

# Living in the Long-COVID Era: From Diagnosis to Disability and Everything in Between

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The Social Support and Resource Specialist position is a Federal contract position funded through an “Expanding the Public Health Workforce” (PHW) grant offered to centers for independent living to better serve ongoing public health needs of our communities in response to COVID-19

# Breaking Down Barriers

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## The Big Question: Is COVID Still a Threat?

We wrestled with important questions like:

- Why now? Does COVID still pose a major public health threat?
- We still have CARES Act funding available, how is this different?
- Does this mean we have to be trained in clinical knowledge of COVID?
- Do we have to hire a medical professional with the funding?
- Are additional COVID services needed and relevant in our communities?
- Is this another example of government being out of touch with the disability community and what the gaps in services are?
- COVID became so political – how do we bridge this gap?

# Brookings Institute and CDC Household Pulse Survey

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Brookings Institute partnered with The Census Bureau and the CDC's updated Household Pulse Survey (HPS), to report on the prevalence of Long-COVID and to understand the labor market and economic impact of the condition. The survey found:

- At least 23 million Americans currently have Long-COVID, 16 million are working-age (18-65)
- Of those 16 million, up to 4 million are out of work due to Long-COVID
- The annual cost of those lost wages alone is around \$170 billion per year (possibly up to \$230 billion)

The speed at which these burdens will grow, depends largely on four factors:

- The availability and accessibility of improved treatment options that increase the long Covid recovery rate or move people from “severely ill” to “moderately” or “mildly” ill
- Whether vaccines reduce the odds of getting Long-COVID
- Whether repeat infections carry additional Long-COVID risk
- Whether or not policy interventions are put into place that reduce the workforce impact of Long-COVID

Sources:

<https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

<https://www.brookings.edu/research/new-data-shows-long-covid-is-keeping-as-many-as-4-million-people-out-of-work/>

# Coining the Term “Long-COVID”

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Source: [Research Article] “How and Why Patients Made Long Covid”, archived, National Library of Medicine  
*Research prov. By Felicity Callard, Univ. of Glasgow, Elisa Perego, Univ. College London; January, 2021*

“How scientists engage with knowledge about new diseases, affects how meaning about a disease accrues, how terminology solidifies, and which evidence is prioritized. In a global health crisis, we need contributions made by those with wide ranges of expertise – including, crucially, patients.”

Excerpt: “Patients collectively made Long-Covid – and cognate term ‘Long-haul Covid’ – in the first months of the pandemic. Patients, many with initially ‘mild’ illness, used various kinds of evidence and advocacy to demonstrate a longer, more complex course of illness than laid out in initial reports from Wuhan. Long Covid has a strong claim to be the first illness created through patients finding one another on Twitter: it moved from patients, through various media, to formal clinical and policy channels in just a few months. This initial mapping of Long Covid – by two patients with this illness – focuses on patients in the UK and USA and demonstrates how they marshalled epistemic authority. Patient knowledge needs to be incorporated into how COVID-19 is conceptualized, researched, and treated.”

# What is Long-COVID?

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“Long COVID is a complex, chronic illness that requires a robust, personalized approach for symptom management. There is currently no cure. However, based on the scientific literature from previous post-viral conditions, resting and pacing can be the most effective management techniques. Not allowing time for a full recovery from COVID-19 could increase the likelihood of long COVID worsening and turning into a longer-term disability. It’s vital that policymakers learn lessons from COVID long haulers in order to promote wide-ranging social resilience against current and future infections. Long haulers represent the largest influx of new members to the disability community in a generation.” *[source: The Century Foundation, Ryan Prior, Contributor, July 07, 2022]*

“Long COVID threatens to amass into a new wave of chronic illness with ramifications for health care systems and the economy for years to come.” *[source: U.S. News & World Report, Cecelia Smith-Schoenwalder, July 8, 2022]*

“Long COVID has been described as our “next national health disaster” and the “pandemic after the pandemic,” but we know little about how many people are actually affected, how long it will last for those affected, and how it could change employment and health coverage landscapes. Long COVID involves a range of potentially disabling symptoms and may affect 10 to 33 million working-age adults in the United States” *[source: Kaiser Family Foundation (KFF) Policy Watch, August 1, 2022 <https://www.kff.org/policy-watch/what-are-the-implications-of-long-covid-for-employment-and-health-coverage/> ]*

# Clinically Defined Long- COVID

- Also known as Long-Haul COVID, Post-COVID Conditions (PCC), Post-Acute COVID-19, Chronic COVID, Post-COVID 19 syndrome
- Must be at least 4 weeks after COVID diagnosis (symptoms within 4 weeks are not considered Long-COVID) Further broken down into:
  - Acute COVID-19 often refers to the signs and symptoms from positive test through the first 4 weeks
  - Ongoing Symptomatic COVID-19 refers to ongoing signs and symptoms from 4-12 weeks not explained by an alternative diagnosis
  - Long-COVID (or Post-COVID-19 Syndrome) refers to signs and symptoms that develop during or following a COVID-19 infection, continue for more than 12 weeks and cannot be explained by an alternative diagnosis
- Signs and Symptoms cannot be explained by an alternate diagnosis
- Can affect anyone who has had COVID-19, from mild illness to severe illness
- Vaccinated individuals are less likely to develop Long-COVID but may experience breakthrough infections
- Lasts weeks, months or even a year or more after the initial 4-week period
- Signs and symptoms can be multisystem, overlapping, fluctuating and may follow a relapsing-remitting pattern that changes over time and can affect any bodily system

Source:  
Center for Disease  
Control (CDC)

# Clinically Defined Long- COVID

The World Health Organization refers to Long-COVID as Post-COVID Condition and states this official definition:

“Post-COVID condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”

*Source:*

*The World Health  
Organization (WHO)*

# Clinical Symptoms of Long-COVID

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- **General:**

fatigue, sleepiness, fever, worsening symptoms after physical or mental effort

- **Respiratory:**

Shortness of breath, cough, chest pain, fast-beating or pounding heart

- **Neurological:**

brain fog/difficulty concentrating, headache, sleep disruptions, dizziness when standing, pins-and-needles, loss of smell or taste, depression or anxiety

- **Digestive:**

diarrhea, stomach pain, nausea

- **Other symptoms:**

joint or muscle pain, rash, changes in menstrual cycles



# Additional Patient-Reported Symptoms

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## Patient-Reported Symptoms – *Source: Survivor Corp et. al.*

- Sleep Apnea
- Low Blood Pressure
- Hair Loss
- Beau's Lines: “horizontal ridges or dents in one or more of your fingernails or toenails. They're a sign that an illness, injury or skin condition interrupted your nail growth.” – *Cleveland Clinic*
- Severe Vomiting
- Rib Pain
- Ear Pain, Pressure & Tinnitus
- Numbness in Back
- “Internal Vibrations” – usually felt in the chest/upper torso area
- Uncontrolled shaking – mostly in hands and arms
- “Burning, Red” Feet

# The Impact of Long-COVID on Mental Health

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“COVID “long haulers” face an array of challenges, including an invisible but no less formidable foe: mental health burdens, in the form of anxiety, depression, mood disorders, post-traumatic stress disorder (PTSD) and more. These issues are often entwined with physical issues. Other symptoms may include chronic fatigue; shortness of breath; brain fog; and nerve, joint and muscle pain, just to name a few.”

- *UC Health (University of Colorado), Tyler Smith, contributor, April 4, 2022*

“The reality is our brains don’t exist in a bubble. So if you have systemic inflammation problems or viral syndromes that are affecting other organs, it makes sense that they would also affect the brain and cause other psychological symptoms. It’s unfortunately something that patients with chronic fatigue syndrome and fibromyalgia, for example, have experienced for years.”

– *Dr. Heather Murray, MD, MPH, Sr. Instructor, Psychiatry, University of Colorado School of Medicine*

## Mental and Emotional Effects of Long-COVID:

Source: John Hopkins School of Medicine; Dr. Tae Chung, M.D. and Dr. Megan Hosey Mastalerz, PhD, et. al., contributors; published June 14, 2022

- Depression
- Anxiety Disorders
- Mood Disorders
- Thoughts of Suicide
- Suicide Attempts and Completions
- Loneliness/Isolation
- Extreme Stress
- Post Traumatic Stress Disorder

# Mental Distress: a Factor in Developing Long-COVID

Some studies have shown that pandemic-related psychological stress PRIOR to a COVID infection, was a factor in whether or not a patient developed Long-COVID

Psychological distress, including depression, anxiety, worry, perceived stress, and loneliness, before COVID-19 infection was associated with an increased risk of long COVID, according to researchers at Harvard T.H. Chan School of Public Health. The increased risk was independent of smoking, asthma, and other health behaviors or physical health conditions. [Press Release, Sept. 7, 2022; Harvard T.H. Chan School of Public Health]

“We were surprised by how strongly psychological distress before a COVID-19 infection was associated with an increased risk of long COVID,” said Siwen Wang, a researcher in the Department of Nutrition at Harvard Chan School who led the study. “Distress was more strongly associated with developing long COVID than physical health risk factors such as obesity, asthma, and hypertension.”



# Psychological Aspects of Long-COVID

Not all researchers agree to having pinpointed what causes these distressing symptoms, but there are a few possibilities for why they may occur as identified by the University of California, San Francisco, Department of Psychiatry and Behavioral Sciences

- They could be the result of the specific effects of COVID-19 on the brain, the immune system, or other organ systems.
- They could be the result of traumatic aspects of the experience of having COVID-19. It is well known that long-term hospitalization, particularly in intensive care units, can lead to what is called post-intensive care syndrome, which often includes severe weakness, cognitive problems (including poor concentration), and even post-traumatic stress disorder. This explanation, however, would not explain why severe mental health symptoms occur in people who were not seriously ill at the time of their initial COVID-19 infection.
- Ongoing psychological symptoms could be the result of despair patients experience from long-term breathing problems or fatigue with no end in sight.



# Video: Long-COVID: A Parallel Pandemic

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# A Case Study in Long-COVID:

Image Description: A Middle-aged black woman wearing a gray t-shirt with short black hair and glasses sits on a bed looking out the window.

Caption: “Chantelle James, a Registered Nurse living in Cedar Park, Texas, as seen through the window of her guest bedroom on the first floor of her home. James is unable to walk upstairs due to balance issues from Long-COVID.”

*Source: U.S. News & World Report  
Chelsea Cirruzzo, April 15, 2021*



# Article: Long-COVID Sufferers are Seeking Disability Benefits. Will they Change the System?

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## The Power of Peer Support and Self-Advocacy!

“People who are ill and unable to work long after a positive test for COVID-19 could help overhaul the delivery of disability benefits in the U.S.” – *Chelsea Cirruzzo, writer, U.S. News & World Report*

“It's still unclear precisely how many people have the condition now called long COVID, which is often characterized by persistent symptoms of illness weeks or months after an initial case of COVID-19. Sometimes, symptoms can surface well after infection. Concerns have warranted an initiative by the National Institutes of Health aimed at identifying the condition's underlying causes and treatments, while **support groups and clinics have cropped up to help the multitude of people suffering from it.**”



# Long-COVID as a Disability

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As of July 2021, The Office of Civil Rights within the U.S. Department of Health and Human Services determined that Long-COVID can be considered a disability and protected under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act, if an individual assessment determines that it “**substantially limits one or more major life activities, a record of such an impairment or being regarded as having such an impairment**”

- Basic definition of “disability” under the ADA applies to Long-COVID
- the ADA Amendments Act of 2008 (ADAAA) expanded the definition of “major life activities, redefined who is “regarded as having a disability” and modified the regulatory definition of “substantially limits”
- Major life activities include but are not limited to
  - Caring for oneself
  - Performing manual tasks
  - Seeing, hearing
  - Eating, sleeping
  - Walking, standing, lifting, bending
  - Speaking, breathing
  - Learning, reading, concentrating, thinking
  - Communicating
  - Working

Sources: U.S. Department of Labor, Office of Federal Contract Compliance Programs  
HHS.gov “Guidance on Long-COVID as a Disability Under the ADA, Section 504 and Section 1557”



# Will People get the Benefits they Need?

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The reality is, getting disability benefits for Long-COVID may be more difficult than it sounds. Consumers need to understand Long-COVID, recognize the symptoms, and advocate for themselves. The clinical world needs to do more research to better understand Long-COVID, doctors need to believe their patients, and support their needs.

Despite the recognition that Long-COVID can be a disability, to qualify for federal programs, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), applicants **must be unable to work** and have health conditions **that last for at least one year or result in death**. At this point, it is unclear how many people with long COVID will qualify for disability benefits under this definition.

The hope: If people with Long-COVID do qualify for federal disability programs, more people will have publicly funded health insurance through Medicare and Medicaid. People who are eligible for SSDI become eligible for Medicare after a 2-year waiting period and people who are eligible for SSI are generally eligible for Medicaid. If people with Long-COVID are unable to work, these **federal disability programs** could play a key role helping those patients access the health care they need to recover.

# Make Your Voice Heard!

## The Challenge:

“People with post-COVID conditions (a.k.a. Long-COVID) may develop or continue to have symptoms that are hard to explain and manage. Clinical evaluations and results of routine blood tests, chest x-rays, and electrocardiograms may be normal even though a patient is presenting with symptoms.

The symptoms may be similar to those reported by people with [ME/CFS \(myalgic encephalomyelitis/chronic fatigue syndrome\)](#) and other poorly understood chronic illnesses that may occur after other infections. People with these unexplained symptoms may be misunderstood by their healthcare providers, which can result in delayed diagnosis and the receiving of appropriate care or treatment.”

## The Solution:

Advocacy, Advocacy, Advocacy! YOU are your best ally and advocate. You know how you feel and what you're experiencing. Medical professionals often try to take what you're describing and tweak it just enough to fit into a better-understood category. This goes right back to the above comment about being misunderstood and delaying diagnosis and possible treatment. The only one that can mitigate this is you. Don't give up!



# Tips for Talking to your Dr. about Long-COVID

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- Keep explaining and re-explaining your symptoms until they are repeated back to you accurately
- **Make it clear to your doctor that you need someone who will see you through this complicated process**
- Bring along an advocate if needed – whether because of a disability, a communication gap or just for additional support and reassurance and to help make sure you are being heard and taken seriously
- **Request records and visit summaries and check for accuracy - this is your right!**
- Most medical facilities have online portals where you can
  - **Access medical records**
  - **Access test results**
  - **Message your doctor or nurse**
  - **Set up and cancel appointments**

When testing for COVID at a walk-in or emergency clinic:

- **Always request to have a copy of the visit and results sent to your primary care doctor**
- When scheduling a Covid test online for walk-in clinics (Walgreen's, CVS etc.) simply check the box that says "send results to my physician" and fill in the requested information
- **If you test positive, whether at home or in a clinic, always follow up with a phone call to your primary care doctor making sure they record the results on your medical chart. Documentation is critical!**

# Resources: Long-COVID as a Disability

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- Guidance on Long Covid as a Disability Under the ADA, Section 504 and Section 1557 <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/guidance-long-covid-disability/index.html>
- The Office for Civil Rights of the Department of Health and Human Services (HHS) has the following page on civil rights and COVID-19: <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/index.html>.
- Filing a civil rights complaint <https://www.hhs.gov/ocr/complaints/index.html>

# How Will the Workplace Adapt?

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- Estimates of 16 to 23 million working-age Americans (those aged 18 to 65) currently have Long-Covid
- Of those, 2 to 4 million are out of work due to long Covid.
- The annual cost of those lost wages alone is around \$170 billion a year (possibly as high as \$230 billion).

“COVID-19 likely resulted in 1.2 million more disabled people by the end of 2021 alone — **workplaces and policy will need to adapt**. Workplaces will need to adapt to significant increases to both the disabled population and disabled workforce, and **future labor market analysis must center disability**”

“Workplaces must accommodate the needs of disabled workers by **decreasing the barriers that make it difficult for them to apply, obtain, and maintain employment**. In addition, it will be crucial for labor market analysts and policymakers to understand the economy through the lens of disabled people’s experiences.”

- *Center for American Progress, Lily Roberts, contributor, February 9, 2022*

# Employers are Concerned, but are They Ready to Adapt?

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Survey: Employers concerned about long-term mental health issues post-Covid

<https://www.fiercehealthcare.com/payers/employers-concerned-about-long-term-mental-health-issues-post-covid-survey> - Fierce HealthCare, Paige Minemyer, Aug 24, 2022

- Nearly half (44%) of employers surveyed by the Business Group on Health said they have seen this trend in their workforces
- another 44% expect to see worsening mental health in the future
- Most (85%) said they anticipate enhanced mental health benefits launched under the pandemic to continue
- about half of employers said they expect to expand mental health networks for 2023
- Employers also expect the lingering effects of COVID to be felt in other ways:
  - an increase in medical services due to delayed care
  - Keeping employer pandemic programs in place beyond enhanced mental health and well-being programs.
  - Ninety-four percent said they will continue to provide expanded virtual care and telehealth offerings
  - 53% said they will offer programs that continue to support workers remotely

# Employer Tips

Implementing workplace accommodations can help companies retain employees experiencing long-term effects from COVID-19 and other chronic illnesses.

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- Educate yourself on long COVID
- Create a safe environment for open communication
- Offer remote options
- Consider job flexibility and be open to change
- Reevaluate benefits and paid leave policies
- Invest in peer-mentoring programs
- Encourage collaborative work systems

*source: MIT Sloan Management Review, Fiona Lowenstein, founder of Body Politic, contributor  
<https://sloanreview.mit.edu/article/how-managers-can-support-employees-with-long-covid/>*

Note: This is what people with disabilities have already been advocating for in the workplace! Should it take a pandemic and a newly identified chronic illness to get the attention of employers?

# Additional Resources and Information for Employers

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- JAN (Job Accommodation Network) & EARN (Employer Assistance and Resource Network on Disability Inclusion Supporting Employers with Long COVID: A Guide for Employers  
<https://askjan.org/publications/upload/Supporting-Employees-with-Long-COVID-A-Guide-for-Employers.pdf>
- Guidance on Long Covid as a Disability Under the ADA, Section 504 and Section 1557  
<https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid-19/guidance-long-covid-disability/index.html>
- Questions and Answers on the Final Rule of Implementing the ADA Amendments Act of 2008:  
<https://www.eeoc.gov/laws/guidance/questions-and-answers-final-rule-implementing-ada-amendments-act-2008>
- What you should know about COVID-19 and the ADA, the Rehabilitation Act, and Other EEO Laws  
<https://www.eeoc.gov/wysk/what-you-should-know-about-covid-19-and-ada-rehabilitation-act-and-other-eeo-laws>
- Supporting Employers with Long COVID: A Guide for Employers – from the JAN Network  
<https://askjan.org/publications/upload/Supporting-Employees-with-Long-COVID-A-Guide-for-Employers.pdf>



# Centers for Independent Living

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## Who and what are we and how can we help?

Independence, Inc. is one of about 400 Centers for Independent Living across the United States and one of 10 in the State of Kansas. CIL's were born from the Independent Living movement of the 1970's where disability rights advocates fought for their civil rights live independently in the community, establish expectations that places will be accessible, and that community programs and services will be available to all. CIL's are staffed by and provide services for people with disabilities through the five required core services of:

- Advocacy
- Information & Referral
- Independent Living Skills Training
- Peer Support
- Transition services: Transitioning from institution to community-based living and Youth Transition from school to adult life.

CIL's can also offer an array of additional services like

- Transportation
- Financial Management Services
- Housing assistance and an Accessible Housing Program
- Business & Community Services
- Independent Living Counseling through the Working Health program
- Kansas TAP program
- Medical Equipment Loan Bank
- Computer Lab

# Breaking Down the Barriers:

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- *We haven't had any calls or inquiries for Covid-related services*

The idea of Long-COVID is still quite new and the general public may be experiencing it and not realize it. Doctors often dismiss these claims of ongoing symptoms and say to give it more time without ever seeing the patient in office

- *We don't currently offer Covid-related services and aren't sure there's really a need*

All the research around Long-COVID shows that the need is great and services to assist consumers needs to expand

- *We didn't accept the Federal Public Health Work Force grant for Covid-related services*

You don't need to specifically fund a new position to incorporate Covid-related services like I&R, assisting with disability claims, providing community COVID resources etc.

- *We don't offer Covid-related peer support and don't know of any Covid-related support groups in the area*

Long-COVID, like any other disability, doesn't necessarily warrant it's own specific group of peers. Many chronic health conditions take the same mental and physical toll on people. Already established groups can incorporate people living with Long-COVID

- *We don't have any staff trained in Covid-related issues*

Staff can intake and assist people with Long-COVID just as any other person with a disability. The key is to educate the public about Long-COVID through established resources

- *Long-COVID isn't a big problem in our area*

Chances are, it actually is and is either not yet recognized and understood by consumers, or consumers aren't reaching out for help. Educating the community and participating in outreach is essential

- *We still have the first round of CARES Act funding to spend and aren't sure what to do with it*

The PHW Grant is completely different and is meant to go towards the salary of a dedicated PHW to serve the community

- *We don't feel equipped*

You are! You don't have to fully understand it to be able to assist someone with a COVID-related disability

- *I don't know the COVID lingo*

That's ok! The more people you assist, the more you'll learn alongside them

# Outreach is Key:

## Inform your community!

As with any type of product or service, it takes **marketing** and **outreach** to draw in consumers. Most consumers will likely think of Covid in only clinical terms. Once it becomes Long-COVID and may become, or has already become, a **disability**, this consumer is like any other that we see. Clinical knowledge or specific Covid-related programs are not needed to assist Long-COVID consumers

- **Create Flyers or Brochures**
- Utilize Social Media and your website to share info
- **Send out Newsletters**
- Contact Consumers Directly
- **Create Covid-related Community Partnerships**
- Send Information through your List Servs
- **Direct Mail or Email to your Donors**
- Leave info at PT's, Rehab Facilities, Clinics etc.

## SOCIAL SUPPORT & RESOURCE SPECIALIST



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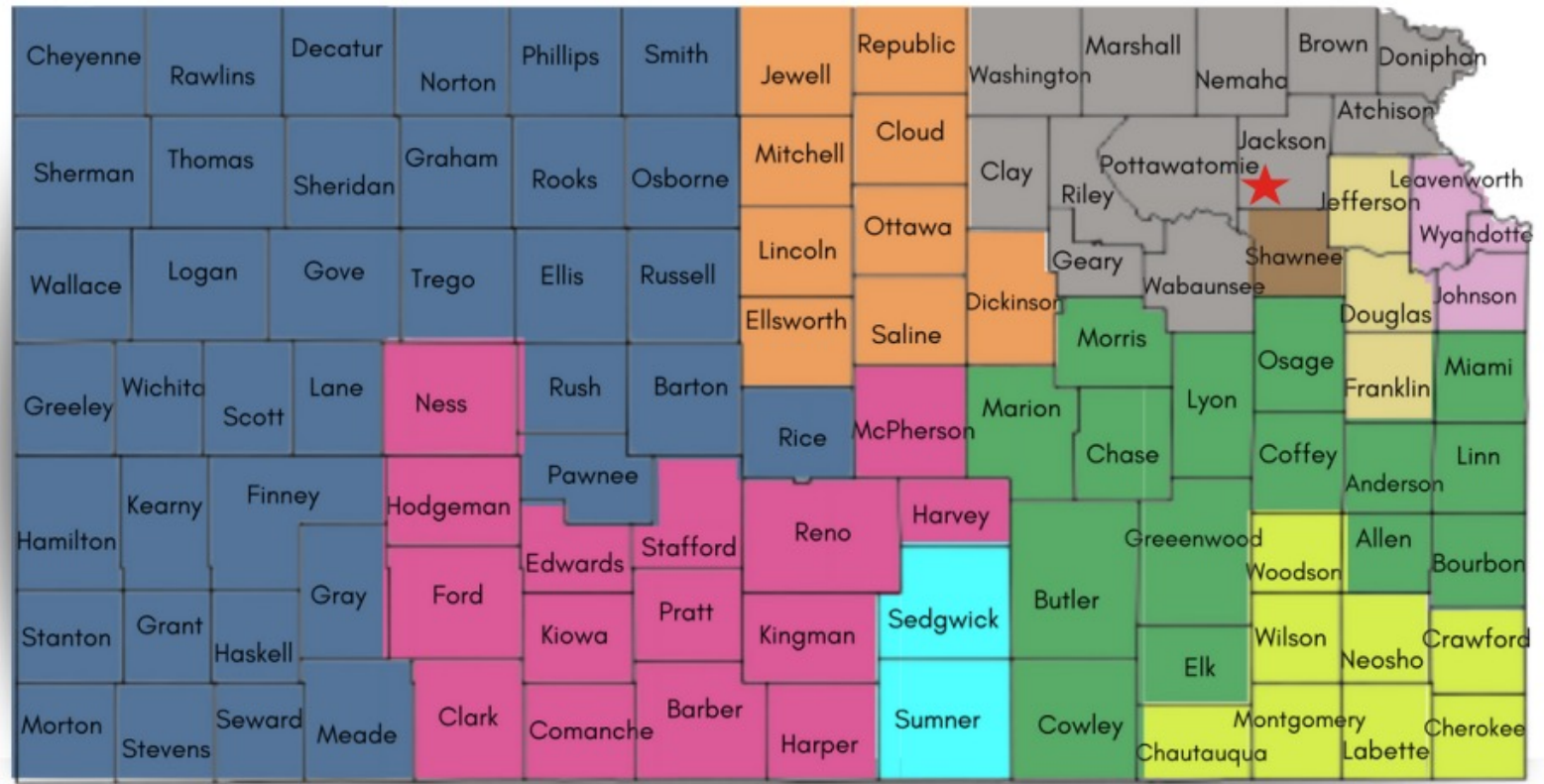
- Information and Referral
- PPE Distribution
- Transportation
- Long-COVID Support
- Reasonable Accommodation Requests
- Medicaid Application/Renewal
- Advocacy & MORE!

# Specific ways to Assist Long-Covid Consumers

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- Apply for SSDI, SSI, Medicare, Medicaid, Unemployment, Housing/mortgage/rent assistance, food stamps etc.
- Get vaccinated [Yale Medicine research, Akiko Iwasaki, PhD, Prof. of Immunobiology; April 12, 2021]
- Provide or find transportation
- Connect them with peer support (newly acquired disability, chronic illness, mental health etc.)
- Assist with making sure the consumer has documented illness and symptoms in their medical charts
- Utilize DME loan bank or help locate one
- Locate funding for home modifications
- FMS/PASS assistance if they qualify for a caregiver
- Reasonable Accommodation requests
- Advocacy with landlords over disputes, ESA or Service animals
- Housing services: finding accessible and or affordable housing
- Provide PPE to Consumers and Caregivers

# Map of Kansas CIL's By County

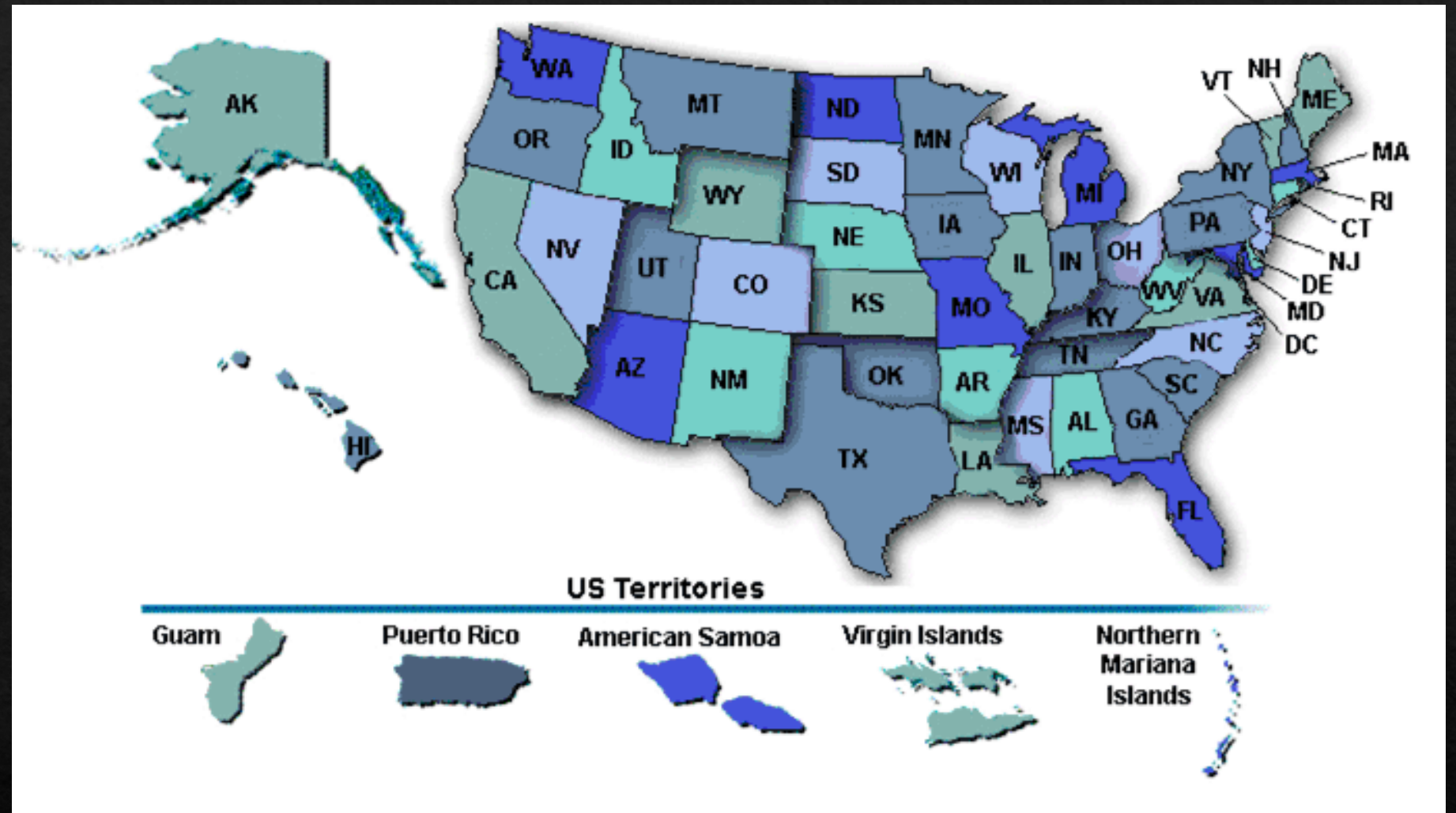


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| <p><b>LINK, Inc.</b><br/>2401 E. 13th St., Hays, KS 67601<br/>785-625-6942   1-800-569-5926<br/>Fax: 785-625-2334</p> <p><b>Beyond Barriers</b><br/>Main office: 17 S. Main, Hutchinson, KS 67501<br/>620-663-3989   1-888-715-6818<br/>Video: 620-860-0140   Fax: 620-663-4711</p> <p><b>Independent Connection, Inc.</b><br/>436 S. Ohio St., Salina, KS 67401<br/>785-452-9580<br/>Fax: 785-515-2190</p> <p><b>Independent Living Resource Center</b><br/>3033 W. 2nd St. N, Wichita, KS 67203<br/>316-942-6300   1-800-479-6861<br/>Fax: 316-927-2186</p> | <p><b>Topeka Independent Living Center</b><br/>501 SW Jackson St., Suite 100<br/>Topeka, KS 66603<br/>785-233-4572   Fax: 785-233-1561</p> <p><b>3 Rivers Inc.</b><br/>504 Miller Dr., PO. Box 408<br/>Wamego, KS 66547   785-456-9915<br/>1-800-555-3994   Fax: 785-456-9923</p> <p><b>Native American<br/>Independent Living Project</b><br/>office located on the Prairie Band<br/>Potawatomi Nation</p> | <p><b>The Whole Person</b><br/>3710 Main St., Kansas City, MO 64111<br/>MO 816-561-0304   KS 913-871-4188<br/>Fax: 816-931-052</p> <p><b>Independence, Inc.</b><br/>2001 Haskell Ave. Lawrence, KS 66046<br/>785-841-0333<br/>Fax: 785-841-1094</p> <p><b>Resource Center for Independent Living</b><br/>111137 Laing St., Osage City, KS 66523<br/>785-528-3105   1-800-580-7245<br/>Fax: 785-528-3665</p> <p><b>Southeast Kansas Independent Living</b><br/>1801 Main St.,   PO Box 957<br/>Parsons, KS 67357<br/>620-421-5502   Fax: 620-421-3705</p> |
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# To Locate CIL's in Your State:

## Independent Living Research Utilization Program (ILRU)

ILRU is a national center for information, training, research and technical assistance in independent living (IL) aimed at expanding the body of knowledge in IL and improving utilization of research results and demonstration projects in this field.



<https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

# Survivor Corps

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“Survivor Corps is the largest grassroots movement in America dedicated to actively ending the pandemic”

- Selected for inclusion in The United States Library of Congress Coronavirus Web Archive: <https://www.loc.gov/web-archives/?q=Survivor+corps>
- Founder Diana Berrent – Her Personal Story: <https://www.survivorcorps.com/story>
- Take Action – Medical, Scientific and Academic research, studies and survey opportunities: <https://www.survivorcorps.com/take-action>
  - Long-COVID: Long Hauler Symptom Studies: (Indiana University School of Medicine)
  - Recovery Corps: To better understand how individuals recover from COVID (Columbia University)
  - Yale Long COVID Vaccine Study: How vaccines might improve Long Covid symptoms (Yale University)
- Join their Facebook group: information, support, community, webinars and news across the nation



Empathize • Organize • Mobilize

# Resources and Work Cited (1 of 3)

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