# Services and Supports for Longer-Term Impacts of COVID-19



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# **Executive Summary**

On April 5, 2022, President Biden issued the Memorandum on Addressing the Long-Term Effects of COVID-19 outlining actions needed to support the American people in addressing the longer-term effects of COVID-19. The President charged the Secretary of Health and Human Services with coordinating a U.S. government-wide response to Long COVID. An element of that response was for the Department of Health and Human Services, in collaboration with federal partners, to develop two reports: the Services and Supports for Longer-Term Impacts of COVID-19 Report (Services Report and the National Research Action Plan on Long COVID (Research Plan. The Services Report outlines current federal services and mechanisms of support available to the American public in addressing the longer-term effects of COVID-19, including Long COVID and related conditions, medical health and substance use challenges, and bereavement. The Research Plan provides the first U.S. government-wide national research agenda focused on advancing prevention, diagnosis, treatment, and provision of services and supports for individuals and families experiencing Long COVID.

### Longer-term effects of COVID-19 including Long COVID

COVID-19 has affected all aspects of health, including mental health, and disrupted daily life. It created additional obstacles for those experiencing mental health and substance use challenges. Further, many people have been forced to cope with the death of loved ones, especially children, and face the aftermath of those losses. Millions of Amercians continue to experience lingering symptoms after an initial infection with SARS-CoV-2, the virus that causes COVID-19. This report outlines federally funded supports and services for individuals experiencing the effects of COVID-19 in the areas of mental health, substance use, and bereavement. In addition, the Services Report lists federally funded supports and services for individuals experiencing disabilities due to Long COVID and associated conditions.

### Long COVID

In April 2020, shortly after the beginning of the pandemic, anecdotal reports from patients started to emerge that previously healthy individuals were experiencing lingering symptoms and were not fully recovering from infection with SARS-CoV-2, the virus that causes COVID-19. Recovery from infection can vary from person to person, most individuals seem to recover quickly and completely; however, some individuals report symptoms that persist or emerge weeks or even months after the acute phase of the infection has passed, even when the infection was asymptomatic. These sets of conditions are often referred to as "Long COVID." Long COVID is a term created and promulgated by patients, and recognizes the importance of two technical terms, Post-COVID-19 conditions, or PCC, broadly equivalent to Long COVID, and Post-acute Sequalae of SARS-CoV-2 infection, focused on the direct effects of the virus.

### About this Report

This report provides webpage information and telephone numbers that are relevant for

- Individuals experiencing Long COVID and associated conditions
- Health care personnel who work with and treat individuals experiencing Long COVID
- Individuals experiencing longer-term impacts of COVID-19, including mental health and substance use challenges
- Individuals dealing with the loss of family members or loved ones to COVID-19.

The report serves as an initial resource guide to help individuals, their families, and caregivers find needed supports, services, and reasonable modifications to receive health care and treatment, work, go to school, and stably live in the community. It is also useful for community organizations, health care enterprises, and public health agencies who work with individuals experiencing longer-term effects of COVID-19. It will inform the development of additional resources and tools created by the federal government for individuals, families, and communities to naviagate the federal supports and services available to them.

The COVID-19 pandemic has placed significant stresses on health systems, hospitals, primary care practices, and health care personnel. Health care personnel have faced a novel clinical entity threatening the life and well-being of unprecedented numbers of people. They worked with limited available knowledge or consensus on basic treatment protocols. These health care personnel continue to face challenges at work and home due to the pandemic's sustained impact. To better support these personnel and their continued efforts to care for individuals with COVID-19 and Long COVID, this report provides resources along with supports to deal with the stresses and traumas experienced from being on the front lines of the COVID-19 response.

There are critical barriers to equitable access to and utilization of health care and other services and supports for both COVID-19 and Long COVID as well as associated conditions, mental health and subsutance use challenges, and bereavement, all exasperated by the pandemic. To achieve our vision, this report is guided by health equity principles, building upon prioritized recommendations made by the Presidential COVID-19 Health Equity Task Force. These critical barriers include, but are not limited to, understanding how racism, ableism, and discrimination are associated with health care access, symptom recognition, disease progression, and severity of Long COVID in communities of color, people with disabilities, and other underserved populations; and the resultant limitations on access to appropriate services and supports.

### **Future Direction**

The U.S. government will continue to invest in supports, further refine the scope of services, and address gaps as we learn more through experience and research about Long COVID and the

other longer-term impacts of COVID-19. Engagement with public and private partners has informed both reports and will continue to be integral to our process as we ensure resources are accessible to those who need them.

# Letter from the Secretary of Health and Human Services

Thank you, President Biden, for the opportunity to coordinate a U.S. government effort that outlines federally-funded resources available to the American public in the face of COVID-19, titled the Report on Services and Supports for Longer-Term Impacts of COVID-19.

On January 20, 2020, health officials identified the first case of COVID-19 on U.S. soil. Eleven days later, the Department of Health and Human Services declared a public health emergency. On March 11, 2020, the World Health Organization declared the COVID-19 outbreak a pandemic in light of the alarming spread and severity of the disease across the world. Now, two years later, not only has the United States experienced over 86 million confirmed COVID-19 cases and a staggering one million deaths from COVID-19, but also these numbers continue to rise. The pandemic has disproportionately impacted communities of color and other underserved groups, especially those with disabilities and older adults, exacerbating the existing health inequities in our country and highlighting social and racial injustices that impede equitable health outcomes.

We have lost neighbors, parents, spouses, children, friends, and colleagues because of the pandemic, and millions continue to grieve the loss of loved ones.

Beyond the human toll, COVID-19 changed the way we live. It contributed to job losses, business closures, children staying home from school, food insecurity, and housing instability. Efforts to reduce the spread of the disease have contributed to social isolation, loneliness, and detriments to mental and emotional health.

Today, we continue to make advancements in addressing this pandemic by improving vaccine availability, increasing access to testing, expanding treatment for COVID-19, and enhancing research to advance our understanding of the epidemiology and impact of the disease. The American Rescue Plan has led to a remarkable and historically equitable economic recovery. Although much work remains, we are thankfully moving towards a future in which we have additional tools to prevent, treat, and mitigate the risks associated with COVID-19.

Despite these gains, emerging evidence suggests that, for many people, COVID-19 can have long-lasting health implications, commonly known as "Long COVID." Long COVID refers to the constellation of symptoms that can linger or arise anew long after the acute phase of SARS-CoV-2 infection. For persons affected by Long COVID, symptoms like fatigue, shortness of breath, heart palpitations, and joint pain can persist long after the acute infection. Individuals with Long COVID can have symptoms that persist or emerge four weeks or longer after contracting COVID-19, and our understanding of the longer-term persistent symptoms remains uncertain. Long COVID can hinder an individual's ability to work, attend school, participate in community life, and engage in normal everyday activities. Further, the pandemic has increased

the burden of mental health and substance use challenges, both directly and indirectly related to COVID-19. Although our nation continues to make advancements in addressing this pandemic, a new emphasis is necessary to address the impact of Long COVID and associated conditions.

Further, we recognize the extensive leadership and work of state and local governments in delivering supports and services. It is only through continued collaboration that we can hope to mitigate the longer-term effects of COVID-19 and plan for future pandemics. In response to the President's directive to coordinate a federal response and provide individuals with the resources they need, this report outlines the services and mechanisms of support across agencies that can assist people in America with addressing the longer-term impacts of COVID-19. Principles guiding this report include a commitment to health equity, patient and stakeholder engagement, and public-private collaboration.

I want to thank the staff in the 14 Departments and agencies who worked diligently to prepare this report. I also want to thank the Assistant Secretary for Health and the Assistant Secretary for Mental Health and Substance Abuse for their leadership in conceptualizing and driving the production of this report. Finally, I want to express my sincere gratitude to numerous organizations and individuals who contributed their time, resources, contacts, and invaluable conversations with us. This collaboration remains critically important in advancing the science and paving the way for progress. Those with lived experiences are central to these efforts.

Sincerely,

Xavier Becerra Secretary of Health and Human Services

# Chapter 1: Introduction

COVID-19 is a viral disease caused by SARS-CoV-2, a coronavirus that emerged in 2019. The virus spreads mainly from person to person through aerosolized respiratory droplets produced when an infected person coughs, sneezes, or talks. Some people who are infected may not have symptoms. For others, symptoms may appear 2 to 14 days after exposure and can include fever, chills, and cough. Symptomatic and asymptomatic infected persons can be contagious. Adults 65 years and older and people of any age with underlying medical conditions are at higher risk for severe illness, but anyone can have severe illness from COVID-19.1 Not only has the pandemic affected individuals, but it has also had major economic and social impacts on communities and reduced the availability of resources for individuals who live and work in those communities. COVID-19 has caused major economic disruptions, disconnected many from community resources and support systems, and created widespread uncertainty and fear. This in turn placed considerable stress on individuals and communities and may contribute to or exacerbate interpersonal or community violence.<sup>2</sup> The COVID-19 pandemic has placed significant stresses on health systems, hospitals, primary care, practices and health care personnel. It is only through extensive coordination and collaboration with state, tribal, and local governments that we can together achieve our aims.

COVID-19 has affected every U.S. community and so many aspects of our lives.

- There have been 86.6 million confirmed cases of the illness, 4.8 million hospitalizations, and over one million deaths from COVID-19<sup>3</sup>
- Over 200,000 children have lost a parent to COVID-19.<sup>4</sup>
- Almost 50 million people either did not work or worked fewer hours due to COVID-19<sup>5</sup>

COVID-19 was the third leading cause of death in 2020<sup>9</sup> and 2021<sup>10</sup> and second leading cause of death in January 2022.<sup>11</sup>

- In the first year of the pandemic ninety-three percent of children switched from classroom education to distance learning<sup>6</sup>
- In July 2020 thirty million people reported their household did not have enough to eat<sup>7</sup>
- In July 2020 fifteen million people reported being behind in paying rent<sup>7</sup>
- In August 2020 sixty-six percent of adults and 75percent of young adults reported feeling socially isolated.<sup>8</sup>

In 2020, the unemployment rate reached its highest peak since data collection began in 1948,<sup>12</sup> and almost 50 million people either did not work or worked fewer hours due to COVID-19.<sup>5</sup> Although the unemployment rate has since returned to roughly its pre-pandemic level, the labor force participation rate is lower than it was before the pandemic.<sup>13</sup>

At one time, early in the pandemic, , 77 percent of public schools and 73 percent of private schools reported moving classes to online distance-learning formats. <sup>14</sup> Though most children have since returned to the classroom, more than 80 percent of public schools reported that the COVID-19 pandemic has negatively impacted student behavior and socio-emotional development. <sup>15</sup> Children receiving virtual instruction are less active, less social, and have worse mental and emotional health. <sup>16</sup> As children struggle with the challenges of maturing in a new and uncertain virtual world, parents struggle to balance their financial security with the safety of their families.

Estimates from the Department of Agriculture show the number of people in food-insecure households increased from 35.2 million in 2019 to 38.3 million in 2020, and the number of children in households where at least one child was food insecure rose from 5.3 million in 2019 to 6.1 million in 2020.<sup>17</sup> In addition, analysis of the Census Household Pulse Survey showed that food insecurity doubled overall, and tripled in households with children at the start of the pandemic, and that 30 million people reported their household did not have enough to eat in January 2021.

Though only limited data on homelessness has been collected since the start of the pandemic, we know that housing insecurity is still an issue for many Americans: 15 million people reported that their household was behind on rent in January 2021.<sup>7</sup>

Studies show that social isolation can have a significant negative impact on health, including increased risk of dementia, heart disease, and stroke. COVID-19's death toll, which has left millions grieving, and its health, social, and financial effects have also brought mental health to the forefront of public concern.

# **Disparities and COVID-19**

Though everybody is at risk of COVID-19 and its effects, research shows that some racial and ethnic minority groups, older adults, people with disabilities, and people with lower incomes are disproportionately affected by COVID-19 and its impacts. COVID-19 data show that Black, African American, Hispanic, Latino, American Indian and Alaska Native persons in the United States experience higher rates of COVID-19-related hospitalization and death compared with non-Hispanic White populations, and that these disparities persist even when accounting for other demographic and socioeconomic factors. Age-adjusted case, hospitalization, and death rates were highest in American Indian, Alaska Native individuals. Non-Hispanic Black or African American people and Hispanic people are both more than twice as likely to be hospitalized due to COVID-19 than non-Hispanic White people. In 2020, residents of long-term care facilities made up less than 1 percent of the U.S. population but accounted for more

than 35percent of all COVID-19 deaths, with even more disproportionate impacts in nursing homes with higher percentages of residents from racial and ethnic minority groups.<sup>34</sup> Compared with ages 18 to 29 years, the rate of death is 330 times higher in those who are ages 85 years and older.<sup>35</sup> In addition, people ages 18 years and older with certain underlying medical conditions and certain disabilities are at increased risk for severe illness from COVID-19.26 In addition, immunocompromised individuals may experience weaker immune responses to COVID-19 vaccines.36

Social determinants of health (SDOH) are conditions in the environment that affect a wide range of health outcomes and risks.<sup>37</sup> These SDOH include neighborhood and the physical environment, health and health care, occupation and job conditions, income and wealth, and education. Discrimination, including racism, ableism, and associated chronic stress, influences each of these important topic areas. Together, disparities in each of these areas have contributed to disproportionately worse COVID-19 related outcomes for people from

### **Disparities and COVID-19**

### **Racial and Ethnic Minority Populations**

- Had higher rates of positive test results, hospitalizations, severe illness, and death from COVID-19, even after adjusting for age<sup>19-22</sup>
- Experienced greater unemployment<sup>12</sup> and were more likely to be behind on rent<sup>7</sup>
- Had higher rates of anxiety symptoms, depressive symptoms<sup>23</sup> and suicidal ideation<sup>24</sup>
- Were twice as likely to report having lost a relative or close friend to COVID-19<sup>25</sup>

### **Older Adults**

- Age is the strongest risk factor for severe COVID-19 outcomes<sup>26</sup>
- U.S. adults ages 65 years and older accounted for 81% of COVID-19 related deaths in 2020<sup>26</sup>

### **People with Disabilities**

People with disabilities, including attention-deficit/hyperactivity disorder, cerebral palsy, intellectual and developmental disabilities, spinal cord injuries, Down syndrome, and other chronic health conditions such as HIV/AIDS may be more likely to get very sick from COVID-19 because of underlying medical conditions, living in congregate settings, or systemic health and social inequities.<sup>27-29</sup>

racial and ethnic minority groups, people with disabilities, and for older people.<sup>29, 37, 38</sup>

### **Bereavement**

Over 1 million people have lost their lives to COVID-19. They were beloved parents, grandparents, children, siblings, spouses, neighbors, and friends. Each soul is irreplaceable, and the families and communities left behind are still reeling from profound loss. Many families and communities have already received support from federal programs that help with the loss they

have experienced. As we move forward, we commit to ensuring that families and communities can access these support programs and connect to resources they may need to help with their healing, health, and well-being.

Every COVID-19 death leaves behind approximately nine bereaved kin.<sup>39</sup> One-fifth of Americans had lost a relative or close friend in early 2021, when there were roughly half as many deaths from COVID-19 as today.<sup>40</sup> Over 200,000 children have lost a parent to COVID-19.<sup>4</sup> Compared with the group at lowest risk, White children, we found American Indian and Alaska Native

children, Black children, Hispanic children, and Asian children were 4.5, 2.4, 1.8, and 1.1 times more likely, respectively, to lose a parent or caregiver.<sup>41</sup> Providing support and resources to individuals who have lost loved ones during the pandemic remains an important priority in the process of grief and bereavement.

### Mental Health and Substance Use

Fear, anxiety, anger, and depression have been common emotions as individuals cope with the stressors associated with the COVID-19 pandemic. Over 41percent of Americans, more than four times the amount in 2019, reported feelings of anxiety and depression during the peak of the pandemic. Thoughts of suicide increased and over a quarter of Americans experienced stress-related symptoms. In a nationally representative survey conducted by CDC in June 2020, it was determined that thirteen percent of Americans started or increased alcohol or substance use as a way to cope with the stress of COVID-19. Substance use in the study was defined as use of alcohol, legal or illegal drugs, or prescriptions drugs that are taken in a way not recommended by your doctor.

Drug overdose deaths, already on the rise before 2020, increased rapidly during the COVID-19 pandemic, reaching a record 107,000 in 2021.<sup>44</sup>

### COVID-19 Impacts on Mental Health and Substance Use

- Thirteen percent of Americans started or increased substance use as a way to cope with the stress of COVID-19<sup>43</sup>
- Individuals infected with COVID-19 were 60% more likely to have a mental health condition or mental health-related prescription<sup>45</sup>
- Drug overdose deaths increased throughout the pandemic reaching a record of 107,000.<sup>44</sup>
- More than half of parents expressed concern about their children's mental well-being<sup>46</sup>

Social, emotional, and economic stressors, as well as disruptions in health and emergency services, may have contributed to increases in interpersonal violence. Studies have documented increases in domestic violence and gender-based violence during the COVID-19 pandemic.<sup>47, 48</sup> A CDC analysis also found that the firearm homicide rate grew nearly 35percent from 2019 to 2020, a historic increase that resulted in the highest firearm homicide rate in more than 25 years.<sup>49</sup> Multiple studies found that suicide risk increased during the COVID-19

pandemic across a range of population groups. For example, 25% of young adults age 18 to 24 years, 15percent of non-Hispanic Black adults, and 19percent of Hispanic respondents in one survey reported experiencing suicide ideation in the past 30 days. Emergency department visits for suspected suicide attempts among young females aged 12 to 17 years increased 51percent in 2021 compared to the same period in 2019. 50

The COVID-19 pandemic has contributed to substantial economic and social impacts that have reduced the availability of resources and supports for individuals, and these impacts have in turn exacerbated the effects on individuals. Although this report focuses on services for individuals, it is important to note that, because COVID-19 impacted family members, caregivers, organizations, and communities, the federal response includes community-level programs and services. These community-level programs and services, however, remain outside the scope of this report.

### **Long COVID**

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after initial COVID-19 or SARS-CoV-2 infection. The signs, symptoms, and conditions

- are present four weeks or more after the acute phase of infection;
- may be multisystemic;
- and may present with a relapsing remitting pattern and progression or worsening over time, with the possibility of severe and life-threatening events even months or years after infection.

Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risk factors and outcomes.

### **Long COVID**

Amidst the many challenges of the pandemic are the persistent health effects some individuals face well after their acute COVID-19 infection. Recovery from infection with SARS-CoV-2, the virus that causes COVID-19, can vary from person to person. Most people seem to recover

"I went to the emergency room because I was exhausted all the time. It was a horrible experience! They admitted me to an inpatient psychiatric ward. Much later, after many scary medical problems, I was diagnosed with Long COVID."

—Person with Long COVID

quickly and completely. However, some report symptoms that persist or emerge weeks or even months after the acute phase of illness has passed, sometimes even in asymptomatic cases. This condition is often referred to as "Long COVID."

At this time, no laboratory test can definitively distinguish post-COVID conditions from other causes. A positive SARS-CoV-2 viral or antibody test result may help determine if there is a

current or previous infection; however, these laboratory tests are not required to establish a diagnosis of post-COVID conditions.

The medical, scientific, and public health communities have developed precise terms with agreed-upon, interim definitions of Long COVID, such as Post-COVID-19 conditions (PCC) and Post-acute Seguelae of SARS-CoV-2 infection (PASC), to use for communicating about clinical, research, and public health activities (see Appendix C in the Research Report). The first, Post-COVID-19 Conditions, is equivalent to Long COVID and includes both direct and indirect effects of the virus. It is useful in various clinical setting, assessing the burden to the health care system, and surveillance. The second, is Post-acute Sequalae of SARS-CoV-2 infection, which aims to capture the direct effects of the virus. It is used often in clinical contexts and critical to the medical research community aiming to understand the root causes of Long COVID. Additional research is needed to sufficiently separate the various forms and conditions of Long COVID, including from preexisting ones. The differences and nuances among the definitions reflect the central challenge of defining, studying, and addressing the impact of Long COVID. In addition, some scientists and patient advocate communities point to the importance of conditions associated with Long COVID, drawing parallels in symptoms and underlying biology to other diseases, such as post-infectious conditions. The terminology of Long COVID and associated conditions leverages existing experience and knowledge to recognize commonalities to better treat and care for the many affected individuals, including the domains of disability and insurance coverage. Although the definitions will likely change as we learn more, using terms with commonly understood definitions helps research and public health communities compare findings across studies and facilitates turning surveillance and research findings into action to improve patient care.

Throughout this report, it will be noted if and where specific research uses a more specific term (i.e., PCC, PASC). Also, it is emphasized that "Long COVID" is not just

### Common Symptoms of "Long COVID"<sup>51</sup>

### **General symptoms**

- Tiredness or fatigue that interferes with daily life
- Symptoms that get worse after physical or mental effort (also known as "post-exertional malaise")
- Fever

### Respiratory and heart symptoms

- Difficulty breathing or shortness of breath
- Cough
- Chest pain
- Fast-beating or pounding heart (also known as heart palpitations)

### **Neurological symptoms**

- Difficulty thinking or concentrating (sometimes referred to as "brain fog")
- Headache
- Sleep problems
- Dizziness when you stand up (lightheadedness)
- Pins-and-needles feelings
- Change in smell or taste
- Depression or anxiety

### **Digestive symptoms**

- Diarrhea
- Stomach pain

### Other symptoms

- Joint or muscle pain
- Rash
- Changes in menstrual cycles

one condition, and the use of the term Long COVID in this report should not be construed as such.

Long COVID can affect nearly every organ system and hinder an individual's ability to work, attend school, participate in community life, and engage in normal everyday activities. Long COVID can affect people regardless of race, age, gender, or baseline health status. It is more common in people with severe COVID-19 who require hospitalization or intensive care, individuals with underlying health conditions, unvaccinated individuals, and people affected by health disparities.<sup>51</sup>

A new CDC study reports that at least 30 days after having COVID-19, one in five COVID-19 survivors aged 18–64 years and one in four survivors aged 65 years or older have a health condition that might be related to their previous COVID-19 illness. People who had previous COVID illness had twice the risk for developing pulmonary embolism or respiratory conditions.<sup>52</sup>

The study looked at rates of 26 conditions known to occur after COVID-19 (post-COVID conditions). The report found that people that had past COVID-19, had twice the risk of developing a new condition compared with people without evidence of COVID-19. The highest risks were for conditions involving the lungs, including blood clots in the lungs, and respiratory symptoms, although the conditions examined affected multiple body systems. The most common new conditions were respiratory symptoms and musculoskeletal pain.<sup>52</sup>

Estimates from the CDC study may not be generalizable to the broader U.S. population, but the breadth of symptoms and conditions that are manifestations of Long COVID, and the potential scale, are consistent throughout the scientific literature. Despite more precise estimates of risk, it is evident that Long COVID already impacts a substantial number of people. This number may continue to grow, although vaccinations and prevention measures can help. The response to Long COVID will have to be at a scale and scope necessary to respond to the short-term and longer-term health care needs of persons with this lived experience.

Human-centered design and human-centered research, such as the HHS Health+ ("health plus") cycle for Long COVID, will be necessary to understand common experiences of individuals living with Long COVID. The latest involves over 1,000 hours of interviews, workshops, listening sessions, and human-centered research to co-create solutions with—not for—those impacted by Long COVID. Through human-centered research Health+ will identify opportunity areas that matter most to patients and help to guide federal action.

Beyond the health complications it causes, Long COVID has resulted in decreased employment and billions of dollars in lost income. As individuals experiencing Long COVID disproportionately work in the service sector, this has led to a labor shortage in this industry, which may contribute to inflation. Health care cost burdens are also expected to increase for new chronic conditions, such as heart disease, diabetes, and kidney disease, that may be attributable to COVID-19.

# Individuals Who Experience Disabilities from Long COVID

For some, whose Long COVID substantially limits their major life activities, their illness may qualify as a disability under disability rights laws. Whether Long COVID is a disability depends on how Long COVID affects the individual. Other laws define disability differently, and individuals will need to meet those definitions to qualify for those programs. The following examples highlight cases where Long COVID may be a disability according to the Americans for Disabilities Act (ADA) and other disability rights laws.<sup>56</sup>

- A person with Long COVID who has lung damage that causes shortness of breath, fatigue, and related effects is substantially limited in respiratory function, among other major life activities
- A person with Long COVID who has symptoms of intestinal pain, vomiting, and nausea that have lingered for months is substantially limited in gastrointestinal function, among other major life activities
- A person with Long COVID who experiences memory lapses and cognitive impairment (or "brain fog") is substantially limited in brain function, concentrating, and thinking.

When Long COVID qualifies as a disability under federal disability rights laws, individuals are eligible for reasonable accommodations, such as<sup>56, 57</sup>

- Modifying a policy to allow a person who experience dizziness when standing to be accompanied by their service animal that is trained to stabilize them
- Providing an employee who has fatigue issues a modified work schedule

### Long COVID and Disability<sup>56</sup>

- According to official guidance from the Office for Civil Rights of the Department of Health and Human Services, the Civil Rights Division of the Department of Justice, and the Equal Employment Opportunity Commission, Long COVID can be a disability under the ADA, Sections 501 and 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act if it substantially limits one or more major life activities
- These federal laws provide protection from discrimination for people with disabilities
- Major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, sitting, reaching, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, writing, communicating, interacting with others, and working. The term also includes the operation of a major bodily function, such as the functions of the immune system, cardiovascular system, neurological system, circulatory system, or the operation of an organ
- The limitations do not need to be severe, permanent, or long-term

- Modifying procedures so a customer who finds it too tiring to stand in line can announce their presence and sit down without losing their place in line
- Allowing an employee who has joint or muscle pain caused by walking to the meeting place the ability to participate in staff meetings by video
- Providing an employee who is having respiratory problems with a portable air purifier in their office.

Long COVID may be less prevalent in children, but it can still occur. Children especially may have trouble describing their experiences with Long COVID. Extra accommodations, such as extra time on tests, scheduled rest periods throughout the day, or a modified class schedule may be necessary for children experiencing Long COVID.<sup>58</sup> This guidance also applies to colleges and universities, although they are not required to identify students with disabilities. Rather, college and university students may request accommodations.<sup>59</sup>

A student may also qualify for special education based on the Individuals with Disability Education Act (IDEA) if the student has limited strength, vitality, or alertness due to a chronic or acute health problem that adversely affects the child's educational performance, as determined by a comprehensive evaluation. For example, children with developmental delays due to severe cases of Long COVID may qualify. IDEA requires states to have a system in place to identify and evaluate children with a disability and provide early intervention services as soon as possible.

### **Purpose of the Report**

On April 5, 2022, President Biden issued the Memorandum on Addressing the Long-Term Effects of COVID-19, charging the Secretary of Health and Human Services (Secretary) with coordinating the federal response, in engagement with public- and private-sector partners, to the longer-term effects of COVID-19. As part of the federal response, President Biden directed the Secretary, with input from federal agencies, to produce two reports within 120 days. This first report, the *Report on Services and Supports for Longer-Term Impacts of COVID-19*,

"Honestly, I don't know where to refer people who have Long COVID symptoms. There are so many people suffering. Even when there is a Long COVID expert in the area, there is a wait time of at least 4 months for an appointment."

—Community health worker

outlines the services and mechanisms of support across agencies that assist the American public in addressing the longer-term effects of COVID-19, including mental health, substance use, bereavement, Long COVID and related conditions. The second report, titled the *National Research Action Plan*, provides the first government-wide national research agenda focused on understanding and treating Long COVID.

The purpose of this report is to outline the current services and supports across federal agencies to address the far-reaching and longer-term effects of COVID-19, including Long COVID and associated conditions, mental health and substance use challenges, and bereavement. This report highlights over 200 services and supports that are currently supported by the U.S. government. This report, as well as the National Research Action Plan on Long COVID, are intended to serve as two tools in the larger ecosystem of the needed response to the longer-term impacts of COVID-19. The federal government will continue to invest in services and supports, and strive to improve how these programs can address the specific needs of the population as we continue to learn more. In development of this report and through engagement with a broad group of partners it is recognized that more will be needed. In addition, it is recognized that some individuals may need supports across multiple domans such as services for Long COVID and supports for bereavement. Finally, many of the resources listed are accessible to broader populations with disabilities. In addition, many federal agencies have resources that are specific to individuals with pre-existing medical conditions, such as individuals with HIV and AIDS. Those resources are beyond the scope of the report.

This report provides practical information and describes the federally funded services and supports available for

- Individuals experiencing Long COVID and associated conditions
- Health care personnel who work with and treat individuals experiencing Long COVID
- Individuals experiencing longer-term impacts of COVID-19, including mental health and substance use challenges
- Individuals dealing with losing a family member or loved one to COVID-19.

# **Methodology for Assembling this Report**

This report is published by the Secretary of Health and Human Services, supported within the Department of Health and Human Services by the Assistant Secretary for Health and the Assistant Secretary for Mental Health and Substance Use. The content of the report was guided by the recommendations issued last year by the Presidential COVID-19 Health Equity Task Force. The Department of Health and Human Services' Office of Intergovernmental and External Affairs hosted a series of interactive listening sessions from April through June 2022 to help develop this report. The sessions included a broad range of individual stakeholders including persons affected by the longer-term impacts of COVID-19, researchers, health professionals and their specialty organizations, and advocacy organizations. The messages that U.S. government leadership and workgroup members heard across sessions are reflected in the development of this report. Contributors included relevant nongovernmental experts, organizations and stakeholders, including individuals affected directly by the longer-term effects of COVID-19. For a full list of the U.S. federal departments and agencies that contributed to this report, please see the Acknowledgements in Appendix B.

The Biden Administration has made a commitment to combat and respond to the COVID-19 pandemic with the full capacity of the federal government. Federal agencies, working in partnership with health care professionals, clinical workforce, and community support organizations will continue to work with and for individuals experiencing longer-term effects of COVID-19.

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# Chapter 2: Federal Supports and Services for Americans Experiencing Long COVID

Some people with Long COVID, as well as their families or caregivers, may need a variety of services, supports or reasonable modifications to access health care and treatment, work, go to school, and stably live in the community. They may not know where to start.

This chapter is intended to be a resource guide to help people navigate needed supports, services, and modifications. It provides a list of federal programs, supports and services that can help individuals with Long COVID and their families and caregivers. In addition, some of the resources may also support individuals, their families and caregivers are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges, and bereavement.

The chapter is divided into ten sections that cover common areas of need

- 1. Know Your Rights
- 2. Health care Coverage and Access
- 3. Community Services and Supports
- 4. Income and Financial Assistance
- 5. Job Assistance
- 6. Housing
- 7. Food and Nutrition Support
- 8. Child Care and Early Childhood Development and Education
- 9. Education Supports
- 10. Caregiver and Family Support

Each section begins with a "Not Sure Where to Start?" section that provides navigation resources for the topic, like a website or phone number. The sections include a list of relevant programs, supports and services for each topic, with a short description and a telephone number or hyperlink to a website to get more information. You do not need to have Long COVID to access these resources. Most of the resources are relevant to anyone with a disability or who meets the program criteria.

# **Know Your Rights**

If you have Long COVID, you may be considered an "individual with a disability" under civil rights laws, including the Americans with Disabilities Act (ADA), Section 501 of the Rehabilitation Act of 1973 (Section 501), Section 504 of the Rehabilitation Act of 1973 (Section 504) and Section 1557 of the Patient Protection and Affordable Care Act (Section 1557). Under these laws, someone with Long COVID has a disability if the individual's condition or any of its symptoms is a physical or mental impairment that substantially limits one or more major life activities. There are additional rights discussed throughout this chapter.

Each of these federal laws protects individuals with disabilities from discrimination by "covered entities," which are the employers and providers who must comply. Each law is slightly different in terms of rights and obligations, but there is information about how these laws can help meet the needs of people with Long COVID in different topic areas, such as in workplaces, schools, housing, or in accessing community services. In some topic areas, such as education, there are additional federal laws that require services for someone with a disability.

- The Department of Health and Human Services (HHS) Office for Civil Rights (OCR) and the Department of Justice (DOJ) Civil Rights Division have issued <u>Guidance on</u> <u>"Long COVID"</u> as a <u>Disability Under the ADA</u>, Section 504, and Section 1557
- The Equal Employment Opportunity Commission
  (EEOC) addresses Long COVID as a disability and
  the employment rights of individuals with Long COVID. See section N within their
  guidance document What You Should Know About COVID-19 and the ADA, the
  Rehabilitation Act, and Other EEO Laws | U.S. Equal Employment Opportunity
  Commission (eeoc.gov)
- ➤ DOJ and HHS OCR also provide education to the public on the rights and responsibilities of individuals and entities under the ADA and Section 504 during the COVID-19 pandemic. For more information, visit <a href="Emergency Preparedness and Response">Emergency Preparedness and Response</a> | U.S.

### **Not Sure Where to Start?**

Q. Do you believe that you have been discriminated against because of your race, color, national origin, disability, age, gender, or religion?

A. Visit Office for Civil Rights |
U.S. Department of Health and
Human Services (hhs.gov) or
Contact the Civil Rights Division
| Department of Justice or
Home | U.S. Equal Employment
Opportunity Commission
(eeoc.gov)

Q. Do you have a complaint about housing, law enforcement, labor, education or employment discrimination?

**A.** Find other Federal civil rights agencies that can help you

Visit Contact the Civil Rights

Division | Department of Justice

<u>Department of Justice (ada.gov)</u> and <u>Civil Rights and COVID-19 | U.S. Department of Health and Human Services (hhs.gov)</u>

➤ DOJ also has a team of ADA Specialists available by phone, Monday through Friday, to provide technical assistance on the requirements of the ADA. These Specialists can be reached at 1 (800) 514-0301 (Voice) and 1 (800) 514-0383 (TTY)

The federal government recognizes that equity requires non-discrimination in the availability of, and access to, care, treatment, supports and services, and employment opportunities for people with Long COVID. Federal civil rights laws not only protect individuals with Long COVID from discrimination on the basis of disability, but also on the basis of race, color, national origin (including limited English proficiency), age, religion, pregnancy, sexual orientation, and gender identity.

- For additional resources on addressing civil rights issues related to the COVID-19 pandemic, more can be found in the Department of Justice (DOJ) Civil Rights Division's Statement on a Coordinated Civil Rights Response to Coronavirus: <a href="Statement by the Principal Deputy Assistant Attorney General for Civil Rights Leading a Coordinated Civil Rights Response to Coronavirus">COVID-19</a>) | OPA | Department of Justice.
- The U.S. Equal Employment Opportunity Commission has issued <a href="What You Should Know About COVID-19">What You Should Know About COVID-19</a> and the ADA, the Rehabilitation Act, and Other EEO Laws, a series of technical assistance questions and answers on COVID-19 issues, such as return to work, hiring, vaccinations, caregivers, the definition of disability that includes Long COVID, reasonable accommodation, and retaliation.
- ➤ The Department of Health and Human Services Office for Civil Rights has issued a bulletin: <u>Bulletin: Ensuring the Rights of Persons with Limited English Proficiency in Health Care During COVID-19</u> | <u>Guidance Portal (hhs.gov)</u>.

### Legal Assistance and Information

Sometimes people with Long COVID may have questions about their eligibility for some of the programs discussed in this chapter. They or their family member may have been told they are not eligible, or that services are not covered, and they want to know their legal rights. They may be subject to a legal proceeding, such as an eviction or a collection on a bill they could not pay because they lost their job. They may be eligible for free legal help for some or all of these questions.

# Legal Assistance for People with Disabilities through Protection and Advocacy Systems

Protection and Advocacy Systems (P&As) are congressionally mandated agencies that provide a range of legal advocacy services to people with disabilities. P&As can assist if a person has been denied access to a service or an opportunity to take part in an activity, such as employment or

education, and can address allegations of neglect or abuse and conduct monitoring and investigations of facilities. For people with Long COVID, their local P&A may help assess their status and needs, provide case management, ensure access to services, and address accessibility barriers. There are 57 P&As—one in each state and territory, as well as one which serves the Navajo and Hopi Nations in Colorado, New Mexico, Arizona, and Utah.

Find a local P&A, visit Member Agencies | National Disability Rights Network (ndrn.org)

### Legal Assistance for Older Americans

The Older Americans Act (OAA) provides funding for legal assistance to older adults ages 60 and older provided through Area Agencies on Aging (AAAs). There are approximately 1,000 OAA-funded legal services providers nationwide. The legal services network can provide important assistance for older persons in accessing long-term care options and other community-based services. Legal services also protect older persons against direct challenges to their independence, choices, and financial security. These legal services are specifically targeted to "older individuals with economic or social needs." OAA-funded legal services providers may address issues such as health care coverage, income security, housing, utilities, protective services, abuse, neglect, and age discrimination.

Find local services, visit <u>Eldercare Locator | Administration for Community Living</u> (<u>eldercare.acl.gov</u>) or call 1 (800) 677-1116

### Americans with Disabilities Act National Network

The Americans with Disabilities Act (ADA) National Network provides information, training, and technical assistance to individuals, including students with Long COVID, educators, businesses, and agencies with rights and responsibilities under the ADA. There are 10 Regional ADA Centers located throughout the United States and an ADA Knowledge Translation Center (ADAKTC), providing technical assistance about the ADA, Sections 501 and 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act (IDEA).

- ➤ Learn more about the ADA National Network, visit <u>ADA National Network | Information</u>, Guidance and Training on the Americans with Disabilities Act (adata.org)
- ➤ Reach a representative, call the ADA National Network hotline 1 (800) 949-4232 or visit Email Us | ADA National Network (adata.org)

# Health Care Coverage and Access

The COVID-19 pandemic has highlighted the critical importance of having health care coverage for yourself and your family. The pandemic has worsened the inequities that underlie our health care system, and the federal government is continually working on both federal and state levels to improve access to and quality of care for everyone. Symptoms of Long COVID, which may present differently in each person and often appear similar to other conditions, can pose significant challenges to our health care system and to patients, especially those with other underlying disabilities. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges, and bereavement. Indivuidals who many have lost a loved one whose health care coverage you depended or who lost health coverage due to job loss may also benefit from the supports and services in this chapter. This section covers eight topics.

- Health Insurance Coverage
- Health Insurance Support after Job Loss
- Community Health Centers and Health Care for Underserved Communities
- Veterans, Military Service Members, and Military Families
- Tribal Communities
- Home Medical Equipment
- Telehealth and Long COVID
- Long COVID Study Enrollment.

### **Not Sure Where to Start?**

# Q. Need health insurance coverage?

A. Contact a Health Insurance
Navigator and Assister. Search Local Assistance for Health
Insurance Application |
(HealthCare.gov)

# Q. Need help paying for your health care costs?

A. Find out if you might save on Marketplace premiums, or qualify for Medicaid or Children's Health Insurance Program (CHIP), based on your income at Saving Money on Healthcare Costs | (HealthCare.gov)

### Q. Need assistance with Medicare coverage, enrollment, or costs?

A. Contact Medicare at 1 (800) MEDICARE or 1 (800) 633-4227 and 1 (877) 486-2048 (TTY). Welcome to Medicare | Medicare (medicare.gov)

# Q. In need of health insurance coverage after job loss?

**A.** Contact a Benefits Advisor. <u>Ask EBSA | U.S. Department of Labor (dol.gov)</u> If you have problems getting health insurance coverage or getting services you need, you may want to review the Legal Assistance portion of the *Know Your Rights* section.

### Health Insurance Coverage

### HealthCare.gov

If you have private insurance through the individual market, the Affordable Care Act's (ACA) "Essential Health Benefits" generally provide coverage for the diagnosis and treatment of COVID-19, including Long COVID. Coverage and cost-sharing details can vary by plan. Generally, individuals can enroll in coverage during the annual open enrollment period or if they qualify for a special enrollment period. You may be eligible for a special enrollment period if you loose your health insurance because you lost your job. Uninsured people under age 65 who are eligible to enroll in coverage through the ACA Marketplaces and consumers who are currently enrolled in Marketplace coverage can get help with plan enrollment and consult with health insurance Navigators and Assisters.

- Find assistance near you, visit <u>Search Local Assistance for Health Insurance Application</u> (<u>HealthCare.gov</u>)
- Find out if you can lower your Marketplace premium costs, visit <u>Saving Money on Healthcare Costs</u> (<u>HealthCare.gov</u>)
- For translated resources, visit Other Language Resources | HealthCare.gov

### Medicaid and the Children's Health Insurance Program

Medicaid and the Children's Health Insurance Program (CHIP) are joint federal-state programs. Medicaid provides health coverage to eligible adults with lower incomes, children, pregnant individuals, older individuals, and people with disabilities. CHIP provides health coverage to uninsured children in families with incomes too high to quality for Medicaid, but too low to afford private coverage. COVID-19-related treatment is available with no cost-sharing for most Medicaid and CHIP beneficiaries. These coverage requirements and cost-sharing prohibitions generally end in the year following the end of the COVID-19 public health emergency. This coverage includes treatments and therapies for Post-COVID-19 conditions, including Long COVID. Additionally, states must cover the treatment of a condition, which is usually covered under Medicaid and CHIP, and that may otherwise seriously complicate the treatment of COVID-19. Medicaid and CHIP also cover a wide range of other health care benefits, services, and treatments that are relevant for individual's with Long COVID.

Medicaid and CHIP also cover a wide range of health care benefits and treatments.

Learn whether you are eligible for Medicaid or CHIP, visit <u>Get Coverage. Health Insurance Marketplace</u> | HealthCare.gov

### Medicare

Medicare provides health insurance coverage for people who are 65 and older and for some people with disabilities. This includes coverage of diagnosis and treatment for Long COVID as well as a wide range of health care benefits and treatments.

- Learn about Medicare coverage of Long COVID by calling 1 (800) MEDICARE or 1 (800) 633-4227 and 1 (877) 486-2048 (TTY)
- Explore how Medicare can best fit your needs, visit Welcome to Medicare | Medicare
- For translated resources, visit <u>Information in Other Languages | Medicare (medicare.gov)</u>
- If you need help paying for your Medicare costs, see Medicare Savings Program and Extra Help for Medicare Part D topics below
- ➤ If you are enrolled in a Medicare Advantage Plan, you should check your plan details for COVID-19 related benefits

### Medicare Savings Programs

If you are eligible for Medicare, you can get help from your state for paying your Medicare premiums. In some cases, Medicare Savings Programs may also pay Medicare Part A (Hospital Insurance) and Medicare Part B (Medical Insurance) deductibles, coinsurance, and copayments if you meet certain conditions.

Contact your state Medicaid agency, visit <u>Talk to someone | Medicare</u>, select your state and then choose "Other insurance programs" from the menu on the left

### Extra Help for Medicare Part D Participants

If you are eligible for Medicare and meet certain income and resource limits, you may qualify for Extra Help with your prescriptions. This program helps pay for your Medicare drug coverage, such as plan premiums, deductibles, and costs when you fill your prescriptions, called copays or coinsurance.

Some people automatically qualify for Extra Help. You'll get the Extra Help program if you have Medicare and get any of the following: full Medicaid coverage; help from your state Medicaid program paying your Part B premiums (from a Medicare Savings Program); or Supplemental Security Income (SSI) benefits. If you do not automatically qualify, you can apply for Extra Help at any time.

Apply for Extra Help online, visit <u>Welcome!</u>, <u>Extra Help With Medicare Prescription Drug Plan Costs</u>, <u>Social Security (ssa.gov)</u> or call Social Security toll-free at 1 (800) 772-1213 and 1 (800) 325-0778 (TTY)

### State Health Insurance Assistance Program

State Health Insurance Assistance Program (SHIP) is a national program that offers one-on-one assistance, counseling, and education to Medicare beneficiaries, their families, and caregivers

- Find your local SHIP, visit <u>Home | State Health Insurance Assistance Programs</u> (shiphelp.org)
- > Talk to a counselor by calling (877) 839-2675

### Federal Employees Health Benefits Program

There are approximately 250 Federal Employees Health Benefits (FEHB) Program plan options available to the more than 8.2 million federal employees, retirees, and family members. The plans offer comprehensive benefits that include inpatient, outpatient, office-based care, pharmacy services, and telehealth. The diagnosis of Long COVID and related conditions is covered by FEHB plans, and there are no general exclusions based on this condition or cluster of conditions. Federal employees and retirees can join the program during the annual Open Season (November to December) or when they join federal service.

Learn more about FEHB, visit <u>Eligibility (opm.gov)</u>

### Health Insurance Support after Job Loss

### Consolidated Omnibus Budget Reconciliation Act Continuation Coverage

If you've lost your job or had your hours reduced, there are options available to workers and their families to maintain health coverage, including the Consolidated Omnibus Budget Reconciliation Act (COBRA). COBRA provides a way for workers and their families to temporarily maintain their employer-provided health insurance during situations such as job loss or a reduction in hours worked.

- ➤ Find out if you qualify for COBRA, call 1 (866) 444-3272; dial 7-1-1 to access telecommunications relay services
- Request assistance from a Benefits Advisor, visit <u>Ask EBSA | U.S. Department of Labor (dol.gov)</u>

### **Employer-Sponsored Insurance**

The Employee Benefits Security Administration (EBSA) provides answers to your questions and assists you if you believe you have been inappropriately denied employee benefits, including health benefits. They can help answer questions on issues such as denied health or disability benefits, COBRA, or plan administration and compliance.

- Reach a Benefits Advisor, visit Ask EBSA | U.S. Department of Labor (dol.gov)
- > Speak to a Benefits Advisor, call (866) 444-3272; dial 7-1-1 to access telecommunications relay services

# Community Health Centers and Health Care for Underserved Communities

### Federally Qualified Health Centers

Federally Qualified Health Centers (FQHCs) are community-based health care organizations that provide comprehensive, culturally competent, high-quality primary health care services for people who have lower incomes, who are uninsured, or face other obstacles to getting health care. FQHCs provide services regardless of patients' ability to pay and charge for services on a sliding fee scale.

- Find a health center near you, visit Find a Health Center (hrsa.gov)
- While not part of the FQHCs, many state and local health (and public health) departments provide health care. To find find a public health department near you, visit <u>Directory of Local Health Departments - NACCHO</u>

### **Rural Health Clinics**

Rural Health Clinics (RHCs) make up a critical part of the rural health care infrastructure and help address health equity gaps in medically underserved rural communities to improve health outcomes for rural residents. There are nearly 5,000 RHCs in 45 states located in rural, underserved areas.

Find additional information about RHCs, visit <a href="Expanding COVID-19 Response"><u>Expanding COVID-19 Response in Rural Communities through Rural Health Clinics | Official web site of the U.S. Health Resources and Services Administration (hrsa.gov)</u></a>

### **Rural Hospitals**

More than half of all hospitals in the United States are in rural areas. Rural hospitals serve individuals living in rural areas.

Find additional information about rural hospitals, visit Rural Hospital Programs | HRSA

### Veterans, Military Service Members, and Military Families

### Veterans Affairs Health Care

Veterans enrolled in the Veterans Affairs (VA) Health Care System can access primary and specialty care appointments, including those to cardiologists, gynecologists, and mental health

providers). In addition, veterans enrolled in VA health care can also access VA health care services like home health care, and you can get medical equipment, prosthetics, and prescriptions. Veterans with Long COVID and those with health needs related to the longer-term impact of the pandemic may access health services through the VA Health Care System.

- Find out more about eligibility for VA health care and learn how to apply for these benefits by calling Health benefits hotline at (877) 222-VETS or (877) 222-8387
- Find more information about VA health care services, visit <u>VA Health Care | Veterans</u> Affairs (va.gov)
- Find a VA service provider near you, visit Find VA Locations | Veterans Affairs (va.gov)

### Military Health System and TRICARE

The Department of Defense provides treatment and care to Military Health System beneficiaries through TRICARE. TRICARE is the health care program for eligible uniformed service members, retirees, and their families around the world. TRICARE provides comprehensive coverage to all beneficiaries, and most TRICARE health plans meet the requirements for minimum essential coverage under the Affordable Care Act. Depending on their plan type, TRICARE beneficiaries, including those with persistent Long COVID symptoms may be able to access care through military medical treatment facilities (MTFs) or through the community network.

- ➤ Patients concerned about prolonged symptoms or symptoms associated with Long COVID, any non-COVID-19 symptoms, or other health questions may call the Military Health System Nurse Advice Line at 1 (800) TRICARE or 1 (800) 874-2273 and select option 1
- Find military treatment facilities and TRICARE providers close to you, visit <u>Find a Military</u> <u>Hospital or Clinic | TRICARE (www.tricare.mil)</u>
- Find a network or non-network provider, visit Find a Doctor | TRICARE (www.tricare.mil)

### **Tribal Communities**

### Indian Health Service

If you are an American Indian or Alaska Native (AI/AN) person affected by any longer-term consequences of COVID-19, the Indian Health Service (IHS) supports a comprehensive health service delivery system through a series of Federal, Tribal, and Urban Indian Organization programs. The IHS offers primary care, mental health, substance use treatment, emergency services, and hospital care, although the range of services may vary by location. AI/AN persons with Long COVID and those with health needs related to the longer-term impact of the pandemic may seek primary health services at IHS.

Find a health center near you, visit Find Health Care | Indian Health Service (IHS.gov)

# Indian Health Service Community Health Representative Program

The Community Health Representative (CHR) Program is a culturally oriented and tailored concept for providing health care, health promotion, and disease prevention services. CHRs are frontline public health workers who are trusted members of the community with a close understanding of the community, language, and traditions. They assist by increasing health knowledge of patients and communities through a broad range of activities, such as transportation to health visits, outreach, community education, informal counseling, social support, and advocacy.

Learn more about the CHR program, visit <u>Community Health Representative | Indian Health Service (IHS)</u>

# **Indian Health Service Pharmacy Program**

The Indian Health Service Pharmacy Program serves as an integral part of a comprehensive, community-based, health care delivery system. Pharmacy services are patient-centered and are directed toward optimal patient care outcomes, health promotion, and disease prevention.

- Learn more about the Pharmacy Program, visit <a href="Pharmacy Program">Pharmacy Program</a> | Division of Clinical and Community Services (ihs.gov)
- ➤ For information on Pharmacy Expanding Vaccine Access, visit Pharmacy Expanding Vaccine Access (PEVA) | Commissioned Corps of the U.S. Public Service (dcp.psc.gov/OSG/pharmacy)

# Indian Health Service Division of Behavioral Health

The Indian Health Service Division of Behavioral Health (DBH) serves as the primary source of national advocacy, policy development, management, administration of mental health, alcohol and substance use challenges, and family violence prevention programs for AI/AN people. Working in partnership with Tribes, Tribal organizations, and Urban Indian health organizations, DBH coordinates national efforts to share knowledge and build capacity through the development and implementation of evidence-based, practice-based and culturally-based activities in Indian Country. DBH also established Long-Term COVID resources to develop a DBH IHS planning document of long-term recovery and resilience from mental and behavioral impacts of COVID-19.

Learn more about DBH, visit <u>Division of Behavioral Health | Indian Health Service (IHS)</u>

#### Indian Health Service Telehealth Resources

Indian Health Service offers telehealth services to help achieve the mission of raising the physical, mental, social, and spiritual health of AI/AN people to the highest level. IHS telehealth services support and promote long-distance clinical health care, patient and professional health-related education, and public health and health administration. Using telehealth brings specialty care locally to the AI/AN population including patients affected by any longer-term consequences of COVID-19.

Learn more about the IHS Telehealth resources, visit <u>Telehealth | IHS (ihs.gov)</u>

# The Indian Health Service Teleophthalmology Program

Established in 2000, this program uses telemedicine technology to provide high-quality, cost-effective, annual diabetic eye exams to AI/AN people.

- Learn more about the Teleophthalmology Program, visit <u>Joslin Vision Network</u> <u>Teleophthalmology Program | IHS (ihs.gov)</u>
- Find a list of sites, visit <u>List of Facilities (ihs.gov)</u>

# The Indian Health Service Telebehavioral Health Program

Provides direct, ongoing care via televideo to patients of all ages at IHS, Tribal, and Urban Indian operated facilities across the country. Current clinical services include: Adult Psychiatry; Addictions Psychiatry; Geriatric Psychiatry; Child and Adolescent Psychiatry; Adult Therapy; Family, Couples, and Group Therapy; Child and Adolescent Therapy; and Trauma and PTSD Therapy.

- Learn more about the Telebehavioral Health Program, visit <a href="HTML">HEALTH TELEBEHAVIORAL HEALTH TELEBEHA
- Find a list of TBHCE sites, visit Current TBHCE Sites | Telebehavioral Health (ihs.gov)

# Tribal Employer Health Insurance via the Federal Employees Health Benefits Program

Health insurance coverage through the Federal Employees Health Benefits Program (FEHB) can be purchased by Tribes or tribal organizations carrying out programs under the Indian Self-Determination and Education Assistance Act (ISDEAA) or the Tribally Controlled Schools Act of 1988 (TCSA) (25 U.S.C. 2501 et seq.), and urban Indian organizations carrying out programs under Title V of the Indian Health Care Improvement Act (IHCIA). It can be offered to eligible employees and their family members. The plans offer comprehensive benefits that include inpatient, outpatient, office-based care, pharmacy services, and telehealth. Similar to FEHB coverage for federal employees, retirees, and their families, there are not health plan restrictions in coverage for Long COVID.

- Learn more about Tribal Employee Health Insurance by visiting <u>Tribal Employers</u> (opm.gov).
- Find a Quick Guide to FEHB for Tribal Employees, visit Quick Guide to FEHB for Tribal Employees (opm.gov)

# Home Medical Equipment

# Home Medical Equipment

Health insurance may cover a range of home medical equipment (sometimes known as durable medical equipment). Home medical equipment includes, but is not limited to oxygen equipment, crutches, home infusion pumps and supplies, nebulizers, wheelchairs, and walkers. Check with your health insurance to see if it covers home medical equipment if needed.

> See the *Health Care Coverage and Access* section for more information.

# Telehealth and Long COVID

# Health and Human Services Telehealth Guidance for Patients

Telehealth has been extended across many health programs. It is safe, convenient, and more cost-effective for patients who may have mobility and transportation concerns that make getting to the office difficult. However, for people experiencing Long COVID, including older adults, people with limited English proficiency, and people with low digital literacy, there may be accessibility issues.

- For more information on HHS Telehealth Guidance, visit For Patients | Telehealth (telehealth.hhs.gov)
- For information about accessibility, visit <a href="Improving Access to Telehealth">Improving Access to Telehealth</a> (Telehealth.hhs.gov)
- See telehealth resources for specific populations such as tribal communities within the Health Care Coverage and Access section

# Long COVID Study Enrollment

# Innovative Support for Patients with SARS-CoV-2 Infections

A Centers for Disease Control and Prevention funded study called the Innovative Support for Patients with SARS-CoV-2 Infections (INSPIRE) will describe and increase our understanding of the longer-term effects of COVID-19 infection. Participants will be asked to describe how they are feeling by completing online surveys and sharing their medical information through a secure, confidential, cloud-based personal health platform.

Learn more about how you can be involved in INSPIRE, visit Covid Inspire

# Researching COVID to Enhance Recovery Initiative

The Researching COVID to Enhance Recovery (RECOVER) Initiative at the National Institutes of Health (NIH) is a major study to improve the understanding of and ability to predict, treat, and prevent Long COVID. RECOVER is a patient-centered study of national scale with inclusive diverse participation and community and patient engagement. It includes longitudinal observational studies across the lifespan, ancillary clinical studies leveraging cohort data and specimens, clinical trials, a patient registry, pathobiology studies, a mobile health platform, and electronic health record studies. Studies include children, adults, and pregnant people.

Learn more about how you can be involved in RECOVER, visit About the Initiative | RECOVER COVID (RecoverCOVID.org)

# **Community Services and Supports**

If you have Long COVID, you may need assistance to do things you did by yourself in the past. You also may need to make changes in your life or to your home to adapt to the changes in your abilities. Below are networks and programs that offer a wide range of services and supports to meet your needs. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges and bereavement.

#### This section includes six topics

- Community Based Services to Assist with Activities of Daily Living
- Navigation Support
- Transportation
- Assistive Technology
- Consumer Supports
- Community Economic Development.

If you need legal assistance with accessing community services, including the right to receive services in the most integrated setting under disability rights laws, you may want to review the Legal Assistance section of the *Know Your Rights* section.

#### **Not Sure Where to Start?**

Q. Looking for information about community-based supports and services that you are eligible to receive?

A. Contact the Disability Information and Access Line (DIAL). To use DIAL, call (888) 677-1199 Monday through Friday, 9:00 a.m. to 8:00 p.m. ET or email

<u>DIAL@usaginganddisability.org.</u> Learn more at <u>acl.gov/DIAL</u>.

Q. Are you an older adult or a caregiver for an older adult looking for local support resources?

**A.** Call the Eldercare Locator at 1 (800) 677-1116 or visit eldercare.acl.gov to chat live or browse resources.

# Community Based Services to Assist with Activities of Daily Living

# Access to Services in the Community

One form of discrimination prohibited by non-discrimination laws that is specific to community services is the unnecessary segregation of people with disabilities. States and local governments must provide the services and supports they offer in the most integrated setting appropriate, meaning a setting that enables people with and without disabilities to interact to the fullest extent possible. When states and local governments provide services and supports to people with Long COVID, they must offer those services in community settings, such as a

person's own home, as opposed to only in nursing facilities or other institutional settings, when doing so would not fundamentally change their program of services and supports.

Learn more about the guidance for public entities to provide services and supports to qualified individuals with disabilities in integrated settings, visit <a href="Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. (ada.gov)</a>

# Navigation Support

## Aging and Disability Resource Centers

Aging and Disability Resource Centers (ADRC) provide objective information, advice, counseling and assistance, and help people access public and private programs that assist with community living. For people with Long COVID, ADRCs can help navigate state systems of services, including determining eligibility and connecting individuals to the organizations, critical resources, and services that can help meet their needs.

Find an ADRC near you, visit <u>Eldercare Locator | Administration for Community Living</u> (eldercare.acl.gov)

# Disability Information and Access Line

Disability Information and Access Line (DIAL) provides information about community-based supports and services that people with Long COVID may be eligible for to live independently, go to school and work, and fully participate in all of life's activities.

- ➤ Learn more about DIAL, visit <u>Disability Information and Access Line | ACL Administration</u> for Community Living
- Reach DIAL at (888) 677-1199, Monday through Friday, 9:00 a.m. to 8:00 p.m. ET or email DIAL@usaginganddisability.org

#### Eldercare Locator

The Eldercare Locator is a nationwide service that connects older adults and their caregivers with trustworthy local support resources. The Eldercare Locator can provide information to help older adults and caregivers find transportation to medical appointments, make repairs or modifications to their homes, receive in-home assistance, get meals delivered to the home, and more.

Reach out to Eldercare Locator, call 1 (800) 677-1116 or visit Eldercare Locator (acl.gov) to chat live

# Family-to-Family Health Information Centers

Family-to-Family Health Information Centers (F2F) are family-staffed centers that provide critical support to families caring for children and youth with special health care needs, particularly families of children with complex needs and those from diverse communities. F2Fs help people find effective care and services, apply for Medicaid, Children's Health Insurance Program, or private insurance, get referrals to providers, address insurance denials, identify and access community support programs, advocate to ensure effective and cost-efficient care and connect with parent mentors.

Find F2Fs near you, visit Affiliate Archive - Family Voices | (familyvoices.org)

## State Health Insurance Assistance Program

State Health Insurance Assistance Program (SHIP) is a national program that offers one-on-one assistance, counseling, and education to Medicare beneficiaries, their families, and caregivers to help them make informed decisions about their care and benefits. If you have Long COVID, you may want to find out if you can reconsider your Medicare options to make sure you have the best Medicare coverage for you.

- Review your options and learn about enrollment periods, contact your local SHIP by visiting <a href="Home">Home</a> | State Health Insurance Assistance Programs (shiphelp.org)
- > Talk to a counselor, call (877) 839-2675

#### Area Agencies on Aging

Area Agencies on Aging (AAA) serve older adults (age 60 years and greater) and family caregivers. Most also serve people with disabilities. AAAs contract with 20,000+ local providers nationwide to provide services and programs that may include congregate and home-delivered meals, information and assistance, evidence-based chronic disease prevention programs, caregiver respite, case management, transportation, homemaker and chore support, and personal care.

Find your local AAA, visit <u>Eldercare Locator | Administration for Community Living</u> (<u>eldercare.acl.gov</u>) or call 1 (800) 677-1116

# **Centers for Independent Living**

Centers for Independent Living (CIL) support people of all ages with all types of disabilities and are in communities in every state and most territories. They offer, at a minimum, the following services: information and referral, independent living skills training, peer counseling, individual and systems advocacy, transition and diversion from nursing homes and other institutional settings back into the community, and transition of youth to postsecondary life.

Find a CIL near you, visit CIL Center and Association Directory | ILRU (ilru.org)

# Home and Community-Based Services

Home and Community-Based Services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a variety of targeted populations groups, such as people with intellectual or developmental disabilities, physical disabilities, or mental health disabilities. Eligibility for HCBS varies by state.

- Learn more about HCBS, visit State Resources Map | CMS
- Learn about your eligibility for Medicaid, how to apply, and other frequently asked questions, visit Medicaid & You: Frequently Asked Questions | Medicaid (medicaid.gov)

#### Tribal and Native American Grantees

Native American Elderly Service Centers provide supportive services, nutrition services, and caregiver support to native elders and their families. Age for eligibility is determined by each tribe; there are 282 grantees serving over 400 tribes. For tribal and Native American elders with Long COVID, these programs may provide case management and assistance organizing transportation. They may also help educate individuals and communities on Long COVID and the resources available to assist people with Long COVID and caregivers.

Find services in your area, visit <u>Service Locator | National Resource Center on Native</u>
American Aging (nrcnaa.org)

# **Transportation**

# Area Agencies on Aging

Area Agencies on Aging (AAA) serve older adults (age 60 and older) and family caregivers. Most also serve people with disabilities. AAAs contract with more than 20,000 local providers nationwide to provide services and programs including transportation.

Find your local AAA, visit <u>Eldercare Locator | Administration for Community Living</u> (eldercare.acl.gov) or call 1 (800) 677-1116

# Centers for Independent Living

Centers for Independent Living (CIL) support people of all ages with all types of disabilities and are in communities in every state and most territories. They offer a range of services, including assistance with transportation.

Find a local CIL, visit <u>CIL Center and Association Directory | ILRU (ilru.org)</u>

# Disability Information and Access Line

Disability Information and Access Line (DIAL) provides information about community-based supports and services that people experiencing Long COVID may be eligible for, including transportation.

- Learn more, visit <u>Disability Information and Access Line | ACL Administration for Community Living</u>
- Reach a representative, call (888) 677-1199, Monday through Friday from 9:00 a.m. to 8:00 p.m. ET or email <a href="DIAL@usaginganddisability.org">DIAL@usaginganddisability.org</a>

#### **Eldercare Locator**

The Eldercare Locator is a nationwide service that connects older adults and their caregivers with trustworthy local support resources, including transportation.

➤ Reach Eldercare, call the Eldercare Locator at 1 (800) 677-1116 or visit <u>eldercare.acl.gov</u> to chat live or browse resources

# Half or Reduced Fare, Urbanized Area Formula Grants

This program makes federal resources available to urbanized areas (population over 50,000) for public transportation, buses, commuter trains, ferries, etc. Public transportation law requires grantees receiving funding under this program to offer half fare or reduced fare to people with disabilities and older adults during off-peak hours for fixed-route services. Local transit agencies may also have a reduced fare policy for additional groups of riders such as children, students, active-duty military members, or military Veterans.

Learn more, visit <u>Understanding Half Fare/Reduced Fare Requirements | The National Aging and Disability Transportation Center (NADTC.org)</u>

# National Aging and Disability Transportation Center

National Aging and Disability Transportation Center (NADTC) serves professionals in the fields of transportation, aging, disability, human services, and caregiving. It supports the availability and accessibility of transportation options for older adults, people with disabilities, and their families to find the best transportation options in their local communities.

- Explore NADTC resources, trainings, and information, visit <u>National Aging and Disability</u> <u>Transportation Center (nadtc.org)</u>
- For technical assistance, email at <a href="mailto:contact@nadtc.org">contact@nadtc.org</a> or call at (866) 983-3222, Monday through Friday, 9:00 a.m. to 5:00 p.m. ET

# **Assistive Technology**

## State Assistive Technology Programs

State Assistive Technology (AT) programs help make AT devices and equipment and services available. Their efforts range from "low tech" (e.g., built-up handle on spoon to improve ability to grasp) to "high tech" (e.g., computers controlled with eye movement). Other examples of supports are home automation solutions and services to obtain and use devices. AT support can also include assessment, customization, repair, and training. For people with Long COVID, their state program may be able to provide them with AT, subject matter expertise, and technical assistance related to accessibility and AT.

Find a local AT program, visit <u>Find a local AT program | Assistive Technology Act</u> Technical Assistance and Training Center (at3center.net)

# Consumer Supports

# **Centers for Independent Living**

Centers for Independent Living (CIL), discussed in more detail above, support people of all ages with all types of disabilities and are in communities in every state and most territories.

Find a local CIL, visit CIL Center and Association Directory | ILRU (ilru.org)

## Area Agencies on Aging

Area Agencies on Aging (AAA), discussed in more detail above, serve older adults (age 60 and older) and family caregivers. Most also serve people with disabilities. AAAs contract with more than 20,000 local providers nationwide to provide services and programs including transportation.

Find your local AAA, visit <u>Eldercare Locator | Administration for Community Living</u> (<u>eldercare.acl.gov</u>) or call 1 (800) 677-1116

## State Long-Term Care Ombudsman Programs

State Long-Term Care Ombudsman Programs (LTCOP) advocate for people living in nursing homes, board-and-care homes, assisted living facilities, and similar facilities to resolve individual problems and to bring about changes that improve their care, quality of life, and rights. For people with Long COVID living in long-term care facilities, their ombudsman may serve as a resource to provide information on Long COVID and help if any issues arise in meeting new needs as a result of Long COVID.

- Reach a representative, call 1 (800) 677-1116
- Find an ombudsman program near you, visit Program Locator | ConsumerVoice.org

# **Community Economic Development**

# **Community Action Agencies**

A network of Community Action Agencies (CAA) throughout the United States connects people to greater opportunities and could be a good resource for people with Long COVID. CAAs are the frontline resource for people living in poverty, providing education, employment and family support services for families with low incomes. Community Action Agencies also promote community economic development through community partnerships and collaborations that enhance business development and create jobs.

- Learn more about Community Action Partnership, visit National CAP | Community Action (communityactionpartnership.com)
- Find a CAA near you, visit <u>Find A CAP | National CAP (communityactionpartnership.com)</u> or call (202) 265-7546

# **Income and Financial Assistance**

People experiencing Long COVID may need financial assistance due to lost wages or unemployment. There are federal programs to help you address financial difficulties that are the result of Long COVID. In addition, some of the resources may also support individuals, their families and caregivers are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges and bereavement. Individuals who lost income due to the loss of a loved one my also find assistance from these federal supports.

#### This section covers five topics

- Disability and Survivor Benefits
- Unemployment Benefits
- Tax Credits
- Retirement Benefits
- Assistance Programs for Families with Children.

If you need help applying for financial assistance, or have applied for financial assistance and been denied, you may want to review the Legal Assistance section in the *Know Your Rights* section.

# Disability and Survivor Benefits

# Social Security Disability Insurance

The Social Security Disability Insurance (SSDI) program provides assistance to people who are disabled under the Social Security Act. The SSDI program may pay benefits to you and certain family members if you are "insured." This means that you worked long enough—and recently enough—and paid Social Security taxes on your earnings. To be eligible for SSDI you also have to meet the program requirements to be found disabled, which may be different from the requirements to be considered disabled under the ADA. If you meet the requirements, monthly benefits are paid if you have a medical condition that prevents you from working and is expected to last at least one year or result in death.

Learn about the SSDI program and apply online, visit <u>Disability Benefits | (ssa.gov)</u>

# **Not Sure Where to Start?**

- Q. Lost your job and want to know whether you are eligible for unemployment benefits?
- A. Find out about the programs in your state by visiting

  <u>Unemployment Benefits Finder</u>
  | CareerOneStop.org
- Q. Does your family need some financial assistance since you were diagnosed with Long COVID?
- A. Find out if your family is eligible to participate in the Temporary Assistance for Needy Families (TANF) by contacting a program in your area by visiting Help for Families | The Administration for Children and Families (hhs.gov)

- Make an appointment to file your application, call 1 (800) 772-1213 and 1 (800) 325-0778 (TTY)
- Find a Social Security Office near you, visit Social Security/SSA Office Locator I (ssa.gov)

# Supplemental Security Income

The Supplemental Security Income (SSI) program pays benefits to adults and children with disabilities who have limited income and resources. Like the SSDI program, the SSI program can provide assistance to people who qualify as disabled due to a medical condition like COVID-19, if it results in functional limitations that prevent a person from working. The SSI program provides assistance to some people who are disabled under the Social Security Act, which may be different from the requirements to be considered disabled under the ADA. Unlike SSDI, for a person to receive SSI, they also must have limited limited income and resources. SSI payments are also made to people age 65 and older without disabilities who meet the financial qualifications. You may be eligible to receive monthly SSI payments even if you are receive SSDI or retirement benefits.

- Learn more about the SSI program or apply online, visit <u>Supplemental Security Income (ssa.gov)</u>
- Make an appointment to complete your application and call 1 (800) 772-1213 and 1 (800) 325-0778 (TTY)
- Find a Social Security Office near you, visit Social Security/SSA Office Locator | (ssa.gov)

# **Survivors Benefits**

If someone in your family dies from for any reason, including from a medical impairment such as COVID-19, you may be entitled to Survivors Benefits. If the deceased individual was employed and paid into Social Security, then their spouse, children, and parents could be eligible for benefits based on their earnings.

- Learn more about Survivors Benefits, visit Survivors Benefits | SSA (ssa.gov)
- Make an appointment to complete your application, call 1 (800) 772-1213 and 1 (800) 325-0778 (TTY)
- Find a Social Security Office near you, visit <u>Social Security/SSA Office Locator | SSA (ssa.gov)</u>

# **Unemployment Benefits**

# **Unemployment Insurance Programs**

- Unemployment Insurance provides unemployment benefits, usually in the form of weekly payments, to eligible workers who become unemployed through no fault of their own and meet certain other eligibility requirements. Unemployment Insurance is administered by the states. Each state develops their own system for delivering benefits. Find more information and check your eligibility, visit <a href="Unemployment Unemployment Unsurance I U.S. Department of Labor">Unemployment Unsurance I U.S. Department of Labor</a> (dol.gov)
- Find information about your state's Unemployment Insurance opportunities, visit Unemployment Benefits Finder | CareerOneStop.org

# **Extended Unemployment Benefits**

Extended Benefits are available during periods of elevated unemployment to workers who have exhausted regular unemployment insurance benefits. The basic Extended Benefits program provides up to 13 additional weeks of benefits. Some states have also enacted a voluntary program to pay up to seven additional weeks (20 weeks maximum) of Extended Benefits during periods of extremely high unemployment. Contact your state's Unemployment Insurance Agency to ask whether your state supports an Extended Unemployment Benefits program.

➤ To find Extended Unemployment Benefits program contact information for your state, visit <u>Unemployment Benefits Finder | CareerOneStop.org</u>

# Unemployment Compensation for Ex-Service Members Program

The Unemployment Compensation for Ex-Service members (UCX) Program provides unemployment compensation benefits to individuals transitioning from military service to the civilian labor market.

Contact your state's Unemployment Insurance Agency to ask about UCX program in your state, visit <u>Unemployment Benefits Finder | CareerOneStop.org</u>

# Unemployment Compensation for Federal Employees Program

The Unemployment Compensation for Federal Employees (UCFE) program provides unemployment compensation for federal employees who lost their employment through no fault of their own. In general, the unemployment insurance law of the state in which the former federal employee had his or her last official duty station in federal civilian service will be used to determine eligibility for UCFE benefits.

Contact your state's Unemployment Insurance Agency to ask about UCFE program in your state, visit Unemployment Benefits Finder | CareerOneStop.org

## Workers' Compensation for Federal Employees

The Federal Employees' Compensation Act (FECA) covers injury in the performance of duty; injury includes COVID-19 proximately caused by federal employment. The FECA provides medical benefits and compensation for disability or death of an employee who is diagnosed with COVID-19 while in the performance of duty. Coverage is extended for Long COVID if it develops as the result of the initial, work-related COVID-19 infection. Further, the American Rescue Plan Act of 2021 (ARPA) has made it much easier for federal workers diagnosed with COVID-19 to establish coverage under the FECA.

➤ Learn more about filing a claim, visit <u>Claims under the Federal Employees'</u> Compensation Act due to COVID-19 | U.S. Department of Labor (dol.gov)

# **Employer-Sponsored Insurance**

The Employee Benefits Security Administration (EBSA) provides answers to your questions and assists you if you believe you have been inappropriately denied employee benefits, including a retirement, disability, or other employee benefit. They can help answer questions on issues such as denied health or disability benefits, COBRA, or plan administration and compliance.

- Reach a Benefits Advisor, visit <u>Ask EBSA | U.S. Department of Labor (dol.gov)</u>
- ➤ Speak to a Benefits Advisor, call (866) 444-3272; Dial 7-1-1 to access telecommunications relay services

#### Tax Credits

#### Earned Income Tax Credit

The Earned Income Tax Credit, sometimes called EITC, is a tax credit for workers with low to moderate income. Eligibility for the tax credit is based on various factors including family size, IRS filing status, and income.

- For more information on EITC, visit EITC | IRS (irs.gov)
- To check your eligibility, visit Use the EITC Assistant | (irs.gov)

# **Retirement Benefits**

# Social Security Retirement for Workers and Some Dependents

When you reach age 62 years, you may be eligible to start receiving monthly Social Security benefits. The age you begin receiving your retirement benefit affects how much your monthly benefits will be for as long as you receive benefits. The longer you wait to begin receiving benefits, the higher your monthly benefit amount will be.

- Learn more and apply online, visit Retirement Benefits | SSA (ssa.gov)
- ➤ To talk with a Social Security Administration (SSA) representative about your eligibility or to apply by phone, call 1 (800) 772-1213 and 1 (800) 325-0778 (TTY), Monday through Friday, 8:00 a.m. to 7:00 p.m. local time
- Find a local Social Security office, visit Social Security/SSA Office Locator | (ssa.gov)

# Assistance Programs for Families with Children

# Temporary Assistance for Needy Families

The Temporary Assistance for Needy Families (TANF) program provides states, territories, and tribes with funds to operate programs designed to help families with lower incomes and children achieve economic self-sufficiency. The program provides monthly cash assistance payments to families with lower incomes and children, as well as a wide range of services.

- Find more information regarding the TANF program, visit <u>TANF | The Administration for Children and Families (acf.hhs.gov)</u>
- Find information about your state's TANF program, visit <u>Help for Families | The Administration for Children and Families (acf.hhs.gov)</u>

# **Job Assistance**

People experiencing Long COVID may need accommodations in the workplace or assistance with finding a new job. There are federal programs to help you address job-related needs—whether in your search for a new job or issues dealing with your current job/employer—that are the result of Long COVID. In addition, some of the resources may also support individuals, their families and caregivers are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges, and bereavement. Individuals who are newly seeking employment due to the loss of a loved one my find assistance through these federal supports and services.

Topics covered in this section include

- Workplace Accommodations
- Job Training and Reemployment Assistance
- Support for Employers.

If you need legal assistance in getting workplace accommodations due to Long COVID or because you have faced discrimination in the workplace, you may want to review the Legal Assistance section of the *Know Your Rights* section, in addition to the information below.

# **Workplace Accommodations**

# Workplace Accommodations under the Americans with Disabilities Act

Long COVID can be a disability under the Americans with Disabilities Act (ADA) and Sections 501 and 504 of the

Rehabilitation Act of 1973, if it substantially limits one or more major life activities. The ADA prohibits employers from discriminating on the basis of disability. It also requires employers to make reasonable accommodations, unless doing so would cause significant difficulty or expense for the employer. A reasonable accommodation is any change in the work environment (or in the way things are usually done) to help a person with a disability apply for a job, perform the duties of a job, or enjoy the benefits and privileges of employment. For example, reasonable accommodations may include

#### **Not Sure Where to Start?**

# Q. Need accommodations to perform your job since being diagnosed with Long COVID?

A. Contact the Job Accommodations Network (JAN). JAN is a free service that provides confidential guidance to individuals regarding job accommodations and disability employment issues.

For more information contact JAN at 1 (800) 526-7234 (VOICE) and 1 (877) 781-9403 (TTY)

You can also reach JAN via online chat, email or JAN on Demand by visiting <u>Information</u>
<u>By Role (askjan.org)</u>

# Q. Recently unemployed and unsure of what benefits you may be entitled to?

A. Find unemployment programs and benefits in your state by visiting <u>Unemployment Benefits Finder |</u>
CareerOneStop

job restructuring, part-time or modified work schedules, telework, exceptions to workplace policies, or reassignment to a vacant position.

- Learn more about your rights and the types of accommodations available to individuals with Long COVID, visit What You Should Know About COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws | U.S. Equal Employment Opportunity Commission (eeoc.gov)
- For more information on COVID-19 and the ADA, visit: <a href="COVID-19">COVID-19</a> and the Americans with Disabilities Act | Beta.ADA.gov
- Learn about your rights, visit <a href="Home">Home</a> | U.S. Equal Employment Opportunity Commission (eeoc.gov), or call 1 (800) 669-4000 (voice) and 1 (800) 669-6820 (TTY), or (844) 234-5122 (ASL Video Phone)

#### Job Accommodation Network

Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on job accommodations and disability employment issues. Serving customers for more than 35 years, JAN provides individualized consultation to assist

- Employers and their representatives seeking guidance on practical ways to engage in the interactive process, provide job accommodation solutions, and comply with Title I of the ADA
- Individuals with medical conditions and disabilities seeking information about job accommodation solutions, employment rights under the ADA, and self-employment and entrepreneurship opportunities
- Family members and rehabilitation, medical, educational, and other professionals in their effort to support successful employment outcomes for individuals with medical conditions and disabilities.
- Find more information, call JAN at 1 (800) 526-7234 (voice) and 1 (877) 781-9403 (TTY)
- Reach a representative by phone, live chat, or email, visit <u>Information By Role</u> (<u>askjan.org</u>)

#### Ticket to Work

Social Security's Ticket to Work (Ticket) Program supports career development for people ages 18 through 64 who receive SSDI or SSI and want to work. The Ticket Program is free. It helps people with disabilities move toward financial independence and connects them with the services and support they need to succeed in the workforce.

- ➤ Learn more about achieving your work goals, identifying providers, services, and job resources, visit Find Help Ticket to Work Social Security (ssa.gov)
- > Speak to a representative, call the Ticket to Work Help Line at 1 (866) 968-7842 and 1 (866) 833-2967 (TTY), Monday through Friday, 8:00 a.m. to 8:00 p.m. ET
- ➤ Reach the helpline and email support@choosework.ssa.gov

#### Vocational Rehabilitation

The State Vocational Rehabilitation (VR) Services Program, funded by the Rehabilitation Services Administration in the Department of Education, provides employment-related services for individuals with disabilities so that they may prepare for and engage in competitive, integrated, and gainful employment that is consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. To be eligible for the VR program, individuals must have a physical or mental impairment, which can include Long COVID, that results in a substantial impediment to employment and who require and can benefit from VR services to achieve employment and maximize career goals.

- To learn more about the State Vocational Rehabilitation Services Program in your state, visit RSA State Vocational Rehabilitation Service Agencies (rsa.ed.gov/about/states)
- ➤ To learn more about other vocational rehabilitation programs, visit <u>Rehabilitation</u> Services Administration (rsa.ed.gov)

## Protection and Advocacy for Beneficiaries of Social Security

The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program serves people with disabilities who receive SSDI or SSI who want to work by helping to remove barriers to employment. PABSS staff help recipients understand and secure employment protections. They provide legal representation when needed.

➤ If you get disability benefits, call the Ticket to Work Help Line for PABSS contact information at 1 (866) 968-7842 and 1 (866) 833-2967 (TTY), Monday through Friday, 8:00 a.m.to 8:00 p.m. ET

# Job Training and Employment Assistance

# Comprehensive American Job Centers

There are nearly 2,400 American Job Centers located throughout the United States that provide free help and training to job seekers for a variety of career and employment-related needs. Many have special programs to accommodate the needs of individuals experiencing Long COVID.

Find a Comprehensive American Job Center near you, visit <u>American Job Center Finder | CareerOneStop.org</u>

# Self-Employment Assistance Program

Some states offer the Self-Employment Assistance (SEA) program. SEA programs provide qualifying dislocated workers the opportunity for early re-employment through self-employment. The program is designed to encourage and enable unemployed workers to create their own jobs by starting their own small businesses. States operating an SEA program can pay participants a weekly allowance while they are getting their businesses off the ground.

Find SEA program contact information for your state, visit <u>Unemployment Benefits</u>
<u>Finder | CareerOneStop.org</u>

## Work Incentives Planning and Assistance

Social Security's Ticket to Work (Ticket) Work Incentives Planning and Assistance (WIPA) projects provide free benefits counseling to help people receiving disability benefits make informed choices about work. Trained Community Work Incentive Coordinators provide personalized counseling about services and supports and explain how working may affect benefits. More than 70 organizations provide these services.

Learn more about WIPA, call the Ticket to Work Help Line at 1 (866) 968-7842 and 1 (866) 833-2967 (TTY), Monday through Friday, 8:00 a.m.to 8:00 p.m. ET

# Reemployment Services and Eligibility Assessment Program

This program is for unemployment compensation claimants determined to be most likely to exhaust benefits and former U.S. military service members receiving unemployment compensation for the Ex-Service Members Program. In some states, this service is also open to other unemployment claimants. The program is administered by the states, and not all states support this program. The foundational element of the Reemployment Services and Eligibility Assessment (RESEA) Program is an in-person meeting between the claimant and a trained employment specialist.

Find RESEA program contact information for your state, visit <u>Unemployment Benefits</u>
<u>Finder | CareerOneStop.org</u>

# Support for Employers

# The Employer Assistance and Resource Network on Disability Inclusion

The Employer Assistance and Resource Network on Disability Inclusion (EARN) offers information and resources to help employers recruit, hire, retain and advance people with disabilities. It helps employers build inclusive workplace cultures and meet diversity, equity, inclusion and accessibility goals.

Find more information about EARN and additional resources, visit <a href="Employer Assistance">Employer Assistance</a> and Resource Network on Disability Inclusion | (AskEARN.org)

# Community Economic Development

Community Economic Development (CED) is a federal grant program funding Community Development Corporations that address the economic needs of low-income individuals and families through the creation of sustainable business development and employment opportunities. CED awards funds to private, non-profit organizations Community Development Corporations, including faith-based organizations and Tribal and Alaskan Native organizations. CED-funded projects create or expand businesses, create new jobs for individuals with low incomes, and leverage funding investments in communities.

Find more information about CED, visit Community Economic Development (CED) | Administration for Children and Families (acf.hhs.gov) or call the Office of Community Services at (202) 401-9333

# Housing

Individuals experiencing Long COVID may need financial assistance to maintain their home or housing assistance to find affordable housing. If you are experiencing housing insecurity due to the loss of a loved one from COVID, then you may have options through federal supports. Several federal programs are available that can help. This section covers five topics

- Fair Housing Act
- Assistance for Renters
- Assistance for Homeowners
- Affordable Housing Programs
- Utilities Assistance.

If you are facing eviction because you could not pay your rent or need other legal assistance related to housing benefits, you may want to review the Legal Assistance section in the *Know Your Rights* section.

# Fair Housing Act

The Fair Housing Act protects people, including people with disabilities such as Long COVID, from discrimination when they are renting or buying a home, getting a mortgage, seeking housing assistance, or engaging in other housing-related activities. Additional protections apply to federally-assisted housing.

- ➤ Do you have a question? Contact the Department of Housing and Urban Development Office of Fair Housing and Equal Opportunity (FHEO) intake specialist by calling 1 (800) 669-9777 or 1 (800) 877-8339.
- Would you like more information about filing a complaint? Visit <u>How to File a Complaint | U.S.</u> <u>Department of Housing and Urban Development</u> <u>FHEO (hud.gov)</u>

#### **Not Sure Where to Start?**

# Q. Worried about falling behind on rent for your home?

**A.** Find emergency rental assistance programs in your area by visiting <u>Find Help with Rent and Utilities | Consumer Financial Protection Bureau</u> (ConsumerFinance.gov).

Visit the HUD Housing
Counseling Office at Office of
Housing Counseling | HUD.gov /
U.S. Department of Housing and
Urban Development (HUD)

You can also visit the Office of Fair Housing and Equal Opportunity to File a Complaint — Main Page | HUD.gov / U.S. Department of Housing and Urban Development (HUD)

# Q. Are you homeless or have you recently lost your home?

A. Reach out to the Housing Authority in your state at PHA Contact Information - HUD | HUD.gov / U.S. Department of Housing and Urban Development (HUD).

Find Homeless Assistance programs in your area by visiting Need Homeless
Assistance? - HUD Exchange.

# **Assistance for Renters**

## **Emergency Rental Assistance Program**

State and local organizations can help landlords and renters struggling to keep up with rent and other bills. Many programs take applications from both landlords and renters.

Find rental assistance program in your area, visit <u>Find Help with Rent and Utilities |</u>
Consumer Financial Protection Bureau (ConsumerFinance.gov)

If you are facing eviction because you could not pay your rent, you may want to review the Legal Assistance section in the *Know Your Rights* section.

# Assistance for Homeowners

#### Homeowner Assistance Fund

The purpose of the Homeowner Assistance Fund (HAF) is to prevent homeowners from losing their homes due to mortgage delinquencies, foreclosures, loss of utilities or home energy services, and displacement of homeowners experiencing financial hardship after January 21, 2020. Funds from the HAF may be used for assistance with mortgage payments, homeowner's insurance, utility payments, and other specified purposes.

- Find out if you are eligible for HAF, visit <u>Help for Homeowners | Consumer Financial</u>

  <u>Protection Bureau ConsumerFinance.gov</u>
- Find a HAF program in your state or tribal community, visit <a href="Homeowner Assistance Fund">Homeowner Assistance Fund</a>
  National Council of State Housing Agencies (ncsha.org)

# Rural Housing Repair Loans and Grants

The Rural Housing Repair Loans and Grants program provides loans and grants to very low-income homeowners to repair, improve, modernize, or to remove health and safety hazards in their rural dwellings. Grants may be arranged for recipients who are 62 years and older and can be used only to pay for repairs and improvements to remove health and safety hazards.

- Find information about the Rural Housing Repair Loans program, visit Single Family Housing Repair Loans Grants | U.S. Department of Agriculture Rural Development (rd.usda.gov) or call the USDA Information Hotline (202) 720-2791
- > Apply for a loan or grant, visit <u>USDA Service Center Agencies eForms</u> (forms.sc.egov.usda.gov)
- Contact your state's Rural Development field office, visit <u>USDA Service Centers Locator</u> (offices.sc.egov.usda.gov/locator/app)

# Affordable Housing Programs

# **Housing Voucher Programs**

HUD has several voucher programs, which provide ongoing rental assistance to eligible households, including ones targeted to people with disabilities, older adults, and Veterans, to help them access affordable housing.

- Find information on housing choice voucher programs, visit <a href="HCV Programs and Unitiatives">HCV Programs and Unitiatives</a> | HUD.gov / U.S. Department of Housing and Urban Development (HUD)
- Learn more about voucher options from public housing agencies in your state, territory or tribal community, visit <a href="PHA Contact Information">PHA Contact Information</a> | U.S. Department of Housing and Urban Development (HUD.gov)

## Homelessness Assistance Programs

Homelessness assistance programs provide funding to states and local governments and nonprofit providers to serve individuals and families who are affected by homelessness.

- Learn more about homelessness assistance programs in your area, visit Need Homeless Assistance? HUD Exchange
- Find resources about homelessness assistance programs, visit <a href="Homelessness Resources">Homelessness Resources</a> and Programs | HHS.gov

# **Public Housing**

Public housing was established to provide decent and safe rental housing for eligible low-income families, the elderly, and persons with disabilities. Local housing authorities operate public housing in all sizes and types, from scattered single-family houses to high rise apartments for elderly families.

- ➤ Learn more about public housing, visit <u>HUD's Public Housing Program | U.S. Department of Housing and Urban Development (HUD.gov)</u>
- ➤ Learn more about public housing in your state, territory or tribal community, visit <a href="PHA">PHA</a>
  Contact Information | U.S. Department of Housing and Urban Development (HUD.gov)
- ➤ Find contact information for the Housing and Urban Development field offices, visit Local Offices | HUD.gov / U.S. Department of Housing and Urban Development (HUD)Local Offices | U.S. Department of Housing and Urban Development (HUD.gov)

# **Assisted Multifamily Housing**

Private owners of multifamily developments offer housing at assisted rents under contract with HUD. Some types of developments are designed to serve older people or individuals with disabilities and offer service coordinators.

- Learn more about private assisted multifamily housing: <u>Rental Assistance | U.S.</u>
  Department of Housing and Urban Development (hud.gov)
- ➤ Search for an assisted multifamily apartment: <u>Resource Locator | U.S. Department of</u> Housing and Urban Development (resources.hud.gov)

#### Utilities Assistance

## Low Income Home Energy Assistance Program

The Low Income Home Energy Assistance Program (LIHEAP) assist families with energy costs. The program provides federally funded assistance in managing costs associated with home energy bills, energy crises, weatherization, and energy-related minor home repairs.

- Find information about LIHEAP programs in your state or territory, visit <u>LIHEAP Map State and Territory Contact Listing</u> | The Administration for Children and Families (hhs.gov)
- Find information about LIHEAP programs in your tribal community, visit <u>LIHEAP Map</u>
  Tribal Contact Listing | The Administration for Children and Families (hhs.gov)
- Reach a representative, call the National Energy Assistance Referral (NEAR) hotline at 1 (866) 674-6327

# Low Income Household Water Assistance Program

Low Income Household Water Assistance Program (LIHWAP) provides funds to assist households that are behind in paying their water or wastewater bills. States, territories and tribes administer the program.

- Learn more about the LIHWAP program, visit <u>LIHWAP | The Administration for Children and Families (hhs.gov)</u>
- Find information about LIHWAP programs in your state or territory, visit <u>LIHWAP Map State and Territory Contact Listing | The Administration for Children and Families (hhs.gov)</u>
- Find information about LIHWAP programs in your tribal community, visit <u>LIHWAP Tribal</u> Contact Listing | The Administration for Children and Families (hhs.gov)

# **Food and Nutrition Support**

People with Long COVID may be unable to continue to work and earn money, putting them at risk of being unable to afford food or getting enough nutrition for themselves and their families. If you or your immediate family members need help purchasing food, there are several federal programs that can help you put nutritious food on your family's table. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges and bereavement. Individuals who may be experiencing food insecurity due to the loss of loved one may also find assistance through these federal supports and services. This section covers three topics

- Child and Family Nutrition Programs
- Food Distribution Programs
- Nutrition Program for Seniors.

If you are found ineligible for food assistance programs like SNAP, or if your SNAP benefits are being reduced or discontinued, you may want to review the Legal Assistance section of the *Know Your Rights* section.

# **Child and Family Nutrition Programs**

# National School Lunch Program

The National School Lunch Program (NSLP) is a federally assisted meal program operating in public and nonprofit private schools and residential child care institutions. It provides nutritionally balanced, low-cost or free lunches to children each school day.

Find information about the nutrition programs in your state, visit Contact Map | Food and Nutrition Service (usda.gov)

# Special Supplemental Nutrition Program for Women, Infants, and Children

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides federal grants to states for supplemental foods, health care referrals, and nutrition education for women with lower incomes, pregnant, breastfeeding, and non-breastfeeding postpartum

#### **Not Sure Where to Start?**

# Q. Concerned about being able to feed your family?

**A.** Find emergency food distribution programs in your area Contact Map | Food and Nutrition Service (usda.gov).

Q. Wondering if you are eligible for the Supplemental Nutrition Assistance Program (SNAP) which can help you purchase healthy foods for your family?

**A.** Find your local SNAP office and talk to them about whether you are eligible <u>SNAP State</u> <u>Directory of Resources | Food</u> and Nutrition Service (usda.gov)

individuals, and to infants and children up to age five years who are found to be at nutritional risk.

- Find information and to learn how to apply, visit <u>Special Supplemental Nutrition</u> <u>Program for Women, Infants, and Children (WIC) | Food and Nutrition Service</u> (usda.gov)
- Learn more about programs in your state, visit <a href="Special Supplemental Nutrition Program for Women">Special Supplemental Nutrition Program for Women</a>, Infants, and Children (WIC) | Food and Nutrition Service (usda.gov)

## Supplemental Nutrition Assistance Program

Supplemental Nutrition Assistance Program (SNAP) provides nutrition benefits to supplement the food budget of families with low incomes so they can purchase healthy food and move towards self-sufficiency. Most SNAP eligibility rules apply to all households, but there are some special rules for households with members who are older or have a disability, including those that experience disability due to Long COVID. For people with disabilities or older adults, allowable medical costs that are more than \$35 a month may be deducted unless an insurance company or someone who is not a household member pays for them.

- Learn about the SNAP rules for individuals with disabilities and older adults, visit <a href="SNAP">SNAP</a> Special Rules for the Elderly or Disabled | Food and Nutrition Service (usda.gov)
- Find your local SNAP office, visit <u>SNAP State Directory of Resources | Food and Nutrition Service (usda.gov)</u>

# Food Distribution Programs

## **Emergency Food Assistance Program**

The Emergency Food Assistance Program (TEFAP) is a federal program that helps supplement the diets of Americans with low incomes by providing them with emergency food assistance at no cost.

- Find more information about TEFAP, visit <a href="https://example.com/">The Emergency Food Assistance Program |
  Food and Nutrition Service (usda.gov)</a>
- Find information about the nutrition programs in your state, visit <u>Contact Map | Food and Nutrition Service (usda.gov)</u>

# Emergency Food and Shelter Program

## Food Distribution Program on Indian Reservations

The Food Distribution Program on Indian Reservations (FDPIR) provides USDA Foods to incomeeligible households living on Indian reservations and to Native American households residing in designated areas near reservations or in Oklahoma. The program supplements and expands the ongoing work of local nonprofit and governmental social service organizations to provide shelter, food, and supportive services to individuals and families who are experiencing, or at risk of experiencing hunger and homelessness.

- Find more information about FDPIR, visit <u>Food Distribution Program on Indian</u> Reservations | Food and Nutrition Service (usda.gov)
- Learn more about eligibility contact your state or tribal organization, visit Contact Map | Food and Nutrition Service (usda.gov)
- Contact USDA by emailing <u>USDAFoods@usda.gov</u>

# **Nutrition Program for Older Adults**

# Senior Nutrition Program

Older adults (age 60 and older) and in some cases, their caregivers, spouses and persons with disabilities may be eligible for certain nutrition programs. The services include both homedelivered meals and healthy meals served in group settings, such as senior centers and faithbased locations. In addition, the programs provide a range of services including nutrition screening, assessment, education, and counseling. Nutrition services also provide an important link to other supportive in-home and community-based supports, such as homemaker, chore and home-health aide services, transportation, physical activity and chronic disease selfmanagement programs, home repair and modification, and falls prevention programs.

- ➤ Learn about elder care programs in your area and to participate in an online chat with an information specialist, visit <u>Eldercare Locator | Administration for Community Living</u> (eldercare.acl.gov)
- Talk with a specialist, call 1 (800) 677-1116, Monday through Friday, 9:00 a.m. to 8:00 p.m. ET
- Learn more about the program by emailing eldercarelocator@n4a.org

# Child Care and Early Childhood Development and Education

Individuals experiencing Long COVID may need assistance with childcare or preschool. In addition, young children with Long COVID might need services, supports or accommodations. Several federal programs are available that may be able to help you. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges, and bereavement. Individuals who may need additional assistance due to the loss of a caregiver may also find assistance through these supports and services. This section covers three topics

- Child Care
- Early Childhood Development and Education
- Tax Credits.

If you need legal assistance with child care or early childhood benefits, you may want to review the Legal Assistance section of the *Know Your Rights* section.

#### Child Care

# Child Care Financial Assistance Options

#### **Not Sure Where to Start?**

# Q. Worried about paying for child care?

A. To find out more about child care financial assistance resources in your state, visit See Your State's Resources |
Childcare.gov

Q. Worried about finding affordable learning opportunities for your preschool age children?

**A.** Reach out to the Head Start Programs and check your eligibility

Call 1 (866) 763-6481, Monday through Friday, 8:00 a.m. to 6:00 p.m. ET.

Visit How to Apply | ECLKC (hhs.gov)

Several federal funding sources are available to help pay for child care. These programs are intended to help eligible working families with low incomes access child care and improve the quality of child care for all children. Subsidized child care services are available to eligible families through certificates (vouchers) or grants and contracts with providers. The Child Care and Development Fund (CCDF) also improves the quality of care to promote children's healthy development and learning by supporting child care licensing, quality improvement systems to help programs meet higher standards, and training and education for child care workers.

Find out more about CCDF resources in your state, visit <u>See Your State's Resources</u> <u>Childcare.gov</u>

# Early Childhood Development and Education

# Head Start and Early Head Start Programs

Head Start and Early Head Start programs provide families with free learning and development services for their children ages birth to five years. Head Start programs must ensure that at least 10 percent of children enrolled are Individuals with Disabilities Education Act eligible children with disabilities, which may include children with Long COVID. Some Early Head Start programs also provide prenatal services for pregnant people. Families qualify for the Head Start program if their household income is at or below the poverty level. Families who receive public assistance (TANF, SSI, or SNAP), those with children in foster care, or children who are homeless also qualify regardless of income.

- Find more information about Head Start and Early Head Start Programs, visit <u>Frequently</u> Asked Questions About Head Start | ECLKC (hhs.gov)
- Check to see if your family qualifies, visit Poverty Guidelines | ASPE (hhs.gov)
- Find a Head Start program near your home, call 1 (866) 763-6481, Monday through Friday, 8:00 a.m. to 6:00 p.m. ET or visit How to Apply | ECLKC (hhs.gov)

#### Tax Credits

# The Child and Dependent Care Credit

The Child and Dependent Care Credit is a tax credit that may help families pay for the care of eligible children and other dependents, referred to as "qualifying persons." The credit is calculated based on income and a percentage of expenses that you incur for the care of qualifying persons (e.g., childcare, day treatment, in home care), to enable you to go to work, look for work, or attend school.

For more information visit <u>Child and Dependent Care Credit FAQs | Internal Revenue Service (irs.gov)</u>

#### The Child Tax Credit

The Child Tax Credit provides money to support American families—helping them make ends meet, more easily afford the costs of raising children, or save for their children's future. On March 11, 2021, President Biden signed into law the American Rescue Plan Act, expanding the Child Tax Credit for 2021 and providing additional tax relief to the vast majority of families.

- For more information and to check your eligibility visit <a href="Child Tax Credit">Child Tax Credit</a> Internal Revenue Service (irs.gov)
- For 2021 visit The 2021 Child Tax Credit | Information About Payments & Eligibility

# **Education Supports**

Students with Long COVID may need supports, services and accommodations to succeed in school. They also are protected against discrimination by federal law. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges, and bereavement. This section covers four topics

- The Americans with Disabilities Act
- Section 504 of the Rehabilitation Act
- Special Education under the Individuals with Disabilities Education
- Higher Education.

# Laws Related to Students with Disabilities, including Long COVID

Long COVID can be a disability under the Americans with

Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Individuals with Disabilities Education Act (IDEA). These laws collectively require covered entities to provide services, supports and accommodations to students with disabilities. You may want to review the *Know Your Rights* section for more information.

In addition to the resources in that section, there are other resources that specifically help students with disabilities, including Long COVID.

- Department of Education's Office for Civil Rights and Office of Special Education and Rehabilitative Services "Long COVID under Section 504 and the IDEA: A Resource to Support Children, Students, Educators, Schools, Service Providers, and Families"
- > The Department of Education's Office for Civil Rights enforces civil rights laws on behalf of students, including students with disabilities.
- ➢ If you believe your student has faced discrimination at school, including on the basis of disability, you can file a complaint with the Department of Education's OCR How to File a Discrimination Complaint with the Office for Civil Rights (ed.gov), or the Department of Justice's Civil Rights Division and Contact the Civil Rights Division | Department of Justice.

#### **Not Sure Where to Start?**

Q. Do you need more information about education supports for someone, age birth to 26 years, with Long COVID?

**A.** Find your Parent Center by visiting Find Your Center | (ParentCenterHub.org)

Q. Do you need an advocate or attorney to assist with accessing services, supports or accommodations?

**A.** Connect with a Protection & Advocacy System by visiting Member Agencies | NDRN

# Section 504 of the Rehabilitation Act of 1973

Section 504 prohibits discrimination based on disability in any program or activity operated by recipients of federal funds. Section 504 requires programs to provide students with disabilities ages 3 to 22 years equal access to the program, including by making reasonable accommodations and modifications.

Find out more and learn how to file a complaint, visit Office for Civil Rights | U.S. Department of Education (ed.gov) and Civil Division | U.S. Department of Justice (ada.gov)

#### The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities in everyday activities. The ADA applies to public schools and certain private schools.

Find out more and learn how to file a complaint, visit Office for Civil Rights | U.S. Department of Education (ed.gov) and Civil Division | U.S. Department of Justice (ada.gov)

#### Special Education Services under the Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) is a federal civil rights law that makes available a free appropriate public education (FAPE) to eligible children with disabilities from ages birth to 21 years throughout the nation and ensures special education and related services to those children. Parents and caregivers who suspect their child may need special education services should contact their local public school and request an evaluation to determine eligibility.

Find more information about IDEA, visit the <u>IDEA website | U.S. Department of Education (sites.ed.gov/idea)</u>

# Parent Training and Information Centers

Parent Training and Information Centers (PTI) work with families of infants, toddlers, children, and youth with disabilities, including those experiencing Long COVID, from ages birth to 26 years. PTIs help parents participate effectively in their children's education and development and partner with professionals and policy makers to improve outcomes for all children with disabilities.

Find your Parent Center listed alphabetically by state or U.S. Territory, visit <u>Find Your Center | ParentCenterHub.org</u>

# Branch—Military Families Technical Assistance Center

The Branch—Military Families Technical Assistance Center provides resources for military families of children and youth with disabilities, as well as young adults between ages 18 to 26 years who have a disability and who grew up in a military family.

Learn more about the Branch program, visit <u>Home - Military Parent Technical Assistance</u> <u>Center (branchta.org)</u>

# Charting the Lifecourse ™& Charting the LifeCourse Nexus

Charting the Lifecourse™ helps students with disabilities, including those experiencing Long COVID, families, caregivers, and those who support them organize their ideas, vision, and goals, as well as problem-solve, navigate, and advocate for supports, including primary medical care, behavioral health care (mental health and substance use challenges), health education, case management, and nutrition education. The LifeCourse Nexus provides workshops and technical assistance to shape and support innovation in policy, practice, procedure, and culture, including around school-based supports for children with Long COVID.

Learn more about LifeCourse, visit <u>LifeCourse Nexus – Exchange Knowledge | Build</u> Capacity | Engage Collaboratively (lifecoursetools.com)

## 4-H

Funded by the Department of Agriculture, 4-H is delivered by Cooperative Extension—a community of more than 100 public universities across the nation that provides experiences where young people learn by doing. Individuals with Long COVID may benefit from these programs. 4-H programs and resources are available at home or through local in-person and virtual 4-H clubs, 4-H camps, in-school and after-school programs. With the support of adult mentors, youth select from a menu of hands-on project ideas to complete. 4-H programs are available for kids and teens ages 8 to 18 years. 4-H Cloverbud programs are available for children ages five to seven years.

Find your local 4-H program, visit Find Your Local 4-H | 4-H

# Higher Education

Colleges and universities are required by Section 504 and the ADA to provide students with disabilities with appropriate academic adjustments and auxiliary aids and services that are necessary to afford an individual with a disability an equal opportunity to participate in the school's program. An example of an academic adjustment is extra time to take a test. Examples of auxiliary aids include note takers, interpreters, readers, and specialized computer equipment.

# The National Center for College Students with Disabilities

The National Center for College Students with Disabilities (NCCSD) is the only federally-funded national center in the United States for college and graduate students with any type of disability, chronic health condition, or mental or emotional disabilities. College students experiencing Long COVID can access a variety of resources using the NCCSD Clearinghouse.

Learn more about NCCSD, visit <u>National Center for College Students with Disabilities</u> <u>Clearinghouse (nccsdclearinghouse.org)</u>

# **Caregiving and Family Support**

Caregivers who are experiencing Long COVID, are caring for someone who has Long COVID, or both, may find they now need additional support. That support may come in the form of respite care, which gives caregivers temporary relief from their caregiving responsibilities, which can range from a few hours to a few days or weeks. It may also include paid leave from work to care for themselves or their loved ones, training to adapt to changes in their abilities or the abilities of their loved ones, or counseling and support groups. Some of the resources in this section may also support individuals, their families and caregivers who are experiencing the longer-term impacts of the COVID-19 pandemic, such as mental health and substance use challenges and bereavement. Individuals who may need additional assistance with family acare due to the loss of a lovd one my also find assistance through these federal supports and services.

#### This section covers five topics

- Navigation Support
- Family and Medical Leave and Sick Leave
- Respite Care
- Individual Counseling and Support Groups
- Child Welfare.

If you need legal assistance with caregiving and family supports, you may want to review the Legal Assistance section of the *Know Your Rights* section.

# **Navigation Support**

# Kinship Navigator

The Kinship Navigator assists grandparents and other kin caring for children, including families involved in the child welfare system. Kinship Navigator programs assist kinship caregivers in learning about, finding, and using programs and services to meet the needs of the children they are raising and their own needs.

#### **Not Sure Where to Start?**

- Q. Wondering what support services are available for caregivers in your area?
- **A.** Call the Eldercare Locator at 1 (800) 677-1116 or visit Eldercare Locator (acl.gov) to chat live or browse resources
- Q. Are you caring for a veteran or are you a veteran caring for a non-veteran family member?
- **A.** Call the Caregiver Support Line at 1 (855) 260-3274 or visit Caregivers Support Line (CSL) -VA Caregiver Support Program

Find a program or contact in your state, territory or tribe, visit <a href="State Kinship Care">State Kinship Care</a>
Contacts and Programs | Administration for Children and Families (ChildWelfare.gov)

# Family and Medical Leave and Sick Leave

People with Long COVID may need time away from work—whether a few occasional sick days or longer periods of leave—to seek treatment or for recovery. Workers may also need to take time off to care for family members experiencing Long COVID.

For more information, visit <u>COVID-19</u> and the Family and <u>Medical Leave Act Questions</u> and <u>Answers | U.S. Department of Labor (dol.gov)</u>

# Family and Medical Leave Act

Employees impacted by Long COVID may be able to take leave from work under the Family and Medical Leave Act (FMLA). The FMLA entitles eligible employees of covered employers to take up to 12 weeks each year of unpaid, job-protected leave for certain qualifying reasons, including for a serious mental or physical health condition that makes the employee unable to work or care for the employee's spouse, child, or parent who has a serious health condition. FMLA leave may be taken intermittently in short increments of time or in longer blocks of up to 12 weeks in leave a year for FMLA serious health conditions. FMLA does not require employers to provide paid leave, but employees may elect, or employers may require concurrent use of paid leave, such as accrued vacation or sick leave. The FMLA also requires employers to continue group health insurance coverage under the same terms and conditions as if the employee had not taken leave. The Department of Labor's Wage and Hour Division (WHD) is responsible for administering and enforcing the FMLA. Your state may offer stronger protections for family and medical leave than those under the FMLA, including paid family and medical leave benefits.

- For more information about your FMLA eligibility and use of leave, visit Fact Sheet #28: The Family and Medical Leave Act of 1993
- ➤ If you have questions or concerns, you can contact WHD at 1 (866) 487-9243 or visit WHD | U.S. Department of Labor (dol.gov)

#### State Paid Family and Medical Leave Programs

Some states operate programs that entitle eligible workers to receive wage replacement when they cannot work due to covered family caregiving or medical reasons. Eligibility rules and wage replacement rates vary by state and are based on prior earnings and work history. Eligible workers are entitled to paid leave benefits for qualifying reasons including a serious health condition that makes them unable to work and caregiving leave for family members with a serious health condition. As of 2022, paid family and medical leave benefits can be accessed through state programs in California, New Jersey, Rhode Island, New York, the District of Columbia, Washington, Massachusetts, and Connecticut.

- For more information about state paid family and medical leave programs, visit
  - California: State Disability Insurance (ca.gov)
  - New Jersey: <u>Division of Temporary Disability and Family Leave Insurance | Family Leave Insurance (nj.gov)</u>
  - Rhode Island: <u>Temporary Disability / Caregiver Insurance | RI Department of Labor & Training</u>
  - New York: <u>New York State Paid Family Leave (ny.gov)</u> or <u>Introduction to the Disability Benefits Law (ny.gov)</u>
  - District of Columbia: DC Paid Family Leave | does
  - Washington: Washington State's Paid Family and Medical Leave Washington
    workers will have up to 12 weeks of paid family or medical leave starting in 2020.
    Employers begin payroll withholding in 2019
  - Massachusetts: <u>Paid Family and Medical Leave (PFML) overview and benefits</u> <u>Mass.gov</u>
  - Connecticut: CT Paid Leave Authority (PFMLA) | Home | Official Site

#### Paid Leave for Federal Employees

Leave options available to federal employees who are experiencing Long COVID symptoms include sick leave, annual leave, advance sick and annual leave, and donated leave under the Voluntary Leave Transfer or Leave Bank programs. Federal employees on an alternative work schedule may request to adjust their hours of duty to accommodate medical appointments or accrue and use credit hours. Federal employees may also use any accumulated and accrued compensatory time.

Learn more about federal policies, visit <u>Pay & Leave | OPM (opm.gov)</u>, <u>Work Schedules |</u> OPM (opm.gov), Fact Sheets | OPM (opm.gov)

#### Paid Sick Leave for Employees of Federal Contractors

Employees of certain federal contractors may be entitled to paid sick leave to care for themselves or a family member experiencing Long COVID. Executive Order 13706, Establishing Paid Sick Leave for Federal Contractors, requires certain employers that contract with the federal government to provide employees working on or in connection with those contracts with one hour of paid sick leave for every 30 hours they work—up to 56 hours of paid sick leave each year. The Wage and Hour Division (WHD) is responsible for making sure covered employers comply with this requirement.

- For information on whether you are entitled to accrue and use paid sick leave, visit <a href="How do I know if I am working on a federal contract under which I am entitled to accrue and use paid sick leave?">How do I know if I am working on a federal contract under which I am entitled to accrue and use paid sick leave?</a>
- ➤ If you have questions or concerns, you can contact WHD at 1 (866) 487-9243 or visit www.dol.gov/agencies/whd.

## Respite Care

Respite care provides short-term relief for caregivers. It is an important component of family support and home and community-based long-term services and supports. Respite services strengthen family systems while protecting the health and well-being of both caregivers and care recipients.

### National Caregiver Family Support Program

National Caregiver Family Support Program (NFCSP) provides a range of services that assist family and other caregivers to care for their family members at home for as long as possible. Services to family caregivers include information about caregiver services and supports, connecting caregivers with services, caregiver education and training, respite care provided by trained caregivers, and other supplemental services.

- Find services available near you, call the Eldercare Locator at 1 (800) 677-1116 or visit Eldercare Locator (acl.gov) to chat live or browse resources
- Learn more about the program, visit <u>National Family Caregiver Support Program | ACL</u> Administration for Community Living (acl.gov)

# Individual Counseling and Support Groups

# Veterans Affairs Caregiver Support Program

The VA Caregiver Support Program (CSP) offers an array of supports and services to family members and friends who care for Veterans, including online courses, face-to-face classes, telephone support, and peer support. These services are offered in addition to the support provided to families and caregivers across VA by clinicians as part of a Veteran's care. Every VA

medical center has dedicated Caregiver Support Program staff who assist with information and referrals to these programs.

- Find more information, call the <u>Caregivers Support Line (CSL) VA Caregiver Support Program</u> toll-free at 1 (855) 260-3274, Monday through Friday, 8:00 a.m. to 10:00 p.m. ET, and Saturday, 8:00 a.m. to 5:00 p.m. ET
- ➤ Visit the CSP Teams/Caregiver Support Coordinators Locator at <u>Caregiver Support</u> <u>Program (CSP) Teams/Caregiver Support Coordinators - VA Caregiver Support Program</u>
- Learn more about the program, visit <u>VA Caregiver Support Program Home | VA (caregiver.va.gov)</u>

#### Child Welfare

Child Welfare programs focus on improving the lives of children and families by reducing child abuse and neglect, increasing the number of adoptions, and strengthening foster care. They may provide some assistance to individuals who are caring for children who lost their parents due to COVID-19 and Long COVID.

- The Title IV-E Foster Care Program provides board and care payments for eligible children under the supervision of the state and placed in foster family homes or child care institutions that are safe and licensed
- The Title IV-E Prevention Program provides time-limited prevention services for mental health conditions, substance use concerns, and in-home parent skill-based programs for children or youth who are candidates for foster care, pregnant or parenting youth in foster care, and the parents or kin caregivers of those children and youth
- The Title IV-E Guardianship Assistance Program to support relatives who become legal guardians of children for whom they previously cared for as foster parents
  - Access more information about child welfare programs, visit <a href="Children's Bureau">Children's Bureau</a> (CB) |
    The Administration for Children and Families (hhs.gov) or call (202) 205-8618

# Chapter 3: Enabling Health Care Personnel to Improve Treatment of People Experiencing Long COVID

The longer-term effects of COVID-19 encompass not just the ongoing challenge of providing care for people with Long COVID, but also the physical and psychological stresses on health care personnel, their patients, and their families due to the pandemic's disruptions.

At the pandemic's onset, health care personnel faced a novel clinical entity threatening morbidity and mortality to unprecedented numbers of people. Health care personnel worked with limited available knowledge or consensus on basic treatment protocols. We have since gained more clinical knowledge about the prevention, diagnosis and management of acute COVID-19 infection, while evidence for Long COVID is just emerging. However, health care personnel are now coping with the still novel entity of Long COVID, and once again confronting uncertainty and rapidly evolving evidence.

COVID-19 initially presented as acute pulmonary disease with high rates of mortality but rapidly was recognized as a multisystem disease. The virus demonstrated its ability to attack a wide range of organ systems, creating serious neurologic, cardiac, hematologic, renal, pulmonary, rheumatologic and other consequences that make support and treatment of individuals with COVID-19 exceptionally complex. Long COVID presents with an unusually broad set of symptoms and affects multiple organ systems, creating additional challenges in identifying and treating patients.

The COVID-19 pandemic has placed significant stresses on health systems, hospitals and individual health care personnel. While hospitals are less crowded with people with COVID-19, many challenges remain in the ongoing function of health systems. These include increased demand due to delayed preventive and chronic care during the pandemic, supply chain delays for some medical equipment, and national shortages of staff, especially nurses. The resulting pressure to get by with fewer staff members leaves remaining health care personnel under great stress, potentially resulting in further shortage and increasing the risk of providers themselves contracting COVID-19.

In addition to stress at work, many health care personnel face challenges at home due to the impact of COVID-19 on their family members, including both children and older people. The majority of health care personnel are women, many of whom shoulder considerable caregiving responsibilities.1 The psychological stress of providing health care during the pandemic is powerful, with greater impact on those who are younger, people from racial and ethnic minority groups, and those with minor children or an ill family member.2 In addition, health care personnel are now confronting the consequences of delayed preventive care and chronic

disease management resulting from the pandemic along with higher rates of mental health and substance use.

This chapter covers two main components

- Resources for healthcare personnel caring for individuals with Long COVID
- Supports for healthcare personnel who are dealing with the stressors and traumas of serving on the front lines in the COVID-19 response and the continued challenges of working in a system under stress.

# Resources for Health Care Personnel Caring for Individuals with Long COVID

This chapter presents U.S. government resources available to guide health care personnel in treating individuals with Long COVID. A sample of non-federal sources is also included.

Clinical practice guidelines for treating individuals with Long COVID are emerging. As the state of evidence is still evolving, there is a need for living evidence reviews, guidelines, and clinical decision support to bring the best evidence to the point of care. This report and referenced resources help mitigate provider misconceptions and biases, where they exist, in making the diagnosis of Long COVID.

The resources linked in this section use what is known so far. Enhanced coordination will be required to ensure optimal consistency in best practices. Health care personnel referring to these websites should check back regularly for updates.

# Federal Clinical Care Guidance for Long COVID

## Agency for Healthcare Research and Quality

#### **Evidence-Based Practice Centers Program**

Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Centers (EPCs) produce evidence reports on medications, devices, and other health care services with the goal of helping consumers, health care professionals, and policymakers make informed and

# Resources for Healthcare Personnel

#### This section includes

- Federal Clinical Care Guidance for Long COVID
- Sample of Clinical Care Guidance from Professional Associations
- Federally Sponsored Educational Programs for Healthcare Personnel
- Healthcare Delivery Systems Equipped for Long COVID Care
- Development of Best Practices for Long COVID Clinical Care.

evidence-based health care decisions. The EPC Program has created several COVID-19 resources that may be helpful to health care personnel.

➤ Learn more about EPC's COVID-19 resources, visit <u>COVID-19 Resources Developed by</u> AHRQ's Evidence-based Practice Centers | Effective Health Care (EHC) Program

#### Centers for Disease Control and Prevention

#### Interim Guidance on Evaluating and Caring for Patients with Post-COVID Conditions

Centers for Disease Control and Prevention (CDC) has many resources for health care personnel addressing the needs of Long COVID patients. The interim guidance documents provide practical guidance for providers caring for people with Post-COVID-19 conditions.

- ➤ See the full list of topics, visit <u>Interim Guidance on Evaluating and Caring for Patients</u> with Post-COVID Conditions | CDC
- ➤ View the CDC overview for healthcare personnel working with patients with post-COVID conditions, visit Post-COVID Conditions: Information for Healthcare Providers (cdc.gov)
- CDC-INFO offers live agents by phone and email to help the public find the latest, reliable, and science-based health information on more than 750 health topics. For example, help your patient find a vaccine provider or learn more about other CDC resources, visit CDC INFO | CDC

#### Department of Defense

#### Military Health System COVID-19 Toolbox

The Department of Defense (DOD) provides resources to health care personnel to facilitate the treatment and care of Military Health System (MHS) beneficiaries infected with COVID-19, including those that have persistent Long COVID symptoms.

Resources in the COVID-19 Toolbox help DOD clinical staff address the needs of their COVID-19 patients. The Toolbox includes the Practice Management Guide which provides information to assist in decision-making, general information on symptoms persisting for four or more weeks after infection, presentation of potential symptoms by patients, recommendations for patient evaluation and diagnosis, treatment and clinical management for patients with sustained symptoms, and summary of the prospective prognosis of Long COVID. The Toolbox website includes additional patient care clinical skills augmentation that may be necessary and provides just-in-time training videos with critical care training for health care personnel.

Learn more about the Toolbox, visit <a href="COVID-19 Toolbox">COVID-19 Toolbox</a> | Health.mil</a>

#### Health Resources and Services Administration

Tens of millions of Americans receive quality, affordable health care and other services through Health Resources and Services Administration's (HRSA) 90-plus programs and more than 3,000 grantees. HRSA programs have been leveraged to enable the nation's health care safety net to address COVID-19 and emerging priorities and issues, such as Long COVID.

#### **Health Center Resource Clearinghouse**

HRSA and the National Association of Community Health Centers, a HRSA-funded National Training and Technical Assistance Partners (NTTAP), developed the Health Center Resource Clearinghouse, which provides an up-to-date selection of high-quality technical assistance resources relevant to health centers, including COVID-19.

Learn more about COVID-19 Resources, visit <u>COVID-19 | Health Center Resource</u> <u>Clearinghouse (healthcenterinfo.org)</u>

#### **AIDS Education and Training Center**

The AIDS Education and Training Center Program, National Coordinating Resource Center supports national HIV priorities by building clinician and care team capacity and expertise along the HIV care continuum.

Find COVID-19 Resources for HIV Providers, visit COVID-19 Resources for HIV Providers | AIDS Education and Training Centers National Coordinating Resource Center (AETC NCRC) (aidsetc.org)

#### Substance Abuse and Mental Health Services Administration

#### Center for Mental Health Services Expert Summit on Behavioral Effects of Long COVID

SAMHSA convened an expert panel of researchers, clinical care professionals, and individuals experiencing firsthand the cognitive and other behavioral health effects of Long COVID to create guidance on the identification and management of the mental health conditions that some with Long COVID experience. A report and materials to guide health care personnel and individuals with Long COVID address the neurological and mental health symptoms of Long COVID will be available on the SAMHSA.gov website.

# Sample of Clinical Care Guidance from Professional Associations

Below are some consensus statements and guidance documents developed by various professional groups. It is outside the scope of this report to vet the methodological rigor and quality of current professional association guidance related to Long COVID. As such, none of the resources below are endorsed by the U.S. government.

The body of evidence on Long COVID is rapidly evolving, so clinical practice guidance will need to be kept up-to-date through living reviews, regular updates to practice guidelines, and strategies to effectively make the latest evidence available at the point of care. This guidance can let clinicians know what works and what is not effective, and may also help clinicians address misinformation among the people and communities they serve.

#### American Academy of Physical Medicine and Rehabilitation

#### Consensus Guidance Statements Related to Long COVID

- Learn more about the methodology used by American Academy of Physical Medicine and Rehabilitation, visit Consensus methodology for the development of postacute sequelae of SARS-CoV-2 guidance statements -Maley -2021 PM&R Wiley Online Library
- Read about the consensus guidance regarding fatigue among SARS-COV-2 infection patients, visit Multidisciplinary collaborative consensus guidance statement on the assessment and treatment of fatigue in postacute sequelae of SARS-CoV-2 infection (PASC) patients Herrera 2021 PM&R Wiley Online Library
- ➤ Read about the consensus guidance regarding breathing discomfort among Long COVID patients, visit Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of breathing discomfort and respiratory sequelae in patients with post-acute sequelae of SARS-CoV-2 infection (PASC) Maley 2022 PM&R Wiley Online Library
- ➤ Read about the consensus guidance regarding cognitive symptoms among Long COVID patients, visit Multi-disciplinary collaborative consensus guidance statement on the assessment and treatment of cognitive symptoms in patients with post-acute sequelae of SARS-CoV-2 infection (PASC) Fine 2022 PM&R Wiley Online Library
- Read about the consensus guidance regarding Long COVID Cardiovascular Complications, visit <u>AAPM&R Long COVID Cardiovascular Complications Guidance</u> <u>Statement Released (aapmr.org)</u>

# American College of Cardiology

#### **Expert Consensus Decision Pathway**

➤ Read about the consensus decision pathway regarding cardiovascular sequelae among COVID-19 patients, visit 2022 ACC Expert Consensus Decision Pathway on Cardiovascular Sequelae of COVID-19 in Adults: Myocarditis and Other Myocardial Involvement, Post-Acute Sequelae of SARS-CoV-2 Infection, and Return to Play: A Report of the American College of Cardiology Solution Set Oversight Committee | Journal of the American College of Cardiology (jacc.org)

#### American Nurses Association

#### American Nurses Association's Well-Being Initiative

Resource includes free tools and apps to support the mental health and resilience of all nurses.

➤ Learn more about the American Nurses Association's Well-Being Initiative, visit Coronavirus | Well-Being Initiative | Mental Health | ANA (nursingworld.org)

#### **European Respiratory Society**

Read the European Respiratory Society statement on Long COVID Follow-Up, visit <u>European Respiratory Society Statement on Long COVID-19 Follow-Up | European</u> Respiratory Society (ersjournals.com)

#### Other External Resources for Long COVID Information Relevant to Clinicians

- ➤ Read the National Institute for Health Care Excellence guideline on managing the longerterm effects of COVID-19, visit Overview | COVID-19 rapid guideline: managing the longterm effects of COVID-19 | Guidance | NICE
- Read the National Health Service guidance on when you need to seek help, visit When Do I Need To Seek Help? | Your COVID Recovery
- Read about the neurological effects of Long COVID, visit <u>Long-COVID</u>: <u>neurological</u> manifestations and management PMC (nih.gov)
- ➤ Read about proposed clinical guidelines for Long COVID diagnosis and disease management, visit <a href="IJERPH">IJERPH</a> | Free Full-Text</a> | Long Covid-19: Proposed Primary Care Clinical Guidelines for Diagnosis and Disease Management (mdpi.com)
- Read the Chartered Society of Physiotherapy's Long COVID clinical guidance, visit Long COVID clinical guidance | The Chartered Society of Physiotherapy (csp.org.uk)
- ➤ Read the Indiana Department of Health's Long COVID clinical guidance, visit COVID-19-LTC-Clinical-Guidance-2.8.22.pdf

# Federally Sponsored Educational Programs for Healthcare Personnel

Clinicians have struggled throughout the pandemic to access reliable and up-to-date information to identify COVID-19-related symptoms and treatments. This task is exacerbated by the large amount of inaccurate advice that is not evidence-based and can be harmful to patients. This section provides links to trusted channels of dissemination to help clinicians access the most current and accurate information and training related to treating Long COVID.

## Centers for Disease Control and Prevention

#### **Clinician Outreach and Communication Activity**

Clinician Outreach and Communication Activity (COCA) helps prepare clinicians to respond to emerging health threats and public health emergencies by communicating relevant, timely information related to disease outbreaks, disasters, terrorism events, and other health alerts.

- Read about Clinician Outreach and Communication Activity, visit Home | Clinician Outreach and Communication Activity (COCA) (cdc.gov)
- ➤ View a webinar on evaluating and supporting COVID-19 patients with cognitive symptoms, visit Webinar Thursday, May 5, 2022 Evaluating and Supporting Patients Presenting with Cognitive Symptoms Following COVID (cdc.gov)
- ➤ View a webinar on evaluating and supporting COVID-19 patients with fatigue, visit Webinar September 30, 2021 Evaluating and Supporting Patients Presenting With Fatigue Following COVID-19 (cdc.gov)
- ➤ View a webinar on evaluating and caring for patients with Long COVID, visit <u>Webinar</u>

  <u>June 17, 2021 Evaluating and Caring for Patients with Post-COVID Conditions (cdc.gov)</u>
- View a webinar on what clinicians, pharmacists, and public health partners need to know about antibiotic prescribing for COVID-19, visit <u>Webinar Thursday</u>, <u>November 18</u>, <u>2021 -What Clinicians</u>, <u>Pharmacists</u>, <u>and Public Health Partners Need to Know about</u> Antibiotic Prescribing and COVID-19 (cdc.gov)

#### TeleECHO Program

Project ECHO, "Extension for Community Healthcare Outcomes," is an innovative knowledge-on-demand model for providing treatment to patients with chronic, common, and complex diseases who do not have direct access to specialty health care providers. There are several examples of ECHO or ECHO-like programs that have been adopted by federal agencies.

One example is CDC's Long COVID and Fatiguing Illness Recovery Program, which aims to improve the health of people who are medically underserved who have Long COVID and other complex chronic conditions with similar symptoms, such as myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS) and other post-infectious fatiguing illnesses. This low-cost, scalable model has potential to reduce health inequities by increasing the capacity of health care providers in underserved communities to deliver effective care informed by the latest clinical advances. The program implements a randomized trial at the Family Health Centers of San Diego, a large, Federally Qualified Health Center and a cohort comparison with patients at the University of Washington Long COVID Rehabilitation and Recovery Clinic. The program is evaluating telementoring involving multi-specialty case consultation and peer-to-peer sharing of emerging promising clinical practices for managing Long COVID and improving provider- and patient-level outcomes. The program also disseminates educational content in monthly topic-

focused webinars and quarterly short courses open to providers nationwide. Although the main focus is Long COVID, the similarities to ME/CFS and other post-infectious fatiguing illnesses is recognized and included in the curriculum, with the idea that the clinics could serve patients with Long COVID-like symptoms, whether or not they had a positive COVID test result. Multi-speciality faculty/mentors include national experts in the care of Long COVID, ME/CFS, and other post-infectious chronic illnesses, as well as lived experience experts (patients, patient advocates, and caregivers). The program has attracted 40 nationally recognized faculty/mentors representing multiple medical specialties who have started a social media discussion group for sharing evolving knowledge and emerging clinical practice. Investigators have documented increasing webinar attendance of up to 650 participants and have received inquiries indicating interest in participation from health care providers nationally and internationally

- Register to start receiving invitations to monthly Long COVID and Fatiguing Illness Recovery Program webinars: Webinar Registration - Zoom
- ➤ Read more about the Long COVID and Fatiguing Illness Recovery Program, visit <u>Does a Technology Enabled Multi-disciplinary Team-based Care Model for the Management of Long COVID and Other Fatiguing Illnesses Improve Clinical Care of Patients and Represent a Sustainable Approach Within a Federally Qualified Health Center? Full Text View ClinicalTrials.gov</u>
- ➤ Read about the Family Health Centers of San Diego, visit <u>Family Health Centers of San Diego</u>: Low Cost Clinic No Insurance (fhcsd.org)
- Read about Project ECHO, visit <u>Project ECHO | Agency for Healthcare Research and Quality (ahrq.gov)</u>
- Read about the University of Washington's guidance on Long COVID rehabilitation and recovery, visit <u>Post-COVID Rehabilitation | UW Medicine</u>
- Read about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, visit What is ME/CFS? | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) | CDC

#### Centers for Medicare & Medicaid Services

#### Centers for Medicare & Medicaid Services Medicare Learning Network

Centers for Medicare & Medicaid Services (CMS) works with providers to advance recognition and understanding of Long COVID and associated conditions, including by sharing culturally competent information and resources through platforms like the CMS Medicare Learning Network (MLN) and engaging stakeholders across the health sector to share best practice and new findings from research occurring across HHS.

The MLN offers a weekly email newsletter for health care personnel. It compiles news from across CMS into a single source for program and policy details; news and announcements; press

releases; upcoming educational event registration and reminders; claim, price, and code information; and updates new and revised MLN Matters Articles® and publications.

As more clinical information on the diagnosis for Long COVID and its treatment become available from ongoing research at the Department's research agencies, CMS can use its established channels and ability to convene stakeholders to get this information directly to providers.

Accurate and Effective Use of Long COVID Diagnostic Code

This year, the Administration is set to develop and launch targeted clinician and medical coder education on the ICD-10-CM code U09.9, which became effective last year to support diagnosis, billing, and tracking of Long COVID.

➤ Read about the Long COVID diagnostic code, visit page 30 of FY2022 April1 update ICD-10-CM Guidelines (cms.gov)

#### **Veterans Affairs**

#### COVID-19 ECHO

The Veterans Health Administration provides live, interactive, hour-long educational sessions which cover evidence-based care recommendations, discussion of models of care, optimizing virtual care delivery during the pandemic, and best practices. All sessions offer continuing education. Sessions vary from weekly, bi-weekly, or monthly. Learners include clinical providers and allied health; management, administration, and leadership; non-clinical team members; and health care trainees. Non-VA clinicians are also welcome at most sessions at no cost.

Register and start receiving invites to the COVID-19 VA-ECHO sessions, visit <u>VA-ECHO</u> (iths.org)

#### Health Resources and Services Administration

#### Telehealth Technology-Enabled Learning Program

The purpose of Telehealth Technology-Enabled Learning Programs (TTELP) is to connect specialists at academic medical centers with primary care providers who work with people from rural areas and those who are medically underserved, providing evidence-based training and support to help them treat patients with complex conditions in their communities. TTELP recipients develop learning community models that emphasize collaborative partnerships between such providers (i.e., telementoring models such as Project ECHO, distance learning, clinical decision support, and other emerging models in the field), to provide training and facilitate the dissemination of best practice specialty care to PCPs and care teams in rural areas, frontier, and underserved populations. The \$4.28 million in funding, which began in FY2021, funds nine grantee recipients. The grants assist specialists at academic medical centers to provide training and support to primary care providers in rural, frontier, and other underserved

areas to help treat patients with complex conditions ranging from Long COVID to substance use challenges in their communities. TTELP is in its first year of the five-year program. Five out of the nine TTELP grantees are working on Long COVID issues with the potential of two additional grantees adding it to their work plans over the course of the program's five years.

- View grantee recipients, visit FY 2021 Telehealth Awards | HRSA
- ➤ Learn about the Telehealth Technology-Enabled Learning Program, visit <u>Telehealth</u> <u>Technology-Enabled Learning Program | Official web site of the U.S. Health Resources & Services Administration (hrsa.gov)</u>

#### Indian Health Service

#### **National Pharmacy and Therapeutics Committee**

The National Pharmacy and Therapeutics Committee (NPTC) provides COVID-19 Emergent Treatment Updates to IHS clinical providers. Updates include new and changing recommendations and guidelines, authorizations for relevant medications related to COVID-19, and vaccinations.

View all Emergent Treatment Updates, visit <u>COVID-19 | National Pharmacy & Therapeutics Committee (ihs.gov)</u>

#### COVID-19 ECHO

This COVID-19 ECHO Program is designed to connect Federal, Tribal, and Urban IHS clinicians, administrators, and staff with up-to-date information on clinical care and emerging health topics. ECHO sessions are open to those interested in staying current on the rapidly evolving pandemic to inform their COVID-19 response efforts. This program is focused on Federal, Tribal, and Urban IHS clinical providers, administrators, and staff, and it is free to register.

- ➤ Learn more about this ECHO program, visit <u>COVID-19 ECHO Programs Indian Country ECHO</u>
- Register for a myECHO account, visit <u>Login Indian Country ECHO</u>

#### **Pharmacy Program**

The IHS Pharmacy Program is the primary source of national advocacy, management, and policy development for IHS pharmacies across the United States. IHS pharmacists are intimately involved in improving patient care through active involvement with Pharmacy and Therapeutics Committees, formulary management, policy and procedure development and education across the healthcare spectrum. The IHS Pharmacy Program provides vaccine training and certification for Federal, Tribal, and Urban Pharmacists and Pharmacy Technicians to expand the number of people eligible to administer vaccines available during COVID-19. Some IHS facilities lead the Pharmacy Expanding Vaccine Access (PEVA) workgroup, an initiative to decrease the prevalence of vaccine-preventable diseases. The primary focus of PEVA is to increase access to and demand

for immunization services by using subject matter experts to advise, educate and implement improved immunization practices to the public health service field.

- Read more about the Pharmacy Program, visit <u>Pharmacy Program | Division of Clinical and Community Services (ihs.gov)</u>
- Read more about Pharmacy Expanding Vaccine Access, visit <u>Pharmacist Professional</u> <u>Advisory Committee (psc.gov)</u>

# Healthcare Delivery Systems Equipped for Long COVID Care

Clinical expertise on Long COVID is not equally available across the United States. This section aims to give examples of existing programs that can be leveraged to address Long COVID and to provide information for clinicians who wish to refer patients who need resources beyond what is locally available.

#### Health Resources and Services Administration

#### **Federally Qualified Health Centers**

Health centers funded by the Health Resources and Services Administration (HRSA) operate more than 14,000 service delivery sites across all U.S. states and territories. Nearly 29 million people, or 1 in 11 nationwide, rely on a HRSA-funded health center for affordable, accessible health care. These centers provide care to people who are medically underserved, including people with HIV, people who are pregnant, mothers and their families, those with low incomes, residents of rural areas, AI/AN persons, and those otherwise unable to access high-quality health care. Health centers are located in medically underserved communities, providing access to affordable, comprehensive, and high-quality primary health care services for people who have low incomes, who are uninsured, or face other obstacles to getting health care.

- Read more about Health Centers, visit What is a Health Center? | Bureau of Primary Health Care (hrsa.gov)
- Find a Health Center, visit Find a Health Center (hrsa.gov)

#### National Maternal Mental Health Hotline

The National Maternal Mental Health Hotline provides 24/7, free, confidential support before, during, and after pregnancy. Any expecting or new mom experiencing mental health challenges, and their support networks and providers can call the hotline. The Hotline offers callers phone or text access to trained, professional counselors who are culturally and trauma-informed; real-time support and information; response within a few minutes, 24 hours a day, 7 days a week; resources; referrals to local and telehealth providers and support groups; culturally sensitive support; counselors who speak English and Spanish; and interpreter services in 60 languages.

- ➤ Read more about the Hotline, visit <u>1-833-9-HELP4MOMS National Maternal Mental</u> Health Hotline | MCHB (hrsa.gov)
- Access the Hotline, call or text 1 (833) 9-HELP4MOMS or 1 (833) 943-5746. TTY users can use a preferred relay service or dial 711 and then 1 (833) 943-5746.

#### Indian Health Service

#### Federal, Tribal, and Urban Health Centers

COVID-19 has amplified health inequities in AI/AN communities because of underfunded and under-resourced health systems, limited access to health services, poor infrastructure, and underlying health disparities. For example, according to the latest rates reported by CDC, AI/AN individuals are three times more likely to be hospitalized with COVID-19.3

IHS offers comprehensive health services to AI/AN individuals through a series of Federal, Tribal, and Urban health centers. Availability of services (e.g., primary care, emergency services, hospital care, behavioral health, substance use treatment) is dependent on each clinic. Eligible AI/AN individuals affected by longer-term effects of COVID-19—whether physical, mental, social, or spiritual—are encouraged to use the provided website to locate those IHS services nearest to them. Identify the nearest IHS, Tribal or Urban (I/T/U) Indian Health Program facility using the provided website and call to schedule an appointment. Each center will communicate what is needed to register as a patient.

Find a Federal, Tribal, or Urban health center, visit <a href="Find Health Care">Find Health Care</a> Indian Health <a href="Service">Service (IHS)</a>

#### Department of Veterans Affairs

#### **Programs and Services Offered**

VA clinics are offering a combination of in-person and telehealth services for Long COVID care to maximize patient access to these services. As of early 2022, an environmental scan identified that 22 VA facilities offer coordinated Long COVID care and many other facilities are working to stand up similar clinics. A second environmental scan of these rapidly evolving clinics is currently underway and will be completed in mid-2022. Services offered vary based on location and may include physical therapy, occupational therapy, speech therapy, mental health assessment and intervention, pulmonary rehabilitation, cardiac rehabilitation, psychology groups, neuropsychological testing, and medical specialties including geriatrics, primary care, physiatry, psychiatry, neurology, pulmonology, and cardiology.

# Development of Best Practices for Long COVID Clinical Care

#### **Veterans Affairs**

VA standards of care for Long COVID are being developed nationally through a Community of Practice (CoP) concurrent with the development of a Long COVID Integrated Practice Team driven by VHA leadership. These groups are actively working to establish

- Best practices and guidelines for clinical interventions
- Standardized referral processes, tools, and templates
- Data and metric consensus
- · Resources and model of care planning
- Training and education for VA employees, Veterans, and external audiences.

Resources are being developed to guide services for both primary care and specialty care providers across a broad range of VA facilities, including development of note templates and best practice management recommendations.

Providers interested in contacting or coordinating with the VA Long COVID CoP can send inquiries to the email address VHALongCOVID@va.gov

# Support for Health Care Personnel Experiencing Stress and Trauma Related to COVID-19

The realities of our health care system are driving many health care personnel to burnout. They are at an increased risk for mental health challenges and are choosing to leave the health workforce early.4 They work in distressing environments that strain their physical, emotional, and psychological well-being, making it harder for patients to get care when they need it.

COVID-19 has created enormous stresses on both health care systems and their personnel. The vast increase in seriously ill patients, the resulting lack of sufficient medical resources during surges, and the lack of established effective treatments, especially early in the pandemic, affected health care personnel who also had ill family members and children forced out of their ordinary school routine. Current shortages of medications, other medical supplies, and staffing contribute to high ongoing stress levels in medical workplaces. These multiple factors created a devastating impact on health care personnel. We describe several federal employee assistance programs provided by health systems to support their clinical workers at an individual level.

#### Health Resources and Services Administration

To address stress on health care personnel, Department of Health and Human Services (HHS), through the Health Resources and Services Administration (HRSA) provided \$103 million in awards to improve the retention of health care personnel and help respond to the nation's critical staffing needs by reducing burnout and promoting mental health and wellness among the health care workforce. These awards will fund evidence-informed programs, practices and training, with a specific focus on providers in areas where people are medically underserved and in rural communities.

- Learn more about the federal grants to reduce burnout and promote mental health and wellness among health care personnel, visit <u>HRSA Workforce Program Initiatives Fact</u> Sheet
- ➤ Learn more about health care personnel burnout, visit <u>Health Worker Burnout</u> <u>Current Priorities of the U.S. Surgeon General (hhs.gov)</u>

#### Department of Veterans Affairs

#### **Staff Support Programs**

The Employee Whole Health program offers VA staff a holistic approach to self-care, with numerous virtual tools for employees related to stress management, trauma-informed peer support, well-being, professional fulfillment, and personal or family emergencies.

- Read more about Employee Whole Health, visit <u>Employee Whole Health</u> <u>Whole Health</u> (va.gov)
- Read the Whole Health Blog, visit #LiveWholeHealth Archives VAntage Point

In addition, the Reduce Employee Burnout and Optimize Organizational Thriving (REBOOT) task force is working to help alleviate burnout and promote VA employee well-being. The task force engages with employees to identify major contributors to burnout and recommend existing efforts that might be complemented or amplified to address those contributors.

- Access resources on mental health, women Veterans, cultural competency, and common clinician concerns when working with members of the National Guard, Reserve, and Veterans transitioning to civilian work environments, visit <a href="Employee"><u>Employee</u></a> Assistance Program (EAP) Providers Veterans Employment Toolkit (va.gov)
- Learn more about the REBOOT task force, visit Reducing Employee Burnout (va.gov)

#### Indian Health Service

#### **Employee Assistance Program**

The Employee Assistance Program (EAP) is a resource for IHS health care personnel and employees. The voluntary, work-based program offers free and confidential assessments, short-term counseling, referrals, and follow-up services to employees who have personal and work-related problems. EAPs address a broad and complex body of issues affecting mental and emotional well-being, such as alcohol and other substance use challenges, stress, grief, family problems, and psychological conditions. EAP counselors also work in a consultative role with managers and supervisors to address employee and organizational challenges and needs.

- Read more about the Employee Assistance Program, visit <u>Employee Assistance Program</u>
   Working at IHS
- ➤ Read more about Federal Occupational Health where suicide information and prevention resources can be found, visit <u>FOH4YOU</u>

#### **Mental Health Training**

Some of the IHS areas are providing Mental Health First Aid training and train-the-trainer education. This provides supervisors with the tools to evaluate staff for possible mental health intervention needs. Also, agency-wide training for QPR (Question, Persuade and Refer) was provided by the Department of Behavioral Health. This provides an effective tool to screen for suicidal ideation and provide immediate intervention and referral.

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# Chapter 4: Services for Individuals Dealing with Mental Health, Substance Use, or Bereavement Challenges in the Wake of the Pandemic

The COVID-19 pandemic impacted our lives in numerous ways, and as a result, many of us have faced a variety of stressful challenges that can be overwhelming. The COVID-19 pandemic has affected people's mental health and created additional obstacles for those in need of behavioral health care to include mental health and substance use care. A growing number of adults in the United States reported mental health concerns since the start of the pandemic, and many children and adolescents have experienced challenges to their emotional health and well-being. While already increasing before COVID-19, substance use and drug overdoses increased in the United States after the COVID-19 pandemic began, and we have learned that people with substance use challenges and some mental illnesses are at increased risk for poor COVID-19 outcomes. In addition, as the full impact of COVID-19 unfolds, many Americans have been forced to cope with the death of loved ones and face the aftermath of those losses.

Resources are available to help. In this chapter, you will find three sections that feature federally funded supports and services for individuals experiencing the effects of COVID-19 in the areas of

- 1. Mental Health
- 2. Substance Use
- 3. Bereavement.

Although we have separated these sections, the social and medical factors underlying them are strongly inter-related and relevant as are the resources to assist those in need. Therefore, there is some repetition in each section. For each support or service, a telephone number or a hyperlink to appropriate websites are provided. You do not need to have Long COVID to access these resources. Most of the resources are relevant to anyone with a disability or who meets the program criteria.

For information about mental health and substance use, please visit <u>SAMHSA</u> - Substance Abuse and Mental Health Services Administration

- For information about the protection and advocacy of individuals with mental illness, please visit <a href="Protection & Advocacy for Individuals with Mental Illness (PAIMI)">Program | SAMHSA</a>
- ➤ For information about non-discrimination protections for individuals with mental health or substance use conditions, please visit File a Complaint | Beta.ADA.gov
- For more information about the rights of students, please visit <u>Supporting and</u> <u>Protecting the Rights of Students at Risk of</u> <u>Self-Harm in the Era of COVID-19 (PDF)</u> (ada.gov).

# Mental Health Supports and Services

The COVID-19 pandemic brought about unprecedented changes to our lives that had implications for not only our physical health, but also our mental health and well-being. People experienced a variety of stressors, including uncertainty about the future, changes in daily routines, financial concerns, employment instability, and social isolation. Challenges from the pandemic often prompted mental health challenges to develop and worsened existing mental health concerns. Studies show increases in the number of U.S. adults who report symptoms of stress, anxiety, and depression during the pandemic, compared to reports before the pandemic.<sup>6-7</sup> A variety of federal mental health resources and supports are available to help. This section covers five topics

- Treatment Locators
- Helplines
- Self-Help Resources

#### **Not Sure Where to Start?**

Q. Are you thinking about taking your life, or are you worried about a friend or loved one who is talking about suicide?

**A.** Call, text, or chat the National Suicide prevention Lifeline by pressing 988 to connect to counselors who will listen, provide support, and connect you to treatment and other resources.

Find support, visit Lifeline

You may also contact the National Suicide Prevention Lifeline at 1 (800) 273-8255; TTY Users can use your preferred relay service or dial 711 then 1 (800) 273-8255.

Q. Do you need to find treatment to help you cope with depression, anxiety or your emotions generally?

**A.** Call the National Helpline at 1 (800) 662-HELP (4357) and 1 (800) 487-4889 (TTY)

Find treatment through the
Behavioral Health Treatment
Services Locator at Home - SAMHSA
Behavioral Health Treatment
Services Locator, through the
Department of Veterans Affairs at
Find VA Locations | Veterans Affairs
or the Department of Defense
Treatment Locator at Find a Military
Hospital or Clinic | TRICARE

- Resources for Military Veterans, Service Members, and their Families
- Indian Health Service Resources.

#### **Treatment Locators**

#### Behavioral Health Treatment Services Locator

This Behavioral Health Treatment Services Locator provides confidential and anonymous information for anyone seeking treatment facilities in the United States or U.S. Territories for substance use challenges and mental health problems.

Find treatment, call 1 (800) 622 HELP or 1 (800) 622-4357 or visit <a href="Home-SAMHSA">Home - SAMHSA</a>
Behavioral Health Treatment Services Locator

#### Early Serious Mental Illness Treatment Locator

The Early Serious Mental Illness Treatment Locator provides a confidential and anonymous source of information for people and their family members who are seeking treatment for a recent onset of serious mental illnesses such as psychosis, schizophrenia, bipolar disorder and other conditions. These evidence-based programs provide medication, therapy, family and peer support, assistance with education and employment and other services.

Find early serious mental illness treatment, visit <u>Early Serious Mental Illness Treatment</u> Locator | SAMHSA

# Helplines

#### The Lifeline and 988

988 is the new three-digit dialing code that will route callers to the National Suicide Prevention Lifeline. When people call, text, or chat 988 on their phone, they will be connected to trained counselors that are part of the existing National Suicide Prevention Lifeline network. These trained counselors will listen, understand how their problems are affecting them, provide support, and connect them to resources if necessary.

- Connect with a trained counselor, call, text, or chat 988
- Find support, call 1 (800) 273-8255; (TTY) Dial 711 then 1 (800) 273-8255
- Learn more about The Lifeline and 988 : Lifeline (suicidepreventionlifeline.org)

#### Disaster Distress Helpline

The Disaster Distress Helpline provides 24 hours-a-day, 365-day-a-year crisis counseling and support to people experiencing emotional distress related to natural or human-caused

disasters, including the COVID-19 pandemic. Callers to the hotline can also connect with counselors in over 100 other languages via 3rd-party interpretation services.

- Connect with a trained crisis counselor, call or text 1 (800) 985-5990
- Connect directly to an agent in American Sign Language, call 1 (800) 985-5990 from your videophone
- Learn more about the Disaster Distress Helpline | SAMHSA
- Access Disaster Distress Helpline informational on-page documents in multiple languages, visit <u>disasterdistresshelpline Publisher Publications Issuu</u>

# Health Resources and Services Administration, Maternal & Child Health Bureau, National Maternal Mental Health Hotline

The National Maternal Mental Health Hotline provides 24-hours-a-day, free, confidential support before, during, and after pregnancy. Any expecting or new mom experiencing mental health challenges, and their support networks and providers, can call the hotline. The Hotline offers callers voice or text access to professional counselors, real-time support and information, referrals to local and telehealth providers and support groups, and counselors who speak English and Spanish. Interpreter services are available in 60 languages.

- Find support, call or text 1 (833) 9-HELP4MOMS or 1 (833) 943-5746; (TTY) Dial 711 and 1 (833) 943-5746
- For support and resources, visit <u>1-833-9-HELP4MOMS National Maternal Mental Health Hotline | MCHB (hrsa.gov)</u>

# Self-Help Resources

#### **COVID-19 Parental Resources Kit**

COVID-19 can affect children and young people directly and indirectly. Beyond getting sick, many young people's social, emotional, and mental well-being are impacted by the pandemic. The COVID-19 Parental Resource Kit provides information about ensuring children and young people's social, emotional, and mental well-being.

Find parenting resources, visit <u>COVID-19 Parental Resources Kit (cdc.gov)</u>

#### Disaster Behavioral Health Information Series Resource Center

The SAMHSA Disaster Technical Assistance Center (DTAC) provides resources and useful information for those in the disaster behavioral health field and those who have experienced disasters.

Learn more about the Resource Center | SAMHSA

#### How Right Now

How Right Now is a communications campaign designed to promote and strengthen the emotional well-being and resiliency of populations adversely affected by COVID-19-related stress, grief, and loss. The website includes tools and information to help individuals cope and be resilient.

Access How Right Now resource, visit How Right Now | Finding What Helps (cdc.gov)

#### MentalHealth.gov

This resource provides one-stop access to mental health and mental health-related problems, including coping with stress related to the COVID-19 pandemic.

Access resources about coping with stress at <a href="Home">Home</a> | MentalHealth.gov</a>

#### Stress and Coping with COVID-19

Centers for Disease Control and Prevention (CDC) provides resources for adults experiencing stress from COVID-19.

Find resources for stress and COVID-19, visit <a href="Stress and Coping (cdc.gov">Stress and Coping (cdc.gov)</a>

#### Support for Teens and Young Adults

Stress and coping resources are available to help support teens and young adults struggling during the COVID-19 pandemic.

Find resources for young people and visit <u>Support For Teens and Young Adults (cdc.gov)</u>

#### Tools for Supporting Emotional Wellbeing in Children and Youth

Easy-to-use and interactive web tools are available to help children and teens cope with stress and worries and deal with thoughts and feelings in a healthy way.

➤ Learn more about supporting children and teens, visit <u>| The National Academies Press |</u>
Tools for Supporting Emotional Wellbeing in Children and Youth

# Mental Health and Wellbeing Resources for Youth

The Youth gov website includes a list of resources to help youth learn about topics related to mental health, find places where they can get help if they need it, hear from other youth about their struggles with mental health challenges, and help others get through tough times.

Find resources for youth and visit Mental Health and WellBeing (engage.youth.gov)

#### National Child Traumatic Stress Network

The National Child Traumatic Stress Network (NCTSN) is federally funded and was created to raise the standard of care and increase access to services for children and families who experience or witness traumatic events.

Find resources on supporting children and families impacted by COVID-19, visit <a href="Search | The National Child Traumatic Stress Network (nctsn.org)">Search | The National Child Traumatic Stress Network (nctsn.org)</a>

# Resources for Military Veterans, Service Members, and their Families

#### Department of Veterans Affairs Treatment Locator

The Department of Veterans Affairs (VA) provides a resource to identify VA treatment locations or in-network community care providers. Just enter a location (street, city, state, or postal code), the type of facility, and the type of service for a list of providers.

Access information about VA treatment, visit Find VA Locations | Veterans Affairs

#### Department of Veterans Affairs COVID Coach

The COVID Coach app was created for everyone, including Veterans and Service members, to support self-care and overall mental health during the COVID-19 pandemic. The app is available on Apple and Android devices.

➤ Learn more about COVID Coach, visit COVID Coach | VA Mobile

#### Department of Veterans Affairs Mindfulness Coach 2 App

Mindfulness Coach 2 was developed to help Veterans, Service Members, and others learn how to practice mindfulness. The app provides a gradual, self-guided training program designed to help individuals understand and adopt a simple mindfulness practice. Mindfulness Coach 2 also offers a library of information about mindfulness, 12 audio-guided mindfulness exercises, a growing catalog of additional exercises available for free download, goal-setting and tracking, a mindfulness mastery assessment to help you track your progress over time, customizable reminders, and access to other support and crisis resources.

Access the Mindfulness Coach 2 app, visit Mindfulness Coach | VA Mobile

#### Department of Veterans Affairs National Center for Posttraumatic Stress Disorder

The National Center for Posttraumatic Stress Disorder (PTSD) has strategies that can help with the stress, grief, and anxiety related to COVID-19. Information is available to support self-care, the work of providers, and community efforts.

➤ Learn more about the COVID-19 resources, visit <u>COVID-19: Resources for Managing Stress - PTSD: National Center for PTSD (va.gov)</u>

#### Department of Veterans Affairs Veterans Crisis Line

Veterans Crisis Line, text-messaging service, and online chat provides free confidential support for all Service members, including members of the National Guard and Reserve, and all Veterans, even if they are not registered with the VA or enrolled in VA health care.

- Find support, dial 988, then select 1
- > Text 838255 from your mobile device
- Access the online chat, visit Chat (veteranscrisisline.net)

#### Department of Veterans Affairs Whole Health Resources

The self-help VA Whole Health app is a free, easy-to-use tool created for Veterans and others who are ready to take the next step in their Whole Health journey. Available on Apple and Android devices, Whole Health is the VA's holistic approach to care that supports your health and well-being. With this app, you can fill out your personal health inventory, set goals, and learn more about Whole Health.

Access the Whole Health Mobile app and other on-line resources, visit Mobile Apps and Online Tools - Whole Health (va.gov)

#### Department of Defense Treatment Locator

Military hospitals and clinics are found at military bases and posts around the world. They are also referred to as "military treatment facilities" or "MTFs." Use this resource to find a military hospital or clinic near you.

Access military treatment facilities, visit Find a Military Hospital or Clinic | TRICARE

#### Department of Defense Military OneSource

Military OneSource is a free helpline service provided 24-hours-a-day, 7-days-a-week by the Department of Defense to service members and their families to help with a broad range of concerns, including possible mental health problems.

Find support, call 1 (800) 342-9647 or visit <u>Support for Military Personnel & Families • Military OneSource</u>

#### Department of Defense Psychological Health Center of Excellence

The Psychological Health Center of Excellence (PHCoE) provides psychological health research self-help consultation and expertise to leaders, providers, service members, and their families, with a helpline available 24 hours-a-day.

- ➤ Learn more about this service, visit <u>Psychological Health Center of Excellence</u> | Health.mil or call 1 (866) 966-1020
- You may also <u>Live Chat</u> or email the Center at <u>dha.ncr.j-9.mbx.intransition@mail.mil</u>

#### Department of Defense Psychological Health Resource Center

A free, trusted Department of Defense source of psychological health information and resources related to how to get into treatment, types of treatment for mental health conditions, and many other topics. Individuals have access to professional health resource consultants, all of whom are master's-level mental health clinicians that understand military culture. This is not a treatment or counseling center, but helps service members, Veterans, family members, clinicians and commanders to access mental health care.

- ➤ To find a psychological health resource center, call 1 (866) 966-1020, 24 hours-a-day, 7 days-a-week
- ➤ Learn more about the Psychological Health Resource Center, visit <u>Crisis Hotlines</u> <u>TRICARE</u>

#### Department of Defense in Transition Program

This is a free confidential program that provides a helpline with specialized coaching and assistance for service members, National Guard members, reservists, Veterans, and retirees. Resources are available to those who need access to mental health care when relocating to another assignment, returning from deployment, transitioning between active duty and reserve component, preparing to leave military service, or any other time they need a new mental health provider, or need a provider for the first time.

- Talk with an inTransition Program specialist, call 1 (800) 424-7877
- Learn more about inTransition, visit inTransition | Health.mil

#### Indian Health Service Resources

#### Indian Health Service Mental Health Program

Many tribes run their own mental health programs. The Indian Health Service's Mental Health Program is a community-based clinical and preventive service program that provides access to vital outpatient mental health counseling, dual diagnosis services, mental health crisis response

and triage teams, case management services, community-based prevention programming, outreach, and health education activities.

- Access local treatment, visit <a href="#">IHS Mental Health Programs | Mental Health</a> and check "Behavioral Health" under "Choose facility types"
- Learn more about mental health resources, visit Mental Health | Indian Health Service (IHS)

#### Resource for the Healing Process

In Tribal communities, schools, health care services, and tribal programs play an important role in providing the necessary services to aid in the healing of mental and behavioral health issues including suicide, substance use, depression, and trauma. These resources are available to those seeking assistance.

Find behavioral health resources, visit <u>Resources for the Healing Process | Mental</u> Health (ihs.gov)

#### Stronghearts Native Helpline

This helpline provides access to a confidential and anonymous domestic, dating, and sexual violence hotline for American Indian or Alaska Native (AI/AN) individuals, offering support, referrals, and advocacy. The trained professionals can assist family members or friends of abuse victims with information to give to loved ones.

- Access the Stronghearts Native Helpline, call 1 (844) 762-8483 or 1 (844) 7NATIVE
- Learn more about this resource, visit StrongHearts Native Helpline

#### **Suicide Prevention Resources**

Depression and suicide affect people of all ages and populations. AI/AN populations experience a higher rate of suicide than any other group in the United States. If you are experiencing a crisis, there are options available to help.

Access support resources through Suicide Prevention | Health Topics (ihs.gov)

# Treatment Locator for Indian Health Service, Tribal or Urban Indian Health Program

This online locator and map can be used to find Indian Health Service, Tribal or Urban Indian Health Program facilities, including behavioral health facilities.

Find local services, visit Find Health Care | Indian Health Service (IHS)

## Two-Spirits and the LGBTQ+ Community

Two-Spirits provides resources for Two-Spirit and LGBTQ+ individuals and loved ones (third party) within the American Indian and Alaska Native community. Includes information on finding a provider, community support, mental health care, and legal rights.

Find more information, visit <u>Two-Spirit | Health Resources (ihs.gov)</u>

#### WERNATIVE

WERNATIVE provides comprehensive health resources and information for Native youth, by Native youth. It includes information about culture, environment, mental health, physical health, relationships, life tips, spirituality, wellness, and activism.

Find resources, visit Home - We R Native

#### Indian Health Service Telebehavioral Health Program

Provides direct, ongoing care via televideo to patients of all ages at IHS, Tribal, and Urban Indian operated facilities across the country. Current clinical services include: Adult Psychiatry; Addictions Psychiatry; Geriatric Psychiatry; Child and Adolescent Psychiatry; Adult Therapy; Family, Couples, and Group Therapy; Child and Adolescent Therapy; and Trauma and PTSD Therapy.

- Learn more about the Telebehavioral Health Program, visit <a href="HTML">HEALTH TELEBEHAVIORAL HEALTH TELEBEHA
- Find a list of TBHCE sites, visit <u>Current TBHCE Sites | Telebehavioral Health (ihs.gov)</u>

# **Substance Use Supports and Services**

The ongoing stress and uncertainty prompted by the pandemic continues to have an impact on people's health and well-being. Increases in substance use and drug overdoses have emerged in the United States since the COVID-19 pandemic was declared a national emergency in March 2020. Research shows that 13% of Americans started or increased substance use as a way of dealing with stress or emotions related to COVID-19,8 and people with substance use conditions are at increased risks for poor COVID-19 outcomes. The federal government has resources available to help address substance use issues. This section covers four topics

- Treatment Locators
- Self-Help Resources
- Resources for Military Veteran, Service Members, and their Families
- Indian Health Service Resources.

#### **Treatment Locators**

#### Behavioral Health Services Treatment Locator

The Locator provides confidential and anonymous information for anyone seeking treatment facilities for substance use challenges and mental health problems.

#### Not Sure Where to Start?

# Q. Are you looking for substance use treatment?

**A.** Visit the Behavioral Health Treatment Services Locator through Home - SAMHSA

Behavioral Health Treatment
Services Locator

# Q. Do you feel like you need to talk with someone to figure out your treatment options?

**A.** Call the National Helpline at 1 (800) 662-HELP (4357); For TYY Users Dial 1 (800) 487-4889

This helpline provides free, confidential information, 24 hours-a-day, 365 days-a-year, in English and Spanish, for individuals and family members facing mental health conditions and substance use challenges.

Finding treatment, call 1 (800) 622 HELP (4357) or visit <a href="Home | FindTreatment.gov">Home | FindTreatment.gov</a>

#### Buprenorphine Practitioner Locator

This easy-to-use resource helps you to use an interactive map to find practitioners authorized to treat opioid dependency with buprenorphine by state.

Find local opioid dependency treatment, visit <u>Buprenorphine Treatment Practitioner</u> <u>Locator | SAMHSA</u>

#### **Opioid Treatment Program Directory**

This resource allows you to find opioid treatment programs in your state.

Find opioid treatment programs in your state, visit OTP Directory (samhsa.gov)

# Self-Help Resources

### Alcohol and COVID-19

Alcohol misuse is a public health concern in the United States.

Access resources about alcohol treatment at <u>Alcohol and COVID-19 | National Institute</u> on Alcohol Abuse and Alcoholism (NIAAA) (nih.gov)

#### Alcohol Screening Tool

CDC has launched a new tool for adults to anonymously check their drinking, identify barriers and motivators for drinking less, and print or save a personalized change plan. This evidence-based tool is a free resource.

Access the Alcohol Screening Tool, visit Check Your Drinking | Alcohol | CDC

## COVID-19 Information, Support, and Resources

Substance use concerns can make people more likely to become severely ill from COVID-19, and as such additional precautions are needed for protection against COVID-19.

- Find information, support, and resources, visit <a href="COVID-19 Information">COVID-19 Information</a>, Support, and <a href="Resources">Resources</a> | Drug Overdose | CDC Injury Center</a>
- Find additional resources, visit <u>COVID-19 & Substance Use | National Institute on Drug</u> Abuse (NIDA) (nih.gov)

## Resources for Families Coping with Mental Health Conditions and Substance Use Challenges

Every family is different, but families may share a bond that can be used to support one another during trying times including this pandemic. Family support can play a major role in helping a loved one with mental health conditions and substance use challenges.

Find resources for families, visit <u>Resources for Families Coping with Mental and Substance Use Disorders | SAMHSA</u>

#### Resources on Harm Reduction

Harm reduction practices aim to reduce the harms associated with substance use by providing non-judgmental services and supports to people who use drugs.

- Find resources on harm reduction strategies at <a href="Harm Reduction">Harm Reduction</a> | SAMHSA
- Learn about CDC's National Harm Reduction Technical Assistance Center, visit Home (cdc.gov)
- Find resources on novel harm reduction and treatment strategies to support individuals with opioid use concerns, visit <a href="Harm Reduction National Council for Mental Wellbeing (thenationalcouncil.org">Harm Reduction National Council for Mental Wellbeing (thenationalcouncil.org)</a>

# Resources for Military Veterans, Service Members, and their Families

#### Department of Veterans Affairs Substance Use Treatment for Veterans

If you are struggling with substance use concerns, you are not alone. Many Veterans have problems with the use of alcohol, tobacco, street drugs, and prescription medicines.

Find out how to get support for substance use concerns, visit <u>Substance Use Treatment</u>
For Veterans | Veterans Affairs (va.gov)

## Department of Veterans Affairs Substance Use Resources

The VA has substance use resources, information, treatment options, and more—all accessible to Veterans, Veterans' supporters, and the general public. Explore these pages to learn more about a substance use topic or to find information specifically tailored to your needs.

Find more information on substance use resources, visit Mental Health Home (va.gov)

# Department of Veterans Affairs Veterans Crisis Line

Veterans Crisis Line, text-messaging service, and online chat provide free confidential VA support for all Service members, including members of the National Guard and Reserve, and all Veterans, even if they are not registered with VA or enrolled in VA health care.

- Dial 988, then press 1
- > Text 838255 from your mobile device
- Chat with a representative by visiting Chat (veteranscrisisline.net)

## Department of Veterans Affairs Whole Health Resources

The VA Whole Health app is a free, easy to use tool created for Veterans and others who are ready to take the next step in their Whole Health journey. Available on Apple and Android devices, Whole Health is VA's holistic approach to care that supports health and well-being. With this app, you can fill out your personal health inventory, set goals, and learn more about Whole Health.

Learn more about Whole Health, visit Employee Whole Health - Whole Health (va.gov)

#### Department of Defense Military OneSource

Military OneSource is a free service provided by the Department of Defense to service members and their families to help with a broad range of concerns, including possible mental health problems.

➤ Call and talk anytime, 24 hours-a-day, 7 days-a-week, at 1 (800)-342-9647. For more information, visit Support for Military Personnel & Families • Military OneSource

#### Department of Defense Psychological Health Center of Excellence

The Psychological Health Center of Excellence (PHCoE) provides psychological health research consultation and expertise to leaders, providers, service members, and their families, with a help line available 24 hours-a-day.

- To talk with someone at PHCoE call 1 (866) 966-1020
- You may also Live Chat or email the Center at dha.ncr.j-9.mbx.intransition@mail.mil
- For more information about this service, visit <a href="Psychological Health Center of Excellence">Psychological Health Center of Excellence</a> | Health.mil

#### Department of Defense Psychological Health Resource Center

A free, trusted Department of Defense source of psychological health information and resources related to how to get into treatment, types of treatment for mental health conditions and substance use challenges. Provides access to professional health resource consultants, all of whom are master's-level mental health clinicians that understand military culture. This is not a treatment or counseling center, but we can help service members, veterans, family members, clinicians and commanders to access mental health care.

- > To find a resource center, call 1 (866) 966-1020, 24 hours-a-day, 7 days-a-week
- For more information, visit Crisis Hotlines | TRICARE

#### **Indian Health Service Resources**

#### Alcohol and Substance Abuse Program

The Alcohol and Substance Abuse Program (ASAP) is designed to reduce the incidence and prevalence of alcohol and substance use challenges among AI/AN persons to a level at or below the general U.S. population. ASAP strives to meet this goal through the implementation of alcohol and substance use programs within Tribal communities, including emergency treatment, inpatient and outpatient treatment, and rehabilitation services, in rural and urban settings.

Learn more about ASAP, visit <u>Alcohol and Substance Abuse Program | Indian Health</u> Service (IHS)

#### Indian Health Service's Mental Health Program

The Indian Health Service Mental Health Program is a community-based clinical and preventive service program that provides access to vital outpatient mental health counseling, dual diagnosis services, mental health crisis response and triage teams, case management services, community-based prevention programming, outreach, and health education activities.

- Find mental health programs in your area, search the <a href="HS Mental Health Programs">IHS Mental Health Programs</a> <a href="Mental Health">Mental Health</a> by checking "Behavioral Health" under "Choose facility types"
- Learn more, visit Mental Health | Indian Health Service (IHS)

#### Resources for Substance Use Challenges

Understanding the warning signs, risk factors, and protective factors associated with substance use challenges are critical to providing effective prevention, intervention, and treatment. This Indian Health Service page includes information and resources.

Find resources and more information, visit <u>Substance Abuse | Health Topics (ihs.gov)</u>

#### Resource for the Healing Process

In Tribal communities, schools, healthcare services, and tribal programs play an important role in providing the necessary services to aid in the healing of mental and behavioral health issues including suicide, substance use, depression, and trauma.

Find supportive resources, visit <u>Resources for the Healing Process | Mental Health (ihs.gov)</u>

# Treatment Locator for Indian Health Service, Tribal or Urban Indian Health Program

This resource includes a map that can be used to find Indian Health Service, Tribal or Urban Indian Health Program facilities, including behavioral health facilities.

➤ Identify local treatment, visit Find Health Care | Indian Health Service (IHS)

# **Bereavement Supports**

Millions are coping with the death of loved ones since the COVID-19 pandemic. One-fifth of Americans had lost a relative or close friend in early 2021, when there were roughly half as many deaths from COVID-19 as today. <sup>27</sup> Providing support and resources to individuals who have lost loved ones during the pandemic remains an important priority in the process of grief and bereavement. People cope with losses in different ways. If you need bereavement support or help dealing with your loss, federal resources are available to help. This section includes federal supports and services. There are additional community and state supported services that may be available to individuals who have lost a loved one.

This section covers five topics

- Treatment Locators
- Self-Help Resources
- Caring for Children Who Lost Caregvers
- Survivor Benefits
- Funeral Assistance.

#### **Treatment Locators**

#### Behavioral Health Services Treatment Locator

The Locator provides confidential and anonymous information for anyone seeking treatment facilities for substance use challenges and mental health problems.

Finding treatment, call 1 (800) 622 HELP (4357) or visit Home | FindTreatment.gov

#### **Not Sure Where to Start?**

# Q. Need help paying COVID-19-related funeral expenses?

A. Call the Federal Emergency Management Agency (FEMA) to see if you are eligible for financial assistance to cover COVID-19-related funeral expenses. Toll free number: (844) 684-6333, Monday-Friday, 9:00 a.m. to 9:00 p.m. ET. If you use a relay service, please provide FEMA with the specific number assigned to you for the service so FEMA can follow up with you about your application. Multilingual services are also available.

For more information you may also want to visit <a href="Mailto:COVID-19 Funeral">COVID-19 Funeral</a>
<a href="Assistance">Assistance</a> | FEMA.gov</a>

# Q. Having problems coping with your loss?

**A.** Call the National Helpline at 1 (800) 662-HELP (4357); 1 (800) 487-4889 (TTY)

Access local services through the Behavioral Health Treatment Services Locator and visit Home - SAMHSA Behavioral Health Treatment Services Locator

#### Department of Veterans Affairs Bereavement Counseling

If you are the surviving spouse, child, or parent of a service member who died while serving their country, you may qualify for bereavement counseling through the VA. Bereavement counseling (also sometimes called "grief counseling") provides assistance and support for people going through emotional and psychological stress after the death of a loved one.

Access information about VA Bereavement Counseling, visit <u>Bereavement Counseling</u> |
 Veterans Affairs (va.gov)

# Self-Help Resources

#### Resources on Grief and Loss

CDC has resources available that can help you cope with the loss of loved one during the COVID-19 pandemic.

Learn more information and access resources, visit Grief and Loss (cdc.gov)

#### Helping Children Cope

CDC provides information for adults on how to help children cope with loss, and help support their mental health in light of the COVID-19 pandemic.

Learn more information about children and coping, visit Helping Children Cope (cdc.gov)

#### How Children Grieve and How Parents and Other Adults Can Support Them

SAMHSA provides a resource for parents and other adults to help children who have suffered the loss of a parent or loved one.

Learn more on supporting children with grief, visit After a loved one dies - how children grieve: And how parents and other adults can support them | SAMHSA

#### **Bereavement Resources**

MedlinePlus links to health information from the National Institutes of Health and other federal government agencies and provides resources on bereavement, grief, and loss.

Find bereavement resources, visit <a href="Bereavement: MedlinePlus">Bereavement: MedlinePlus</a>

## Department of Defense Resources on Understanding Grief

Grief is a natural response with the loss of a loved one. This resources provides tools and services to help you cope, make informed decisions, grieve in healthy ways, and begin to envision a life with new opportunities.

Find more bereavement resources, visit <u>Grief and Loss • Bereavement • Military</u> OneSource

### Coping with Grief: Life after Loss

This resource from the National Institute of Mental Health provides information on adapting to loss, types of grief, and discusses life beyond the loss of a loved one.

Learn more about coping with grief, visit Coping With Grief | NIH News in Health

### Caring for Children Who Lost Caregivers

#### Children Who Have Lost a Parent or Caregiver to COVID-19

Thousands of children in the United States have lost a parent or caregiver during the COVID-19 pandemic.<sup>9</sup> These children have experienced the deaths of one or both parents, and grandparent caregivers. CDC and the Administration for Children and Families, Children's Bureau has resources about family-based care support services and protecting children who experienced the loss of a parent or caregiver.

- Find additional information: <u>Children: The Hidden Pandemic 2021.</u> A joint report of COVID-19 associated orphanhood and a strategy for action (cdc.gov)
- Learn more about global orphanhood: Global Orphanhood Associated with COVID-19 | CDC
- Child Welfare Information Gateway provides information and resources on a wide range of child welfare topics, covering the continuum from preventing child abuse and neglect through adoption. To support professionals working with children and families involved with child welfare, we offer current information, research, statistics, best practices, and other materials. Access information and resources on child welfare topics, visit Topics Child Welfare Information Gateway

### Survivors Benefits

### Social Security Survivors Benefits

The Social Security Administration provides information on the basics of survivor benefits, how to apply, what documents you need, and other related information.

- Apply for benefits, call 1 (800) 772-1213 and 1 (800) 325-0778 (TTY), Monday through Friday, 8:00 a.m. to 7:00 p.m. ET.
- ➤ Find the phone number for your local office by using the SSA Social Security Office Locator here: Social Security Office Locator, SSA Office Locator Social Security Office Locator, Social Security

Learn more about the basics of survivor benefits, visit Survivors Benefits | SSA

#### Funeral Assistance

#### **COVID-19 Funeral Assistance**

If you are responsible for COVID-19-related funeral expenses, the Federal Emergency Management Agency (FEMA) may be able to help.

- ➤ Call FEMA's toll-free helpline to learn more and apply for assistance: (844) 684-6333, Monday through Friday, 9:00 a.m. to 9:00 p.m. ET
- If you use a relay service, please provide FEMA with the specific number assigned to you for the service so FEMA can follow up with you about your application
- ➤ Multilingual services are also available
- Find additional information and visit COVID-19 Funeral Assistance | FEMA.gov

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### Chapter 5: Future Directions

On April 5, 2022, President Biden pledged to harness the full potential of the federal government in coordination with public and private sector partners to respond to the longer-term effects of COVID-19 fully and effectively. The President emphasized a strong commitment to ensuring that individuals, families, and communities affected by COVID-19 and Long COVID have access to programs and resources to help support healing, health, and well-being.

The Services and Supports for Longer-Term Impacts of COVID-19 Report is an important component of the overall federal response. It provides resources that are relevant to individuals with Long COVID, health care personnel addressing the needs of those with Long COVID, and individuals and their families who are experiencing the longer-term effects of COVID-19. To address the longer-term effects of COVID-19, the report includes supports and services that can help address mental health and substance use challenges that have escalated during the pandemic. The report also includes a section on resources for those mourning the loss of their loved ones.

This report compiles federal services and supports into one document. It includes a description of the resources as well as information on how to access them. For each of the resources, a website or phone number is provided.

The Department of Health and Human Services hosted a series of interactive listening sessions

"People experiencing Long COVID symptoms don't know where to go. Even when there is a COVID-19 specialist nearby, the wait is 6-12 months for an initial visit."

—Person with Long COVID

Action Plan on Long COVID. The sessions included a broad range of participants, including persons affected by Long COVID, researchers, health care personnel, organizations representing health care professionals, public health partners, and advocacy organizations. In parallel, the Department of Health and Human Services' Office of the Assistant Secretary for Health ran its Health+™, pronounced "health plus," research model for human-centered design. This Health+Long COVID cycle involves over 1,000 hours of patient interviews, workshops, listening sessions, and human-centered research to co-create solutions with—not for—those impacted by Long COVID. The Health+ model positions people as active participants—experts in their own life challenges—listening and learning from their lived experiences, to uncover their needs and understand their challenges.

Across listening sessions and Health+ engagements, stakeholders repeatedly emphasized the need for accessible supports and services. They indicated that a compilation of these resources could help lessen the burden of COVID-19 on individuals and their families.

It is worth repeating that this report is only the first step. In the coming months, the information within this report will be posted on federal websites. Navigable web pages will help individuals and others affected by COVID-19 and Long COVID quickly and efficiently find services and supports. Printable fact sheets will help health care personnel connect the people they serve to the resources they need. At the same time, the implementation of the National Research Action Plan will inform the development and deployment of additional resources. The work of the federal government will continue to support individuals and communities experiencing the longer-term effects of the ongoing COVID-19 pandemic.

# Engagement of Public and Private Stakeholders in the Development of the Report

A few of the most common messages heard during the listening sessions are summarized below.

### Increase Awareness of Long COVID, Behavioral Health Challenges, and Bereavement

During the listening session, a recurring theme was that more information needs to be available and accessible about the longerterm effects of COVID-19. Many acknowledged that a part of the population remains skeptical about COVID-19 generally. With the combination of lack of information and skepticism, many people do not know what is happening to them when they experience symptoms. They can feel alone, frightened, and sometimes ashamed.

Several suggested that establishing a central location for information, such as a national website, would be a step in the right direction. It would allow individuals experiencing Long COVID and other problems related to the pandemic and others to have confidence in the source of information.

## Listening Session with Stakeholders Informed both Reports

### Listening sessions included:

- Long COVID advocates
- Disability and chronic illness advocates
- Provider groups and organizations (health care organizations and systems, community health centers, mental health, hospitals)
- Researchers, including patient researchers
- Public health partners
- Professional organizations
- Mental health advocates
- Children's advocates.

### Additional Services and Supports for those Experiencing Longer-term Impact of the Pandemic Including Bereavement

Participants in the listening sessions acknowledged the profound impact of the death of a loved one and the reality that some of us experienced numerous losses without time to process and grieve. The loss of a loved one can impact a sense of financial security, cause depression and loneliness, and underscores the need to take intentional action. Participants suggested expanded

"Parents seeking Long COVID care for their children do not have relevant information to challenge pediatricians or teachers who dismiss children's symptoms as puberty, growing pains, or moodiness."

—Parent of a child with Long
COVID

mental health services, particulary school based services, creation of a registry of providers who can support those in need of grief counseling, to focus particularly on the communities hardest hit by the pandemic including the black and American Indican/Alaskan Native communities.

### Increase Attention on the Impact of the Pandemic on Children

Participants in the listening sessions identified the lack of information, research, and education about children with Long COVID as a high priority area to address. Many parents of children with Long COVID and other consequences of the pandemic talked about their frustration with having their pediatricians and school administrators tell them that anxiety disorder, depression, or puberty were to blame for their children's Long COVID symptoms. Many parents reported feeling helpless when their children's doctors wrongly indicated that Long COVID does not occur in children.

## Make Information, Services, and Supports Available to People with Affected by the Pandemic

Many individuals affected by the pandemic, including Long COVID, are not getting the services they require and are at risk of losing their jobs, their homes, and their families. For example, participants in the listening session voiced their experiences with community service providers and their health care providers being reluctant to label their Long COVID symptoms as being a disability. They noted that many of the people who administer public support programs are not aware that Long COVID can cause disabilities. They mistakenly assume they cannot help people with Long COVID by providing financial assistance and other supports. Further, several individuals reported that their employers were unwilling to make workplace accommodations, such as allowing them to telework from home, they had no recourse, and they lost their jobs.

### Clarify that Long COVID can be a Post-Infectious Condition

Many reported that health care providers were too quick to dismiss or ignore some of the features of Long COVID. Features of Long COVID overlap with many mental health conditions, and health care providers need to be able to identify Long COVID to help people manage their symptoms. One person noted that current depression and anxiety disorder screening questions

may falsely classify individuals with Long COVID as having a mental illness (or vice versa) and may miss the association with having had COVID-19. Another person related that emergency department staff informed her that rapid heartbeat, anxiety about her health, and hopelessness were indications of an anxiety disorder rather than recognizing these as common features of Long COVID.

# Ensure that Services are Accessible, Culturally Informed and Linguistically Effective

Many of the individuals in the listening sessions emphasized that communications should be accessible, clear, and provided in the language of the population served. People from racial and ethnic minority groups and the LGBTQI+ community discussed the barriers to receiving services in their communities. They described the stigma, racism, ableism, and provider bias within their communities regarding COVID-19. They noted the lack of COVID-19 research with diverse populations and the lack of providers who work close by and are able and willing to work with non-English speakers. People with disabilities are experiencing barriers in receiving services, including long wait times, and problems with access and safety.

### Reduce Long Waits for Services

A critical workforce shortage exists within the health care system. Not enough providers are available to serve the needs of the anticipated number of individuals experiencing Long COVID

symptoms. People with Long COVID reported waiting 4 to 12 months for an initial appointment with a medical specialist, such as a neuropsychologist, cardiologists, or pulmonologist. An individual shared that very few medical care providers have multidisciplinary practices, so they were forced to visit four to five different provider's offices when they were so tired they could hardly walk. Listening session participants highly recommended telemedicine and clear guidance about how to access immediate care. Several

"I got COVID-19 and I was embarrassed that I continued to have symptoms after the 14 day quarantine. I am 70 years old. I doubted my own symptoms for so long. I was afraid to even go to my doctor because I thought they wouldn't believe me."

—Person with Long COVID

people urged that states eliminate barriers to cross-state telehealth and expand cell phone coverage in rural areas.

### Provide Clinical Guidance and Support for Healthcare Personnel

Health care personnel who participated in the listening sessions reported the need for guidance on how to address the multiple needs of patients with pandemic consequences. They reported treating individual symptoms without having a clear understanding of how to address the overall condition. Very few said that they worked within a Long COVID medical center, and so they felt overwhelmed by the number of people coming to see them since the pandemic

started. They voiced the need for clinical guidance on care coordination and referrals for Long COVID patients. They identified needs for continuing education on topics such as common post-infectious conditions and common Long COVID symptoms, and treatment.

COVID-19 has exacerbated existing shortages in health care personnel, and a critical imperative remains to grow, support, retain, and efficiently deploy the health care workforce. In particular, it is important to identify which factors (e.g., wages, opportunity for career advancement, schedule flexibility, engagement) and which system-level strategies (e.g., education, staffing and safety policies, coaching) can improve the job satisfaction, engagement, and well-being of the health care workforce.

### Challenges with Addressing the Longer-Term Impacts of COVID-19

Influenced by the public listening sessions, 14 U.S. government departments and agencies coordinated to draft this report.

Departments identified current supports and

services available for those experiencing Long COVID and the longer-term effects of COVID-19. Many of the resources existed before the pandemic and offer services and supports to individuals and their family members who have disabilities. Depending on their level of disability and need, many individuals experiencing the longer-term effects of COVID-19 can access these programs to meet their needs.

As part of their work in compiling this report, federal departments also identified challenges to ensuring accessible resources to those in need. The five challenges most commonly reported by federal departments were lack of awareness; difficulties reaching individuals and families due to COVID-19 precautions; statutory limitations; limited resources; and insufficient data. The U.S. government will work to address each of these challenges. These challenges provide an opportunity for federal departments and agencies to improve services and supports.

# Federal Government Efforts That Will Improve Identification of Long COVID and Connect Patients to Care

- Convene public and private partners to better align the definitions of Long COVID and develop agreed upon terminology for clinical care, surveillance, and research
- Develop comprehensive and equitable Long COVID diagnosis, care, and treatment guidance
- Make available tools to help individuals recognize symptoms of Long COVID and to discuss their symptoms with their health care providers
- Advance research that helps separate the broader effects of the pandemic on an individual's physical and mental health from those of the initial SARS-CoV-2 infection and re-infections
- Use findings from Health+ Long COVID patient-centered research to improve the way individuals access and receive health care and services.

### Lack of Awareness

Public awareness of the full range of government services and supports for individuals experiencing longer-term effects of the ongoing pandemic remains limited. Individuals experiencing the impacts of COVID-19, their family members, health care providers, schools, employers, and state agencies that administer federally-funded programs may be unaware of the resources and services available through U.S. government programs. Many were also unaware of changes to eligibility criteria for these programs that now allow for individuals with Long COVID to participate. Other times, individuals may know about a resource but not know how to access it. Expanding awareness will require enhanced coordination and outreach to ensure consistency in various activities and programs.

### Difficulties Reaching Individuals and Families

Some federal programs leverage technology to create flexible ways of connecting with individuals. Other programs have difficulty maintaining sufficient engagement with patients through remote settings. The problem has persisted and created a gap in services and supports, especially among those focused on recovery support services for substance use concerns.

The COVID-19 pandemic expanded how federal agencies use technology to engage with clients, and efforts are underway to determine how technology can be further and effectively leveraged.

### **Insufficient Data**

We are only beginning to understand the exact nature of Long COVID. Insufficient data about the longer-term impacts of COVID-19 make it difficult to accurately inform federal programs serving target populations. For example, some people have well-recognized longer-term illnesses related to COVID-19, such as myocarditis, lung fibrosis, or diabetes. Management of these illnesses can follow established medical approaches. Others with Long COVID may experience non-specific symptoms, such as periodic fatigue, "brain fog," or anxiety, which can be more challenging to recognize and manage. Enhancing the capacity to capture and analyze data may accelerate learning about how to prevent, diagnose, and manage the longer-term effects of COVID-19. As the evidence accumulates, living evidence reviews, guidelines, and clinical decision supports will need to be developed so that individuals and their families receive the full array of services and supports that they need. With more knowledge from persons affected by Long COVID, based on their experiences of living with it, programs can offer relevant and needed services.

#### Limited Resources

Limited resources, such as staffing or funding, limit the impact of programs. The most common gap identified was created due to stagnant funding levels. Understanding and articulating the impact of these limited resources will support future request to Congress for funding to address

the longer-term impact of COVID-19, including Long COVID and associated conditions, mental health and substance use challenges, and bereavement.

### The National Research Action Plan on Long COVID

The companion document to this report, the National Research Action Plan on Long COVID, will be essential in advancing progress in the provision of services and supports for individuals and families experiencing Long COVID.

Understanding the need for and access to services and supports, including disability services and caregiver supports, is part of the National Research Action Plan. Research must identify strategies to address the pandemic's disproportionate impact on certain communities and populations. We must identify ways to translate research into equitable service delivery. Qualitative and quantitative research methods are complementary for a more complete understanding of the health and socioeconomic burdens on individuals affected by COVID-19, and among different races, ethnicity groups, pregnant people, and those with underlying disabilities.

### **Conclusion**

Although we are still learning about Long COVID and the longer-term impacts of COVID-19, a lot has been done, and there are substantial services and supports through many U.S. government programs to support those affected. This report is the first iteration of a compendium of supports for use by individuals, communities, and health enterprises. In upcoming months and years, the U.S. government will continue to invest in supports and further refine the scope of services as we learn more through lived experiences and research about Long COVID and the other longer-term impacts of COVID-19.

Moving forward, federal departments will continue to engage with partners, including state and local governments. Engagement of nongovernmental experts, organizations, and stakeholders, including individuals affected directly by the longer-term effects of COVID-19, has played an essential role in shaping the government's response to COVID-19 and Long COVID, including the development of this Report and the National Research Action Plan.

### Appendix A: Report Abbreviations

AAA Area Agency on Aging

ACA Affordable Care Act

ADA Americans with Disabilities Act

ADAKTC ADA Knowledge Translation Center

ADRC Aging and Disability Resource Center

AHRQ Agency for Healthcare Research and Quality, HHS

Al/AN American Indian, Alaska Native

ASAP Alcohol and Substance Abuse Program

AT Assistive Technology

CAA Community Action Agencies

CCDF Child Care and Development Fund

CDC Centers for Disease Control and Prevention, HHS

CDS Clinical Decision Support

CED Community Economic Development

CHIP Children's Health Insurance Program

CHR Community Health Representative

CIL Center for Independent Living

CMS Centers for Medicare & Medicaid Services, HHS

COBRA Consolidated Omnibus Budget Reconciliation Act

COCA Clinician Outreach and Community Activity

CoP Community of Practice

COVID-19 Coronavirus disease 2019

CSL Caregivers Support Line

CSP Caregiver Support Program

DBH Division of Behavioral Health, IHS, HHS

DHS Department of Homeland Security

DIAL Disability Information and Access Line

DOD Department of Defense

DOJ Department of Justice

DSM Diagnostic and Statistical Manual of Mental Disorders

DTAC Disaster Technical Assistance Center

EAP Employee Assistance Program

EARN Employer Assistance and Resource Network on Disability

Inclusion

EBSA Employee Benefits Security Administration

ECHO Extension for Community Healthcare Outcomes

EEOC Equal Employment Opportunity Commission Emergency

EHV Housing Voucher

EIC Earned Income Credit

EITC Earned Income Tax Credit

EPC Evidence-based Practice Center

F2F Family-to-Family

FAPE Free Appropriate Public Education

FDA Food and Drug Administration, HHS

FDPIR Food Distribution Program on Indian Reservations

FEHB Federal Employees Health Benefits

FEMA Federal Emergency Management Agency, DHS

FHCSD Family Health Centers of San Diego

FHIR Fast Healthcare Interoperability Resources

FQHC Federally Qualified Health Center

FY Fiscal Year

HAF Homeowner Assistance Fund

HCBS Home and Community-Based Services

HHS Department of Health and Human Services

HIV/AIDS Human Immunodeficiency Virus / Acquired

Immunodeficiency Syndrome

HRS&D Health Services Research and Development

HRSA Health Resources and Services Administration, HHS

HUD Department of Housing and Urban Development

IDEA Individuals with Disability Education Act

IHS Indian Health Service, HHS

IPT Integrated Practice Team

IT Information Technology

JAN Job Accommodations Network

LC&FIRP Long COVID and Fatiguing Illness Recovery Program

LIHEAP Low Income Home Energy Assistance Program

LIHWAP Low Income Household Water Assistance Program

LTCOP Long-Term Care Ombudsman Program

MCC Multiple Chronic Conditions

ME/CFS Myalgic Encephalomyelitis, Chronic Fatigue Syndrome

MHS Military Health System

MLN Medicare Learning Network

MTF Medical Treatment Facility

NADTC National Aging and Disability Transportation Center

NCCSD National Center for College Students with Disabilities

NEAR National Energy Assistance Referral

NFCSP National Family Caregiver Support Program

NIH National Institutes of Health, HHS

NPTC National Pharmacy and Therapeutics Committee National

NSLP School Lunch Program

OAA Older Americans Act

OCR Office for Civil Rights

P&A Protection and Advocacy System

PABSS Protection and Advocacy for Beneficiaries of Social

PASC Security Post-Acute Sequelae of COVID-19

PCC Post-COVID Conditions

PCOR Patient-Centered Outcomes Research

PCP Primary Care Provider

PHCoE Psychological Health Center of Excellence

PMG Practice Management Guide

PMHCA Pediatric Mental Health Care Access

PTI Parent Training and Information Centers

PTSD Post-Traumatic Stress Disorder

QPR Question, Persuade, and Refer

RECOVER Researching COVID to Enhance Recovery

RESEA Reemployment Services and Eligibility Assessment

RHC Rural Health Clinic

SAMHSA Substance Abuse and Mental Health Services

Administration, HHS

SARS-CoV-2 Severe Acute Respiratory Syndrome Coronavirus 2

SDOH Social Determinants of Health

SEA Self-Employment Assistance

SHIP State Health Insurance Assistance Program Supplemental

SNAP Supplemental Nutrition Assistance Program

SSA Social Security Administration

SSDI Social Security Disability Insurance

SSI Supplemental Security Income

TANF Temporary Assistance for Needy Families

TEFAP The Emergency Food Assistance Program Telehealth

TTELP Technology-Enabled Learning Program Teletypewriter

TTY Teletypewriter

UCFE Unemployment Compensation for Federal Employees

UCX Unemployment Compensation for Ex-Service members

USDA Department of Agriculture

VA Department of Veterans Affairs

VR Vocational Rehabilitation

WIC Women, Infants, and Children

WIPA Work Incentives Planning and Assistance

## Appendix B: Contributing U.S. Government Departments

### **Departments**

Department of Defense (DOD)



Department of Labor (DOL)



Department of Education (ED)



Department of the Treasury (DOT)



Department of Energy (DOE)



Department of Veterans Affairs (VA)



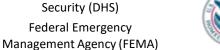
Department of Health and Human Services (HHS)\*



**Equal Employment Opportunity** Commission (EEOC)



Department of Homeland Security (DHS)



National Council on Disability (NCD)



Department of Housing and **Urban Development (HUD)** 



Office of Personnel Management (OPM)



Department of Justice (DOJ)



Social Security Administration (SSA)



#### **HHS Divisions\***

Administration for Children and Families (ACF) Administration for Community Living (ACL) Agency for Healthcare Research and Quality (AHRQ) Centers for Disease Control and Prevention (CDC) Centers for Medicare & Medicaid Services (CMS) Food and Drug Administration (FDA) Health Resources and Services Administration (HRSA) Indian Health Service (IHS) National Institutes of Health (NIH) Office for Civil Rights (OCR) Office of Global Affairs (OGA) Office of Intergovernmental and External Affairs (IEA)

Office of the Assistant Secretary for Administration (ASA) Office of the Assistant Secretary for Health (OASH) Office of the Assistant Secretary for Planning and **Evaluation (ASPE)** Office of the Assistant Secretary for Preparedness and Response (ASPR) Office of the Secretary (IOS) Office of the Surgeon General (OSG) Substance Abuse and Mental Health Services Administration (SAMHSA)