about disability is that it is less about how people are not working in a particular

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“Cut into the curb, and we create a path forward for everyone.”⁶

The “curb-cut effect” describes how more inclusive design and policies for one community can benefit many. In the early 1970s, a Berkeley activist poured concrete to make a small ramp from the curb to the street for better wheelchair access. The city eventually installed curb cuts more broadly to give wheelchair users more freedom and mobility throughout Berkeley. Parents with strollers, travelers with rolling luggage, shoppers with carts, workers with trolleys, skateboarders and rollerbladers, and others in the community appreciated them as well.

environment, and more about how an environment is failing to work for people. The curb-cut effect is a real-life example.

We also want to emphasize that disabled people contribute positively to our workforce, even though it is not a focus of our research; unfortunately it still needs to be stated explicitly.⁷ Inclusion of disabled people improves corporate performance; an Accenture study showed companies that are inclusive of disabled workers had 28% higher revenue, double the net income, and 30% higher profit margins.⁸ Yet disabled people are still twice as likely to be unemployed as non-disabled people, with an unemployment rate of 9.7% compared to 4.5%.⁹

Some people with non-apparent disabilities refuse to ask for accommodations, telling themselves to save it for the ‘real’ disabled people. That kind of thinking is internalized ableism and does not help anyone. If you have a mental health condition that substantially limits one or more major life activities, then that’s a disability under the ADA. Employers should create supportive workplaces where anyone who needs a disability accommodation feels safe making that request.

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There's a substantial differential between the number of disabled people in the population and the number of disabled people actually in the workforce.

And, as Haben Girma told us, "Many of those who are in the workforce feel terrified of employment discrimination, and are often hiding their needs for fear of discrimination." A number of respondents shared having to go out of their way, take on exhausting, difficult tasks that push their body past its limit in order to mask their disability and be taken seriously at work.

We found several themes in the qualitative survey responses and in our conversations with experts. Distrust was one of the biggest themes that surfaced. This distrust stems from broad societal ableism inside and outside the workplace. It means our society doesn't trust disabled people to know what they need, to have a clear understanding of their capacity, and to know the ways their disability impacts their everyday lives. Many people have written about these patterns of distrust that make it more difficult for disabled people to thrive in our society,¹⁰ and all our experts described how disabled people are often unfairly assumed to be untrustworthy at work.

Some people do not self-identify as disabled; even though 70% of survey takers said they had one or more specific disabilities, only 9% self-identified as disabled. 16% of survey takers did not answer one or more of the three survey questions about disabilities.

"Nearly every disabled person has been told at one time or another 'you're faking it.'"

HABEN GIMA

Overview

For the 1,964 respondents whose experiences we focused on in this report:

23.6%	have anxiety
1.9%	are blind or have low vision
10.5%	have chronic pain or illness
1.5%	are D/deaf or hard of hearing
7%	have depression
2.6%	are neurodivergent
1.1%	have PTSD
0.4%	use a wheelchair or other assisted device
4.0%	specified otherwise as described below
47.4%	have or experienced more than one of the above

When asked “Do you identify as disabled?” 9% of all respondents said “yes,” and 1% chose to individually expand on the question with more nuance. Most of the latter respondents (85%) shared they were disabled but didn’t choose “yes” for various reasons, often saying “it’s complicated,” “sometimes,” or because their disabilities are non-apparent, temporary, or partial. Some mentioned that they chose not to disclose their disability at work, with several mentioning fear of discrimination as the reason.

When asked what kinds of disabilities or conditions people had, 4% of disabled respondents chose to write in longform answers. People named ADHD, asthma, autism, bipolar, chronic or physical injuries, CPTSD, diabetes, dyslexia, eating disorders, endometriosis, insomnia, limited mobility or vision,

migraines, OCD, racism, surviving strokes, trauma-induced stress, and more.

We deliberately choose to use one category for disabilities in this report, moving away from the two-category approach in our survey questions.¹¹

The variety of experiences that disabled respondents shared highlight both the nuances and burdens people have when considering when and how to report or disclose when it comes to disabilities, especially in the workplace. It’s also a reminder that the term disability includes a wide range of individuals and experiences.

I think that one of the things that people get mixed up with a lot is that able-bodied people are not necessarily not disabled. [I] have started to call everybody who doesn't have a disability 'abled people,' because that covers both physical and mental and invisible disability. A lot of them are hiding the fact, because people have a special kind of harassment for those people.

TINU ABAYOMI-PAUL

Harmful Ableist Myth	Truth
<p>Disabilities are conquerable; they can be overcome and “fixed.” You must be pretending or not trying hard enough if you are disabled.</p>	<p>Many people have disabilities that cannot be overcome and/or do not inherently need to be overcome. The level of disability people experience often varies day-to-day. People do not show up the same way every time.</p>
<p>People fake disability to get disability payments from the government or their employees or to obtain drugs they don’t need.</p>	<p>Applying for and maintaining disability status is hard. Pain medications are so heavily regulated that it is often hard to get a number of medicines as a disabled person.</p>
<p>Disability is binary. Disability is physical. Mental disability is not a physical disability. Disability levels are constant. Wheelchairs and devices are always or never needed.</p>	<p>Disability falls on a spectrum. It has many forms, including mobility, neurological, psychiatric, intellectual, learning, ADHD, speech and language, ASD, visual, hearing, medical, brain injury. People vary in the level of help they need from each other and on their own, and individuals vary in their needs day to day. Some people need assistance sometimes; others may need it all the time. Doing more one day will make some people need to do less the next day(s) to recover.</p>
<p>Disabilities are a punishment, and people with disabilities are defined by their suffering and victimization.¹³</p>	<p>Disabilities can happen to anyone, and will happen to most of us as we age. Post-Covid symptoms can be disabilities, and we don’t know how many people are or will be affected.</p>

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People don't understand the concept of flare ups. 'Why aren't you pushing through and doing what you always do?' I think it's important for people to hear that it's not the same thing every day. And it's not a choice to push through or not.

MARYAM AJAYI

Another recurring theme in our research was the systemic impact of distrust and ableism on the workplace. One form of it was accessibility gate-keeping, where companies force workers to disclose their disabilities and then provide “proof” to access accommodations and medical or disability leave. Managers also exhibited ableism in the form of increased micromanagement and surveillance of disabled people.

Since Covid-19, expectations of longer work hours and more availability affected most workers, but impacted disabled people even more, and especially Asian, Black, Latinx, and multiracial disabled people, and women and/or nonbinary disabled people. (Note: We used the broad category of “multiracial,” because we did not have enough respondents to analyze work experiences at the granular level of specific multiracial groups, such as Asian Black, Black Indigenous, or Black Latinx people.¹⁴)

We learned of many disabled people quitting their jobs since the pandemic because of these negative experiences. Many opted to take on

freelance work even though these jobs often paid less and offered less employment security and medical coverage or none at all.

In addition to distrust, we found disabled people were more likely to experience increased harassment and hostility since Covid-19 than non-disabled people, and women and nonbinary disabled people were even more likely. Harassment can include yelling at coworkers, uncomfortable or repeated questions about identity or appearance, dismissive attitudes, teasing put-downs, repeated requests for dates, groping or grinding, or quid pro quo requests for sex.¹⁵ We found that harassment of disabled people often included statements of distrust, especially questioning the credibility of disabled coworkers around their level of disability and need for accommodations. It often came up in the form of challenging whether they were able to do more of a work activity—ranging from flying on a plane to commuting to work to walking without a wheelchair—because they had shown an ability to do the activity at some point at some level once.

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“Some of the things that I find to be extremely frustrating about the discourse on returning to in-person work are the failures to account for the ways that Black and Brown disabled folks have a whole different set of challenges that we navigate. As people talk about compelling return to the office, whatever that means, questions arise for me about the amount of time that we just forfeit as a result. I reflect on the extent to which we, as disabled workers of color, are much more likely to live further away from the place we are commuting to than white non-disabled folks in our organizations, who are more likely to be part of the leadership structure trying to bring people back into the office. I’m also thinking about people who work irregular schedules or don’t know their schedule in advance and how absolutely difficult and challenging that is in normal circumstances, let alone in a pandemic. And the extent to which disabled workers and workers of color who are overrepresented in those kinds of sectors and work impossibly long and irregular hours face real adverse health effects as a consequence and face real barriers to being able to meet their own needs—and as a consequence, experience higher rates of burnout, depletion and other adverse outcomes.”

AZZA ALTIRAI

9%

identified as disabled

70%

have a disability

16%

did not answer at least one question about disability

Overview

This systemic ableism and the stigmatization of disabled people make it harder for disabled people to trust their coworkers and companies. It is a significant factor when disabled people decide whether or not to share their disabled identities with others, especially coworkers, managers, and HR.

Unsurprisingly, disabled people are often uncomfortable disclosing their disability at work. Several survey respondents wrote long-form answers about not wanting to disclose their disabled identity to their employers, because of a lack of trust from employers that led to a lack of trust of disabled people, and our experts described significant problems and experiences around trust and disclosure.

This lack of trust also means that while disabled people are more likely to have experienced harassment, they are equally unlikely to report it as non-disabled people.¹⁶ Disabled people were twice as likely to have experienced harassment than non-disabled people. The harm was compounded for people with multiple disabilities, who are most likely to have experienced harassment. Disabled people were also more likely to lack company support in calling out harm in the first place. Only half as many disabled people reported harassment compared to the number of disabled people who experienced it. One third of disabled people (33%) shared that they did not have company support to call out harm or harassment at work in the first place. Nearly a quarter of non-disabled people (24%) felt the same.

Disabled respondents shared many factors ranging from individual to institutional experiences, from emotional to financial to legal fears or harms, in their decisions whether to report harassment to someone in power, whether to disclose their disability/ies at work, and/or even how to answer our anonymous survey. For example, multiple disabled respondents shared they used to report harassment, but have since learned not to report from past experience, with some saying nothing was done. Others said they feared losing their jobs if they reported. Sometimes the person perpetuating harm was in HR or the CEO themselves, so there was no one to report to.

On the one hand, if you mask [your disability] then you're being lazy and ineffective and a whiner and a complainer. Because you don't really want to tell people about the reason why you're having these complaints is that you're disabled. On the other hand, it can be dangerous for people to disclose and some people don't care.

TINU ABAYOMI-PAUL

Overview

We share a list of solutions we encourage companies, leaders, and managers to adopt. Core to those solutions are:

Rebuilding culture. Fairness requires dismantling ableism and rebuilding trust. Dispelling societal myths and false assumptions is important. So is education on the systemic nature of ableism and solutions that are needed. Companies, managers, and HR teams need to trust disabled people and earn the trust of disabled people, so in turn disabled people can trust companies. Representation is key to fairness and dismantling ableism.

Solutions and accommodations should be personalized and flexible to empower workers to choose what works best for them. There is no one-size-fits-all or global blanket solution.

Accommodate all needs and accessibility as a default. Remove the gates that prevent all workers from getting what they need to do their work most effectively.

Communicate better. Manage better with fewer meetings and more open information sharing. Again, more flexibility and individual level solutions are important.

If you read our previous report, you know that many of these recommendations are consistent with and often similar to our first report's recommendations for companies. Please read on to understand the unique ways these harms impact disabled people and the solutions to address them that can help everyone in your company.

It's hard to overcome when they see everything as you're trying to cheat them in some way.

MARYAM AJAYI

Disabled people experience several types of distrust.¹⁷ **Individual distrust** comes from people treating them like their disability is a burden, causing them to feel badly about their disabilities and to doubt their right to be treated fairly. **Ideological distrust** comes from the belief that non-disabled people as a group are superior to them—more intelligent, hard working, capable, deserving, and so on, and that this status gives non-disabled people rights of control over them. **Interpersonal distrust** takes the idea of one group's superiority to a personal level, giving permission for individuals to disrespect or mistreat a disabled individual. **Institutional distrust** embeds the idea of one group's superiority into institutions like media, the workplace, the legal systems, policies, political power, medicine, and more.

These types of distrust have real impacts on the structure and culture of workplaces and how everyone, especially disabled people, experience them.

IMPACT 1: Coworkers harass and otherwise harm disabled people, calling them cheaters and worse.

IMPACT 2: Companies discriminate based on disability. They put obstacles in the way of or completely block accommodations.

IMPACT 3: Disabled people have to decide whether or not to disclose their disabilities and needs for accommodations.

IMPACT 4: Managers put added unfair work expectations or surveillance on disabled people.

Distrust and its Impacts

Impact 1

The harassment and harm of disabled people is tied to a deep societal problem that manifests at work, too. All our experts described how disabled people are often unfairly assumed to be untrustworthy, and they may be treated as liars, cheaters, or fakes. In the US, many people misunderstand the Americans with Disabilities Act, which prohibits employer discrimination based on a disability and requires accommodations to disabled employees. They assume disabled people can get whatever they want under the ADA, and that employees fake disabilities to benefit.

We also asked about harassment based on disability on our survey; 33% of disabled people with multiple disabilities, 19% of people with chronic illness or pain, 16% of people who are D/deaf or hard of hearing, and 12% of disabled people with individually specified disabilities experienced an increase in harassment based on disability since Covid. People with multiple mental health conditions and/or mental disabilities were nearly 10x as likely as people with no mental health conditions to experience an increase in disability-based harassment since the pandemic. Specifically, 13% of people with individually specified mental health conditions, 9% of people with multiple mental health conditions, 8% of people with PTSD, 3% of neurodivergent people, 3% of people with depression, 1% of people with anxiety, and 1% of people with no mental health conditions experienced an increase in disability-based harassment since the pandemic.

“People do harass us, especially online and definitely at work. They are upset because of a disabled parking space. They don’t understand that you can use a wheelchair sometimes and be ambulatory. They think you should be 100% paralyzed. There is usually a scale. At the workplace, you get harassed from colleagues and HR.”

TINU ABAYOMI-PAUL

Distrust and its Impacts

“When everybody was home, everybody was online, and they came into contact with us more than they normally do, and then when they did, there’s several types of harassment. I learned when I got cancer about special cancer trolls: They look for people who have cancer and they say that we’re faking.... When you’re at that state, it takes everything up physically, it takes everything mentally, and it is the most hurtful thing to have somebody deny your experience.”

TINU ABAYOMI-PAUL

Our survey results showed that many disabled people experienced hostility, harassment, or inappropriate behavior from coworkers, too, at work, and the likelihood of harm varied by disability. People with chronic illness/pain (44%), blind people (48%), or people with multiple disabilities (56%) were twice as likely to have experienced these harms as non-disabled people (24%). In comparison, 15% of people who are D/deaf or hard of hearing experienced these harms.

We also used an intersectional lens. For disabled people, the difference in harm experienced was even greater by gender. For people with chronic illness or pain, 71% of non-binary/genderqueer women, 64% of non-binary/genderqueer people, and 49% of women who identified solely as women¹⁸ experienced harm since the pandemic (this was 16% of all non-binary/genderqueer women, 10% of all non-binary/genderqueer people, and 5% of all people who solely identified as women). In comparison 0% of people who identified solely as men experienced harm, despite being 56% of all chronically disabled people or people with chronic illness/pain. For non-disabled people, around 10 to 20% of people of each gender experienced harm since the pandemic. Specifically, 24% of non-disabled women (identified solely) and 23% of non-disabled non-binary/genderqueer women experienced harm since the pandemic, double that of the 11% of non-disabled men.

Distrust and its Impacts

Impact 2

The distrust becomes part of the system. At work, company policies built with ableism can mean no accommodations and retaliation. The requirements for medical proof of disability and for disclosure of disability are problematic for their gatekeeping nature and binary framework. In the workplace, company policies—and the laws they are often based on—can make it hard for disabled people by requiring medical proof, filing paperwork, and disclosure to your coworkers.

“The onus of asking for accommodations is always on the person in our American setup of jobs. It’s almost never clear that kind of request would be entertained or accepted. Even to get the courage to ask for an accommodation in the workplace regardless of what it is, is really hard in our current setup.”

EMILY ACKERMAN

“They try to fight you. It’s capitalism: They want to reduce company expenditures and are upset when people have needs or ‘special needs.’”

TINU ABAYOMI-PAUL

“Environments that compel disclosure to the entire organization about your personal health status, to access needed accommodations, supports, or leave is itself ableist and harmful. This is especially the case in workplace environments where we’re at a disadvantage in a million different ways.”

AZZA ALTIRAIFI

Distrust and its Impacts

In one of my previous roles, my boss was a disabled person, but it remained a months-long fight to get my accommodations in place. Afterwards, I was subjected to exactly that form of surveillance where I had to check in for up to 30 minutes every single morning to recite every single task that I was going to do that day, in addition to a one-hour check-in in the middle of the week, to make sure that I was on track with that. I had a stellar performance and some of the highest volume of output on that team, but I was the only staff member subjected to this form of review and surveillance. I excelled; there's literally no other way to put it. And I still faced intense scrutiny and surveillance from senior management at my organization, and these were practices that were in place before the pandemic. I faced this kind of scrutiny in an organization and work environment which ostensibly understood the harms of ableism, but still allowed such practices to persist because the balance of power is so intensely skewed in favor of management. For me as an at-will employee, those kinds of disclosures of my disabilities and needs feel terrifying, because they'll make a claim or they'll reverse engineer something about my performance not being what they needed to justify greater surveillance or even termination, when in reality the actual nature of such a decision would be driven by ableism and my own disability....

“The vast majority of paid leave policies or medical leave policies are designed in such a way where I'm not going to qualify for short-term disability until after I've forfeited my wages for two weeks or entirely depleted my other leave options. Only after those two weeks elapse does short-term disability kick in. It is not uncommon for organizations to also not give you 100% of your wages while you are on short-term leave. All of these structures are in place because there is a fundamental distrust and power imbalance that capitalism fosters... It's like, are you really sick? What's our insurance against you faking this and taking advantage of the policy? It's withholding your full wages and refusing to actually let this kick in until you've gone two weeks without it.”

AZZA ALTIRAIFI

Distrust and its Impacts

Impact 3

The Disclosure Bind is real.

Distrust forces disabled people to decide whether to disclose their disability at work so they can get needed accommodations or not to disclose, which protects their personal privacy and avoids potential discrimination. If they disclose and ask for accommodations, they are often denied accommodations, made to “prove” their disability, or face consequences like being denied promotions or even fired. For many disabled people, medical requirements at work for proof of disability bring up medical trauma and make disclosure even more difficult.

“For people with non-apparent disabilities, like many mental health conditions, disclosure often has to be active. And self-acknowledging one’s mental health disabilities can take time. For a long time, I really grappled with coming to terms with my disability as it relates to my mental health. Because I always say it’s a privilege to have invisible disability, but always felt like it was kind of insignificant. Because I wasn’t ‘visibly’ disabled. It took a lot of knowledge, learning and knowledge around my own internalized ableism on the spectrum around disability.... And especially thinking about my boss that would literally message me throughout all hours of the night, and I was always expected to reply right away, no matter the circumstance. At that point, I was grappling with debilitating anxiety, and disclosing to HR, disclosing to my boss, and it almost became a test to see if I can ‘handle it,’ which I found to be super inappropriate and wild. And then thinking about a boss that was on a different continent in a different timezone and expecting me to be at her beck and call, what would be at all times of the morning for myself, and to work until she was done working, which would be late in the night for her and myself. This thing of no regard to just me and my humanity in general, but also that pressure that puts on someone to deal with that expectation who is also dealing with mental illness. And then to also think about not accommodating what it might be like for me to be in a chair for 12 hours out of the day, if it’s someone that suffers from chronic pain.”

MARYAM AJAYI

Distrust and its Impacts

“A lot of my friends, including myself, are traumatized from the experiences that we’ve had interacting with the institution of medicine.”

TINU ABAYOMI-PAUL

The ableist myths create harmful expectations that make disclosure even harder.

“I was taught by everybody that you push through, and that’s actually the opposite of what I should’ve done. I could have preserved a lot more of my function for a lot longer if I had gotten a wheelchair and not seen it as a negative thing but as the freeing thing... You know you’re supposed to be a brave warrior, but for cancer, the energy you need is for survival and hanging on. Sometimes it’s not possible, and sometimes you need to rest.”

TINU ABAYOMI-PAUL

The policies and lack of trust from managers and their failure to respond can lead to disabled people to distrust them. When asked about experiences of workplace harm, multiple disabled respondents shared that they were not only denied basic disability accommodations, even some that are legally required, when requested, but their workplace also used their disability to deny promotions or fire them, in some cases despite strong performance reviews.

Several named ableism alongside racism or sexism as main factors in their harmful workplace experiences. Some disabled people felt pressured to work physically onsite during the pandemic

despite seeking accommodations for Covid-19 risk factors or had expectations of always being online or available. Others were denied paid leave, because managers either didn’t believe they were disabled or didn’t trust them to work due to having doctor appointments. One disabled person was told by a leader that being disabled was a “preference.”

“They hear about other people, ‘I was requesting this accommodation and now my job might be in jeopardy, because now that I have let people know I have self-marginalized and I might be one of the first people out of the company. I’d be more expensive if I got my accommodation.’... People don’t feel like HR are their friend... When people get an accommodation at work and someone steals it, people have a hard time deciding whether to say it to HR or not. Then they don’t have the tool they need, but they don’t put themselves at risk.”

TINU ABAYOMI-PAUL

Distrust makes it hard to get input on needs and policies that would help disabled people, according to Azza: “It’s difficult to collect information without creating an environment of compulsory disclosure, which we would not want to do. I obviously talk about my disabilities, but a lot of people do not have the same kinds of supports and safety that equip them to be able to make those kinds of disclosures without fearing reprisal.”

Distrust and its Impacts

Impact 4: Distrustful managers can cause significant harm

Experts said distrust can lead to micromanagement from managers targeting disabled employees. More than a quarter of deaf people or people who are hard of hearing, 11% of disabled people with multiple disabilities, and 7% of chronically disabled people said their manager checked in with them 2 or more times per day. No blind or low vision people were checked on more than once a day; only 0.2% of non-disabled people were checked in between 2 and 5 times per day, and none were checked in with more than 5 times a day.

Maryam Ajayi experienced repeated checkins that she attributed to her disabilities even before the pandemic. “The boss would check on me multiple times a day, and it made me paranoid that I couldn’t do my job properly,” she said. “My job was in business development/sales, and those numbers don’t lie. I’m literally outperforming my other counterparts, and you’re not asking them how they’re doing if you can help them with anything. And sometimes when they turn in their stuff that Friday at noon, it’s not actually done. There’s no actual reaching out to help with compassion for actual support.”

Some managers did not communicate well online, and many disabled people experienced difficult conversations online with their managers that were poorly handled. 51% of disabled people with multiple disabilities, 36% with chronic illness or pain, 32% with individually specified disabilities, 26% who are deaf or hard of hearing people, 26% who are non-disabled, and 17% who are blind or low vision agreed or strongly agreed.

“You can have a lot of smart people in the room, but how many of them are actually like, emotionally intelligent. Those types of things, especially in tech, are not really valued. I think that there’s just a level of mindfulness that’s missing in managers, because they’re trying to live up to a facade about being a manager at a tech company. Everybody, relax and know your lane, and we’re also not saving lives. So, let’s bring the ego down a little bit. And it comes to just not feeling like they’re teachable.”

MARYAM AJAYI

Distrust and its Impacts

And many managers did not seem to care enough to improve.

“I did a series on wellness and the intersection of social justice for a company. It wasn’t until half-way through that I would see a breakthrough of why this was important with half of the people. And the rest of the people just being like, just tick this off my list of things I have to say I did. Not one of their leaders actually came to our series. Literally not one person in the C suite came.”

MARYAM AJAYI

Ableism also creates unfair work expectations of disabled people from managers and coworkers.

“Especially during the pandemic, I think that for me, it’s a privilege and a double-edged sword having invisible disability, because people are almost like, ‘well, you’re not that disabled,’ and then they also don’t understand it. And they also try to do a Google search and think that I should be a textbook x y and z. And if it doesn’t look like that to them, they’re questioning... I remember, in past work situations, someone said, ‘You had anxiety and you were able to fly for this four-hour trip. Why is it a problem with this eight-hour trip? This shouldn’t be an issue.’ You didn’t have to stay an extra day for your body to acclimate or assimilate to the timezone or to recover. You don’t need to stay an extra day.”

MARYAM AJAYI

The result is high work expectations and pressure. While some disabled people thrive in high stress environments, it can be particularly hard on other disabled workers.

“Things that are unique to being disabled like meeting personal care, doing daily living tasks, getting to work and all that other stuff on top of expected duties of employment. It’s very taxing to live. It’s taxing mentally to live in a society that’s not really made for us or welcoming in a lot of spaces.

“In our community, we really value and need time and rest, because our bodies and minds just don’t hold up to the amount of stress that those kinds of jobs demand. Then to make it a 24/7 thing, I needed a break. When you’re working from home, it’s like, ‘Why aren’t you answering my Slack message? Where’s this email? I want them 20 minutes ago and now I don’t have it. What are you doing?’

“A more systemic version is that there is this overwhelming view that to be successful you must put your body and your brain through an intense amount of work and working long hours, working the fastest, doing things with others that are harmful to you as far as your anxiety and your depression—like working with abusers.”

EMILY ACKERMAN

Distrust and its Impacts

People with certain disabilities were significantly more likely to feel increased pressure to be online for work: 54% of people with anxiety, 56% of people with individually specified mental health conditions, 60% of people with multiple mental health conditions, 60% of neurodivergent people, and 50% of people with PTSD felt increased pressure. In comparison, only 42% of people with no mental health conditions felt the same. People with multiple kinds of mental health conditions (such as anxiety, depression, or PTSD) were also twice as likely as people without mental health conditions to experience a lack of support system or safety net when dealing with stress, emotional issues, or mental health challenges at work (40% compared with 19%).

Work pressure and expectations under an intersectional lens

Racism impacted work pressure experienced by disabled people. 79% of Asian, Black, Latinx, and multiracial people with chronic illness/pain felt more pressure to be online compared with 57% of white people with chronic illness/pain who felt the same. We did not have enough Indigenous or Middle Eastern survey respondents with chronic illness or pain to share data on their experiences.¹⁹ 57% of non-disabled Asian people, 61% of non-disabled Black people, 49% of non-disabled Latinx people, 54% of non-disabled multiracial people, and 48% of non-disabled white people felt more pressure to be online. From the remaining small number of respondents, all non-disabled Indigenous people and half of non-physically

disabled Middle Eastern people felt more pressure to be online.²⁰

Similarly, 86% of Asian, Black, Latinx, and multiracial disabled people with multiple disabilities shared that their work day has gotten longer. 63% of white disabled people with multiple disabilities shared the same.²¹

“When you have biases, like racism and sexism and transphobia, and you have this added work pressure, and then you have this anxiety, they all build up on each other. And I would imagine it’s the same thing when you have this physical or mental disability: It will cause your other ones to get worse when you’re having a negative experience. It makes sense, but we don’t talk about it very much.”

MARYAM AJAYI

The pandemic was even worse for disabled people

We also found that disabled people with certain kinds of disabilities were more likely to have experienced increased anxiety since Covid: Disabled people who specified disabilities (91%), had chronic illness or pain (93%), or were deaf or hard of hearing (96%), had anxiety (89%), were neurodivergent (86%), or had PTSD (90%) felt increased anxiety, compared with non-disabled people (84%) and people who had depression (78%) who felt the same.²²

Distrust and its Impacts

Women and/or nonbinary people were the majority of disabled people who experienced increased anxiety: 84% of people with multiple disabilities, 84% of people with chronic illness/pain, 74% of deaf or hard of hearing people, and 58% of blind or low vision people who experienced increased anxiety were women and/or nonbinary people.

“It’s a weird moment of a premature and problematic push to return to the office, which threatens the wellbeing of disabled workers for whom remote work is a necessary and often difficult to come by accommodation. But it also fails to account for the ways that remote work wasn’t some silver bullet; a lot of the access issues and discrimination persisted, just in very different ways.”

AZZA ALTIRAIFI

“I’m so grateful that I’m actually working for myself during this time, because I hear horror stories of my peers that I know that are working for companies that are dealing with similar issues around expecting to be performing at their best, even though we’re going through a global pandemic and a racial uprising, to be available more than just nine to five. And then also just working literally for 9 to 5, 6, 7, 8 o’clock at night, without proper break, then expecting people to only show up on camera on time to zoom calls, and expecting people to always be on. It actually sends me into a tailspin when I hear about it.”

MARYAM AJAYI

For some disabled people, Covid led to a reevaluation and more self-advocacy.

“I’m more susceptible to Covid than the average person. I’ve been at home for the full two years, a year and a half or whatever; I don’t even know anymore. I have seen the benefit to being at home for me; one of them is that just like living and doing things, it’s easier for me. Coordinating the daily care that I get. In the Delta world, we don’t really know what’s going on. I feel more empowered now to tell my new employer that, for example, I don’t do rain very well. I have a really hard time holding an umbrella. I think up until the pandemic, I would have psyched myself up and sat in the rain and put myself in danger—because my chair doesn’t do well—to go to work. Now I feel more empowered to tell my boss, ‘Hey if it’s raining, I’m not coming.’ Because this work from home has taught me that I’m just as productive at home as I am at my office.”

EMILY ACKERMAN

Distrust and its Impacts

For many, the pandemic led to leaving their jobs and becoming contractors. Two experts said many of their disabled friends quit their full-time jobs to become independent contractors, because they valued the control and protections as a contractor, even if it meant less stability, fewer benefits, and less pay.

Maryam Ajayi tied work pressure to racism and to departures from companies since the start of the pandemic:

“A lot of my [disabled] friends, especially Black women, have either started their own company or been freelancing, because the pandemic made people do a lot of self inquiry and there was a lot of survival, but also, ‘I need to put myself first, and I can’t keep putting myself in toxic, harmful and violent situations.’”

MARYAM AJAYI

Azza said the pandemic exacerbated harms that she was already experiencing as a Black disabled femme:

“It really crystallized the extent to which my life, my access to health care, and therefore my literal life, and safety was tied to wage labor in a way that was terrifying, concerning and infuriating. It changed and shifted priorities for me, since the work that I was doing required me to spend so much time focused solely on wage labor. We’re facing an event that none of us have experienced in this lifetime, and I want to be able to be free enough and flexible enough in my workplace policies to tend to my needs and priorities outside of my wage labor output. This pandemic has crystallized for me why capitalism is a fundamentally exploitative, violent, and ableist structure—even amid the compounding crises and mass death events we are living through, we are expected to carry on producing and laboring as though nothing has changed. The pandemic has reoriented my priorities and radicalized me, and I refuse to remain at organizations whose policies and practices fail to support Black and disabled staff like me.”

AZZA ALTIRAIFI

The key to making life better for disabled people is for us not to be just talking among ourselves. They're going to hit everyone at some point. Anybody can be disabled at any time and some of the issues that they bring apply to all of us. When things happen to us then they spread out to other areas.

TINU ABAYOMI-PAUL

Making disabled people part of the workforce means doing the work to remove systemic ableism. That means including disabled people instead of blocking them. It means shifting from gatekeeping and obstacles to accessibility and accommodations as a default for all employees.

Dismantle harmful ableist myths. Understand that disabled people can have more than one disability, and that many may not be apparent. Many disabled people choose not to disclose their disabilities, because they have learned to distrust the company, their managers, and/or HR. Find better ways to communicate, set reasonable work expectations, give people leave with fewer obstacles, and share more information more broadly with fewer meetings.

We need systemic solutions to reimagine workplaces, ones based on disability justice. That requires every worker—including leaders, especially CEOs—to understand how ableism harms everyone and to learn from disabled leadership and communities about how to build a mutually trusting and caring culture, and to repair our relationships with each other and with work itself. We cannot dismantle ableism without rebuilding culture around trust, decision-making, inclusion, management practices, communication styles, accommodation processes, conflict resolution, and every other interaction at work.

Solutions

“I found in tech, there was a lot of bypassing and a lot of progressive language use, but actually not a lot of progressive and inclusive policies and spaces for people like myself to thrive. At the time, I didn’t know that I was neurodivergent, but I did suffer from chronic pain. I was very open about my PTSD, OCD, anxiety and depression and did disclose that to HR and to my boss, and a lot of times that was thrown against me, and especially being neurodivergent. I might stutter when I speak, and I was always told that I could never be a public speaker then, as opposed to my current boss who is helping me find a resource to work with my neurodivergence, with my anxiety and depression, especially with anxiety. A lot of times my previous boss would be like, ‘You can’t handle this responsibility, because you’re an anxious person, so we’re not going to give it to you,’ But it was never taken into consideration when I was flying and actually not able to function to the best of my ability.”

MARYAM AJAYI

Build trust between your company and its disabled workers.

Start with anti-ableism. Educate leaders and teams about disabilities to dispel false myths about disabled people. Provide disability training for all members, especially managers, recruiters, leadership and people running DEI efforts. Workers should learn about data and statistics on the benefits of diversity. Understand that you will not have all the data on disabled people, because you

are unlikely to eliminate distrust completely. Self-assess your company by answering [specific questions](#) that reveal where you are today in building a disability inclusive culture.

Understand and build solutions on an open framework.

People’s disability experiences and preferences are individualistic, not monolithic. Ask employees how they work best. Ask workers to provide input.

“I know myself better than my employer can generalize. So it doesn’t need to be a company-wide policy—like all people must be in the office—when nobody’s one-size-fits-all. Employers have this generalized approach because it seems easier to them. But it’s really stressful to workers. I don’t know anyone who’s fully happy with their rules of employment. This has really taught us that nobody is living the same situation. I’m hoping that people have learned a little bit about that. It’s about seeing workers as individuals with lives and needs that are not only nice to be met, but must be met. Changing the mindset from one-size-fits-all to really understanding who is in your workforce and what you can do to make them ultimately more productive. And happy.”

EMILY ACKERMAN

Solutions

Individualize ways of working and lead by doing.

“Document asking how does each person work best to foster an environment where people are open to talk about it, at least with myself, and disclose in a safe space. And we actually have a document that we use called ways of working, and how people like information distilled to them, what works for them, and so far as the hours of the day where they are at their best and are at their lowest, and that’s available to everybody. So depending on who’s working with whom on a project, they can see how to best communicate with that person and when they’re optimal. We also instill a hyper, very huge rest culture now, so we literally say there’s no shame in taking naps, it’s one of our values. And that doesn’t necessarily mean naps; it means just taking time for yourself. I always am telling people to care for themselves before anything else. ‘Literally, none of us are neurosurgeons. We’re not frontline workers; we’re not saving anyone’s lives.... If you’re open and honest about where you’re at, we can accommodate you, and you need to take care of yourself first.’ We have a records channel in our Slack and an Instagram channel that we use, where we’re always just sharing information with each other and a lot on ableism in social justice so we can better understand. As a leader, I practice vulnerability a lot. The more I disclose appropriately, it gives people the space that they feel like they can also disclose with myself and with other people.”

MARYAM AJAYI

Set reasonable work expectations based on work volume and output, not time and availability.

“If you are not setting up internal policies and expectations of work volume and output on your workers, that compromises their health, safety and well being.”

AZZA ALTIRAIFI

Backup and distribute expertise.

Several experts recommended redundancy in workers covering critical roles.

Emily Ackerman described how redundancy has improved her experience in a group she participates in: “Each group has multiple board members that run it. It’s very clear from the day you join that if you ever need to quit or step back for six months, you can do that as easy as just saying, ‘I’m stepping back.’ Then it’s over. It completely changed the way I approach doing that work; it’s made me so much more comfortable to be part of the group, because it’s so set-in-stone clear that there is no harm in taking a week off. I wish every group were run where we would just talk about being human and needing time. I think we would end up being so much more productive as people.”

Solutions

“This is a time to really look at how work is distributed and how leave policies can disadvantage workers of color and disabled workers. If work is that essential, it shouldn’t live in one single person. That indicates to me that you have completely failed to invest in the kind of staff capacity that is necessary to sustainably support the work that is existentially core to the organization. But more broadly, it creates real pressure that very much disadvantages disabled staff, staff of color, and otherwise marginalized staff. It burdens the workers who are the ones typically executing the work as opposed to planning it and kind of setting up the structures and processes through which it happens. It has often been the case with me that I am suddenly experiencing a flare up, and I find myself suddenly unable to come into work. As a result, I’m then faced with one of two choices: I can stay home and rest, knowing that the work stops for the duration of my absence and I may face reprisals as a result. Or I can try and force myself to work through the pain, something I can sometimes do, and manage the consequences for my health. These capitalistic structures set an expectation and a norm which have cast disabled and chronically ill people such as myself as the ‘problem worker.’ And in a pandemic, more people are going to have to take unexpected leave, and organizations must be prepared to account for this.”

AZZA ALTIRAIFI

Remove distrust by eliminating obstacles and gatekeeping.

“Removing barriers improves mental health. If you remove barriers, that creates less stress, less stress usually means better mental health.”

HABEN GIRMA

Don’t require employees to prove disability or need for leave. Ideally they would not even have to disclose their disabilities. Minimize medical paperwork burden, especially for Black people who are already facing medical trauma and obstacles to care. Assume some employees are disabled but not sharing status; what does that imply for your accessibility funding and accommodations?

Build trust by making accommodations easy. Normalize asking for needs for all workers, not just “special needs” for disabled people. Ask what needs a new worker has when they are hired without requiring a disability disclosure for necessary work tools or other accommodations. Ask if people need accommodations and provide specific examples, noting that options aren’t limited to those examples. Indicate how much you can be trusted by sharing a situation that shows how you accommodate workers.

“Give something without someone having to fight for it.”

TINU ABAYOMI-PAUL

Solutions

Eliminating waiting periods for accommodations is important. Azza Altiraifi recommended ending the waiting period for disability insurance and leave.

“What these waiting period policies are communicating is that organizations are willing to have me and other disabled workers compromise our health in a way that could have been lethal, in my case, all as insurance for organizations that I’m going to come back to work and that I’m not just going to sit around collecting my wages without performing the wage labor I’m being paid to perform. So yes, I would say make that leave available to people without a waiting period. Leave policies should be available to people as soon as they need them. If you need some sort of documentation that should be balanced against the burden it poses on marginalized workers and the equity considerations therein. For example, how is that documentation collected? Who has access to that information, and to whom are the disclosures being made?”

AZZA ALTIRAIFI

Representation matters.

Having representation at all levels, including disabled people, to ensure accessibility is important and will give you the knowledge you need to take down barriers and provide needed accommodations. Haben recommends each company hire disabled people on all levels and an on-staff accessibility expert (or consultant if that is not possible) for both physical and virtual office

design. She recommends someone who has really deep knowledge and skill sets around accessibility to be part of the team and work on staff. Examples of where they can help range from making bathrooms accessible for wheelchair users to ensuring that social media feeds and virtual meetings have captions.

Build trust by allowing unions.

Unions can provide a trusted and protected channel of communication that organizes requests and needs from workers to management.

“The biggest tool that is going to support workers is their ability to unionize. The single biggest thing that an employer could do right now is support their workers’ right to unionize and recognize their unions. If they have decided that they’re going to create one, don’t fight it; recognize it. That is a gift to your organization.... The most equitable way to ensure that your staff’s needs are being met is: Bring your workers to the table, have a conversation with them about what their needs are, and make a policy based on that feedback”

AZZA ALTIRAIFI

Solutions

Build trust by improving how work happens and how managers lead.

Only meet when you need to meet.

“Meetings need to happen differently and less frequently in a remote environment. Organizations that unexpectedly transitioned to remote work are grappling with the ways that remote work curtails the ability of managers to do the kinds of surveillance they’re used to in in-person working environments; they can’t walk into an office and see you at your computer; the only thing they have to go on is the actual work output that their staff are providing. Even as managers may be talking about flexibility, these kinds of surveillance-driven measures that people need to be completely available pose major equity challenges and are especially burdensome for disabled workers and workers of color. It’s such a contributor to increased anxiety, increased burnout, and increased depletion, and also fundamentally harms our ability to make the choices we need to show up at work in the ways that are most conducive to protecting our well-being and supporting caregiving needs, or whatever other things workers are juggling in order to do this work during a pandemic, climate disasters, and other ongoing crises. The volume of meetings, length of meetings, and video policies can all directly affect the health of disabled workers and their capacity to get their work done. For example, my chronic

pain, my visual processing disability, and minor diversions are all reasons why excessive video meetings, particularly if I am compelled to keep my video on, can exacerbate my chronic pain, and trigger debilitating episodes and flare ups. That will mean that if I am on video for six hours on a Wednesday, I’m also out sick on Thursday.”

AZZA ALTIRAIFI

“I’m a huge less meetings person. Don’t schedule meetings that can be done in an email, or in a voice note. If they are essential, they should be scheduled. And also I am not above saying, ‘I don’t really have much,’ or ‘we can cut this one,’ or just saying, ‘let’s do this another day.’ When I have 1:1s with people, I’m always checking in beforehand. It might have been a good idea two weeks ago to schedule a meeting, but check in with people to see how they are before going into a longer 1:1s with someone. And then always say that people have the autonomy to have their video off or to call in when they need to. And I set the tone for that; sometimes I’ll be like, ‘my videos off’ or ‘we’re just gonna do a phone call.’”

MARYAM AJAYI

Solutions

Time to rest and recharge.

Experts also encouraged better leave policies on two fronts for disabled people, which will benefit all. First, giving people time off, and second, making sure work is scaled down to make sure that time is actual time off.

“One other thing in terms of policy is disabled and chronically ill people are at an extreme disadvantage in this moment, in multiple ways, and one of those really shows up acutely in leave policies. Not disabled folks have the privilege of being able to use their vacation time for actual vacation. I cannot use my leave time for anything other than my own care needs and health needs, or my caregiving needs, because disabled people are really much more likely to be themselves caregivers, because systems and structures have failed our community.”

AZZA ALTIRAIFI

“It’s not enough to give people more leave; you have to scale back the kind of work that’s being done and the volume of work that’s being done to give people the actual flexibility that they need to prioritize their health and well-being. So that required a set of conversations about, ‘what are the things we are going to focus on? What structures will we put in place to make sure we know if the work starts to balloon again.’ Organizations that have had these conversations

found that they were able to move to a four-day work week, which is amazing. Shifting to four-day work weeks has often been dismissed as extraordinarily difficult, but five-day work weeks were an innovation of the labor movement in the 1930s. There is nothing inevitable or necessary about the five-day work weeks or forty-hour work weeks, and workers can and should come together to demand better. Organizations can make this shift right now by identifying what the organization’s particular lane is—and sticking to it. What is it that your organization is focused on? What is its core mission? If there needs to be a process of refining and narrowing then do that.... If the work output and expectations are not constrained such that it actually lets people be restful during their time off, then it isn’t going to do anything to mitigate burnout. Total office closure for everyone in the office at the same time is more equitable, by ensuring everyone is reaping the benefits of this designated time for rest. If I know that everyone is off, and the work has stopped for everybody at the organization, I’m in a much better position to actually make use of that leave in a way where I can stop worrying about work and focus on my self care needs, my health needs, my family and community needs, and more.”

MARYAM AJAYI

Solutions

Better leave means encouraging paid time off, which is more likely when you have a set number of days instead of so-called unlimited time off. It also means better medical leave that covers medical treatments for workers and people who depend on them. It also includes general breaks and pauses that are real breaks because work has been scaled back, which happens when companies do the work of prioritizing.

If you are serious about inclusion, you need to include disabled people. You need to dismantle the ableism that is part of our culture and our workplaces. Build trust by building accessibility, accommodations, and leaves into your company by default. Focus on improving the workplace and culture. Be open and flexible when it comes to accommodations, and allow for variation by individual. Create lines of communication for understanding, and hire for representation at all levels, including an accessibility expert. Minimize meetings, maximize shared communications.

All these issues should be considered every day throughout the year, and today is a good day to start.

04

Appendix



Acknowledgements and Resources

The [disability justice](#) space has many helpful resources, organizations, and leaders. Here is a selection of resources we found helpful in our work and you may, too.

Sins Invalid 10 Principles of Disability Justice: <https://www.sinsinvalid.org/blog/10-principles-of-disability-justice>

Detroit Digital Justice Coalition Principles: <http://detroitdjc.org/principles/>

Mia Mingus. “Changing the Framework: Disability Justice.” <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>

Aubrie Lee. “20 Questions for Disability-Inclusive Employers” <https://disabilityvisibilityproject.com/2021/10/12/20-questions-for-disability-inclusive-employers/>

Accenture with Disability:IN and The American Association of People with Disabilities. “Getting to Equal 2018: The Disability Inclusion Advantage.” https://www.accenture.com/_acnmedia/PDF-89/Accenture-Disability-Inclusion-Research-Report.pdf

Christine Miserandino. “The Spoon Theory.” <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

Derek Newman-Stille. “Disability Tropes 101: Karmically Disabled.” <https://spoonieauthors-network.com/2018/04/19/disability-tropes-101-karmically-disabled/>

Joanne Limburg. “Am I Disabled?” <https://aeon.co/essays/what-does-it-mean-to-consider-yourself-a-disabled-person>

Aparna R. “The Burden and Consequences of Self-Advocacy for Disabled BIPOC.” <https://disabilityvisibilityproject.com/2020/07/19/the-burden-and-consequences-of-self-advocacy-for-disabled-bipoc/>

Blair Imani. Chapter 4: Get Smarter about Disability. Read This To Get Smarter: About Race, Class, Gender, Disability & More. <https://blairimani.com/books>

Alice Wong, editor. Disability Visibility: First-Person Stories from the Twenty-First Century. <https://disabilityvisibilityproject.com/book/>

Evette Dionne and Alice Wong, editors. The Access Series. https://www.bitchmedia.org/sites/default/files/AccessIssue_accessible.pdf

Leah Lakshmi Piepzna-Samarasinha. Care Work. <https://arsenalpulp.com/Books/C/Care-Work>

Biographies of Interviewees

AZZA ALTIRAIFI



A head and shoulders photo of Azza Altiraifi against a black background. She is facing the camera with a serious look. Her right hand is resting on her right shoulder. She is wearing a red blouse under a burgundy and black sweater with a mustard-color scarf covering her hair. She also has on long gold earrings, a black beaded necklace, and a silver nose ring.

Azza (she/they) is a Black disabled labor organizer and Mad activist based in northern Virginia. Azza's work is anchored in an abolitionist praxis, and a fierce commitment to the Disability Justice principles of cross-movement solidarity, interdependence, and sustainability. Azza currently serves on the advisory committee for the Center for Democracy and Technology's project on algorithmic fairness and disability rights, as well as the stewardship and community councils for [Raising the Bar: Health Care's Transforming Role](#).

Previously, Azza worked as a disability policy research and advocacy manager. In 2019, Azza was also selected to join the inaugural cohort of the Forward Promise Fellowship for Leaders by the Robert Wood Johnson Foundation, and served on the working group for the Congressional Black Caucus Emergency Taskforce on Black Youth Suicide and Mental Health, which published its report in 2019. Azza has been featured on outlets such as the TODAY Show, NPR, Al Jazeera, Bloomberg News, and USA Today. For her community-based work, Azza was selected to receive the Charles P. Monroe Civil Rights Award by the NAACP Arlington Chapter in 2019. Outside of work, Azza enjoys hiking, traveling, playing with her dog, and adventuring with her husband Haithem.

Biographies of Interviewees

EMILY ACKERMAN



A photo of Emily Ackerman seated in a wheelchair. She is wearing a mustard-brown mock turtleneck and black pants with black oxford shoes. She is also wearing round, wire-rimmed glasses and a serious look. She has long brown hair with bangs. In the background are several plants, and a wall with several awards and a large window.

As a queer, disabled woman in STEM, [Emily Ackerman](#) is passionate about the advancement of underrepresented populations in STEM. She has had the opportunity to perform diversity and equity work in academia with Future of Research, the TAE Consortium, and the Howard Hughes Medical Institute as a Gilliam Fellow. She is also an active advocate in the disability community for equitable access to education and technology.

She is a recent PhD graduate of the University of Pittsburgh's chemical and petroleum engineering program. Her thesis work can be divided into two areas:

- Antiviral drug target identification using network biology
- Dynamic modeling of the immune response to viral infection

Working at the cellular and systems level, her aim was to better understand the mechanisms driving observed immunoregulatory behavior to improve drug development. While initially using influenza A virus as the primary infection of study, she repeated network controllability studies to efficiently prioritize drug repositioning candidates for treating SARS-CoV-2 infection at the onset of the COVID-19 pandemic.

As of September 2021, she joined Harvard Medical School as a Postdoctoral Researcher in the Systems Biology department studying p53 signaling dynamics. In her free time, she enjoys painting, contributing to the academic unionization movement, and spending time with her cat, Poppy.

Biographies of Interviewees

HABEN GIRMA



A photo of Haben outside with her hand on her dog seated at her feet. She is smiling with long black hair. She is wearing a royal blue dress with a black blazer. She is smiling and facing the camera with pearl earrings. She is seated on a rock in a grassy area with her legs crossed. There is a wooden fence and some cars in the background.

The first Deafblind person to graduate from Harvard Law School, [Haben Girma](#) is a human rights lawyer advancing disability justice. President Obama named her a White House Champion of Change. She received the Helen Keller Achievement Award, a spot on the Forbes 30 Under 30 list, and TIME100 Talks. Haben believes disability is an opportunity for innovation, and she teaches organizations the importance of choosing inclusion. The New York Times, Oprah Magazine, and TODAY Show featured her memoir, *Haben: The Deafblind Woman Who Conquered Harvard Law*.

Haben provides consulting and public speaking on accessibility, diversity, and leadership. The daughter of refugees and a Black disabled woman, Haben built her path to success on the belief that inclusion is a choice. We all have the power to advocate.

Biographies of Interviewees

MARYAM AJAYI



A torso and midsection photo of Maryam Ajayi against a beige background. She is facing the camera with her hands on her waist. She is wearing a long-sleeved black turtleneck. She has long black hair and gold hoop earrings and gold rings.

[Maryam Ajayi](#) is Nigerian born Energy Healer and entrepreneur. She is the CEO & Founder of Dive in Well, cultivates conversations, community, space, and change for a more equitable and accessible wellness industry. She is passionate about de-stigmatizing wellness, advocating for inclusive spaces for marginalized communities, and using her voice to empower and uplift others around the world.

Maryam, along with her work have previously been featured in Vogue, The New York Times, The New Yorker, The Sunday Times, Goop, Refinery 29, The Cut and The Thirty. She's spoken at and worked with brands such as Facebook, Instagram, COS, Victoria's Secret, Lululemon, Nike Women, and Matches Fashion around topics such as Breathwork, Mental Well Being in the Workplace, and Diversity in Wellness.

Biographies of Interviewees

TINU ABAYOMI-PAUL



A head and shoulders picture of Tinu Abayomi-Paul, against a light brown wall. She is a dark-skinned woman with chin-length curly black hair. She has on red lipstick and her left gold colored hoop earring is visible. She is not smiling, but looks content. She has a hand lightly pressed against her chest and is wearing a dark blue, light blue and black blouse patterned in zigzag stripes. She's looking directly into the camera.

Tinu Abayomi-Paul is a writer and a disabled entrepreneur who provides coaching services to other microbusiness owners. She is the founder of [Everywhere Accessible](#), on the advisory board of Women Who Tech, and a community council member of National Pain Advocacy Center and Global Healthy Living Foundation's COVID19 Patient Leadership Council.

Following 20 years as an entrepreneur, 18 as a well-known marketing and Google expert, Tinu had an awakening. After being diagnosed with cancer, she had to take almost three years off building her business, due to having several chronic diseases prior to the cancer, which complicated her recovery. Once safely on the other side, she realized other entrepreneurs, disabled and otherwise, could use the resources she developed to restart her life after cancer.

Language and Methodology Update

We care about how we do our work and the words we use to share it. In our first report,²³ we provided a description of our language choices²⁴ and methodology²⁵ and encourage you to read it. Here we describe additional language and methodology choices we made for this report and why.

For this report, we started with a lot of background reading, since both a lot of information about disability is already available and an active disability community has been working for disability rights for a long time. We focused our efforts on amplifying their messages. We centered our research on interviews of five disability activists and on amplifying their knowledge and recommendations. Instead of using a transparent opacity approach, we took a direct approach that was transparent and open; we sought out activists who had publicly shared their perspectives, and we used a consent framework, reviewing quotes with them for approval to ensure that they were comfortable with the disclosures and ideas we attribute to them. We also paid them for their time. We also had feedback from many people that the first person narratives and perspectives from experts were the most memorable and impactful parts of our first report.

We analyzed our survey data on disabilities using an iterative approach; as we learned more from

our research and interviews, we adjusted some of the ways we analyzed the survey data to reflect more inclusive and justice-centered perspectives, especially in our groupings, comparisons, and language.

One of our biggest changes during this process was breaking down the dichotomy between mental health and other types of disabilities. Last year, when we wrote our survey, we asked three questions: whether they identify as disabled, whether they had any of a list of five disabilities,²⁶ and whether, when it came to mental health, they experienced any of four conditions.²⁷ We also included options for “none of these,” and, importantly, included free response options for all three questions so respondents could share their own long-form answers.

By focusing on disabled people, whom we’re centering in this report, rather than everyone, we avoided statistics that favored non-disabled people and would have been less relevant to our data stories, which mostly focus on experiences of disabled people. We were also able to do a more disaggregated breakdown of percentages. In addition, rather than listing <percentage> <answer choice> like we did in the previous report, we changed language here to be more humanizing, e.g. from “x% anxiety” to “x% have anxiety”, and from “mental health: <stats>” to “for the <n> respondents whose experiences we focused on in this report.”

When we asked about mental health, we intentionally did not use the term “disability” in our question; we know many people do not identify their own

Language and Methodology Update

mental health conditions or others' mental health conditions in general as disabilities and were concerned about the stigma that often accompanies mental health disabilities. We initially separated mental health conditions and other disabilities, and after struggling to describe and define the categories and after helpful input from our experts, we collapsed them into a single category for all disabilities, and we now describe every disability as a disability, no distinctions. Many societies do not distinguish between mind and body; they treat the brain as part of the body.

If we were to run our survey now, we would replace our last two questions. We would again start by asking whether they self-identify as disabled, and then we would ask whether they have told their current workplace that they are disabled, and whether they had any of a longer list of disabilities, with the last question including an option to write in their own description of their disability. We also would have provided more specific listed options to replace the broad option of neurodiversity.

Our interviewees from the disability community shared their perspectives on language as well, and we followed the framework they all described: Use inclusive and individual supporting terms when it's our choice, and use self-identified terms that individuals choose for themselves to honor how they want to be described and identified. In a few of their quotations in the report, their terms do not mirror ours, and we use their terms to reflect their choices.

We used identity-first terms like **“disabled person”** and **“blind person”** in most cases. If individuals had preferred people-first terms (“person with disabilities”), we would have used those terms to refer to them; here, all our interviewees preferred identity-first terms (while acknowledging the alternative and their usage of it to describe individuals who self-identify with people-first terms).

We avoid using language for disabilities that can be viewed as negative, like “impaired” or “handicap,” or euphemistic, like “special” or “different.” We use the term **“non-disabled”** to center the disabled community, and we avoid terms like “normal” or “abnormal” that can be negative, because they marginalize the disability community. Also note that some people find “impairment” to be positive as a euphemism.

In this document, we replaced terms that we have learned can be negative from our survey with more inclusive terms; for example, we no longer use the word “impairment” though it was in our survey. We use **“deaf”** to refer to significant hearing loss and “hard of hearing.” We use **“blind”** to refer to significant vision loss and “loss of vision.” We use **“Deaf”** (capitalized) to refer to the Deaf community.

We use **“non-apparent”** to describe disabilities that are not immediately visible to others. Some other terms can imply active hiding of disabilities, which can reinforce distrust patterns. The use of the term non-apparent to some can also be interpreted as language that centers sight. Our use of the term non-apparent is both literal and figurative

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and communicates the ways in which people perceive or identify disability at work, in their communities, and in their everyday lives.

We made two changes to racial/ethnic groups. We used the term **“SWANA”** for Southwest Asian and/or North African. Despite North Africa technically being part of Africa geographically, some people from North African countries, e.g., Egypt, may not self-identify as “African” in certain contexts, given how race is socially constructed. We did not design our survey last year in a granular way that would give us data for SWANA people, but want to acknowledge the [identity](#) and encourage others to consider it as we will going forward.

We also included **“multiracial”** people in some data stories when they showed significant differences in experiences in our analysis. In an ideal situation, we would have had enough respondents to use a more granular approach, where we could analyze specific multiracial groups (e.g., Asian Black or Black Latinx or Black Indigenous people) instead of aggregating all these groups into one category of multiracial people. Unfortunately, we did not have enough respondents to get to that level of granularity.

[For more on language, check out Radical Copyeditor, What is the difference between a person who is “deaf,” “Deaf,” or “hard of hearing”?, and the NCDJ Disability Language Style Guide \(with Spanish and Romanian translations\).](#)

The Four I's of Distrust

In our analysis of our qualitative interviews and quantitative survey, we found distrust to be a recurring theme. The following framework, adapted from the Chinook Fund, gives us a deeper understanding of how ableist systems are constructed and maintained at work. We utilize the framework not only as a means of understanding the lived experiences of disabled people, but also for developing actionable strategies to dismantle ableism within the workplace.

Individual Distrust

Disabled people are treated like their disability is a burden. They experience erasure and marginalization and are often ignored by a dominant non-disabled society. The expectation is that disabled people feel badly about their disabilities and should therefore not expect to be treated fairly and equitably at work and in our greater society. This can lead to an internalization of ableism where disabled people are expected to question or doubt their strengths, skillset, and even rights to be treated just as well as their non-disabled peers are treated.

Ideological Distrust

Any oppressive system has at its core the idea that one group is somehow more trustworthy than another, and in some measure has the right to control the other group. This idea gets elaborated in many ways—non-disabled people are presented as being more intelligent, harder working, more resilient, more capable, more noble, more deserving, more advanced, chosen, normal, superior, and so on. The non-disabled group often holds this idea about itself in conscious and unconscious ways. And the opposite incorrect qualities are attributed to the disabled communities. This ideological distrust manifests in the ways companies create policies and practices that further perpetuate ableism by disregarding or ignoring the experiences and needs of disabled people or by punishing disabled people for requesting needed accommodations at work.

Interpersonal Distrust

The idea that one group is better than another and has the right to control and perpetually distrust the other, which gets structured into institutions, gives permission and reinforcement for individual members of the privileged group to personally disrespect or mistreat individuals in the oppressed group. Interpersonal racism, for example, is what white people do to Asian, Black, Indigenous, Latinx, and multiracial people up close—the racist jokes, the stereotypes, gaslighting, harassment, retaliation, and more. Similarly, interpersonal misogyny is what men do to women—the harassment, the belittling

The Four I's of Distrust

or ignoring of women's thinking, violence towards women, misogynistic jokes, and more.

Many people in the privileged group are not consciously oppressive. They have internalized negative messages about other groups, and consider their attitudes to be normal and innocuous.

Institutional Distrust

The idea that one group is better than another group and has the right to control the other gets embedded in the institutions of the society—the laws, the legal system, police practice, the education system and schools, hiring policies, immigration policies, housing development, media images, political power, and more. When a disabled person earns two thirds of what a non-disabled makes in the same job, it is institutionalized ableism. When disabled people are twice as likely to experience harassment when compared to their non-disabled peers, it is institutionalized ableism. If a policy or practice unintentionally reinforces and creates new inequities between privileged and non-privileged groups, it is considered institutional oppression.

For more detail, read The Four “I’s” of Oppression from Grand Rapids Community College adapted for use by the Chinook Fund.

Endnotes

- ¹ “Disability Impacts All of Us.” CDC. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>
- ² “1 in 4 US Adults lives with a disability.” CDC. <https://www.cdc.gov/media/releases/2018/p0816-disability.html>
- ³ “A Detailed Study of Patients with Long-Haul COVID” FAIR Health, Inc. June 15, 2021. <https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/A%20Detailed%20Study%20of%20Patients%20with%20Long-Haul%20COVID--An%20Analysis%20of%20Private%20Healthcare%20Claims--A%20FAIR%20Health%20White%20Paper.pdf>
- ⁴ We surveyed 2,796 people between May 2020 and January 2021; 1,964 said they had one or more disabilities. In addition, between July and September 2021, we interviewed 5 disability activists, following on the 22 tech workers and experts we interviewed for our [initial report](#).
- ⁵ Read Acknowledgements and Resources.
- ⁶ Blackwell, Angela Glover. “The Curb-Cut Effect,” Stanford Social Innovation Review, Winter 2017. https://ssir.org/articles/entry/the_curb_cut_effect
- ⁷ “Getting to Equal: The Disability Inclusion Advantage.” Accenture. <https://www.accenture.com/acnmedia/PDF-89/Accenture-Disability-Inclusion-Research-Report.pdf>
- ⁸ Ibid.
- ⁹ For the working age population defined as 16 to 64 years of age in September 2021. “Disability Employment Statistics.” Bureau of Labor Statistics, current population survey. <https://www.dol.gov/agencies/odep/research-evaluation/statistics>
- ¹⁰ For more examples, read Derek Newman-Stille, [“Disability Tropes 101.”](#)
- ¹¹ Read Language and Methodology Update
- ¹² From [@neverbetterforever](#) on Instagram.
- ¹³ Newman-Stille, Derek. Disability Tropes 101: Karmically Disabled. Spoonie Authors Network. <https://spoonieauthorsnetwork.com/2018/04/19/disability-tropes-101-karmically-disabled/>
- ¹⁴ Read Language and Methodology Updated.
- ¹⁵ This definition of harassment comes from Double Loop Game’s CEO Emily Greer, from a talk on rethinking workplace harassment at GDC Summer 2020. Greer, Emily. “R-E-S-P-E-C-T: Practical Tips to Prevent Abuse & Build Team Trust.” GDC Vault. Informa PLC. 2020. <https://www.gdcvault.com/play/1026789/R-E-S-P-E>
- ¹⁶ See table on next page.
- ¹⁷ Read The Four I’s of Distrust, based on the “Four ‘I’s’ of Oppression” adapted by the Chinook Nation. https://www.grcc.edu/sites/default/files/docs/diversity/the_four_is_of_oppression.pdf
- ¹⁸ Our gender identities center people’s self-identification (e.g., “women” includes both trans and cisgender women). Due to small sample size and privacy concerns, we use the term “nonbinary people” to encompass all people who identify with genders that do not exist on the gender binary, including gender nonbinary, gender non-conforming, two-spirit, genderqueer, bigender, as both nonbinary and man or woman, and/or as individually specified.
- ¹⁹ We specifically asked about Middle Eastern and African identities, and did not include an option for SWANA (Southwest Asian and/or North African). Despite North Africa technically being part of Africa geographically, some people from North African countries, e.g., Egypt, may not self-identify as “African,” especially in the context of a US-based survey asking about race.
- ²⁰ These data point out a need for Indigenous-centered and Middle Eastern-centered research in the tech workplace.
- ²¹ Compare with 73% of non-disabled Asian people, 67% of non-disabled Black people, 75% of non-disabled Latinx people, 66% of non-disabled multiracial people, and 58% of non-disabled white people who felt their work day has gotten longer.
- ²² Specific numbers: 91% of people with individually specified disabilities, 93% of chronically disabled people or people with chronic illness/pain, and 96% of D/deaf or hard of hearing people.
- ²³ “Remote Work since Covid-19 is exacerbating harm.” projectinclude.org/remote-work-report
- ²⁴ Ibid., p. 43.
- ²⁵ Ibid., p. 57.
- ²⁶ The specific options were: blindness/visual impairment, chronic illness or pain, deafness/hearing impairment, use a wheelchair, use another assistive device that helps with mobility, none of these apply to me, not listed please specify. Today we would replace the first three options with blind/low vision, chronic illness or pain, deaf/hard of hearing, and combine it with the options in the third question, which were
- ²⁷ The specific options were: anxiety, depression, neurodiversity, PTSD, none of these, and not listed please specify. Today we would add additional options, and in particular replace “neurodiversity” with more specific options.

Endnotes

¹⁶ Percentage of people with specific disability/ies who experienced or reported harassment

	Reported harassment before the pandemic (experienced or witnessed)	Experienced harassment since the pandemic	Reported harassment since the pandemic (experienced or witnessed)
Anxiety	31%	25%	15%
Blindness/Low Vision	32%	48%	27%
Chronic Pain/Illness	43%	44%	28%
Deaf/Hard of Hearing	26%	15%	11%
Depression	31%	20%	9%
Neurodivergent	18%	21%	12%
PTSD	58%	42%	8%
Wheelchair/Other Assisted Device	17%	17%	17%
Specified Otherwise	32%	30%	23%
Multiple	44%	46%	22%

Team

This November 2021 report features new research and recommendations under Project Include. The authors are Yang Hong of Shoshin Insights, McKensie Mack of MMG, and Ellen Pao of Project Include. We are an independent group unaffiliated with technology companies.

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