

inclusively

The Immense Impact of Long COVID on Workers

And What Employers Can Do About It

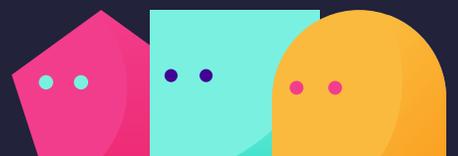
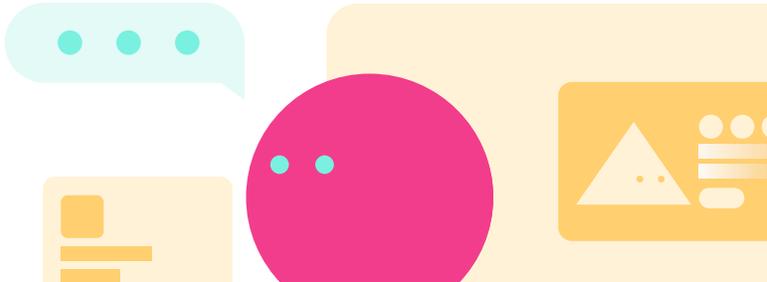


Table of contents

Introduction	3
Executive Summary	5
Part One: Symptoms, Impacts, and Accommodations	9
Part Two: Stigma, Mental Health, and the Human Toll of Long COVID on Employees	15
Part Three: Workplace Accommodations are not Offered or Accessed Equitably	19
Part Four: Companies are not Doing Enough to Support Long Haulers	25
Part Five: Actions to Meet the Needs of Workers and the Organization	28
Methodology	34
Demographics	35
About the Study	38



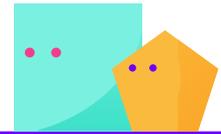
Introduction

As we near the three-year mark of COVID-19 dominating headlines and workplace policies, the true impact of the pandemic on both workers and organizations remains largely unknown. Perhaps the least measured and understood aspect of COVID's imprint on the workplace is that of the condition known as long COVID. Long COVID can include a wide range of ongoing health problems that can last weeks, months, or years. With such a new disease, the long-term outcomes are truly unknowable at this point.

In July of 2021, the Department of Health and Human Services' Office for Civil Rights and the US Department of Justice's Civil Rights Division published guidance clarifying that long COVID is considered a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA). As an organization committed to increasing transparency around workplace accommodations, Inclusively sought a deeper understanding of the experiences of workers with long COVID in order to better counsel employers on best practices around managing a disease that continues to impact a significant percentage of the working population.

Inclusively commissioned nonprofit health literacy organization **Health Literacy Media** to conduct a survey of 500 US-based, working-age employees with long COVID on their experiences in the workplace.

The results are profound, bringing to light the immeasurable effects that the disease wreaks upon individuals and families; dramatic disparities in the experience and outcomes of minority populations; the confusion many workers and employers have about the disease and its status as a condition covered by the ADA; and the inconsistencies with which organizations are informing employees about company policy, programs and other resources that may be beneficial.



What is a workplace accommodation?

Any modification or adjustment to a job or work environment that will enable an applicant or employee with a disability to have equal rights, privileges, and opportunities, including the ability to participate in the application process and perform essential job functions.



This report is intended to help employers:



Better understand the immense toll that long COVID imparts on workers

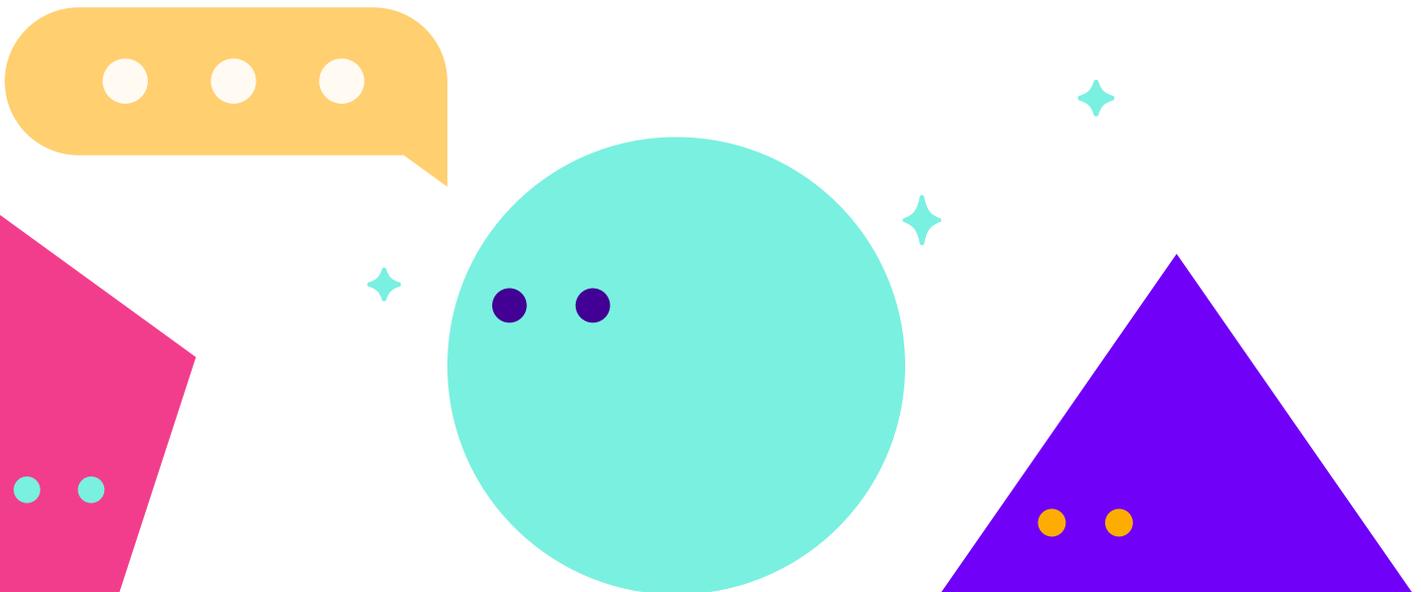


Contextualize the disproportionate impact of the disease on marginalized and underrepresented communities, particularly communities of color



Create proactive processes and interventions to support the employee population, thereby improving outcomes for both individuals and organizations

The data reveals that employers have both a responsibility and opportunity to better meet the needs of those who've been diagnosed with long COVID. The good news is that reasonable accommodations, many of which are likely already being offered to employees with other disabilities, are in most cases free or very affordable. Providing support to employees with long COVID will foment a level of trust among employees that directly impacts workplace culture, retention and engagement. Said another way: the right thing to do for employees is also the right thing to do for the bottom line.



Executive Summary

We're Just Beginning to Understand the Toll of Long COVID on Workers and Organizations

COVID-19 has irrevocably changed both the workplace and the mindset of the average worker. Before the pandemic, only 6% of workers functioned primarily from home.¹ Now, 58% of job holders can work remotely at least some of the time,² and 75% of millennials and gen Z workers (who already make up a majority of the workforce) would prefer a hybrid or remote position.³

Mental health has become a topic far more people are willing to discuss at work, especially among younger generations. In a 2021 survey on mental health at work, 76% of US workers reported experiencing at least one mental health condition in the last year, and half of workers left a role at least in part for mental health reasons.⁴ Those numbers skyrocket in younger generations, with four out of five gen Z workers leaving a job at least in part for mental health reasons.⁵

What we still don't have a grasp of is how long COVID is impacting the workforce. The CDC believes that 7.5% of American adults are currently managing symptoms of long COVID,⁶ and some researchers believe the disease could be accounting for as much as 15% of unfilled jobs.⁷ This is consistent with our own findings.



In this study of workers with long COVID:



48% of those surveyed had to take more time off work



39% cannot work as many hours as they worked before



28% had to stop working entirely

The numbers above are likely underestimated, as many individuals may not know that they are managing symptoms associated with long COVID and may be attributing under or unemployment to other factors. As additional research is published from the medical community, and as more time passes, the picture will become clearer.

¹National Council on Compensation Insurance, Remote Work Before, During, and After the Pandemic, 5/21

²McKinsey, Americans are embracing flexible work—and they want more of it, 7/22

³Deloitte, The Deloitte Global 2022 Gen Z and Millennial Survey, 2022

⁴Mind Share Partners 2021 Mental Health at Work Report, 2021

⁵Mind Share Partners 2021 Mental Health at Work Report, 2021

⁶CDC, Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID", 06/2022

⁷Brookings Institute, Is 'long Covid' worsening the labor shortage?, 2022

In this research, three findings came to light:

- 1** Workers with long COVID feel alienated and misunderstood, finding that they have to justify their need for accommodations (while for some — having to navigate the new reality of being disabled)
- 2** Workplace accommodations are not being accessed equally across different demographics
- 3** Employees do not fully understand their rights and choices — and employers may not either

This report delves into each of these findings in detail, concluding with actions employers can take now and over time to lessen the impact that long COVID will have on their organizations.

Stigma & Mental Health Support: Long Haulers Feel Misunderstood and Alienated

Employee expectations around mental health have evolved rapidly over the last three years, especially with regard to the role employers should play. 91% of workers now believe a company's culture should support mental health.⁸ While it's difficult to extrapolate specific causes of the shift, if 20% of Americans who are infected with COVID develop long COVID, it's fair to assume it is a significant contributor.⁹ And remember, the burden the disease bears isn't just on the patient. For every employee who has developed long COVID, there is another whose spouse, parent or child has developed it and needs their support.

Unfortunately, while many organizations appear to be creating more space and safety for employees to seek support for mental health conditions, it does not appear to be reaching the long COVID community. Respondents in our survey report feeling afraid to share their diagnosis with their employer and misunderstood and alienated when they did. As we discuss in detail in the final section on recommendations, it's imperative that organizations embrace their role in reducing the stigma this community faces, both by proactively sharing information around the disease and by training staff to respond empathetically and with support when an employee discloses their condition and asks for help.

In Their Own Words



"I felt like I had to convince them that something was wrong, that I had to validate myself. Like I was on a [witness] stand and I had to prove my case that I couldn't show up for work."



"They did an EKG, they did blood work ... they did a CT scan and all was normal ...but I didn't feel normal. It felt like I was dying."

⁸ Mind Share Partners 2021 Mental Health at Work Report, 2021

⁹ CDC, Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID", 06/2022

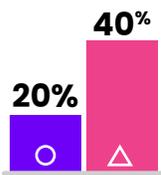
Members of Marginalized Communities Are Not Able to Access Workplace Accommodations Equitably

The dramatic disparity in the infection rates, death rates, and unemployment rates of those in marginalized communities reported throughout the pandemic was highlighted in stark contrast in our own survey.

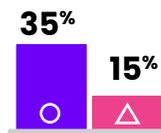
Legend

● Black or African American respondents ▲ White respondents ■ Hispanic or Latino respondents

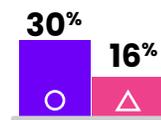
Among survey respondents who shared why they had not asked for formal accommodations:



Only 20% of Black or African American respondents (●) report their workplaces were already flexible, versus 40% of White respondents (▲)

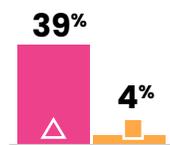


35% of Black or African American respondents (●) said they didn't know they could ask, or whom to ask, versus 15% of White respondents (▲)



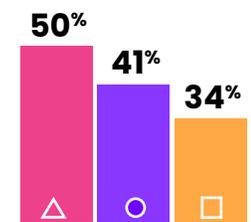
30% of Black or African American respondents (●) report being afraid of what would happen if they asked, versus 16% of White respondents (▲)

One of the broadest disparities in the survey was among those who switched jobs to better accommodate living with long COVID, highlighting the reality that employees of color may have fewer job opportunities than their White counterparts:



39% of White respondents (▲) reported changing where they worked, versus 4% of Hispanic or Latino respondents (■)

And while the stigma that prior generations experienced with regard to mental health conditions in the workplace appears to be abating, it's not abating equitably across all demographics:



50% of White respondents (▲) report suffering from depression or anxiety, versus 41% of Black or African American respondents (●) and 34% of Hispanic or Latino respondents (■)

The disparities in mental effects is especially stark when considering that the study found no significant differences per the physical symptoms of long COVID (trouble breathing, getting tired more easily, feeling dizzy, and mobility issues) across demographics. In other

words, people of color are suffering from the same symptoms, but may feel less able to acknowledge, much less seek treatment for, the mental repercussions of long COVID. It may be that individuals of color feel they simply cannot afford to disclose to their employers the mental toll the condition bears, which will impact the ability to be productive both on the job and at home. Employers have much work to do to support their employees of color, as it is clear they are not getting the accommodations that their white counterparts are. That support should consist of education, proactive outreach, awareness, and support — all things that need to happen to set up employees to successfully request and receive the accommodations they need to work effectively.

Employees Don't Understand Their Rights and Options — And It May Be That Employers Don't Either

Some of the most surprising findings in our study are the impact of an organization's size on its employees' understanding of long COVID and its status under the ADA.

- While 74% of employees at companies under 1000 employees knew that long COVID is a disability covered under the ADA, only 55% of those working at companies with more than 1,000 employees reported knowing
- Employees at smaller companies were 10% more likely to have asked for an accommodation unrelated to COVID before developing long COVID

Both of these findings indicate that smaller organizations may better equip their staff with both general information as well as how to go about requesting accommodations. One potential explanation is that smaller organizations may have stronger human networks for workers to tap; employees may be more likely to know someone in HR who they can ask, or may be more comfortable approaching their supervisor for help, knowing that the supervisor likely knows the right person to ask versus needing to navigate a large department. It's clear that larger organizations have their work cut out for them.



In Their Own Words



"If I had a fracture, that's different, it's easier to say. I wouldn't even know who to go to, what to say, or if it would even make a difference."



"My employer has not mentioned long COVID at all."

Employers Can Take Simple Actions to Improve Access & Experience

Given how little the scientific and medical communities understand the long-term impact of long COVID, it's no wonder employers have been slow to organize a holistic response. The good news is that creating processes to meet the needs of both workers and the organization is straightforward. At the conclusion of this report we offer clear guidelines on how to proactively approach managing long COVID among the employee population. As our collective understanding of the long-term prognosis of long COVID evolves, employers who act now will reap rewards in the years to come.



Part One: Symptoms, Impacts, and Accommodations

ASHLEY JACOBSON

Ashley Jacobson is a disability rights attorney and accommodations specialist living with a physical disability in the state of Michigan.



In July of 2021, the US Department of Health and Human Services and the Department of Justice confirmed that long COVID can be considered a disability. This means that individuals living with long COVID are entitled to disability rights in schools and workplaces. These rights include accommodations — or efforts to remove unnecessary barriers — in the work environment. Accommodations allow the employee to meaningfully contribute to their team and prevent employee turnover, which is known to increase costs for employers and decrease team morale.

Accommodations should always be assessed on an individualized basis. It's helpful to view accommodations as strategies and modifications that allow disabled talent

to meet the essential functions of their jobs without hurdles that were, often unintentionally, placed in their way. To remove those hurdles, you must focus on that employee's disability symptoms and job. In this sense, long COVID accommodations should be assessed in the same manner as other forms of disabilities:

- What are the symptoms experienced by the individual?
- What are the essential functions of this person's job?
- What accommodations could help ensure access and opportunity?

Of those accommodations, which ones are considered reasonable (e.g. based on cost, time to implement, ease of implementing, etc.)?

95% of requested accommodations are either free or under \$500 to implement.¹⁰ Most employers are surprised to learn how easy and affordable it is to implement accommodations and how these accommodations benefit the entire team by creating an inclusive work environment where people are given the opportunity to thrive.



Individuals living with long COVID are entitled to disability rights in schools and workplaces.

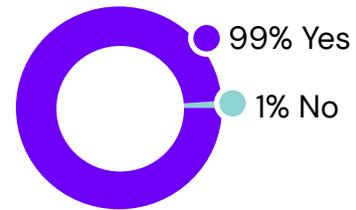


¹⁰ Job Accommodation Network, Accommodation and Compliance: Low Cost, High Impact, 2020.

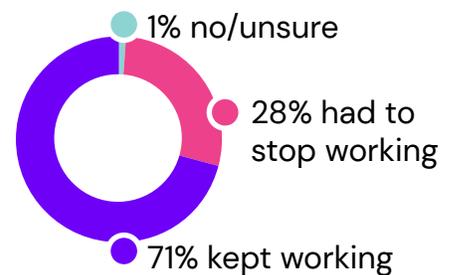
Long COVID Impacts an Individual's Ability to Work

Due to the unique properties of the virus, how it manifests, how our vaccines are designed and administered and how modern society functions, COVID-19 is unlikely to be fully eradicated.¹¹ What differentiates it from seasonal flu is the long-term footprint it imparts on a percentage of those it infects, the folks we now call, "long haulers". While it's clear that vaccines reduce the severity of the initial infection, the medical community does not have definitive data on whether vaccines reduce either the likelihood of developing long COVID or the length or severity of long COVID symptoms. Research has found that the risk of developing seizure disorders, brain fog, dementia, and other mental health conditions protected under the ADA remain high two years after recovering from COVID-19.¹² One thing is certain: long COVID is real, and organizations need to be treating a long COVID diagnosis in the same way they would treat a cancer or stroke diagnosis. Employers have a tremendous opportunity to proactively address the segment of their employees currently managing the disease, and those who will be diagnosed in the future.

Has Long Covid Impacted Your Ability to Work?



Long COVID & Employment



Most Common Symptoms & Impacts

Long COVID typically presents as a combination of physical, mental, and cognitive symptoms. The cognitive impact is associated with an umbrella of symptoms that have come to be called "brain fog". These include needing more time to complete tasks, having trouble remembering things, and trouble working on tasks. Trouble breathing, fatigue, dizziness, and mobility are the most common physical ramifications being experienced by survey respondents.

In this study of workers with long COVID:



48% had to take time off work



45% report having depression or anxiety



39% cannot work as many hours



31% had to change where they worked

¹¹ Forbes, Can We Eradicate Covid? Probably Not. 06/2022

¹² CNN, Long Covid risk extends two years after infection, 08/2022



In what ways have Long COVID symptoms affected your ability to work?

Physical effects N=499



Mental effects N=499



Other effects N=499



71% of Respondents Requested Workplace Accommodations to Help Manage Long COVID

The disability community is the largest minority population in the country and in the world. Before the pandemic, 30% of the professional workforce fit the federal definition of having a disability.¹³ And most of those workers were keeping their status a secret, with only 39% of people disclosing to managers and only 21% to HR, primarily due to fears of being discriminated against.¹⁴



Most workers keep their disability status a secret due to fears of being discriminated against.

The impact of having to hide a part of ones' self in the workplace takes a measurable toll; employees with disabilities who disclose to most people they interact with are more than twice as likely to feel regularly happy or content at work than employees with disabilities who have not disclosed to anyone (65% versus 27%).¹⁵ This fear and the discrimination many face in the workplace is a frustrating reality juxtaposed against the data point that companies that embrace disability inclusion report 28% higher revenues, 30% higher profit margins, and double the net income of peer organizations that do not.¹⁶

It's difficult to assess how many workers are receiving accommodations today versus how many would benefit. While the government does require employers of more than 15 workers to provide reasonable accommodations, there is not an official process by which workers request them. The process can vary dramatically between companies and even between departments within the same company. While many studies estimated that 20–30% of individuals with work-limiting disabilities received accommodations, newer research suggests that the rate of workplace accommodations among those who would benefit is closer to 56–65%.¹⁷

As such, two findings are encouraging:



71% of survey participants asked their employers for accommodations to help manage long COVID



56% of survey participants had asked for unrelated accommodations before having long COVID

One possible explanation for these higher-than-expected numbers is that people who identify as having a disability may have more experience managing a diagnosis and advocating for themselves in the workplace, and may therefore be more willing to pursue or accept a long COVID diagnosis. Another is that people's conception of "accommodations" can vary widely, from taking an extra day or two off of work to getting one's hours reduced.

¹³ Harvard Business Review, Why People Hide Their Disabilities at Work, 06/2019

¹⁴ Ibid.

¹⁵ Harvard Business Review, Why People Hide Their Disabilities at Work, 06/2019

¹⁶ Accenture & AAPD, Getting to Equal: The Disability Inclusion Advantage, 2018

¹⁷ Harvard Medical School, Rate of Workplace Accommodations Higher Than Previously Thought, 10/2019

Those Who Did Not Ask For Accommodations Vary on Why

Of the 29% of participants who did not ask for accommodations, 33% responded that they didn't need to because their workplace was already flexible; 22% said their symptoms were not severe enough; 21% said they didn't know they could ask or whom to ask; and 21% were afraid of what would happen if they asked.

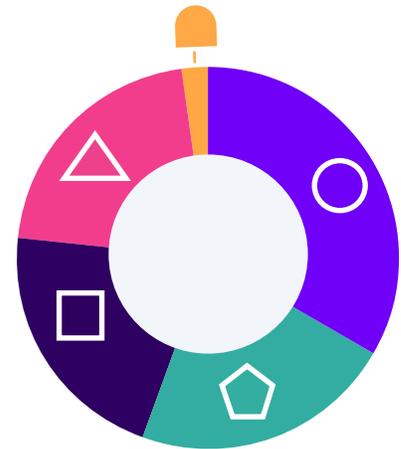
42% of participants either did not have the information or the perception of safety to feel empowered to ask for what they needed.



What's also notable is the dramatic variation in responses across demographics, which are detailed in Part Three.

There are also those who don't want to ask for accommodations because of their own personal or political beliefs. One particular respondent displayed the poignant dichotomy between needing benefits and refusing to request them. This individual reported that "it feels like everything isn't the same. I feel depressed and also anxious. It's hard to put into words. I'm just not giving my 100%." But when asked whether they had requested accommodations, they shared: "I haven't notified my work. I wouldn't even know what to notify them of. If I had a fracture, that's different, it's easier to say. I wouldn't even know who to go to, what to say, or if it would even make a difference." When asked about whether they had applied for disability benefits, the participant said "Honestly, I didn't even think about it. It didn't cross my mind. I just want to get better. I don't want to get benefits. I just want to get better. That's just not an avenue I would care for." One can't help wondering what kind of an impact mental health support would have on this respondent — and many like them — on navigating their path of "new normal".

Why participants did not ask for accommodations:



33%

My workplace is already flexible

22%

My symptoms weren't severe enough

21%

I didn't know I could ask or whom to ask

21%

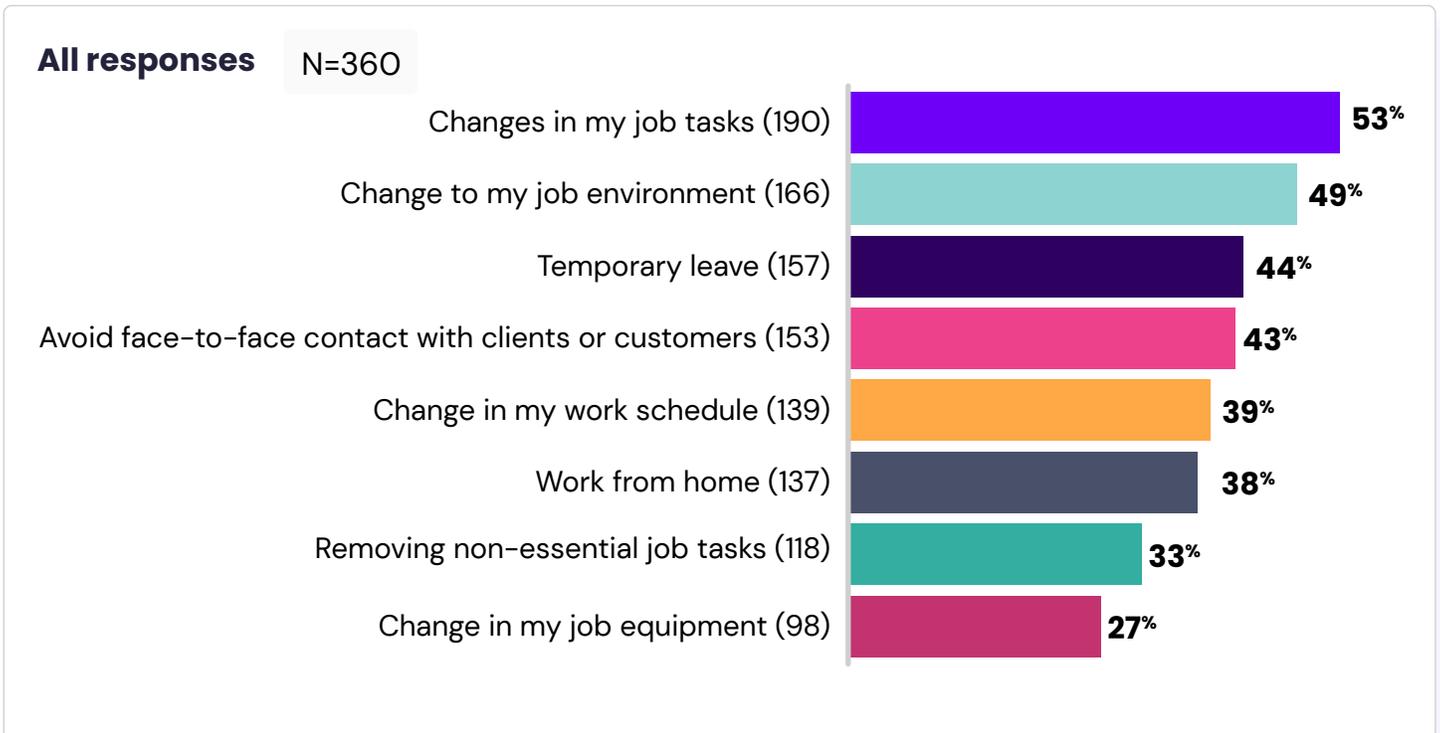
I was afraid of what would happen if I asked

2%

Other

Top Accommodations Being Requested Are Changes in Job Tasks & Environment

Of the top eight accommodations being requested, seven relate to changes in tasks, location, or schedule. Some of the top requests, like changing the job environment, avoiding face-to-face contact, and working from home, are both easy and entirely free to implement. 27% of those asking for accommodations reported asking for changes in job equipment.



Part Two: Stigma, Mental Health, and the Human Toll of Long COVID on Employees

Long Haulers, Feeling Alienated and Misunderstood, Have To Prove They're Sick

One of the more heartbreaking discoveries our study uncovered is the stigma that those with long COVID feel when attempting to seek help. Survey participants describe feeling misunderstood and alienated, and feeling that they had to prove or validate their symptoms. Many shared that they didn't feel like themselves and struggled to fully describe their experience to doctors and employers. Participants also describe the lack of awareness of long COVID as a barrier to receiving workplace accommodations. Specifically, most people said they felt like their employer didn't acknowledge or wasn't aware of long COVID, and many expressed frustration that they had to "convince" their employer that long COVID was real.

MICHAEL CLEVELAND

Michael is a 30+ year veteran of the group life and disability insurance industry. As President of Advisory Services for Brown & Brown Absence Services Group, Michael helps to lead the organization in serving both individuals with disabilities seeking Social Security benefits, as well as working with insurance carriers and employers in developing innovative solutions and increased proficiency in assisting employees with leaves of absences, disability claims, and returning to work.



Long COVID symptoms make it difficult for individuals to return to their "pre-COVID" normal, and many of them must rely on outside support, including the receipt of income replacement benefits, such as short- or long-term disability payments, as well as Social Security Disability Insurance (SSDI). As conditions persist and prevent the return to gainful employment, the transition from short-term to long-term disability, and possibly Social Security Disability, may be inevitable.

Transitioning to Long-Term Disability

Due to mounting medical bills or impending deadlines for health care coverage, the financial protection offered by long-term disability benefits is imperative for those dealing with long COVID or "post-acute COVID-19". Despite more than two years into the pandemic, there is still very much unknown about COVID-19, in both its acute and post-acute phases. How long symptoms are expected to last can vary, and how to identify what a long-haul symptom is differs among medical professionals.

As insurers consider long COVID claims and the symptoms leading to functional limitations, they are faced with the challenge of making informed decisions on incredibly complex claims, including who is eligible for benefits and where and when a person can successfully return to work.

What we do know is how important it is that individuals transitioning to long-term disability feel supported along their journey. It is an incredibly difficult time, as many would have expected a return to normalcy once they navigated their original diagnosis. While it will not be possible or appropriate for every individual, providing options to return to work with accommodations or in another field may often be the best form of support that can be offered.



Providing options to return to work with accommodations or in another field may often be the best form of support that can be offered.

Michael Cleveland



The Critical Importance of Income Replacement Insurance

Sadly, managing disabling conditions such as long COVID affects not just an individual's mental and physical health, but can also have devastating financial impacts. Researchers at Stony Brook University, the University of Tennessee, the National Disability Institute, and the Oxford Institute of Population Ageing collectively conducted a study on how much additional income does a working-age person with a disability need to match the same standard of living they would enjoy without a disability. Their extensive findings concluded that a household with a disabled adult requires an average of 28% more income (or an additional \$17,690 a year) to attain the same standard of living as a household without a disabled adult, even after accounting for available assistance programs and services.¹⁸

Disability costs can be separated into two categories: indirect costs and direct costs. Indirect costs include reduced earnings due to employment discrimination, reduced or underemployment, or by household members that work reduced hours to provide care and support. Direct costs are the expenditures individuals make because they have a disability. The highest direct costs are for personal assistance services and health care, where out-of-pocket costs for people with a disability are more than twice as high as those without a disability. Not surprisingly, additional research calculates that people with disabilities spend more on health care. The average annual health care cost for a person with a disability (\$13,492) is almost five times higher than for a person without a disability (\$2,835), including out-of-pocket costs, which are more than twice as high (\$1,053 versus \$486).¹⁹

Income and Return to Work Support



Social Security Disability Insurance (SSDI): SSDI benefits provide workers who expect to be out of work for at least one-year with additional financial support as they navigate their health complexities. Additionally, beneficiaries who are approved for benefits, and are out of work for at least twenty-nine months, qualify for Medicare health care to help offset the cost of medical expenses associated with COVID-19.

¹⁸ Stony Brook University, the University of Tennessee, the National Disability Institute, and the Oxford Institute of Population Ageing, The Extra Costs of Living with a Disability in the U.S. – Resetting the Policy Table. 10/2020.

¹⁹ National Disability Navigator Resource Collaborative, CHRIL Article Examines Health Care Coverage and Costs for People with Disabilities, 1/2018.





Vocational rehabilitation: For workers who wish to return to work but need additional support, vocational rehabilitation can provide the assistance needed to successfully reenter the workforce. Any workers who are approved SSDI benefits are automatically eligible for vocational rehabilitation assistance through the Social Security Administration's Ticket to Work program, which provides support while allowing beneficiaries to continue to receive disability income and medical coverage.



Physical, occupational, or speech therapy: Before returning to work, those who continue to experience debilitating symptoms may need additional support in the form of therapy. Lingering physical, mental, and cognitive challenges may require additional support through therapeutic means.

Returning to work

Returning to work after a COVID-19 diagnosis complicated by long-haul symptoms may be quite challenging for both the employee and the employer. It is important for both parties to be open about potential restrictions and what is needed to make the return-to-work both effective and productive for everyone involved. It is important to remember that this transition can be mentally, as well as physically, overwhelming, and compassion and communication will be vital in making the transition a successful one.

In Their Own Words



"When I started to request to continue working from home, there was an attitude there, nothing specific or angry, but you could tell they weren't happy. I couldn't move my hands or type, and I felt like I had to convince them that something was wrong, that I had to validate myself. Like I was on a [witness] stand, and I had to prove my case that I couldn't show up for work."



"People with jobs are afraid to tell their employer. There's a lot of people who aren't coming forward, or they're hesitant, or maybe there's just no template for the employer to deal with this."

The Mental Health Impact of Feeling That Life May Never Be The Same

The mental and emotional impact of long COVID is far more devastating than employers may understand, resulting in mental health conditions that are also covered by the ADA. While much attention has been paid to the impact of the pandemic and quarantines on the mental health of young people and the general public, there is far less coverage on how long haulers are managing their diagnosis while also providing for themselves and their families. This may be the biggest area of opportunity for employers, as discussed in detail in Part Five.

“COVID-19 has created this perfect storm of conditions and outcomes that have built upon each other” says Catina O’Leary, PhD, President and CEO of Health Literacy Media, the organization that conducted this study. “The pandemic took an emotional toll on everyone, which is measurable in data from multiple studies over the course of the pandemic. What’s so heartbreaking in this study is how the realities of the pandemic are exacerbated for those still struggling with its aftereffects. The stigma folks report just trying to find the right doctors and the right resources at work certainly correlates with their mental health outcomes, which in turn correlates with people’s ability to remain in the workforce. It’s a vicious cycle that, at present, employers are not getting right, to the detriment of all.”



45% of respondents answered yes to “I have depression or anxiety.”

In Their Own Words



“People just said, ‘take a few days off work and you’ll be fine.’ But that wasn’t it.”



“I didn’t know if I would survive.”



“I didn’t feel like myself, and it was really hard for the doctors to understand. Mentally, it’s so challenging. I have a 6 year old I need to take care of, and I was so scared that I wouldn’t be there for them.”

Organizations That Meet the Needs of Their Employees Gain Trust and Loyalty In Return

While only 12% of respondents reported feeling “very satisfied” with their employer’s response to their long COVID diagnosis and treatment, the vast majority of participants — 72% — reported feeling satisfied or neutral with their employer’s response. This is somewhat surprising considering that only 44% of employees who requested accommodations received all of the accommodations requested.

For the small percentage of respondents who had positive experiences, their feedback is telling: *“In good or bad condition, the company is always here for me. Just like companies give women maternity leave, that was the same scenario that happened with me. The company really prays for me, they are incredible and very helpful.”*

As we’ll discuss in detail in Part Five, employees who feel supported by their employers around mental health are 2.4x more likely to intend to stay; 3x more likely to feel proud to work at their company; and 5.6x more likely to trust their company.²⁰ Simply ensuring that employees feel heard and supported will have a tremendous impact on loyalty, engagement, and productivity over time.

²⁰Mind Share Partners 2021 Mental Health at Work Report, 2021

Part Three: Workplace Accommodations are not Offered or Accessed Equitably

Communities of Color Bear a Disproportionate COVID Burden

As has been reported throughout the pandemic, people of color have been disproportionately affected by COVID-19. In November 2022 the CDC reported that, versus their White peers:²¹

Hispanic or Latino persons were

1.5x
more likely
to be infected

1.9x
more likely to
be hospitalized

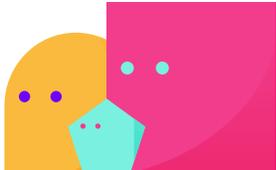
1.8x
more likely to die
from COVID-19

American Indian or Alaska Native, Non-Hispanic persons were

1.6x
more likely to
contract COVID-19

2.5x
more likely to
be hospitalized

2.1x
more likely to die
from COVID-19

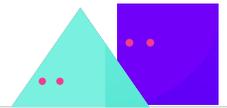


Unfortunately, data around long COVID has been more allusive. The CDC’s “Household Pulse Survey” on COVID-19 did not begin collecting data on long COVID until June 2022. So far, survey results have found that rates of self-reported long COVID are one quarter to one third higher among adults who are female, transgender, Hispanic, and without a high-school degree than they are among all adults.²² Other studies have found that Latino and Black adults had higher rates of workplace exposure than their White counterparts, contributing to higher COVID prevalence — and eventually higher development of long COVID.²³

Our findings are consistent with these statistics, indicating that people of color have dramatically different experiences with long COVID than their White counterparts. We also found that older workers and workers with less education received fewer accommodations than their younger and more educated counterparts.

Studies have found that Latino and Black adults had higher rates of workplace exposure than their White counterparts, contributing to higher COVID prevalence — and eventually higher development of long COVID.

²¹ CDC, Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity, 11/2022
²² Kaiser Family Foundation, Will Long COVID Exacerbate Existing Disparities in Health and Employment? 9/2022
²³ Ibid.



Choosing Whether To Work Is Influenced by Race, Ethnicity, and Education

The disparities in experiences and outcomes between demographic groups became apparent in the first question of our survey, “Have long COVID symptoms affected your ability to work?”

While 71% of survey respondents reported continuing to work, the numbers varied significantly by race and by education level:

- Only 9% of Hispanic or Latino respondents stopped working, versus 30% of White respondents and 32% of African American or Black respondents
- Respondents with only high school education left the workforce at twice the rate of those with some college or an Associates degree.

The high rate of Hispanic or Latino respondents continuing to work may indicate that they have fewer options or less access to disability accommodations, resources, and benefits than other racial or ethnic groups. And the high rate of low-education workers leaving the workforce may indicate that employed income levels were closer to the increased unemployment benefits offered during the pandemic, making unemployment less of a financial pinch than for those with more education and potentially higher wages.

Have long COVID symptoms affected your ability to work?

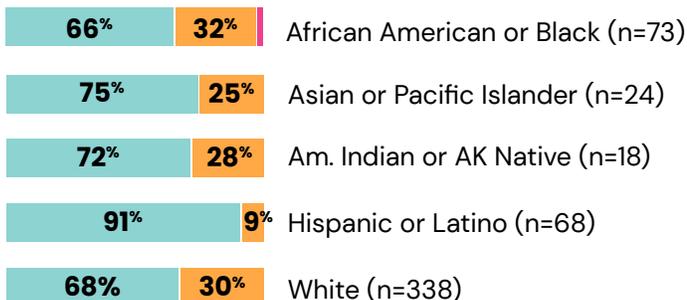
Respondents with only high school education left the workforce at **2x the rate** of those with some college degree

Have Long COVID symptoms affected your ability to work?

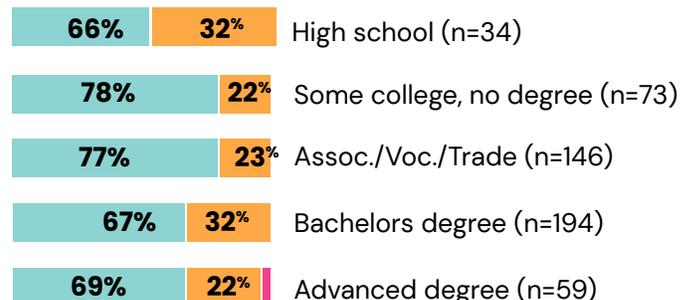
N=506 ▲ Yes, but I've kept working ◆ Yes, and I've stopped working ● No or unsure



By race and ethnicity



By education



Different Racial and Ethnic Populations Experience Long COVID's Impacts Differently

Different populations also experienced the impacts of long COVID differently, bringing to light potential cultural differences and even perceptions of safety in acknowledging certain effects of long COVID.



Compared to all of other populations, White respondents were :

- More likely to say they have anxiety and depression
- More likely to say they cannot work as many hours
- More likely to have changed where they work



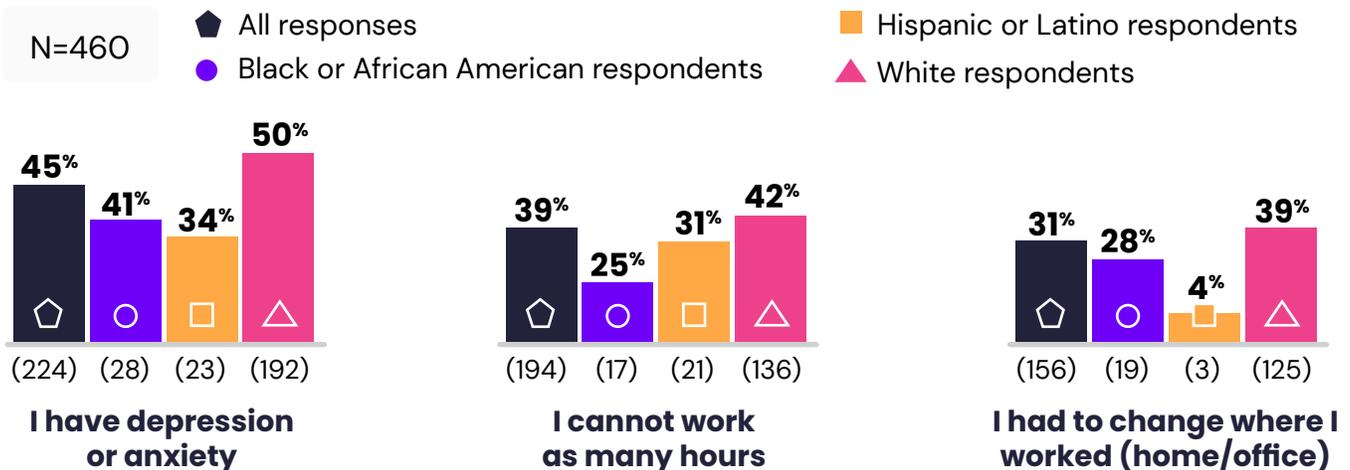
Compared to Hispanic or Latino respondents, White respondents were :

- More likely to change where they worked



One alarming finding is the lower rate of Hispanic or Latino workers who indicated having depression or anxiety — 34% versus 45% of all respondents and 50% of White respondents. As the data found no differences in rates of physical symptoms across different demographics, one wonders whether Hispanic or Latino workers, who left the workforce at far lower rates than their peers, simply do not feel that they can afford to acknowledge the toll that the disease may be taking on their mental health. The long-term consequences of this could be dire, as those who receive accommodations are more likely to be able to remain in the workforce than those who do not.²⁴

In what ways have Long COVID symptoms have impacted your ability to work?



²⁴ Journal of Policy Analysis and Management, Unmet Need for Workplace Accommodation, 05/2019

Awareness of Long COVID Status Under ADA Varies by Race and Ethnicity

While 71% of respondents said they were aware that long COVID fell under ADA protections, and we found no significant differences based on age, gender, education, full-/part-time, or on-/off-site, we did find notable variations by race and ethnicity, with White respondents and American Indian or Alaskan Native reporting higher levels of awareness than other populations.

The high rate of awareness among the American Indian or Alaskan Native population may be due to outreach programs by the Indian Health Service (the federal health program for American Indians and Alaskan Natives). American Indians and Alaska Natives have infection rates 3.5x higher than non-Hispanic whites, are 4x more likely to be hospitalized as a result of COVID-19, and have higher rates of mortality at younger ages than non-Hispanic Whites.²⁵ In the Service’s words, “this has highlighted the need for comprehensive, culturally appropriate personal and public health services that are available and accessible to all American Indian and Alaska Native people.” Perhaps these outreach programs are working, if not prior to COVID infection, at least by the onset of long COVID.

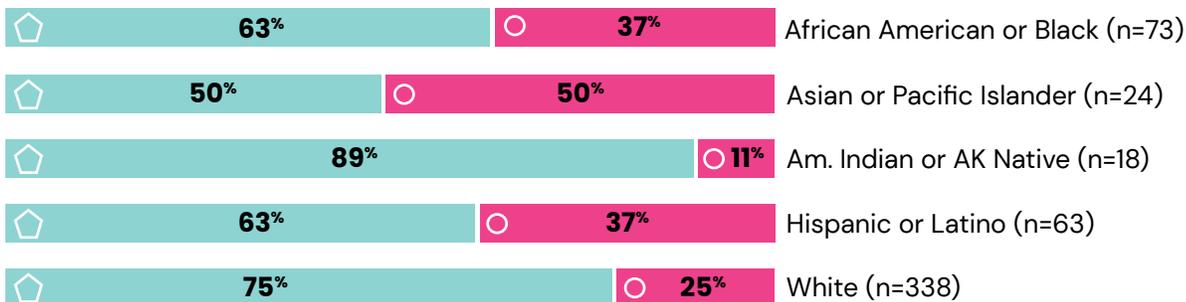
“This has highlighted the need for comprehensive, culturally appropriate personal and public health services that are available and accessible to all.”
Indian Health Service

Were you aware that Long COVID can be a disability under the Americans with Disabilities Act (ADA)?

N=506

Yes

No



Younger Workers Are More Likely to Ask for Accommodations

We wanted to have a deeper understanding of long COVID in the context of workplace accommodations, so we asked respondents whether they had asked for accommodations before contracting long COVID and made a striking discovery. While we found no significant differences across racial or ethnic demographics, we did find variance among age groups: younger respondents were more likely to ask for accommodations than older respondents. This initially counterintuitive finding is consistent with the fact that self-disclosure of disabilities among new hires increased 25% between 2019 and 2021.²⁶

²⁴ Journal of Policy Analysis and Management, Unmet Need for Workplace Accommodation, 05/2019

²⁵ Indian Health Service, Coronavirus

²⁶ DisabilityIn & AADP, Disability Equality Index 2021 Annual Report, 2021



Those entering the workforce now are much more accustomed to the notion of accommodations, as 14% of American students are currently receiving services under the ADA.²⁷ They also have far fewer stigmas around disabilities than prior generations — they’ve grown up with friends who need accommodations as the norm, they’re seeing sports and pop culture icons talk about disabilities and mental health on social media, and they have a far lower tolerance for lack of inclusion.

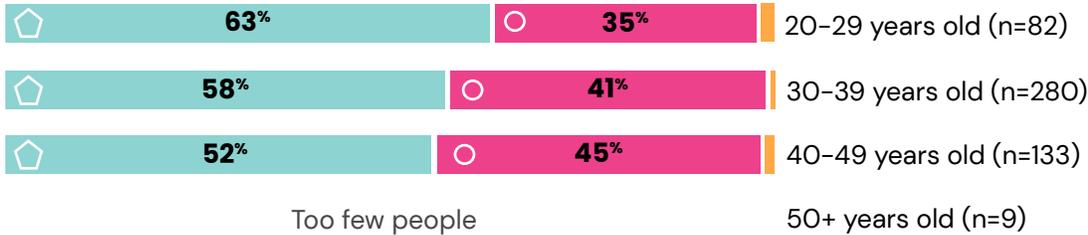
Before you had Long COVID, had you ever asked your employer for accommodations?

N=506

Yes

No

Unsure



More Than Half of Respondents Had Asked for Accommodations Prior to Getting Long COVID

Another surprising finding was that 56% of respondents had experience asking for accommodations prior to getting long COVID. This may indicate that those who already have familiarity with the accommodations process from an existing disability are more likely to advocate for themselves regarding long COVID management.

What employers may not recognize is that accommodating workers with disabilities will open doors to nearly 14 million “hidden workers” in the US.²⁸ It will also improve retention: workers who were accommodated for a health problem in 2014 were 18.5% more likely to work in 2018 than those who were not accommodated in 2014.²⁹



56% of people had asked for accommodations prior to getting long COVID.

Most Workers With Long COVID Ask for Accommodations — But Who Receives Them Varies By Age & Education

A large majority of respondents — 71% — have asked their employer for accommodations. This number was higher than anticipated, as most studies find that the vast majority of workers are not disclosing disabilities in the workplace and are therefore not receiving reasonable accommodations. As mentioned above, a possible explanation is that those with prior experience managing a disability are more likely to seek a diagnosis, treatment, and accommodations



71% of people have asked for accommodations related to COVID.

²⁷ National Center for Education Statistics, Students with Disabilities, 2021

²⁸ Center for American Progress, Removing Obstacles for Disabled Workers Would Strengthen the U.S. Labor Market, 05/2022

²⁹ Journal of Policy Analysis and Management, Unmet Need for Workplace Accommodation, 05/2019

³⁰ Harvard Business Review, Make It Safe for Employees to Disclose Their Disabilities, 06/2021

for a new disability, in this case long COVID. Another possibility not yet clearly established is that long COVID may impact those with preexisting conditions more than those without, thereby collecting more people with other disabilities into a survey like this one.

Of the 71% of respondents who requested accommodations, 44% received “all” accommodations requested, while 56% only received “some”. We found no significant differences based on race or ethnic demographics, but dramatic variance with regard to age and education. People who are younger and more highly educated were more likely to have their employer approve all the accommodations requested compared to those who are older or have less education.

Despite the fact that accommodations requested did not vary dramatically among age groups:

- 2x** Workers with advanced degrees were twice as likely to be granted all accommodations than workers with high school education
- 3x** Workers with advanced degrees were three times as likely to be granted all accommodations than workers with high school education

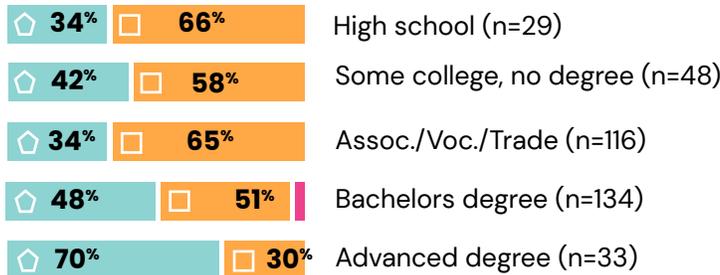
Did your employer approve the accommodations you requested?

Of people who did ask for accommodations:

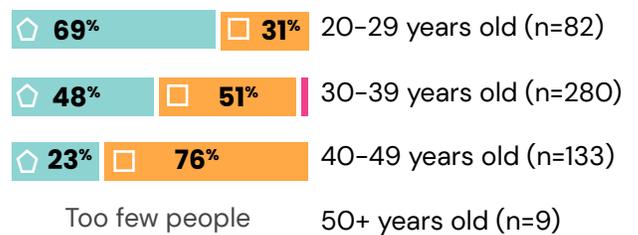
N=360 ◆ Yes, all of them ■ Yes, some of them ● No



By education



By age

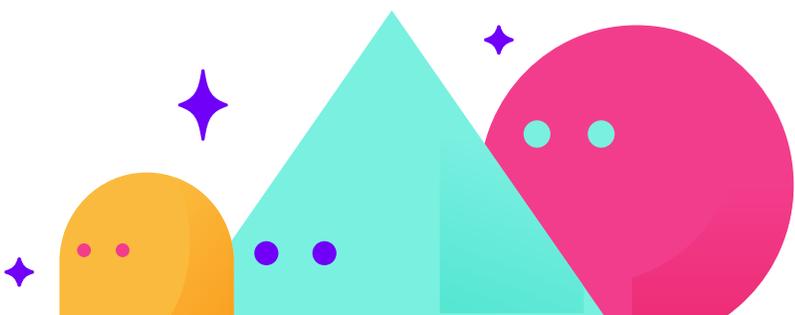
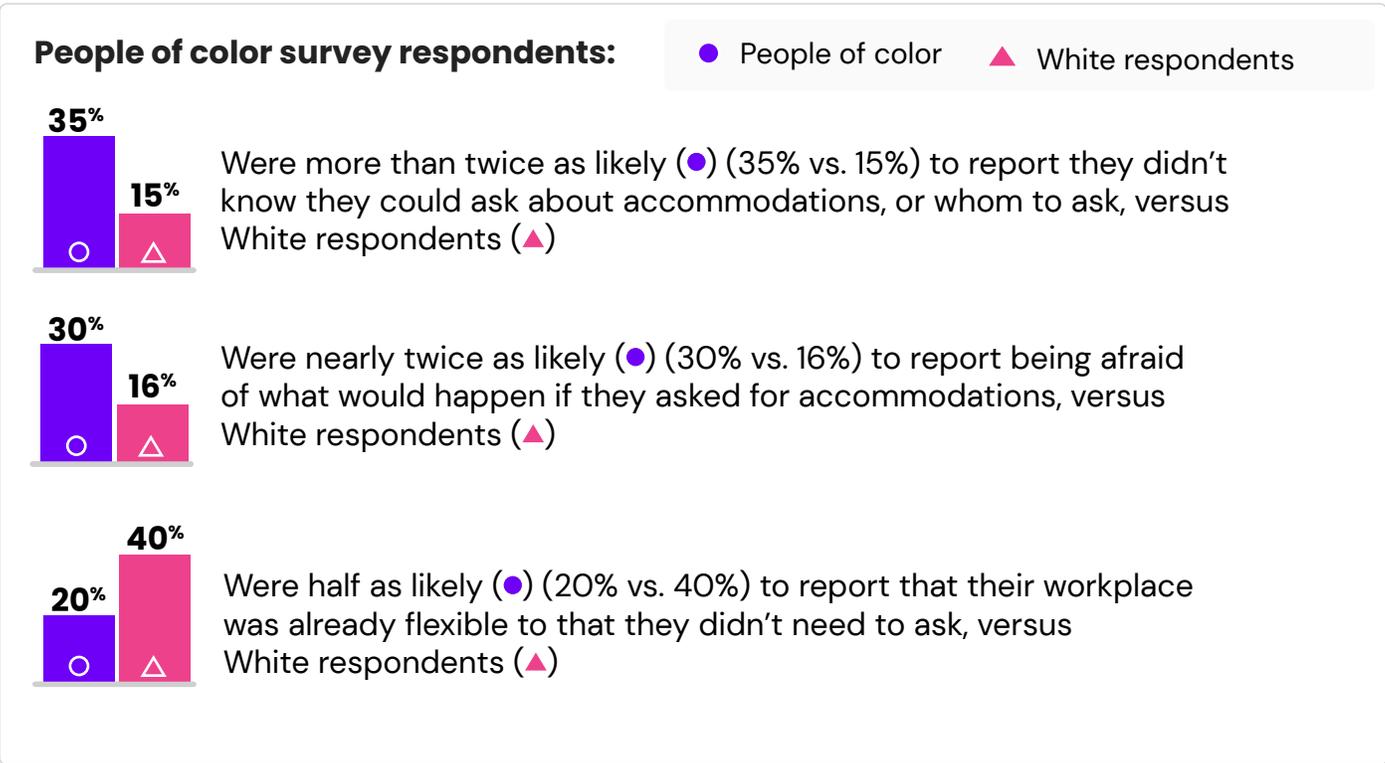


It’s critical that employers create a fully integrated, educational outreach program that meets employees where they are, in a trusted space, whether that’s through existing employee resource groups (ERGs), trusted managers and supervisors, or a newly created structure. It’s clear that some groups are being left behind, the ripple effects of which are deeply detrimental to the organization as a whole.

Part Four: Companies are not Doing Enough to Support Long Haulers

Respondents' Reasons for Not Requesting Accommodations Vary by Racial and Ethnic Demographics – And Indicate More Systemic Problems

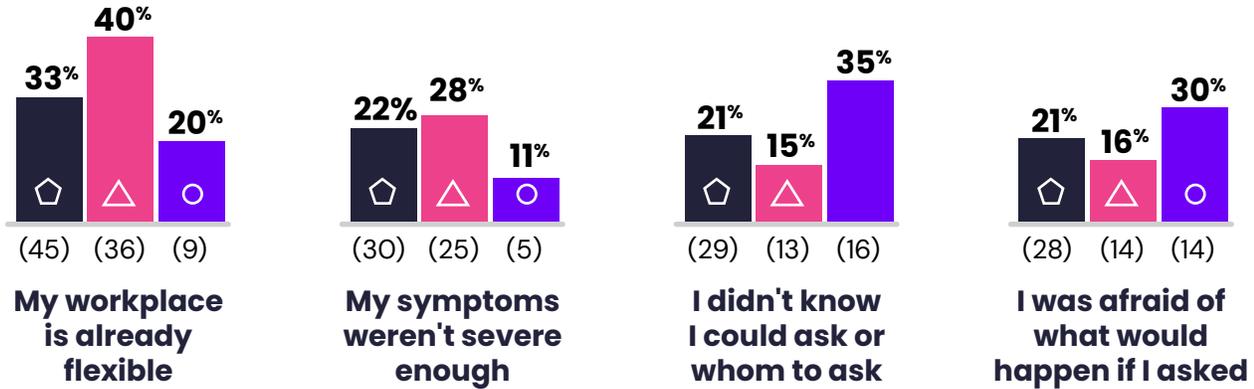
Another disparity came to light regarding why individuals did not ask for accommodations. It appears that employees of color are both less aware than their White counterparts of their rights per asking for disability accommodations and are simultaneously more afraid of the consequences of doing so. One interviewee asked our research interviewer for resources; having not received any information from their employer.



Which of these are the main reason you haven't asked for accommodations because of Long COVID?

Of people who did not ask for accommodations:

N=134  All responses  White respondents  Respondents of color



These findings point to employers needing to expand outreach efforts not just for the entire employee population but to specifically target communities of color within their organizations.

Smaller Companies Are Doing a Better Job of Communicating

Conventional wisdom may have us think that larger companies have more infrastructure and resources in place to accommodate their staff and that this would be reflected in the numbers of employees asking for and receiving accommodations. We found the opposite to be true:



74% of respondents at companies with under 1000 employees understood that long COVID is a disability covered by ADA, versus 55% of those at companies with more than 1,000 employees



Employees at smaller companies were **10% more likely** to have requested an accommodation prior to experiencing long COVID, indicating they had already engaged with their employers around accommodations



In Their Own Words

When asked "How well do you think your employer has responded to supporting employees with long COVID?"



"On a scale of 1-10, I would say a 3. I don't think they know what to make of it..."



"My employer has not mentioned long COVID at all."



"Ideally, I want to be offered disability or aid, like maternity leave. This is a disability. I haven't gone to the SSA and talked about it, but I've always felt like I'm disabled now, and I'm not treated in the workplace as though I am. I remember when I gave birth, I was given disability benefits and that's what I would expect here."

Part Five: Actions to Meet the Needs of Workers and the Organization

Supporting Employees Nets Deep Benefits For All

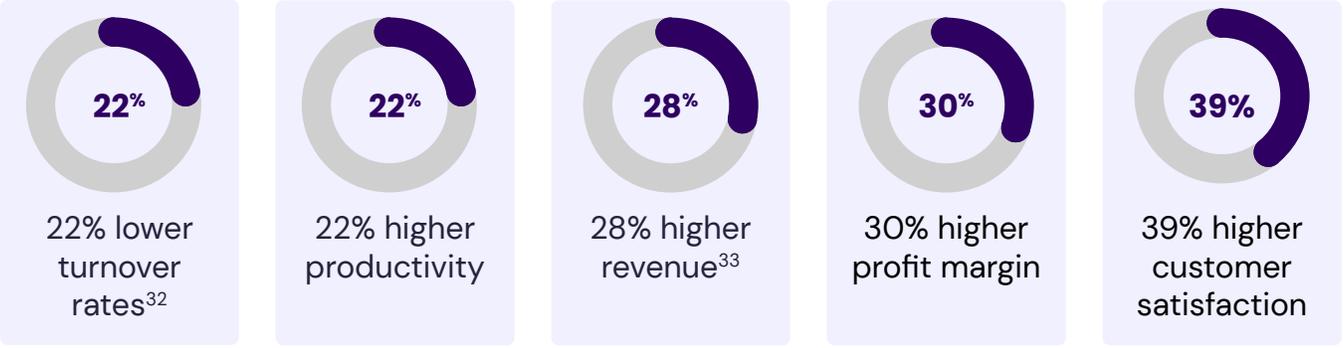
The benefits of inclusive cultures have been proven in countless studies. While the S&P suffered a 35.5% decline between 2007 and 2009, companies with inclusive cultures posted a 14.4% gain.³¹ When it comes to disability inclusion, much of what companies can do starts with simply listening to employees on what they need to be successful in their roles, then making (often small and inexpensive) accommodations to help that employee succeed. What that looks like will vary; with those suffering from long COVID, one employee may need the fluorescent lights in their office switched out to reduce migraines; another may ask to work from home because commuting on public transportation leaves them with too little energy to focus on their work; a third may ask for reduced hours; and a fourth may ask to see a therapist during work hours.

Many employees ask for multiple accommodations; as outlined in Part One, long COVID's symptoms and impacts are physical, mental and emotional, and the onus is on employers to ensure that they are inviting the employee to be supported in all ways that they need to be successful in their role.

The good news is that while disability inclusion is tremendously beneficial to the disability community, it also nets fantastic business results for organizations.



Organizations that embrace disability inclusion lead their peers across multiple business indicators including:



So, what are companies waiting for? Below are simple action items to get started, utilizing long COVID as an inroads that will benefit other workers who could benefit from accommodations.

³¹ Fortune, New Study Reveals That Diversity and Inclusion May Be the Key to Beating the Next Recession, 12/2019
³² Accenture & Harvard Business School, Hidden Workers, Untapped Talent, 09/2021
³³ Deloitte, How mobilizing a diverse workforce can drive business performance, 2018

Action 1:

Acknowledge and Raise Awareness of Long COVID as a Covered Health Condition

The research has highlighted that many employees, especially employees of color, do not know where to go or who to ask about long COVID. The first step in supporting employees is simply to offer publicly available information about the disease and the processes employees can engage to get the accommodations they need.

-  Share symptoms of long COVID with employees, as well as info on when to see a doctor and any local resources like long COVID clinics
-  Proactively disseminate existing or new company policies on long COVID both directly to employees and also to managers so they have everything they need should the need arise
-  Gather and share first-person, anonymized experiences of employees managing their own or a loved one's long COVID
-  Provide guidance on long COVID's status as a disability under the ADA and how to request benefits and/or apply for other disability benefits
-  Consider existing support groups like ERGs as potential centers of information dissemination

In Their Own Words



"I think more open dialog, more awareness – I think even people who have it aren't aware. People don't want to feel like they're the only one. Everybody is just trying to get back to normal, so they're just putting this issue to the side. People try to avoid it, because the idea is to get back to normal – they would say 'why are you going back to that subject [COVID]?' Even the health plans aren't doing anything – HR and upper-management just need to be more aware, [and provide] less stigma for those with it."

Action 2:

Nurture an Environment Where Employees Can Safely Communicate

Employees with long COVID, especially employees of color, indicated that they do not feel safe disclosing their condition both because of the stigma surrounding the disease and because of what might happen as a result. As one respondent in our survey stated: "I haven't notified my work. I wouldn't even know what to notify them of. If I had a fracture,

that's different, it's easier to say. I wouldn't even know who to go to, what to say, or if it would even make a difference."

In this context, it's important to call out the need for more support around mental health needs as well, which can be a significant symptom associated with long COVID. Increasingly, talking about mental health at work is the norm, though comfort levels and the experience of these conversations are still mixed. To ensure these conversations keep happening and remain productive, organizations have an imperative to not only equip managers, teams, and employees to navigate these conversations productively but also to cultivate safe and supportive cultures overall. Employers must establish a culture that offers space for employees to speak to a trusted partner about any health issues they're experiencing that will impact their work performance.



I wouldn't even know who to go to, what to say, or if it would even make a difference.

Respondent



Train managers and supervisors on how to appropriately respond when employees disclose their long COVID symptoms; because of the stigma many already feel around even attaining a long COVID diagnosis, this training must stress both empathy and confidentiality



Ensure that managers, supervisors, and HR Business Partners know what information, policies, and procedures they can share with employees who need it, both for their own potential diagnoses and loved ones who may be covered by the employee's health insurance



Ensure that there is guidance around how to create a plan to help employees continue working whenever possible

Action 3:

Ensure Long COVID is Included in Existing Policies or Create New Policies to Address It

As all employers with more than 15 employees are required by law to make reasonable accommodations for employees with disabilities, each employer likely has systems in place to manage accommodations for other disabilities. These systems and processes should be updated to accommodate the needs of the 7-15% of the employee population that is experiencing long COVID at any given time.



Consider creating an accommodations and long COVID specialist role within the HR organization to make getting assistance and information as easy to acquire as other benefits like parental or open enrollment



Consider engaging Rehabilitation Counselors. Disability rights attorney Ashley Jacobson reports that "rehabilitation counselors have master's-level training in helping people with disabilities address accessibility and disability needs in the workplace. They conduct accommodations assessments and advise the employee and the employer."



Action 4:

Clarify Common Accommodations for Long COVID and How to Request Them

A number of accommodations that are likely already being implemented are applicable to accommodating long COVID. These can include:

-  Allowing employees to work remotely
-  Offering extended and/or more frequent breaks
-  Making adjustments to communication structures. For example, allow employees to attend fewer meetings or to move communications from in-office meetings to email and provide summaries
-  Allowing employees to work flexible hours
-  Offering job sharing or providing support per workload
-  Providing regular one-ones with managers

It's also helpful to provide clear guidance on the organization's sick leave policy and to consider providing extended sick time for those suffering from long COVID. Some organizations have chosen to provide financial support as well, especially to help cover unanticipated out-of-pocket medical costs.

Action 5:

Ensure Employees Understand and Use the Absence and Disability Benefits Available to Them

Securing a leave of absence or disability benefits can be a complex experience during an already stressful time in an individual's life. When an employee files for a leave of absence, they must navigate the intricate provisions of their employer's policy, in addition to any local, state, and federal level leave requirements, adding to the complication of the process.

The employee may rely heavily on their employer or the employer's outsourced leave partner – such as a contracted insurance carrier or third-party administrator – or both to guide them through the process and provide advice on what is needed to fulfill the policy obligations and successfully secure their leave. Support for the employee at each level of the application is essential to maintaining a positive relationship between the employee, employer, and outsourced partner.

While no definition for "leave of absence" expressly exists according to the US Department of Labor, a leave of absence is generally viewed as an allowed time away from work requested by an employee for a qualifying life event, including their own serious health condition. While the Family and Medical Leave Act (FMLA) provides



unpaid job-protected leave for specific family or medical reasons, additional instances of leaves of absence may provide employees with different coverage.

When contacting the employer or the outsourced leave partner, employees may only understand the single fact that they need to file for leave to care for a family member or take care of their own serious health condition. Employees may need – and appreciate receiving – additional education about the various components of their leave.

As each employee's circumstances will differ, the leave of absence provisions may not support them as needed. For some, a reduction in income may create a significant hardship. The employee may need support beyond the reason they applied for leave, such as assistance in paying for groceries, utilities, or even childcare. Utilizing available resources such as an Employee Assistance Program (EAP) or other organizations that may provide assistance, will enable the employee to focus on their personal recovery or caring for a family member. Additionally, providing the employee with the appropriate support during their leave of absence may help mitigate any unintended extensions beyond the original expected duration.

Action 6:

Openly Commit To Supporting Employee Mental Health

Far more people have grown accustomed to talking about mental health conditions, and the expectations of workers are shifting to expect more from employers. While some organizations are catching on, many are not doing so quickly enough. While there's been a noticeable increase in providing mental health accommodations, there remains a significant gap between the percentage of workers who report suffering from a mental health condition and the percentage being accommodated. In addition to the accommodations mentioned above, we recommend proactively providing or extending the following accommodations and support in order to better address the needs of employees:

-  Talk about mental health from both the top down and the bottom up, making it clear that the organization is committed to supporting workers
-  Train managers on how to talk about mental health and what benefits and accommodations are available
-  Consider offering extended health insurance coverage for mental health or access to mental health services
-  Allow employees to attend therapy during work hours
-  Encourage taking time off, taking vacation or PTO
-  Consider adding mental health days as a benefit
-  Create and foster mental health-related ERGs

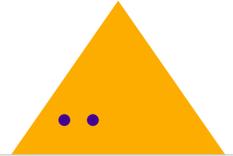


Increase coaching and mentoring opportunities



Provide regular one-on-ones with managers

If you are not already proactively providing accommodations to support the mental health of your workforce, you will likely fail to attract and retain top talent in the future.



In a biennial study of mental health in the workplace, researchers found that those who felt supported in four key areas: mental health, the pandemic and remote work, racial injustices and trauma, and the return to office, were:³⁴



Those four areas: mental health, the pandemic and remote work, racial injustices and trauma, and the return to office, are at the heart of both this study and the realities of managing long COVID. Meet your employees where they are, go deeper to find the employees who are afraid of speaking up, listen, and accommodate. Your organization will foster a virtuous cycle and a more diverse, inclusive culture that in turn benefits employees, the organization, and its shareholders.

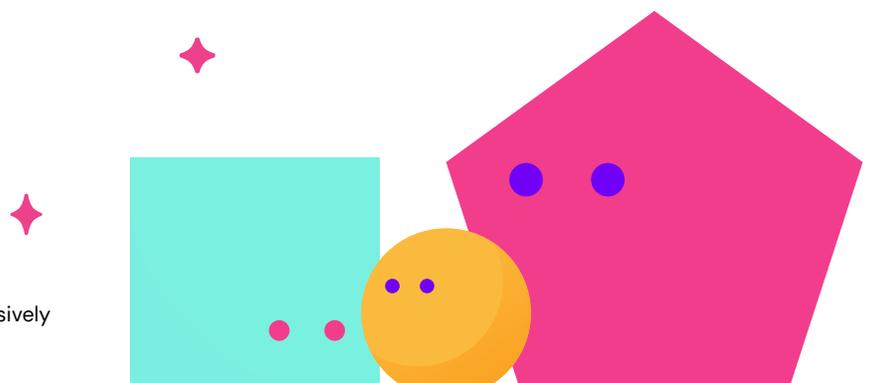
³⁴ Mind Share Partners, 2021 Mental Health at Work Report, 2021

Methodology

From September 6 to October 5, 2022, Health Literacy Media (HLM) conducted an online survey to gather information on how long COVID has affected people's work. HLM created the survey with review and input from Inclusively. HLM recruited people to take the survey via social media, outreach to advocacy and community organizations, HLM's email newsletter, and word-of-mouth. People filled out an online screener form to sign up, which captured their demographic information including if they had long COVID, age, race/ethnicity, gender, employment status, size of employer, and education level. HLM then reviewed the screener responses, selected people to take the survey, emailed a link to the survey, and emailed a \$10 gift card to those who completed the survey.

Of 7,035 survey sign-ups, all but 808 were filtered out because they were flagged as spam or did not meet the survey criteria of having long COVID. The survey was completed after 506 responses. HLM conducted quantitative analyses of the survey responses, including differences based on demographics collected in the screener. HLM then thematically coded the long-form response and identified representative quotes where appropriate.

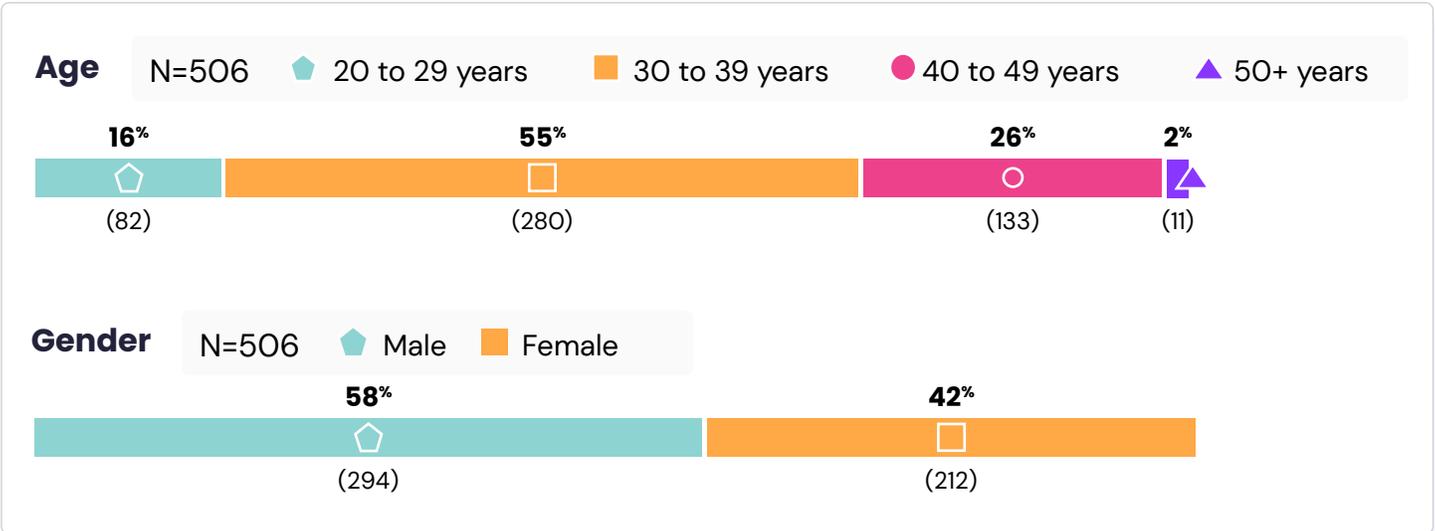
HLM reviewed the survey responses and selected a diverse group of five interview candidates to interview based on age, race/ethnicity, gender, employment status, size of employer, education level, and their employer's response to long COVID. Each participant was emailed a \$100 gift card for their time. HLM then thematically coded the interview transcripts and identified representative quotes where appropriate.



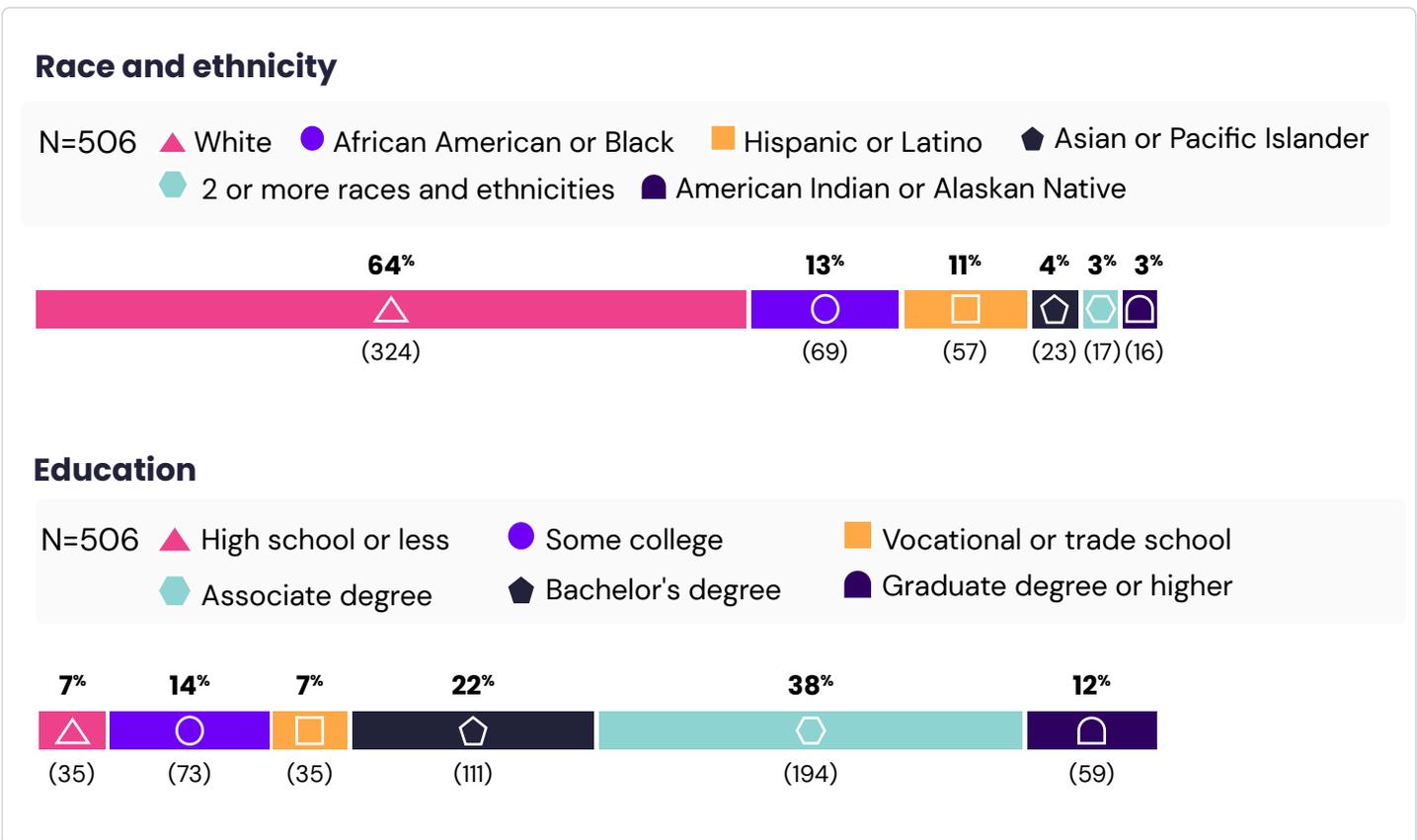
Demographics

This section shows the overall data collected from both the screener and survey related to the people's background, employer, location, and when they had COVID.

Age and gender

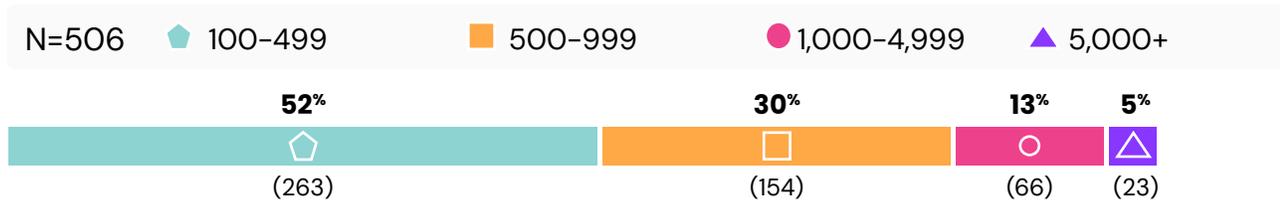


Race, ethnicity, and education

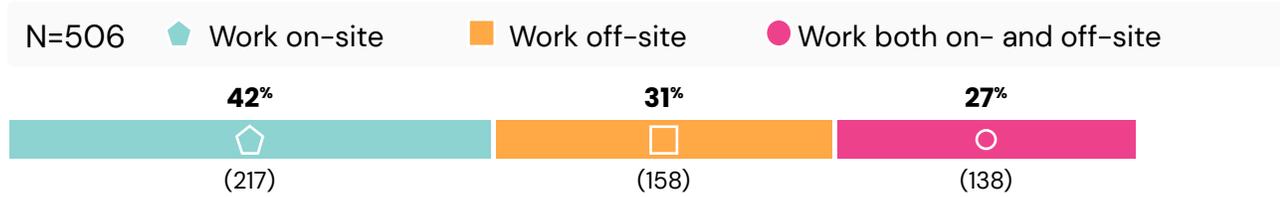


Workplace demographics

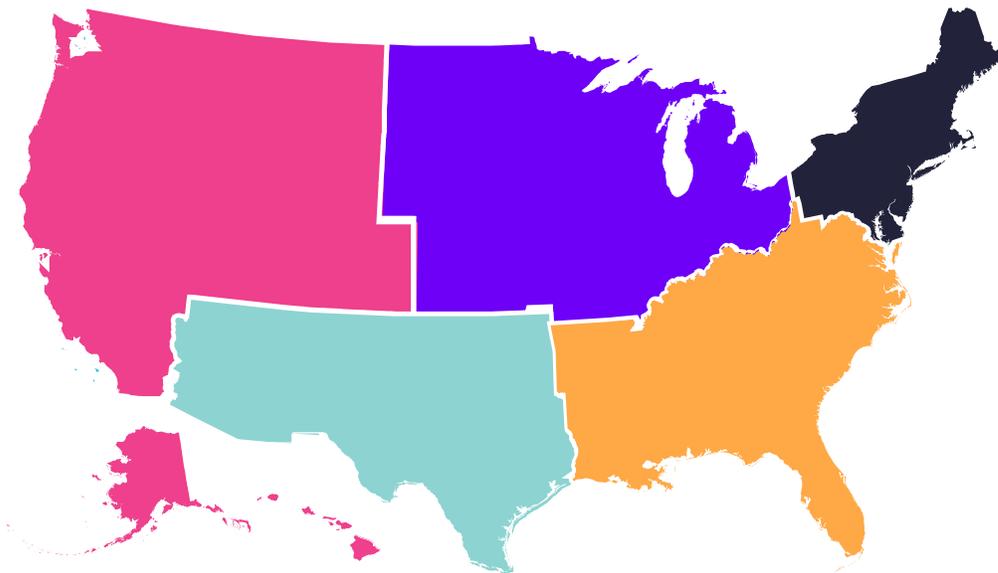
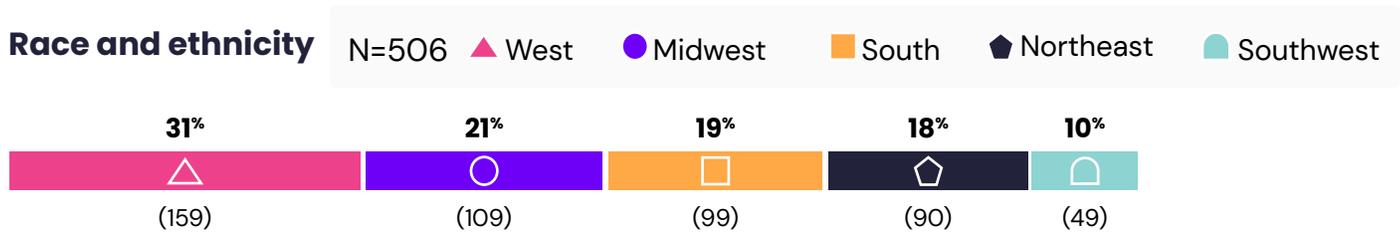
Employer size (number of employees)



On-site or off-site work



Geographic distribution



When did you have COVID?

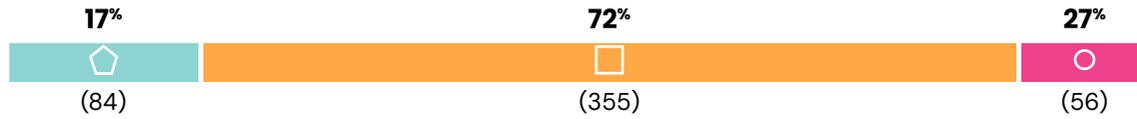
By year

N=495

2020

2021

2022



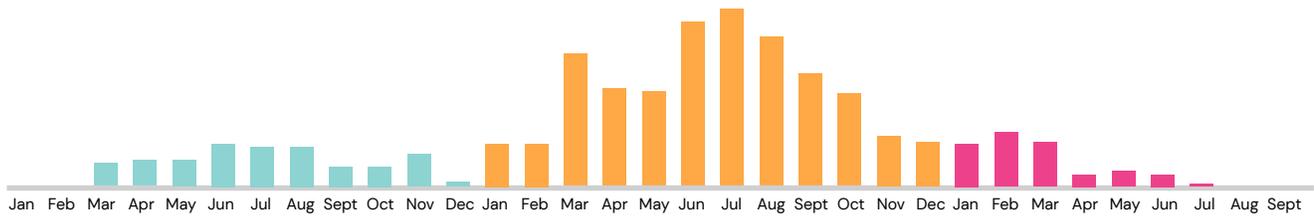
By year and month

N=495

2020

2021

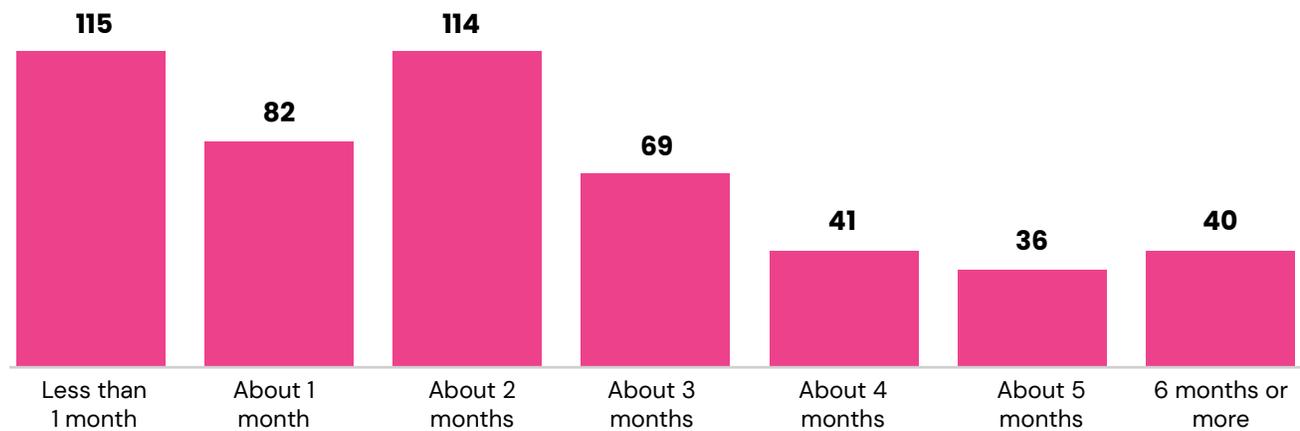
2022



About how long after having COVID did you notice Long COVID symptoms?

Employer size (number of employees)

N=497



About the Study

Commissioner

This study was commissioned by **Inclusively**, a technology platform that empowers employers with the accommodation insights, access, training, and support they need to attract and retain previously hidden talent.

Research Partner

This study was conducted by **Health Literacy Media**, a health communication firm focused on health literacy, public health and policy, research, plain language medical writing, and communications.

Author

Fully Teasdale is a Content Strategist and Market Research Consultant for rapid-scaling technology companies. She has led product and marketing organizations at startups and Fortune 50 companies including Fleishman–Hillard, HP (Snapfish), and Express Scripts/Cigna.

Contributors

Brown & Brown Absence Services Group, LLC, is focused on adding value across the absence continuum by bringing industry-wide experience and extensive capabilities to deliver value-driven solutions that meet the evolving needs of disability insurance companies and self-insured entities. Brown & Brown Absence Services Group's solutions include SSDI advocacy, medical file review, clinical services, advisory services, recovery services, claims management, talent solutions, and consultative solutions. Aevo Services, an affiliate of Brown & Brown Absence Services Group, provides Medicare eligibility and policy decision advisory services.

Ashley Jacobson is a disability rights attorney and accommodations specialist living with physical disability in the state of Michigan. Through her law firm, **Jacobson Law & Advocacy**, she protects the rights of clients with disabilities in workplaces, schools, courtrooms, and communities. Ashley also owns and operates **Adaptive Inclusion**, a nationwide disability counseling and consulting firm, utilizing her master's degree and certification in disability counseling and assessment (CRC).

