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Employment and Material Hardship among Adults with Long COVID in December 2022

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Long COVID, also referred to as post-COVID-19 condition, is a multisystemic condition, sometimes involving severe symptoms like chest pains, cough, cognitive impairment, memory loss, fatigue, postexertional malaise, shortness of breath, and muscle and joint pain (Davis et al. 2023). The US Department of Health and Human Services developed a working definition of long COVID as signs, symptoms, and conditions that are present a minimum of four weeks after initial infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsening over time.[1]

Though estimates of the number of people with long COVID vary, the condition affects at least 1 in 10 people who have had a COVID-19 infection (Davis et al. 2023). This number is likely underestimated because of possible undocumented cases and inconsistent medical care. Studies conducted before March 2022 estimated that 10 to 30 percent of those infected, or between 7.7 million and 23 million people in the US, developed long-term symptoms (GAO 2022). While people of all backgrounds are at risk of developing long COVID, people may be at greater risk if they are female, age 40 or older, have preexisting chronic health conditions, have a more severe infection (e.g., hospitalization, intensive care), or have not had a COVID-19 vaccination (Tsampasian et al. 2023). Surveys have also found a higher prevalence of long COVID among Hispanic/Latinx adults and those with lower educational attainment and income (Perlis et al. 2022).[2] Evidence on effective treatments for long COVID remains limited, and many patients have faced barriers to care in their encounters with the health system (Karpman, Zuckerman, and Morriss 2023; Shaffer 2022).

Long COVID can affect many aspects of a person's life, including their ability to work and afford to meet their basic needs, which can affect their recovery and long-term health and well-being. In this brief, we examine experiences with long COVID related to employment and material hardship among participants in the December 2022 round of the Urban Institute's Well-Being and Basic Needs Survey (WBNS), a nationally representative survey of more than 7,500 adults ages 18 to 64.

How Long COVID Affects Employment

Among adults reporting a prior confirmed or suspected COVID-19 infection, almost 1 in 5 reported experiencing long COVID symptoms lasting four weeks or longer.

As table 1 shows, in December 2022, 58 percent of adults participating in the WBNS reported a prior COVID-19 infection, most of whom had a formal diagnosis or positive test, and a smaller share who thought they had COVID-19 but did not receive a formal diagnosis.[3] Of those adults with a prior confirmed or suspected COVID-19 infection, 18 percent reported they were currently experiencing long COVID symptoms that had lasted four weeks or more. A disproportionate share of adults with long COVID were Hispanic/Latinx (26 percent), female (66 percent), and reported having a disability[4] (38 percent) or having other diagnosed chronic conditions[5] (67 percent; data not shown), though it is not known whether these conditions or disabilities predated COVID-19.

TABLE 1

Share of Adults Ages 18 to 64 Reporting Ever Having COVID-19 and Current Long COVID, December 2022

Reported ever having COVID-19	58%
Told by a doctor or other health professional they had COVID-19 or tested positive for COVID-19	46%
Thought they ever had COVID-19 but did not have a diagnosis or positive test	13%
Among adults who ever had COVID-19, reported current long COVID symptoms lasting 4 weeks or more	18%
Experienced symptoms for 4 weeks to < 3 months	5%
Experienced symptoms for 3 months to < 1 year	7%
Experienced symptoms for 1 year or more	6%
Sample size, all adults	**7,881**
Sample size, adults who ever had COVID-19	**4,373**

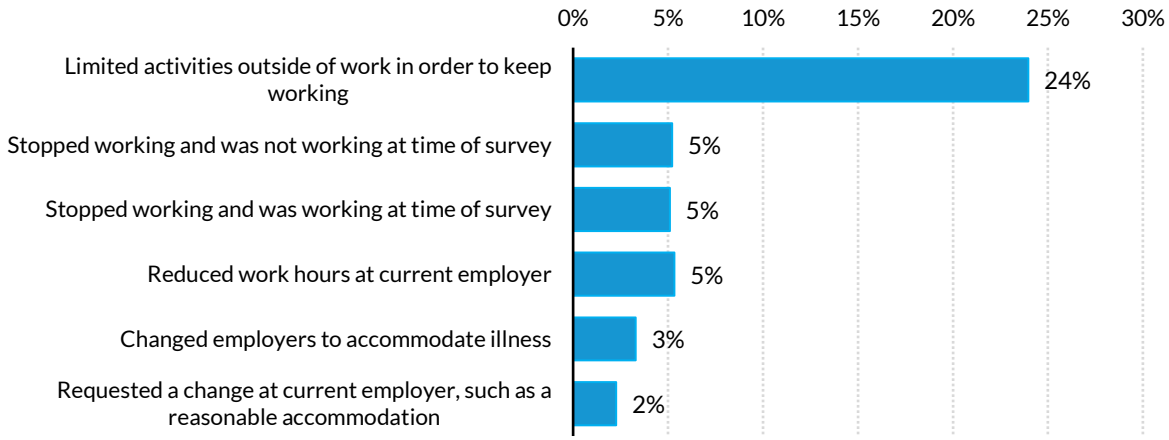
Source: Well-Being and Basic Needs Survey, December 2022.
Notes: Adults with COVID-19 include those with a diagnosis or positive test and those who thought they had COVID-19 but did not have a diagnosis or positive test. Estimated percentages are weighted and rounded to the nearest percentage point. Sample sizes are unweighted.

One in 10 adults with long COVID reported that they stopped working for a period because of their symptoms. In addition, 1 in 4 reported that they limited activities outside of work to be able to continue working.

Ten percent of adults with long COVID reported they stopped working because of their symptoms, including 5 percent who were not working at the time of the survey (figure 1).[6] An additional 5 percent reported reducing their work hours. One in four adults (24 percent) with long COVID reported limiting activities outside of work—such as social activities, errands, or chores at home—so they could continue working. Smaller shares changed employers to accommodate their condition (3 percent) or requested a change at their current employer, such as a reasonable accommodation (2 percent).

FIGURE 1

Self-Reported Impact of Long COVID Symptoms on Employment among Adults Ages 18 to 64, December 2022



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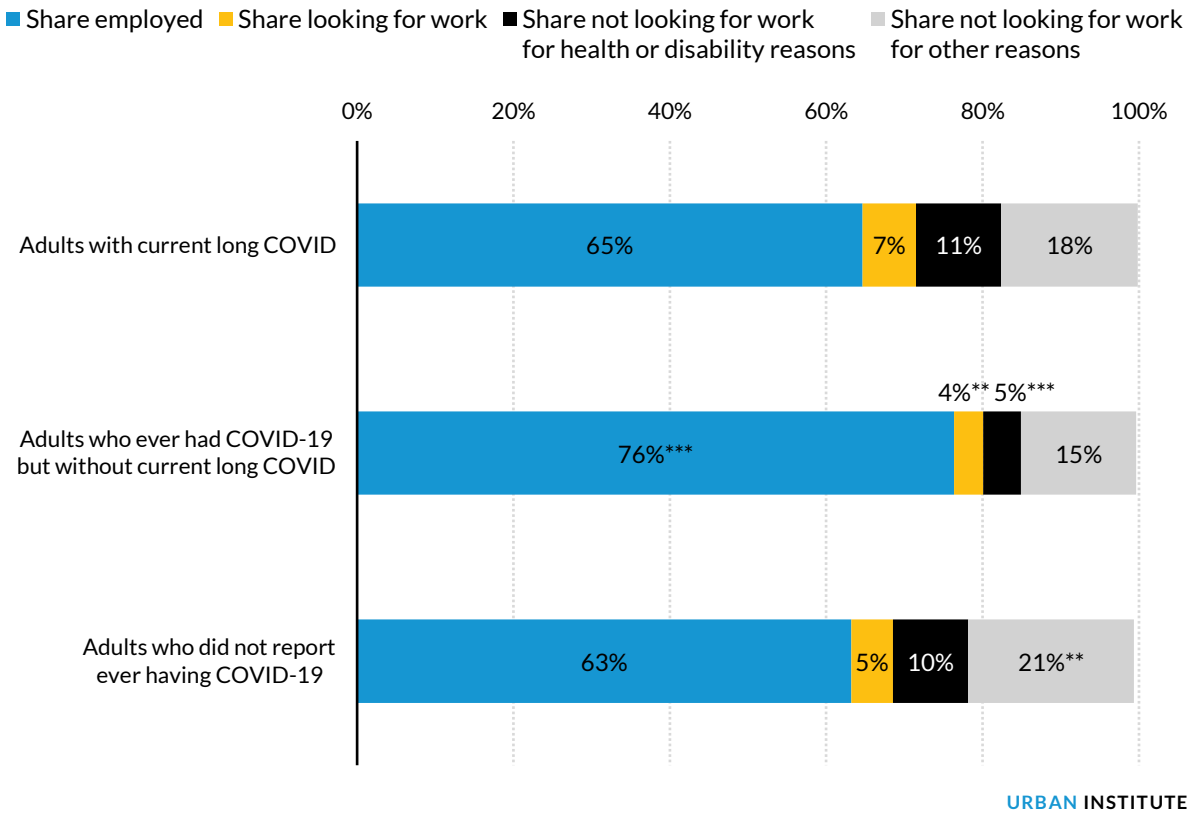
Source: Well-Being and Basic Needs Survey, December 2022.
Notes: Adults with long COVID include those with a COVID-19 diagnosis or positive test and those who thought they had COVID-19 but did not have a diagnosis or positive test. Questions on reduced work hours, requested changes at current employer, change of employers, and limiting activities outside of work were only asked of respondents who did not report that they stopped working.

The need to prioritize work over other activities may partially reflect a disproportionate lack of workplace flexibility: only 59 percent of adults with long COVID who were working for an employer reported having access to paid sick leave at their jobs, compared with 68 percent of all workers (data not shown).

Overall, adults with long COVID were less likely to be working than adults who had COVID-19 but did not report current long COVID (65 percent vs. 76 percent) and were also more likely to be out of the labor force for health or disability reasons (11 percent vs. 5 percent; figure 2).

FIGURE 2

Employment Status among Adults Ages 18 to 64, by Self-Reported COVID-19 and Long COVID Status, December 2022



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Source: Well-Being and Basic Needs Survey, December 2022.
Notes: Adults with long COVID include those with a COVID-19 diagnosis or positive test and those who thought they had COVID-19 but did not have a diagnosis or positive test. Estimated percentages are rounded to the nearest percentage point. Estimates are not shown for 0.5 percent of adults who did not report whether they are working or actively looking for work. */**/*** Estimate differs significantly from the estimate for adults with long COVID at the 0.10/0.05/0.01 level, using two-tailed tests.

Material Well-Being among Adults with Long COVID

Over 4 in 10 adults with long COVID reported food insecurity, with 1 in 4 reporting very low food security. Approximately 1 in 5 adults with long COVID symptoms

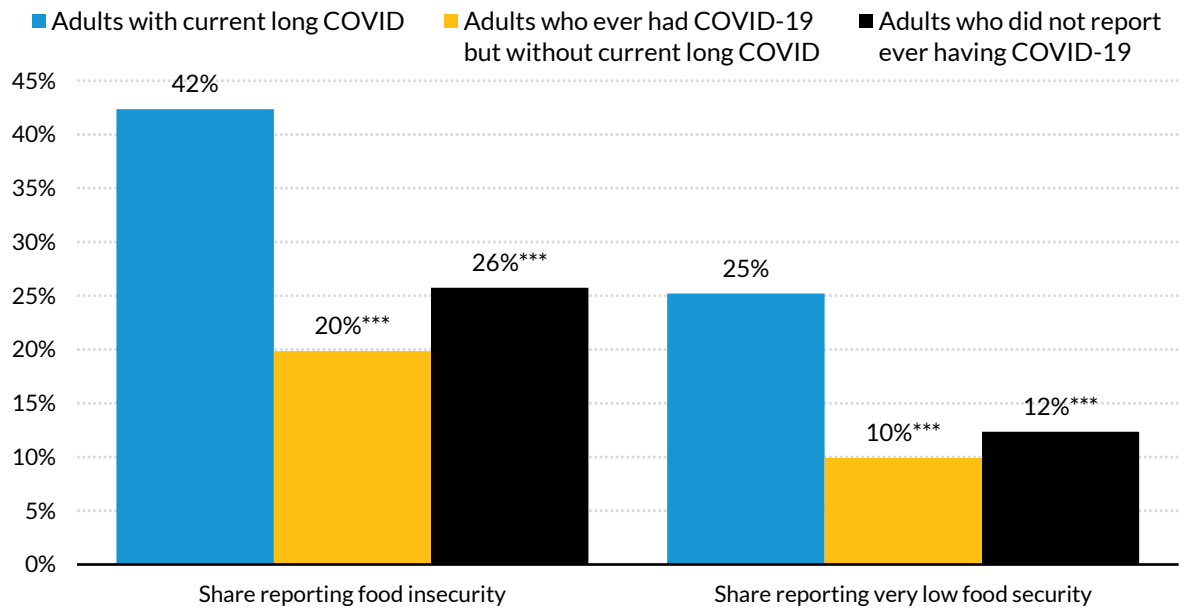
reported difficulties paying their rent or mortgage, and nearly 1 in 4 had trouble paying utility bills.

Earlier studies of the link between long COVID and economic well-being have focused primarily on employment (Bach 2022; Goda and Soltas 2022; Ham 2022; Price 2022; Sheiner and Salwati 2022). The WBNS also allowed us to explore the relationship between long COVID and material hardship, including household food insecurity, difficulty with rent or mortgage payments, and problems paying utility bills in the past 12 months.

Adults with long COVID reported experiencing food insecurity at more than double the rate of adults reporting COVID-19 but not long COVID (42 percent vs. 20 percent) and at a higher rate than adults who did not report COVID-19 (42 percent vs. 26 percent; figure 3).[7] Adults with long COVID were also more likely to report very low food security, an indicator of reduced food intake, such as skipping meals.[8] Further, 20 percent of adults with long COVID reported difficulties paying their rent or mortgage, and nearly 1 in 4 (23 percent) had trouble paying utility bills. Almost 10 percent of adults with long COVID experienced a utility shutoff (figure 4).

FIGURE 3

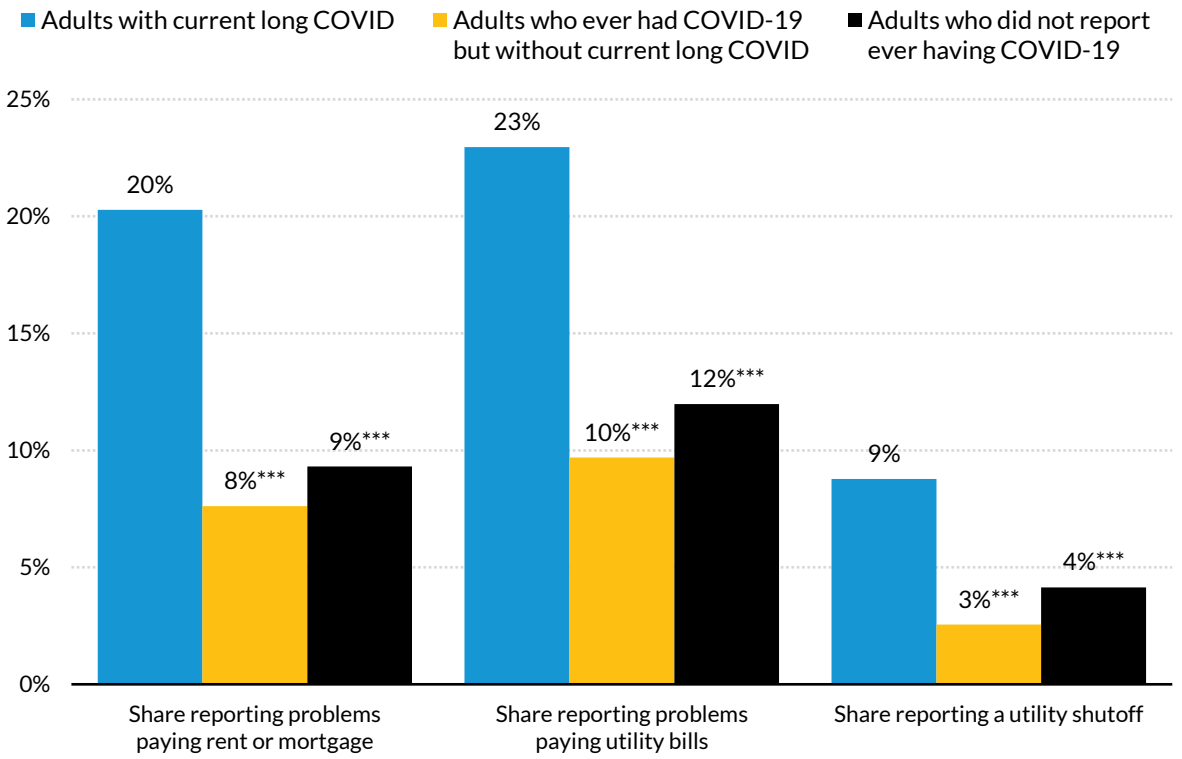
Household Food Insecurity in the past 12 Months among Adults Ages 18 to 64, by Self-Reported COVID-19 and Long COVID Status, December 2022



Source: Well-Being and Basic Needs Survey, December 2022.
Notes: Adults with long COVID include those with a COVID-19 diagnosis or positive test and those who thought they had COVID-19 but did not have a diagnosis or positive test. Food insecurity is based on the six-item short form of the USDA Household Food Security Survey Module and includes reports of low and very low food security.
*/**/*** Estimate differs significantly from the estimate for adults with long COVID at the 0.10/0.05/0.01 level, using two-tailed tests.

FIGURE 4

Problems Paying for Housing Costs in the past 12 Months among Adults Ages 18 to 64, by Self-Reported COVID-19 and Long COVID Status, December 2022



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Source: Well-Being and Basic Needs Survey, December 2022.
Notes: Adults with long COVID include those with a COVID-19 diagnosis or positive test and those who thought they had COVID-19 but did not have a diagnosis or positive test. Utility bills refer to gas, oil, or electricity bills.
*/**/*** Estimate differs significantly from the estimate for adults with long COVID at the 0.10/0.05/0.01 level, using two-tailed tests.

Our findings are consistent with previous studies that have examined the impact of long COVID on employment and the association between long COVID and material hardship. For instance, a 2022 study estimated that COVID-19 illness reduced the number of people in the labor force by 500,000, with average lost earnings of $9,000 (Goda and Soltas 2022). A 2021 longitudinal study found that of the 24 percent of respondents who reported experiencing long COVID, about 1 in 4 reported that symptoms affected their work hours or employment (Ham 2022). Relative to adults without a prior COVID-19 infection, those who reported long COVID affected their ability to work experienced a 10-percentage point reduction in the likelihood of being employed and a 50 percent reduction in work hours (if they remained employed). Other studies have found evidence of reduced workforce participation because of disabilities linked with long COVID symptoms and self-reported reductions in employment among people with long COVID (Davis et al. 2021; Ives-Rublee, Khattar, and Neal 2022; Bach 2022; Sheiner and Salwati 2022; Price 2022).

Research examining material hardship among people with long COVID is more limited but suggests adults with long COVID have greater difficulty meeting basic needs, reporting higher rates of food insufficiency, housing insecurity, and trouble paying for usual household expenses (Latino Policy Forum 2022; Packard and Susser 2023).[9] One analysis using a separate Urban Institute survey fielded in June 2022 found that having long COVID was associated with health care access and affordability challenges, including unmet needs for care because of costs, problems paying medical bills, and past-due medical debt (Karpman, Zuckerman, and Morriss 2023).

Policies to Address Material Hardship among People with Long COVID

Long COVID can lead to and/or exacerbate challenges in meeting basic needs through its effect on employment, the ability to carry out daily activities, and increased health care needs and costs. This is particularly the case for people who are already experiencing material hardship and who may be at greater risk for developing long COVID, including people with chronic conditions and disabilities. Material hardships may make accessing health care more challenging, as those affected may have to make difficult financial decisions to prioritize basic needs.

Fully addressing the long COVID crisis requires a holistic, multidisciplinary, and intersectional lens, both in and beyond medicine. In addition to urgently conducting clinical trials on promising therapeutics, funding research into long COVID's mechanisms and biomarkers, and ensuring universal access to quality and affordable health care, a critical key to reducing cases of long COVID and providing support for those who have or will develop long COVID is ensuring that people's basic needs are met. To facilitate this, policymakers can implement the following changes:

1. Expand access to safety net assistance and increase benefits in programs serving people with disabilities.

The emergence of long COVID has increased the number of Americans with disabilities, including invisible disabilities that are often overlooked by federal safety net programs and make it difficult to complete the often arduous process of applying for benefits.[10] Existing programs like Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), Medicaid, and utility and rental assistance programs are important programs that reduce poverty and material hardship and can help people with long COVID meet basic needs. However, these programs have many barriers to access, particularly for people with disabilities (Burnside et al. 2022). In addition, the critical shortage of housing assistance means many applicants will linger on long waiting lists.

Strategies to increase access to these programs, both for people with long COVID and for the broader population, include simplifying and streamlining application and recertification processes, expanding eligibility to noncitizens, reducing burdensome policies such as asset limits and work

requirements, and expanding the list of qualified medical professionals who can provide medical documentation of an illness or disability (Hahn, Pratt, and Knowles 2023). For programs that consider illness or disability status in eligibility determinations and/or exemptions from work requirements, eligibility and exemption criteria should be expanded to include illness and disability related to long COVID.

SSI and SSDI require significant improvements to ensure people can access benefits in a timely manner (Smalligan and Boyens 2019). These necessary changes include providing more funding to the Social Security Administration (SSA) to reduce application processing times, removing the two-year waiting period between SSDI approval and eligibility for Medicare, and providing free legal assistance for applicants. For long COVID specifically, SSA can issue a Social Security Ruling (SSR) to provide guidance on how they develop evidence to establish that a person has a medically determinable impairment of long COVID, with input from long COVID researchers, clinicians, and patients, as well as experts in overlapping infection-onset chronic conditions. The SSR should ensure that positive COVID tests continue to not be required for approval given limitations to their accuracy, availability, and use—particularly after the ending of the public health emergency.

Even when people are eligible for benefits, they are often either unaware of the programs or that they would qualify. Policymakers can fund community-based organizations to conduct targeted outreach and provide enrollment assistance to increase take-up, particularly for SNAP, TANF, and Medicaid (Hahn, Pratt, and Knowles 2023). This could include long COVID clinics and community health workers providing information on these benefits to people at risk of or who have developed long COVID.

While safety net programs can be a critical support for people, too often they do not provide enough support to lift people out of poverty. For SSI, it is critical for policymakers to update outdated asset limits and income exclusions and to raise SSI benefit amounts to ensure recipients have sufficient income to meet basic needs (Boyens et al. 2021).

2. Provide universal paid leave.

Having access to paid sick leave is crucial for ensuring people who have COVID-19 can stay home and not spread it in their workplace, enabling people to rest while recovering from COVID-19, and enabling people who develop long COVID to have a longer period before they must return to work. Particularly when people with lower incomes often do not have access to paid sick days,[11] these workers are forced to choose between staying home to protect themselves and their community and paying their bills. Research shows that people who did not have adequate rest in the first two weeks of COVID-19 were more likely to develop more severe long COVID (Ziauddeen et al. 2022), and reinfections increase the likelihood of developing long COVID (Thaweethai et al. 2023). Passing universal paid leave would provide support to those who develop long COVID and help ensure people can afford to take time off work to rest during their acute infection and avoid spreading the disease.

3. Make workplaces more accommodating.

Many people who report having long COVID are still employed. Lack of access to benefits is one reason people are in the workplace. But people also want to work for other reasons, both financial and for their well-being. These include feeling connected, contributing, and because they enjoy what they do. The Office for Civil Rights of the US Department of Health and Human Services and the Civil Rights Division of the US Department of Justice have issued guidance that long COVID can be a disability under the Americans with Disabilities Act and other federal antidiscrimination protections.[12] Workplaces need to offer reasonable accommodations that make it possible for people with long COVID to remain employed, including flexible schedules, frequent breaks, and, where possible, working from home.

Conclusion

The disparities in material hardship between people with and without long COVID are stark. In addition to fast-tracking research and increasing health care access, it is critical that policymakers urgently address social determinants of health and bolster the safety net for those who become sick to equitably address the emergence of this new and significant disability.

Data and Methods

This brief draws on data from a nationally representative sample of 7,881 adults ages 18 to 64 who participated in the December 2022 round of the WBNS. The WBNS is an internet-based survey designed to monitor changes in individual and family well-being as policymakers consider changes to federal safety net programs. For each round of the WBNS, we draw a stratified random sample (including a large oversample of adults in low-income households) from the KnowledgePanel, a probability-based internet panel maintained by Ipsos that includes households with and without internet access. Survey weights adjust for unequal selection probabilities and are poststratified to the characteristics of nonelderly adults based on benchmarks from the Current Population Survey Annual Social and Economic Supplement and the American Community Survey. Participants can complete the survey in English or Spanish. For further information about the survey design and content, see Karpman, Zuckerman, and Gonzalez (2018).[13]

All survey respondents were asked if they had ever taken a test that showed they had COVID-19 or been told by a doctor or other health professional that they had COVID-19. Those without a positive test or diagnosis were asked if they thought they ever had COVID-19. Respondents with a confirmed or suspected COVID-19 infection were asked the following question and given information about long COVID: "Are you experiencing symptoms more than four weeks after having COVID-19 that are not explained by something else? This is often referred to as 'long COVID.' Some examples of symptoms include tiredness or fatigue; difficulty thinking, concentrating, or remembering (sometimes referred to as 'brain fog'); difficulty breathing or shortness of breath; joint or muscle pain; fast-beating or pounding heart (also known as heart palpitations); chest pain; dizziness on standing; menstrual changes; changes

to taste or smell; or inability to exercise." Adults reporting long COVID were asked additional questions about the effect of their symptoms on their ability to carry out day-to-day activities and their employment. All respondents were asked questions about household food insecurity, problems paying the rent or mortgage, and problems paying utility bills.

Our analysis has several limitations. The WBNS has a low cumulative response rate, and the survey weights mitigate but do not eliminate potential nonresponse bias. However, studies assessing recruitment for the KnowledgePanel have found little evidence of nonresponse bias for core demographic and socioeconomic measures (Garrett, Dennis, and DiSogra 2010; Heeren et al. 2008), and WBNS estimates are generally consistent with benchmarks from federal surveys (Karpman, Zuckerman, and Gonzalez 2018). The sampling frame for the WBNS also excludes or underrepresents certain groups of adults, including those who are homeless, have low literacy levels, and are not proficient in English or Spanish. Adults with long COVID who have difficulty completing internet surveys because of their symptoms may also be underrepresented on the panel.

Both COVID-19 and long COVID were self-reported, introducing measurement error. Some adults lacking access to COVID-19 tests and other health care or whose tests were inaccurate may have been misclassified as not having had COVID-19 and/or long COVID. Other adults may have been misclassified as having long COVID if their symptoms were unrelated to COVID-19 and caused by another health condition. Because our analysis is based on a single round of data, we lack information on respondents' employment status and material well-being before COVID-19. Therefore, we do not observe all employment changes that could have been affected by long COVID (e.g., not entering or returning to the workforce because of symptoms), nor can we determine the extent to which material hardships were caused or exacerbated by long COVID.

Notes

[1] US Department of Health and Human Services, "What is Long COVID?" accessed June 26, 2023, https://www.covid.gov/longcovid/definitions.

[2] Brian Glassman, "Household Pulse Survey Shows 31.1% Reported Symptoms Three Months or Longer After They Had COVID-19," US Census Bureau, May 1, 2023, https://www.census.gov/library/stories/2023/05/long-covid-19-symptoms-reported.html.

[3] For this analysis, we include adults with both confirmed and suspected COVID-19 infections when producing estimates for those with self-reported long COVID symptoms. Restricting the sample to adults who only had confirmed infections would understate the number of adults with long COVID because of lack of access to COVID-19 tests (especially in the early months of the pandemic) and health care, as well as inaccuracy of tests (e.g., false negatives). Our approach in this brief mitigates these issues but increases the risk of measurement error associated with including adults whose symptoms may have been caused by a condition other than COVID-19. A previous Urban Institute survey conducted in June 2022 limited questions about long COVID to adults with a diagnosed COVID-19 infection (Karpman, Zuckerman, and Morriss 2023).

[4] Our definition of disability includes reporting a hearing, vision, cognitive, ambulatory, self-care, independent living, or communication difficulty because of a health condition.

[5] Our definition of a chronic condition is based on responses to the following question: "Do you currently have a health condition that has lasted for a year or more or is expected to last for a year or more? This could be a physical health condition (such as arthritis, asthma, cancer, diabetes, heart disease, high cholesterol, hypertension, or stroke), a behavioral health or mental health condition, or a developmental disability." Respondents could report having one condition, more than one condition, or no conditions.

[6] Respondents were asked, "Have you stopped working because of these symptoms? That is, you were working before having these symptoms and you are no longer working now?" Though 10 percent of respondents reported they stopped working, half of that group reported they were currently working for pay or self-employed later in the survey. We interpret these responses as indicating the individual stopped working temporarily and later began working again, though there may be measurement error in our estimates.

[7] The sample of adults who reported they were never diagnosed with COVID-19 had relatively low incomes and other demographic and socioeconomic characteristics that have been associated with limited access to COVID-19 tests. For instance, a recent study of "testing deserts" in Massachusetts found that COVID-19 tests were less available in communities of color, Medically Underserved Areas, and communities with low vehicle access (Radford et al. 2023).

[8] US Department of Agriculture, "Food Security in the US – Measurement," updated October 17, 2022, accessed June 29, 2023, https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-u-s/measurement.

[9] Glassman, "Household Pulse Survey Shows 31.1% Reported Symptoms Three Months or Longer After They Had COVID-19."

[10] Richard Deitz, "Long COVID Appears to Have Led to a Surge of the Disabled in the Workplace," Liberty Street Economics (blog), Federal Reserve Bank of New York, October 20, 2022, https://libertystreeteconomics.newyorkfed.org/2022/10/long-covid-appears-to-have-led-to-a-surge-of-the-disabled-in-the-workplace/; Betsy Ladyzhets, "Long COVID Pushes People Out of Work, But Government Help is Hard to Reach," *US News and World Report*, November 7, 2022, https://www.usnews.com/news/health-news/articles/2022-11-07/people-with-long-covid-face-barriers-to-government-disability-benefits.

[11] Bureau of Labor Statistics, "Table 6. Selected paid leave benefits: Access," modified September 22, 2022, accessed June 29, 2023, https://www.bls.gov/news.release/ebs2.t06.htm.

[12] US Department of Health and Human Services, "Guidance on 'Long COVID' as a Disability Under the ADA, Section 504, and Section 1557," July 26, 2021, https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html.

[13] For more information on the WBNS survey instrument for 2022, see https://www.urban.org/policy-centers/health-policy-center/projects/well-being-and-basic-needs-survey.

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