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Understanding and Addressing Long COVID

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Executive Summary

Key Findings

- Commonly reported symptoms of Long COVID include difficulty concentrating or thinking, difficulty breathing, fatigue that interferes with daily life, post-exertional malaise, and muscle and joint pain.
- Long COVID is similar in various respects to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), an often-disabling illness. If research on ME/CFS had been better funded in the past, the U.S. would be in a better position today to address Long COVID.
- According to a May 2022 GAO report, 10 to 30 percent of COVID-19 survivors develop Long COVID. Subsequent research is generally consistent with this range.
- The Census Bureau added questions about post-COVID conditions to the Household Pulse Survey (HPS) in June 2022. Between September and October of 2022, about 7.1 percent of all U.S. adults reported currently having one or more symptoms lasting three months or longer that they did not have prior to having COVID-19.
- In September 2022, Census added a question to the HPS about disabilities (activity limitations) due to Long COVID. Responses to this question suggest that over 14 million US adults are disabled due to Long COVID, with 4.5 million reporting symptoms that interfere with daily activities “a lot”.
- In the monthly Current Population Survey, the number of prime working-age adults reporting disabilities in at least one of six categories has spiked in the aftermath of the initial COVID-19 crisis. The largest single increase is due to people reporting difficulties concentrating or remembering (cognitive difficulties).
- About 1.5 million Americans had ME/CFS prior to COVID-19. Total ME/CFS prevalence could rise to over 5 million people due to COVID-19 and Long COVID.
- The body of research on the labor market impacts of Long COVID on US workers is relatively limited, but growing. Recent analyses suggest about 500,000 people are out of the labor force due to Long COVID.

Key Recommendations

Prevention

- Invest at least \$7.84 billion over the next five years to modernize the currently fragmented and underfunded public health information system.
- Provide additional funding for COVID-19 prevention to combat future surges and accelerate vaccine distribution.
- Provide funding for global vaccination efforts, as previously requested by the Biden administration.
- Support a new issuance of at least \$650 billion in Special Drawing Rights (SDRs), international reserve assets, at the International Monetary Fund.
- Promote and invest in improvements to indoor air quality.

Medical Research and Health Care

- Establish and adequately fund a National Institute on Complex Chronic Conditions (including Long COVID, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), dysautonomia, fibromyalgia, Post-Treatment Lyme Disease Syndrome; Mast Cell Activation Syndrome (MCAS), and Ehlers-Danlos syndrome) at the National Institutes of Health. This new institute should be structured in a way that is consistent with recommendations made by members of the Long-COVID and associated-conditions patient community earlier this year.
- Ensure that people with Long COVID and other complex chronic conditions have access to free or affordable health insurance that provides the care and treatments they need.
- Provide funding to ensure equitable access to Long COVID treatment, multidisciplinary Long COVID clinics, public education, and medical-legal partnerships that help individuals with Long COVID access employment accommodations and social services.

Social Insurance

- Ensure that all workers have access to paid leave, paid sick days, and temporary disability insurance.
- Remove barriers, including lengthy waiting periods, to Social Security Disability Insurance and Supplemental Security Income for people with long-term disabilities.
- Increase access and eligibility to Unemployment Insurance for people with Long COVID and other medical conditions and disabilities.

What is Long COVID?

People who have been infected with the respiratory virus that causes COVID-19 can experience long-term negative effects from the infection. These lasting effects are typically referred to as Long COVID, also known as [post-acute sequelae of COVID \(PASC\)](#), [post-COVID conditions](#), or [Long-Haul COVID](#). Commonly reported symptoms of Long COVID include difficulty concentrating or thinking (“brain fog”), difficulty breathing, fatigue that interferes with daily life, [post-exertional malaise](#), and muscle and joint pain. (For a more complete list of COVID-19 and Long COVID symptoms, see the Appendix). Some people experience damage to one or more organs including the brain, heart, kidneys, lungs, and skin. Anyone who was infected with COVID-19 can develop Long COVID, including people who are vaccinated and people who had an initially mild or asymptomatic infection.

Research on the causes and treatment of Long COVID is ongoing. Many researchers believe that Long COVID is not [one thing](#) but may be multiple conditions. Theories about the causes include an *exaggerated immune response* triggered by the infection; *residual organ damage* due to the body’s own immune response to the infection; and *viral persistence* in various tissues.

According to the Centers for Disease Control and Prevention (CDC), conditions associated with Long COVID can be identified as soon as [four weeks after infection](#). Symptoms can improve over time, though many people experience long-term symptoms. Symptoms can also worsen over time, and new symptoms can develop later on. Similarly, the impact of Long COVID symptoms on activities of daily living fall on a spectrum that ranges from mild to completely disabling.

Are Long COVID and Other Post-COVID Conditions Surprising or Unexpected?

Persistent health problems after severe illnesses and [infectious diseases](#) are not a new phenomenon that started with COVID-19. According to [one study](#), approximately 27 percent of survivors of SARS (severe acute respiratory syndrome), which is also caused by a coronavirus, were suffering from [myalgic encephalomyelitis/chronic fatigue syndrome](#) (ME/CFS), an often-disabling illness, three to four years after being infected.

In fact, a [growing body of evidence](#) has identified multiple similarities between patients with Long COVID and ME/CFS patients who have not had COVID-19. Because of these similarities it will be important for major research studies, like the

National Institutes of Health [RECOVER study](#), to include people with ME/CFS as a comparison group. If research on ME/CFS had been better funded in the past, the U.S. would almost certainly be in a better position today to address Long COVID.

Although distinct from Long COVID, it was also well established before COVID-19 that a substantial share of survivors of treatment in intensive care developed [new or worsening impairments](#) that persisted beyond discharge. Family members of patients in intensive care can also be negatively affected. The diagnostic terms for these conditions are [post-intensive care syndrome](#) (PICS) and PICS-F (family). Risk factors for PICS-F include poor ICU staff communication, being a family member in a decision-making role, and having a family member who died or was close to death in the ICU.

To date, more than [250,000 U.S. children](#) have lost a parent or caregiver due to COVID-19, and many more have experienced parental absence due to COVID-19. While beyond the scope of this report, policymakers need to do [much more to support them](#).

How Many People in the US Experience Long COVID?

In a March 2022 [report, GAO](#) noted that US studies “estimated that 10 to 30 percent of COVID-19 survivors develop long COVID.” Subsequent research is generally consistent with this range. Long COVID estimates vary depending on how and when data was collected (in the initial year of COVID-19 or during later waves); from whom data is collected (from all individuals who have had, or report having had, COVID-19, or from a subset of these persons, such as hospitalized or high-risk patients), how Long COVID is defined (what symptoms are included, how long they need to last, severity), whether the researchers use a control group or other method to estimate how many people in the underlying population report symptoms despite not having had COVID-19, and other dimensions.

The US Census Bureau added [questions about Long post-COVID conditions](#) to the [Household Pulse Survey \(HPS\)](#) in June 2022. In Weeks 49 and 50 of the HPS (conducted between September 14 and September 26, 2022 and October 5 and October 17, 2022, respectively), roughly 17.5 million adults reported currently having one or more “symptoms lasting 3 months or longer that [they] did not have prior to having coronavirus or COVID-19.” In percentage terms, this is equal to 29.6 percent of adults who have ever had COVID. Among all U.S. adults, 7.1 percent reported currently having Long COVID symptoms. Women were more likely than men to report post-COVID conditions. Among racial and ethnic groups, Hispanics and Latinos were most likely to report post-COVID conditions, followed by Blacks and Whites, and then Asians.

Estimates of [Long COVID in the United Kingdom](#), produced by the UK’s Office of National Statistics (UK ONS), are several percentage points lower than the HPS estimates. This could be due to a real difference in the prevalence of Long COVID in the US and UK, or to survey and other differences. The Census Bureau classifies the HPS as an experimental survey, so estimates from the HPS should be thought of as rough and preliminary. As an online survey with a low response rate, the HPS may be [biased](#) in ways that cannot be easily quantified. The [National Health Interview Survey \(NHIS\)](#)—an “official” high-quality, nationally representative health survey—should provide more reliable prevalence estimates, but results probably will not be available until 2023.

In a [May 2022 report](#) using electronic health record (EHR) data covering 63.4 million adults in the US from March 2020 through November 2021, CDC researchers found that 38.2 percent of patients who had previously received a COVID-19 diagnosis experienced at least one of 26 conditions associated with Long COVID. The study also included a control group of patients to determine how common the same conditions were in a group that did not have COVID-19. Taking the result for the control group into account, the researchers concluded that about 20.8 percent of non-elderly patients in the COVID group had conditions that could be attributed to Long COVID as did 26.9 percent of elderly patients in the COVID group.

The most common conditions in the May 2022 report (detailed in [Supplemental Table 2](#) of the report) were musculoskeletal pain, respiratory symptoms, gastrointestinal symptoms, and cardiac dysrhythmia, fatigue and malaise, and neurological conditions. Compared to the control group of non-COVID-19 patients, post-COVID patients faced higher risks of all these conditions, especially fatigue and malaise, and respiratory symptoms.

What Issues Do Long-COVID Patients Have with Health Insurance?

Most working-age adults receive health insurance through their employer. As a result, [many people who have experienced job loss due to COVID-19](#) or Long COVID no longer have job-based health insurance. In theory, most people who lose job-based coverage will be able to purchase coverage in an ACA marketplace and receive a [premium subsidy](#) that reduces their out-of-pocket costs, or qualify for Medicaid. The American Rescue Plan Act temporarily increased ACA premium subsidies and the Inflation Reduction Act extended these increases for three more years. The Families First Coronavirus Response Act (FFCRA) mandated continuous Medicaid enrollment throughout the federal COVID-19 public health emergency period for people enrolled in Medicaid on or after the date it became law (March 18, 2020) through the end of the month in which the emergency declaration is lifted.

As a practical matter, however, [the transition](#) between job-based coverage and other coverage can be challenging to navigate for anyone, and is especially challenging for those with limited resources and a condition that can be debilitating. And while [Medicaid has played a major role](#) in responding to the crisis, [HHS estimates](#) that about 15 million people will lose Medicaid coverage after the emergency declaration is lifted. Moreover, low-income workers in states that did not expand Medicaid after the passage of the ACA remain at high risk of being uninsured because they fall into a [coverage gap](#) that leaves them ineligible for both Medicaid and premium assistance for coverage in the marketplace.

For insured people with Long COVID (and other complex chronic conditions like ME/CFS), their current job-based or other coverage can be inadequate. Employee contribution requirements and deductibles [have increased](#) sharply over time. High utilization and high costs associated with treatment for chronic illnesses can require more comprehensive and costly coverage. Individuals with Long COVID are also more likely to require care from specialists and regularly take prescription medications. This can present challenges for someone who was previously healthy and on a less comprehensive health plan, like an HMO, which typically requires referrals to see a specialist and does not offer coverage for [out-of-network](#) health-care providers.

Long COVID patients are subject to many of the same [medical gaps that have historically existed](#) in the understanding and [treatment of infection-associated chronic illnesses](#). In the case of ME/CFS, most medical students do not [receive education](#) about the disease as a part of their physician training. Lack of clinician knowledge and training, and insufficient research and clinical trials to substantiate coverage of tests and treatments can create additional insurance hurdles that diminish the number of treatment options and clinicians available. Moreover, [current reimbursement](#) models for evaluating, diagnosing, and coordinating treatment for patients with Long COVID are insufficient given the lengthier amount of time required to treat patients. This can also decrease the number of willing providers offering Long COVID treatment, resulting in increased wait times for patients. In order to improve patient access, medical billing codes and reimbursement for health-care providers must be commensurate with time and complexity for treating post-COVID symptoms.

Has Long COVID Reduced Employment and Earnings?

The body of research on the labor market impacts of Long COVID on US workers is limited, but growing. In an October 2022 [analysis](#) that uses the Current Population Survey (CPS), Louise Sheiner and Nashiha Salwati of Brookings estimate that about

420,000 workers have left the labor force due to Long COVID, and that workers with Long COVID who remained in the labor force reduced their average hours of work by 2.2 to 3.4 percent.

In a [working paper](#) distributed by the National Bureau of Economic Research in September 2022, economists [Gopi Shah Goda](#) and [Evan J. Soltas](#) also use the CPS to assess the impact of COVID-19 on the labor force participation rate (the number of people who are employed or looking for paid employment), and reach similar conclusions. The main focus of the working paper is on workers who were initially absent from their job for at least a week due to COVID-19. About 500,000 of these workers went on to leave the labor force by June 2022. On average, these workers lost \$9,000 in earnings through the first fourteen months after an initial week-long absence. Overall, Goda and Soltas put the total earnings loss at about \$62 billion per year. In addition, they estimate that another 250,000 people, including people who were not employed when they had COVID-19, would have returned to the labor force if not for COVID. Thus, the total decline in the labor force due to COVID could be at least 750,000 people. These estimates are limited to people who left the labor force; if we include people who are employed but working fewer hours, the total impact could be much higher.

In a [working paper](#) published in July 2022, but using a different survey (the University of Southern California's Understanding America Study COVID-19 longitudinal survey) and methodology, Dasom Ham, an analyst at the Federal Reserve Bank of Minneapolis, tracked post-COVID experiences of people who reported having had COVID in mid-2021. Ham found that among adults who reported having had COVID, nearly one in four (24 percent) reported "COVID-related symptoms or health complications that lasted at least 12 weeks." Among this group of adults reporting lasting post-COVID conditions, about one in four (25.9 percent) reported that these conditions impacted their employment or work hours. Comparing adults who reported that lasting post-COVID conditions affected their work with adults who did not report a prior COVID infection, Ham estimated they were 10 percentage points less likely to be employed and typically worked 50 percent fewer hours.

These recent papers provide strong evidence that Long COVID is reducing employment. At the same time, all of the papers have limitations—for example, the CPS, used in the first two papers, is not designed to directly track the impact of Long COVID on employment—so these estimates could easily change (in an upward or downward direction) as better data becomes available.

Moreover, overall labor market conditions could change due to monetary policy decisions made by the Federal Reserve and other federal policy decisions. In October 2022, both the employment-to-population ratio and labor force participation

rate—estimated from data collected from households—were only about 1.2 percentage points below their February 2020 level. But in the absence of COVID-19 and Long COVID, there would be more people looking for work and more people filling existing job openings. The tight labor market has also made employers more willing to provide accommodations to retain employees, including by granting employee requests for time off, flexible working conditions, and remote work.

Further research using high-quality data from nationally representative household surveys will be needed to more precisely estimate the impact of Long COVID over time on labor force participation, employment, underemployment, wages and earnings. But the existing research provides strong evidence that the impact is substantial. Moreover, these impacts could increase over time. If the Federal Reserve continues to tighten monetary policy and increase interest rates, the resulting increase in unemployment will make it harder for [vulnerable people](#), including many disabled people, to find and keep jobs.

Is Long COVID a Disability?

The [Americans with Disabilities Act \(ADA\)](#), a federal law that protects disabled people from discrimination, defines disability as a physical or mental impairment that substantially limits one or more major life activities. Other federal laws, including Section 504 of the Rehabilitation Act of 1973 (Section 504), Section 1557 of the Patient Protection and Affordable Care Act (Section 1557), and Parts B and C of the Individuals with Disabilities Education Act (IDEA), also provide protections for people with disabilities.

There is no question that people experiencing Long COVID are disabled under these laws if they have impairments that “substantially limit” one or more major life activities. In [federal guidance](#) issued in July 2021, the Department of Justice (DOJ) and the Department of Health and Human Services (HHS) explained that “substantially limit” is construed broadly under the ADA, Section 504, and Section 1557, and should not demand extensive analysis for persons experiencing post-COVID conditions. For example, as DOJ and HHS noted in the guidance, a person with long COVID who experiences memory lapses and brain fog is substantially limited in brain function, concentrating, or thinking. In [similar guidance](#) released at the same time, the Department of Education has made clear that students experiencing Long COVID or other post-COVID conditions can be covered, and eligible for specialized services, under Section 504 and the IDEA.

How Many People are Disabled Because of Long COVID?

The US lacked direct, nationally representative survey data on Long COVID-related disability until recently. To address the gap, the Census Bureau added a question on Long COVID activity limitations to the Household Pulse Survey beginning in September 2022. Data that includes answers to the question was released on October 5, 2022 and again on October 26, 2022. The results suggest that 5.7 percent of US adults—roughly 14 million people—are currently living with activity-limiting Long COVID symptoms (**Table 1**). Nearly two percent of US adults—4.5 million—indicated that Long COVID symptoms limit their daily activities “a lot”.

Prime-age workers appear more likely to be affected by Long COVID compared to acute COVID-19 hospitalization and death, which has been heavily concentrated among the elderly. Those with recent loss of household employment income are also more likely to report activity-limiting Long COVID.

Among US adults with current Long COVID symptoms, four out of five say these symptoms limit their daily activities, and just over a quarter say these symptoms limit their daily activities “a lot” (**Table 2**). Nine in ten Long COVID sufferers with recent loss of household earnings report symptoms-related activity limitations, and four in ten say their symptoms limit their daily activities “a lot”.

Table 1: Percentage of Adults Currently Experiencing Long COVID Symptoms and Activity Limitations

	Experiencing Long COVID Symptoms	Daily Activities Limited	Daily Activities Limited "A Lot"
All Adults	7.1%	5.7%	1.8%
Prime Working-Age (25–54)	8.0%	6.4%	1.9%
Gender			
Women	8.6%	6.9%	2.2%
Men	5.3%	4.2%	1.2%
LGBT	9.2%	7.9%	2.7%
Race/Ethnicity			
White	7.3%	5.8%	1.6%
Black	5.4%	4.2%	1.5%
Hispanic or Latino	8.0%	6.5%	2.9%
Educational Attainment			
Less than Bachelor's degree	7.6%	6.2%	2.1%
Bachelor's degree or higher	5.9%	4.5%	1.1%
Employment Status			
Employed	7.4%	5.8%	1.4%
Not employed	6.7%	5.7%	2.4%
Annual Household Income			
Under \$50,000	8.3%	7.2%	2.9%
\$50,000–\$99,999	8.0%	6.2%	1.4%
\$100,000 or more	5.9%	4.2%	0.9%
Recent household employment income loss	11.7%	10.5%	4.6%

Shares omit non-responses. "Currently Experiencing Long COVID Symptoms" and "Experiencing Long COVID Symptoms" both refer to those who indicated that they continue to experience symptoms lasting 3 months or longer that they did not have prior to contracting COVID-19.

Table: Hayley Brown • Source: CEPR analysis of Household Pulse Survey (HPS), Phase 3.6, September 14–26 and October 5–17, 2022 (Weeks 49–50).



Table 2: Among Adults with Current Long COVID, Percentage Reporting Symptoms Limit Daily Activities

	Daily Activities Limited	Daily Activities Limited "A Lot"
All Adults	80.7%	25.7%
Prime Working-Age (25–54)	79.8%	23.7%
Gender		
Women	80.4%	26.0%
Men	80.3%	23.6%
LGBT	85.7%	29.1%
Race/Ethnicity		
White	80.1%	22.1%
Black	79.9%	29.1%
Hispanic or Latino	80.5%	36.0%
Educational Attainment		
Less than Bachelor's degree	82.1%	28.1%
Bachelor's degree or higher	76.5%	18.8%
Employment Status		
Employed	78.1%	18.9%
Not employed	84.6%	35.6%
Annual Household Income		
Under \$50,000	87.2%	34.4%
\$50,000–\$99,999	78.5%	18.2%
\$100,000 or more	70.9%	14.8%
Recent household employment income loss	90.2%	39.5%

Shares omit non-responses. "Current Long COVID" refers to those who indicated that they continue to experience symptoms lasting 3 months or longer that they did not have prior to contracting COVID-19.

Table: Hayley Brown • Source: CEPR analysis of Household Pulse Survey (HPS), Phase 3.6, September 14–26 and October 5–17, 2022 (Weeks 49–50).

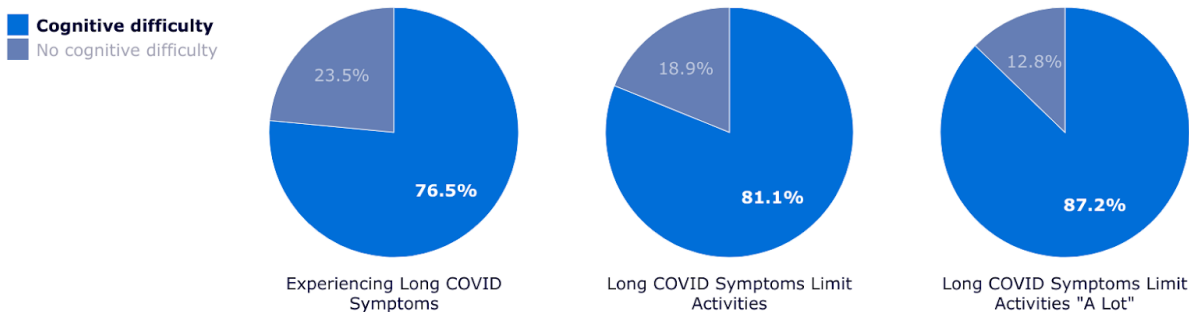


In the HPS, adults with current Long-COVID symptoms are much more likely to also report one or more of the six difficulties most federal surveys use to measure disability. The largest differences are in remembering or understanding, followed by seeing and walking or climbing stairs. As shown in **Figure 1**, over three quarters (76.5 percent) of US adults with current Long COVID symptoms said they experience some amount of difficulty remembering or understanding, a share 1.7 times higher than those without Long COVID. Employed US adults with current Long COVID symptoms experience such difficulty at nearly the same rate (74.8 percent). The HPS doesn't distinguish between people who had limitations before being infected with COVID-19 and those whose limitations arose during or post-COVID. The share who report various types of difficulty, including cognitive difficulty, is also higher in the HPS than it is in other surveys. This may be due in part to the way the questions surrounding difficulty are structured; they allow respondents to identify the degree of difficulty they experience, rather than just answering "yes" or "no".

Figure 1

Cognitive Difficulty Is Common Among Adults With Long COVID

Share reporting difficulty remembering, understanding, or being understood



Shares omit non-responses. "Experiencing Long COVID Symptoms" refers to those who indicated that they continue to experience symptoms lasting 3 months or longer that they did not have prior to contracting COVID-19.

Chart: Hayley Brown • Source: CEPR analysis of Household Pulse Survey (HPS), Phase 3.6, September 14–26 and October 5–17, 2022 (Weeks 49–50).



Cognitive symptoms (difficulty remembering or concentrating) are a common feature of Long COVID. A [study](#) by researchers at the Universities of Cambridge and Exeter in the United Kingdom found that 78 percent of those with Long COVID symptoms reported difficulty concentrating, 69 percent reported "[brain fog](#)", and 67.5 percent reported forgetfulness. Another [study](#), based on results of a [Patient-Led Research Collaborative](#) survey, found that cognitive dysfunction was among the top three most debilitating Long COVID symptoms alongside fatigue and breathlessness.

Although not designed to track Long COVID, the monthly Current Population Survey (CPS), the federal government’s monthly survey of labor force participation and employment, includes a short set of six questions about disabling limitations (seeing, hearing, remembering or concentrating, walking or climbing stairs, caring for self, and independent living). As **Figure 2** shows, the share of prime working-age (ages 25–54) adults reporting at least one of these limitations has spiked in the aftermath of the initial COVID-19 crisis. The largest single increase is due to people reporting difficulties concentrating or remembering. In the third quarter of 2022, 4.1 million prime-age adults reported cognitive disability, over a half a million more than in the last quarter of 2019. This is especially striking given the association between Long COVID and cognitive difficulty. The jump is too large and too specific to be explained solely by demographic or other factors unrelated to COVID-19.

Figure 2
More Adults of Prime Working Age Reporting Cognitive Disability

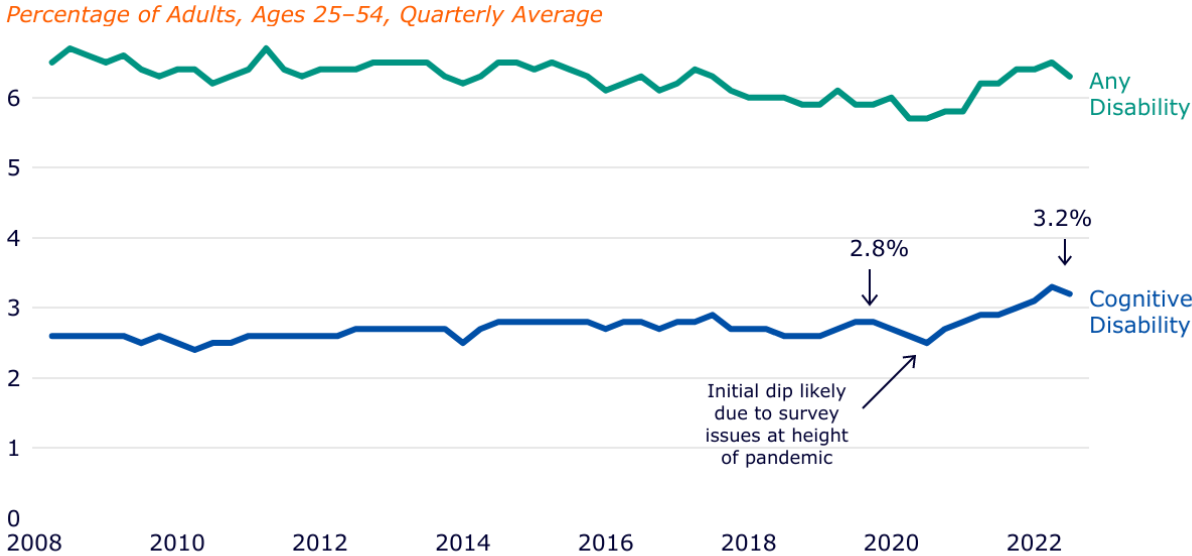


Chart: Hayley Brown and Shawn Fremstad • Source: CEPR analysis of Current Population Survey (CPS) Basic Monthly Sample, April 2008–September 2022.



Employment Increased Among Prime Working-Age Adults With Disabilities

Employment-to-Population Ratio, Ages 25–54

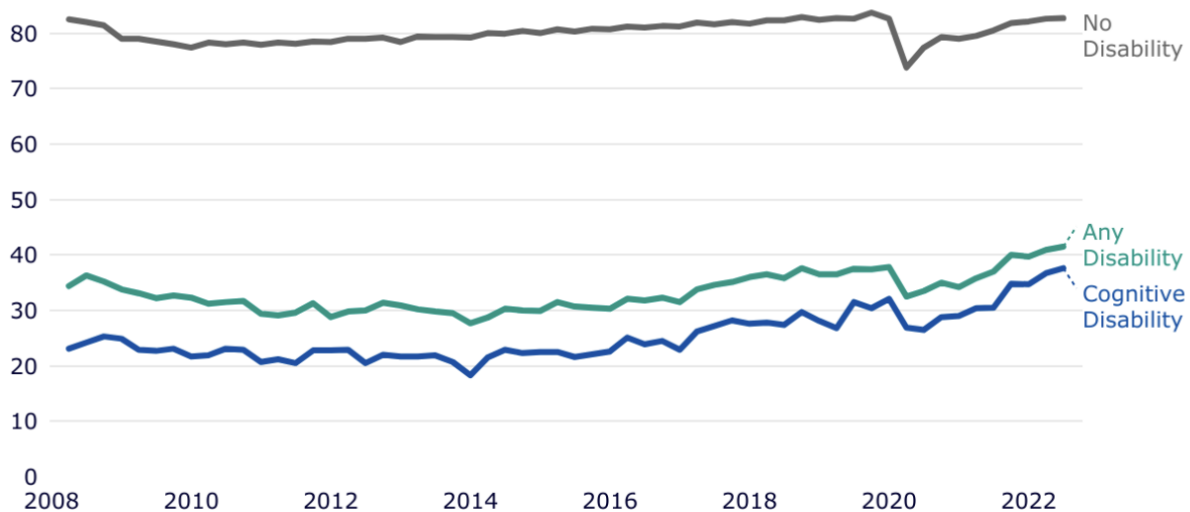


Chart: Hayley Brown and Shawn Fremstad • Source: CEPR analysis of Current Population Survey (CPS) Basic Monthly Sample, April 2008–September 2022.



Finally, research on the prevalence and costs of ME/CFS also provides a useful point of comparison with Long COVID. Like Long COVID, ME/CFS is an infection-associated illness; both have common symptoms, including chronic fatigue, post-exertional malaise and cognitive dysfunctions. Research conducted in the 2000s and early 2010s, and later cited by the [Institute of Medicine](#), estimated that 836,000 to 2.5 million Americans suffered from ME/CFS.

In a [recent publication](#), a team of experts estimated that 1.5 million Americans had ME/CFS prior to COVID-19, and that total ME/CFS prevalence could rise to over 5 million people due to COVID-19 and Long COVID. If this is correct, it would mean an economic impact of \$149 to \$362 billion in medical expenses and lost income, not including disability benefits, social services, lost wages of caretakers, and other costs. The researchers estimate that National Institutes of Health funding for ME/CFS research would need to increase to approximately \$472 to \$600 million annually, up from \$15 million, to be proportionate to what is spent researching similarly costly and burdensome diseases in the United States.

Are People Disabled by Long COVID Eligible for Disability Benefits?

Federal long-term disability benefit programs like Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) typically provide benefits to disabled persons only if they meet additional restrictive requirements. To have a “[qualifying disability](#)” for SSDI and SSI, a disabled applicant generally cannot be earning more than \$1,350 a month in 2022, must have a condition that significantly limits their ability to do basic work-related activities for at least 12 months, have a medical impairment that prevents them from performing any of their past work, and be unable to do any other paid work based on a set of factors including age, education, past work experience, and transferable skills. In short, while the ADA defines disability in a way that views disabled people as deserving of protection and accommodations, programs like SSDI and SSI view them as undeserving until they prove otherwise by running a gauntlet of administrative ordeals.

The number of people submitting applications for SSDI at SSA field offices in the first half of 2022 ([about 895,000](#)) was slightly higher than the number of people who submitted applications in the first half of 2021, but lower than in the first halves of 2018, 2019, and 2020. Over time it will be important to track whether people who are unable to work at least 12 months due to disabling post-COVID conditions are able to access SSDI. Even before COVID, the barriers to SSDI receipt were formidable, especially for prime-age workers.

Employer-based long-term disability insurance can also be an option for workers. But only 35 percent of private-sector workers [have access to it](#), as do only six percent of part-time workers. Access is particularly limited for workers in service and sales jobs; only 13 percent and 19 percent, respectively, of workers in these jobs had access to it. Like SSDI and SSI, employer-based long-term disability insurance generally has very restrictive disability criteria. It can be [especially difficult](#) for people with ME/CFS to successfully claim, especially if they do not have an attorney representing them.

Benefit programs like temporary disability insurance (TDI), paid medical leave and sickness benefit programs are generally less restrictive than SSDI and SSI. TDI and paid medical leave provide non-permanent (less than 12 months), wage-replacement benefits to workers who need to take time off from work (or leave their jobs) because of an illness or impairment that is at least “temporarily disabling.” While these kinds of programs are

common in other wealthy countries, the United States does not currently provide any of these benefits to private-sector workers, and does not require private-employers to provide them. Eleven [states](#), the District of Columbia, and Puerto Rico do have such programs. In these jurisdictions, the length of time a worker can receive paid personal medical leave or temporary disability insurance ranges from six weeks in Delaware to 52 weeks in California.

While some employers provide short-term disability insurance coverage voluntarily, most workers don't have access to such coverage, and [access varies considerably](#) by worker and employer characteristics. In the [South, only about one in three](#) private-sector workers have employer-provided short-term disability insurance. Nationally, only 19 percent of workers in the bottom quartile of the wage distribution (paid less than \$16.00 per hour in 2022) have access to short-term disability benefits, as do only 41 percent of workers in the second quartile (paid between \$16.00 and \$24.50 per hour).

Workers who lose employment due to COVID-19 or Long COVID may be eligible for unemployment insurance (UI) if they have "good cause" for leaving employment, or if they are terminated for reasons that are not their fault. People who voluntarily leave their jobs or are terminated due to Long COVID should generally meet these eligibility requirements. However, to be eligible for UI, a person generally must be "available and able" to accept a job in any given week. State laws vary in how much leeway they give people with illnesses or disability to refuse work or impose conditions on what work they will take. [Nine states](#)—Alaska, Delaware, Hawaii, Idaho, Massachusetts, Nevada, North Dakota, Tennessee, and Vermont—allow a person to be considered available to work during a period of illness or disability as long as the person has not refused "suitable work." If a person's UI claim is based on past full-time work, most states will require them to be able and available for full-time work, but some states have exceptions for people with disabilities or medical restrictions.

Workers who contracted COVID-19 at their workplace may be eligible for workers' compensation benefits. Workers' compensation programs vary by state but most programs provide for payment of lost wages, medical treatment, and rehabilitation services to workers suffering from an occupational injury or disease. According to a [recent study](#) by the Workers' Compensation Insurance Rating Bureau of California (WCIRB), over 200,000 COVID-related workers' compensation claims were filed in the state between March 2020 and March 2022. About 11 percent of workers with mild COVID infections received medical treatments for Long COVID symptoms in the workers' compensation system. Among workers in the system with severe or critical infections (requiring hospitalization), about 36 percent received treatments for Long COVID.

VA disability compensation—operated by the U.S. Department of Veterans Affairs (VA)—provides a monthly benefit to veterans who are disabled by injury or disease incurred or aggravated during active military service. Unlike SSDI or SSI, the benefit amount varies with the degree of the veteran’s disability and the number of their dependents. Under [federal law](#), the VA must presume that COVID-19 diagnoses are service-connected for all active-duty troops or reserve component personnel serving on federal active duty.

What Accommodations Should Employers Provide to Employees with Long Covid?

According to the US Department of Labor, reasonable accommodations required under the ADA for employees who are disabled by Long COVID may include: providing or modifying equipment or devices; part-time or modified work schedules; reassignment to a vacant position; and adjusting or modifying examinations, training materials or policies. Employers generally do not need to remove essential job functions; lower production standards; provide personal need items such as hearing aids and wheelchairs, or provide any accommodation that creates an undue hardship for the employer. However, as the Job Accommodation Network notes, the “benefits of providing accommodations and making changes to improve the overall inclusivity of the workplace [often exceed the costs](#) and improve the workplace environment.” Similarly, providing benefits like paid family and medical leave to workers can reduce other employer costs by improving worker retention and increasing productivity.

While employers have a duty to provide reasonable accommodations for disabled employees under the ADA, obtaining them can be a daunting process, especially for workers in poorly compensated jobs. For these workers, worker advocacy, legal assistance, and [union representation](#) can make a crucial difference in obtaining accommodations. As Katie Bach of Brookings [has argued](#), accommodations will likely be most difficult to secure for poorly compensated workers, especially in the service sector occupations like front-line fast food occupations, [direct care occupations](#) (home health aides, nursing aides, and personal care aids), and front-line retail occupations. These three occupational groups are among the ten largest in the United States. Workers in these groups often live paycheck to paycheck, have few employer-based benefits, and are [disproportionately held](#) by working-class women and working-class people of color. Their jobs are often physically demanding, inflexible on hours, and ineligible for remote work. For many workers who are disabled by Long COVID have these kinds of jobs, access to disability benefits will be essential to their health and well-being.

What is the Federal Government Currently Doing to Track and Address Long COVID?

In December 2020, Congress provided [\\$1.15 billion in funding](#) over four years for the National Institutes of Health (NIH) to support research on Long COVID. Known as RECOVER, the NIH initiative combines data across more than 200 research sites, and uses electronic health records to group common characteristics of tens of thousands of volunteers to better identify risk factors and causes of Long COVID. RECOVER will also fund clinical trials of treatments for people with Long COVID.

The CDC has received [nearly \\$50 million](#) to understand the long-term health effects of COVID-19. Funded and ongoing research include several longitudinal studies of persisting symptoms, their frequency, severity, and overlap with ME/CFS and efforts to improve estimates of prevalence and demographics of Long COVID at the population level. The CDC has also developed guidance on Long COVID for [health-care providers](#) and the public.

In August, the Biden Administration released [two reports](#) from the Department of Health and Human Services—a services report and a research plan—as part of an earlier directive on addressing the long-term effects of COVID-19. The first of the two reports, [the Services and Supports for Longer Term Impacts of COVID-19](#), outlines existing federal programs and services that can provide resources and support to those with Long COVID and their caregivers. Resources include information on navigating health coverage, community services, behavioral health challenges, bereavement, and financial assistance. The report also details resources for health-care personnel in treating patients with Long COVID and associated conditions. The second report, [the National Research Action Plan on Long COVID](#), details a government-wide national research call to action to advance scientific progress in the prevention, diagnosis, and treatment of Long COVID, and facilitate research to improve services and support for caregivers and individuals experiencing Long COVID. The report outlines research priorities in seven key areas, characterizing the causes of Long COVID and similar conditions like ME/CFS, the consequences of these conditions left untreated, and the underlying biological mechanisms and potential therapeutic remedies for Long COVID.

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causes of Long COVID and similar conditions like ME/CFS, the consequences of these conditions left untreated, and the underlying biological mechanisms and potential therapeutic remedies for Long COVID.

While an initial step forward, Long COVID patients and patient-led groups have [rightly criticized](#) the sluggish pace of, and lack of patient involvement in, these efforts. [Much more needs to be done](#) “to support the truly meaningful engagement of people with Long COVID,” as called for in an [open letter to the NIH and other stakeholders](#) in the federally funded Long COVID research process. As was learned during the HIV epidemic, research outcomes improve when [patients have a seat at the table](#).

Various other federal agencies have provided guidance related to Long COVID. As noted above, the Departments of Justice and Health and Human Services (HHS) have issued guidance on the coverage of people with Long COVID under the Americans with Disabilities Act and other federal civil rights laws. HHS’ Administration for Community Living has published [a guide](#) on how disability and aging networks funded by the federal government can assist people with Long COVID.

The US Department of Labor has provided [information and guidance](#) to employees and employers about the kinds of job accommodations—adjustments to the job or work environment—that can help ensure that employees with Long COVID are able to continue working. The Job Accommodation Network (JAN), funded by DOL’s Office of Disability Employment Policy, provides [free, confidential guidance on workplace accommodations](#) that may be needed for workers with Long COVID.

What Should Congress and the Executive Branch Do to Help Address Long COVID?

The recommendations below are grouped into three major categories: prevention, medical research and health care, and social insurance.

Prevention

Provide Necessary Funding to Continue the Federal Effort to Prevent COVID-19

One casualty of the White House’s unmet request for [\\$22.5 billion in emergency pandemic aid](#) from Congress was the [Provider Relief Fund \(PRF\)](#), which had enabled

the federal government to cover COVID-19 testing, treatment, and vaccination for the uninsured. After the fund became depleted in [April 2022](#), some providers began charging uninsured patients for services previously reimbursed by the PRF. It is crucial that lawmakers understand that additional funding for COVID-19 prevention is necessary for combatting future surges and accelerating vaccine distribution. The absence of additional public funding will likely shift testing and immunization costs to individuals and health insurers. Given recent suggestions by the Food and Drug Administration (FDA) that new immunizations [can reduce the risk of developing Long COVID](#), ensuring vaccine availability is extremely crucial to preventing COVID-19 and Long COVID. According to the Biden Administration, federal funding for vaccine purchases and distribution are expected to run out by January 2023.

Lack of universal access to testing [increases the risks](#) of undetected spreading of the virus and local transmission, and is associated with increased morbidity and mortality. These risks are particularly pronounced for people with socioeconomic disadvantages, who have been disproportionately burdened by the COVID-19 pandemic due to societal and environmental factors and barriers to health-care access. Yet, the federal government stopped taking orders for free at-home testing kits on September 2, 2022 due to Congress' failure to continue funding the universal free testing program. Though free tests may continue to be administered at a [limited number of federally supported sites](#), these sites will test a much smaller number of people. Many more will forgo testing due to barriers such as inflexible hours or difficulties finding and getting to sites that offer free tests. While the Biden administration's [requirement](#) that health insurance plans cover COVID testing remains in effect, the uninsured have been left with far fewer options. The federal government must act quickly to accommodate a [likely rise](#) in testing and vaccine demands this fall and winter.

Congress also needs to provide additional funding for new vaccines that provide better protection against multiple variants of COVID as well as Long COVID. This includes funding for "Project COVID Shield", a purported successor to [Operation Warp Speed](#) meant to jumpstart next generation vaccines and treatments. The Biden administration has [requested \\$8.25 billion](#), far less than previous asks and well below what was apportioned to vaccine efforts [earlier in the pandemic](#). While it is [unclear](#) that this latest request will be sufficient, it is a necessary first-step to tackle what increasingly appears to be a [mass-disabling event](#).

The federal government should maintain public control of vaccines and treatments that result from federally-funded initiatives. This includes the pan-coronavirus vaccine being developed by the U.S. Army's Walter Reed Institute of Research, as well as the [intranasal vaccine](#) being developed with funding from the National Institute of Allergy and Infectious Diseases (NIAID). The government should openly license these

vaccines to qualified manufacturers on conditions ensuring fair pricing and equitable access, share vaccine technology and data with the World Health Organization, and prepare to invest in government-owned production facilities. An [amendment](#) to this effect was proposed for the FY 2023 National Defense Authorization Act by Rep. Pramila Jayapal (D-WA-07) but did not receive a vote.

In a global economy, what happens with COVID-19 and Long COVID outside of US borders will continue to impact what happens inside the US. One meta-analysis found that across 31 studies, [a pooled average of 43 percent of COVID-19 survivors worldwide](#) reported experiencing post-COVID symptoms. Ensuring that all nations have the capacity and means to adequately test, vaccinate, and treat COVID-19 and Long COVID is essential to halting the spread of coronavirus globally, ending the pandemic, and reducing global poverty and inequality. Congress should approve funding for global vaccination efforts, as previously requested by the Biden administration. The administration [should also support](#) a new issuance of at least \$650 billion in [Special Drawing Rights](#) (SDRs)—international reserve assets—at the International Monetary Fund.

Improve Indoor Air Quality

The federal government must also promote and invest in improvements to [indoor air quality](#). Numerous [studies](#) have shown that better [ventilation](#) and [filtration](#) substantially reduce transmission of COVID-19 and [other diseases](#). In one particularly striking Italian [example](#), improved ventilation was shown to cut school transmission by 82 percent. The Biden administration has already taken some steps toward addressing infrastructural aspects of transmission through the [Clean Air in Buildings Challenge](#). In addition, the American Rescue Plan and Infrastructure Investment and Jobs Act provided funding for [ventilation upgrades in schools](#).

Further efforts are needed to improve air quality in commercial buildings and other public buildings. Funds should be specifically earmarked for indoor air quality improvements, and increased scrutiny applied to states that [fail to use the funds appropriately](#) or [at all](#). The Occupational Safety and Health Administration (OSHA) must also do more to protect workers from on-the-job exposure by providing clear benchmarks for adequate indoor air quality in the workplace.

Modernize Our Public Health Data Infrastructure

Chronic underinvestment in our public health data infrastructure [has](#) “crippled efforts to understand the pandemic, stranding crucial data in incompatible data systems so outmoded that information often must be repeatedly typed in by hand.” [Data: Elemental for Health](#), a campaign that includes the Council of State and

Territorial Epidemiologists, the National Association for Public Health Statistics and Information Systems, and other related groups, is calling on Congress to invest at least \$7.84 billion over the next five years to modernize the currently fragmented and underfunded public health information system. The Healthcare Information and Management Systems Society (HIMSS) [estimates that](#) \$25.6 billion is needed over the next decade for states, localities, and tribes, along with another \$11 billion for public health interoperability and sustainability.

Medical Research and Health Care

Establish and Fund a National Institute on Complex Chronic Conditions in the National Institutes of Health (NIH)

NIH has 27 separate research institutes and centers that conduct and coordinate research across different disciplines of biomedical science. NIH institutes include the National Institute of Allergy and Infectious Diseases and the National Cancer Institute. NIH also has offices, like the Office of AIDS Research, that coordinate research. Establishing these kinds of focused institutes and specialized offices within NIH has advanced medical knowledge far beyond what would have been accomplished by academia and the private-sector alone.

Given the human and economic impacts of Long COVID, ME/CFS, and other complex chronic conditions (including [Post-Treatment Lyme Disease Syndrome](#); [Mast Cell Activation Syndrome \(MCAS\)](#), and [Ehlers-Danlos syndrome](#)), Congress should establish and adequately fund a National Institute on Complex Chronic Conditions. Alternatively, the federal government could establish an Office of Complex Chronic Conditions Research in the NIH Director's Office. The new institute or office should be structured in way that is consistent with [recommendations](#) made by members of the Long-COVID and associated-conditions patient community earlier this year, and endorsed by [Patient-Led Research Collaborative](#), Strategies for High Impact, [#MEAAction](#), and [Marked by COVID](#).

Improve Access to Affordable and High-Quality Health Care

Barriers in insurance coverage, prompted by denials in coverage from insurers, are resulting in fewer treatment options for some individuals experiencing long-hauler symptoms. Because there has been limited research on Long COVID and no consensus on the treatment of Long COVID, insurance companies can deny coverage of some treatments doctors view as promising on the grounds that they are [“medically unnecessary” or experimental](#). For patients who can't afford to pay for these treatments out-of-pocket, the only options are taking on medical debt or

forgoing treatment. To ensure that people experiencing Long COVID have access to the coverage they need, policymakers need to take regulatory and legislative steps to hold insurance providers accountable. More generally, Congress needs to ensure that all people in the United States [have affordable, high-quality health care](#).

Provide Funding to Ensure Equitable Access to Long COVID Treatment and Social Services

Given the number of individuals who continue to face prolonged COVID-19 symptoms, a growing number of clinics have been established that focus on post-COVID conditions. These post-COVID clinics—sometimes referred to as Post-Acute Sequelae of SARS-CoV-2 Infection clinics, or PASC clinics—treat a wide-range of ailments arising from the persistence of symptoms caused by COVID-19, and provide multidisciplinary assessments and resources for patients. The importance of these clinics cannot be overstated, as they convene a central hub of physician specialists and rehabilitation and occupational therapists to improve the deliverance of comprehensive care and patient outcomes, without requiring travel to multiple health-care providers.

Congressional lawmakers should build on this initial effort by providing support for increased coordination efforts and resources for Long COVID patients. The Targeting Resources for Equitable Access to Treatment (TREAT) for Long COVID Act ([H.R.7482](#) and S. 4015), sponsored by Representatives Pressley, Rochester, and Beyer and Senators Duckworth, Markley and Kaine, would provide funding for multidisciplinary Long COVID clinics that address the physical and mental health needs of patients, and for other activities that would increase equitable access to treatment. Similarly, the Comprehensive Access to Resources and Education (CARE) for Long Covid Act ([S.3726](#)), introduced in March 2022 by Senators Tim Kaine, Ed Markey, and Tammy Duckworth, would provide new funding for research, public education, and medical-legal partnerships that help individuals with Long COVID access employment accommodations and social services.

Social Insurance

Provide Paid Sick Days and Paid Leave, Including Temporary Disability Insurance

As journalist [Ryan Prior](#), author of *The Long Haul: Solving the Puzzle of the Pandemic's Long Haulers and How They Are Changing Healthcare Forever*, [has written](#): “allowing long haulers to rest in the short term might help them avoid years or decades of significant, often disabling long-term health consequences.”

Unfortunately, whether workers can afford to take time off to rest and recover varies

by their employer and their resources. Since the expiration of paid leave provisions in the Families First Coronavirus Response Act (March 31, 2021) and the American Rescue Plan Act (on September 30, 2021), federal law does not require or subsidize the provision of paid sick and family leave for employees who need it due to COVID.

Among private-sector employees in the bottom quarter of the wage distribution, about [45 percent](#) work for employers who do not give any paid sick days. In the absence of paid sick leave, workers are more likely to show up to work ill, which likely increases the spread of COVID-19. Though data on the correlation between COVID-19 reinfections and Long COVID is scarce, at least [one recent study](#) suggests that people who are reinfected are more likely to experience long-term health problems.

The Build Back Better Act, passed by the House but blocked in the Senate, would have established a program that provided paid family and medical leave for all eligible workers in the United States. Ensuring that all workers have access to paid leave and temporary disability insurance would reduce the spread of COVID-19 and the prevalence of Long COVID, and improve the financial security of all families. The federal government should also encourage states to ensure that “able and available” rules in Unemployment Insurance programs accommodate people with health conditions and disabilities.

[Increase Access to Federal Disability Benefits for People with Long COVID and Other Disabilities](#)

Improving access to both short-term and long-term disability benefits would also help improve the lives of individuals struggling with Long COVID. Many Long COVID patients experience [difficulties meeting SSDI/SSI's strict disability requirements](#). To improve access to SSDI and SSI for people with Long COVID, Congress could take a number of steps, including: waiving the 12-month requirement for presence of a medical condition; releasing specific guidance concerning the assessment of Long Covid and burden of proof required to qualify for benefits; and facilitating expedited review of Long COVID-related claims to shorten application processing times.

Even after a claim is approved, SSDI imposes additional unnecessary burdens on disabled people. Federal law requires newly approved applicants to wait five months before they can start receiving monthly benefits, and an *additional* 24 months before they can start receiving SSDI-linked Medicare. These kinds of waiting periods are [harmful](#) to people suffering from chronic illnesses, and should be eliminated to provide immediate access to care and income. The [Stop the Wait Act](#) (H.R. 6583 and S. 3575), sponsored by Representative Doggett and Senator Casey, would remove both of these insurance barriers.

Conclusion

Long COVID affects millions of COVID-19 survivors who experience lasting negative symptoms as a result of infection. The impact that Long COVID has had on individuals and their families cannot be understated, nor can the economic effects and societal disadvantages of the condition be ignored. The existing body of research suggests that the prevalence of Long COVID has a negative effect on US labor force participation rates, employment, and wages, though more data is needed to more accurately estimate the impact of this trend over time. As Long COVID continues to leave individuals unable to work due to disabling post-COVID conditions, ensuring access to adequate healthcare benefits and social insurance programs will be crucial in accommodating the needs of individuals experiencing Long-COVID and similar chronic illnesses.

Appendix: Symptoms of COVID-19 and Long COVID

Organ System	Acute and Severe COVID-19		Post-COVID Conditions and Long COVID
	Common symptoms	Potential complications	Symptoms and complications
Respiratory	Cough Dyspnea Rhinorrhea (runny nose)	Pneumonia Acute respiratory distress syndrome Respiratory failure	Cough Dyspnea Interstitial lung disease
Systemic	Fever Fatigue	Sepsis, kidney injury Liver injury	Fever Fatigue Post-exertional malaise
Nervous System	Headache Confusion Loss of smell Loss of taste	Stroke Seizure Guillain-Barre syndrome	Memory deficit, loss of concentration, sleep difficulty, mood disorder, paresthesia, myelopathy, neuropathy, anosmia, ageusia, blurry vision, tinnitus, headache
Cardiovascular	Chest pain Shortness of breath	Myocardial infarction Myocarditis Cardiogenic shock Stress-induced cardiomyopathy Clotting abnormalities	Chest pain, palpitations, hypertension, angina, myocarditis, pericarditis, cardiac arrhythmias, postural orthostatic syndrome
Gastrointestinal	Nausea Vomiting Diarrhea Anorexia (loss of appetite)	Acute pancreatitis Acute appendicitis Intestinal obstruction Decreased blood flow to intestines Intra-abdominal hemorrhage High abdominal pressure (ACS)	Diarrhea, vomiting, nausea, loss of appetite, hepatitis
Skin	Rash	N/A	Hair loss
Musculoskeletal	Muscle aches and pains	N/A	Joint stiffness Muscle aches and pains Weakness
Endocrine	Hyperglycemia	Diabetes	Hot/cold sensation, thyroid abnormalities, diabetes, hormonal abnormalities

Source: Adopted from Table 1 in [The immunology and immunopathology of COVID-19 | Science](#).