



# **COVID & Long COVID: Doing No Harm In a Mass Disabling Event**

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# Work Overview

## **Assess**

- Current pandemic related issues Vermonters with disabilities are experiencing

## **Respond**

- Support needs that exist, including for COVID longhauers

## **Develop**

- Educational materials and resources for current and future pandemics
- Community for those who are still COVIDing

## **Advocate**

- At the systems and individual levels for equal access to education, healthcare, and civic life



“No one is safe until everyone is safe.”

-Dr Tedros Ghebreyesus, Director  
World Health Organization, 2021

“Far from being a shameful moment of our past, eugenic philosophy is alive and well in the twenty-first century. Nowhere has this been more apparent than in our response to the current public health crisis. The COVID-19 pandemic has exposed the viral nature of eugenic philosophy, which has continued to guide U.S. treatment of the captive and vulnerable for over 100 years. The long tail of eugenics informs our choices over those we institutionalize, detain, and sequester in long-term care and group homes.”

-Hiding in Plain Sight: Public Health, Eugenics, & COVID-19, Harvard Public Health Review, 2021

“The overwhelming number of deaths—over 75 percent—occurred in people who had at least four comorbidities, so really these are people who were unwell to begin with. And, yes, really encouraging news in the context of omicron...We’re really encouraged by these results.”

-CDC Director Dr. Rochelle Walensky, 2022

"Even though you'll find the vulnerable will fall by the wayside, they'll get infected, they'll get hospitalized, and some will die. It's not going to be this tsunami of cases that we've seen."

-Anthony Fauci, 2023


This is a presentation about the “vulnerable” who do not wish to be flung to the wayside.

Those of us who believe that our lives and livelihoods being sacrificed in the name of economic profits is not-in fact- “really encouraging” news.

And this is also a presentation about what it means to do no harm to those already harmed during an ongoing mass disabling event.

What it means to help.



A magnifying glass with a black handle and frame is positioned over a light-colored, textured surface. The word "HISTORY" is written in blue, uppercase, serif letters across the center of the lens. The lens is slightly larger than the word, and the handle extends towards the bottom right corner of the frame.

HISTORY









“Encephalitis lethargica assumed its most virulent form between October 1918 and January 1919. In the United States the epidemic peaked from 1920 to 1924. It is estimated that as many as one million people were diagnosed with encephalitis lethargica during the epidemic period.”

-Wikipedia

**MR100**

**VOCATIONAL REHABILITATION • 1920–2020**





We shall  
OVERCOME

EQ  
OPPOR  
for



# TIME



1977  
**Judith  
Heumann**  
*Fighting  
for access*

## Judy Heumann

Mother of the Disability Rights Movement





**Ed Roberts**  
Father of the Independent  
Living Movement



# Justin Dart, Jr. Godfather of the ADA





## Johnnie Lacy

Co-founder of America's first CIL and introduced intersectionality to our collective work



# Paul Longmore

Leading Disability  
History Scholar





# Sue Williams

VCIL Co-Founder  
& fierce advocate for  
disabled Vermonters





**This is where  
you come in.**



Vermont's State Rehabilitation Council advocates for consumer-directed and **effective** vocational services and for the creation of resources and services that will result in **equal opportunities** for Vermonters with disabilities.



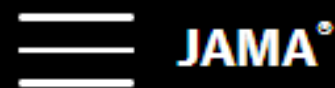
Present

# COVID-19 Was Leading Killer Of People With Developmental Disabilities

by Shaun Heasley | September 26, 2022



JAMA Network™



**News From the Centers for Disease Control and Prevention**

December 13, 2022

# **Inequity in Paxlovid Prescribing**

Bridget M. Kuehn, MSJ



**HHS.gov** 

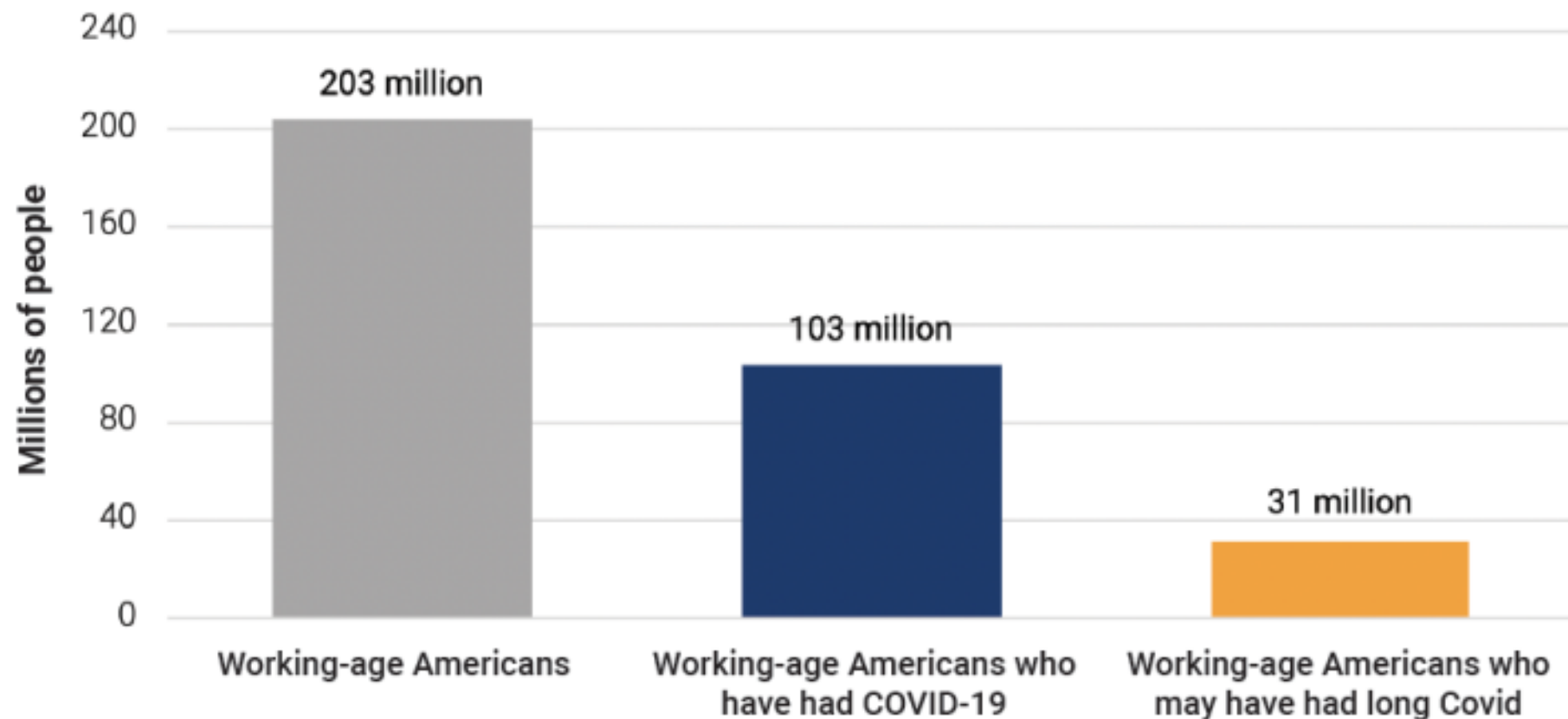
@HHSGov



The more often you get COVID, the higher your risk of complications.

## Figure 1: More than 30 million working-age Americans may have had long Covid

That is one out of seven working-age Americans



Source: Author's estimate based on data from U.S. Census Bureau, CDC, and UC Davis Health.

BROOKINGS



REPORT

## **New data shows long Covid is keeping as many as 4 million people out of work**

**Katie Bach** · Wednesday, August 24, 2022

# Long Covid has an 'underappreciated' role in labor shortage, study finds

PUBLISHED MON, JAN 30 2023 • 2:18 PM EST

- About 18% of people with long Covid hadn't returned to work for more than a year, according to a report by the New York State Insurance Fund, state's largest workers' compensation insurer.
- The finding adds to other research suggesting long Covid is contributing to a labor shortage and hurting the U.S. economy.

# What is Long COVID?



“There is no long COVID without COVID.”

“There’s almost no organ system long COVID doesn’t touch.”

-Dr. Ziyad Al-Aly, clinical epidemiologist and researcher  
Washington University School of Medicine



Long COVID is a patient created term broadly defined as signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection. The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection; may be multisystemic; and may present with a relapsing–remitting pattern and progression or worsen 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.





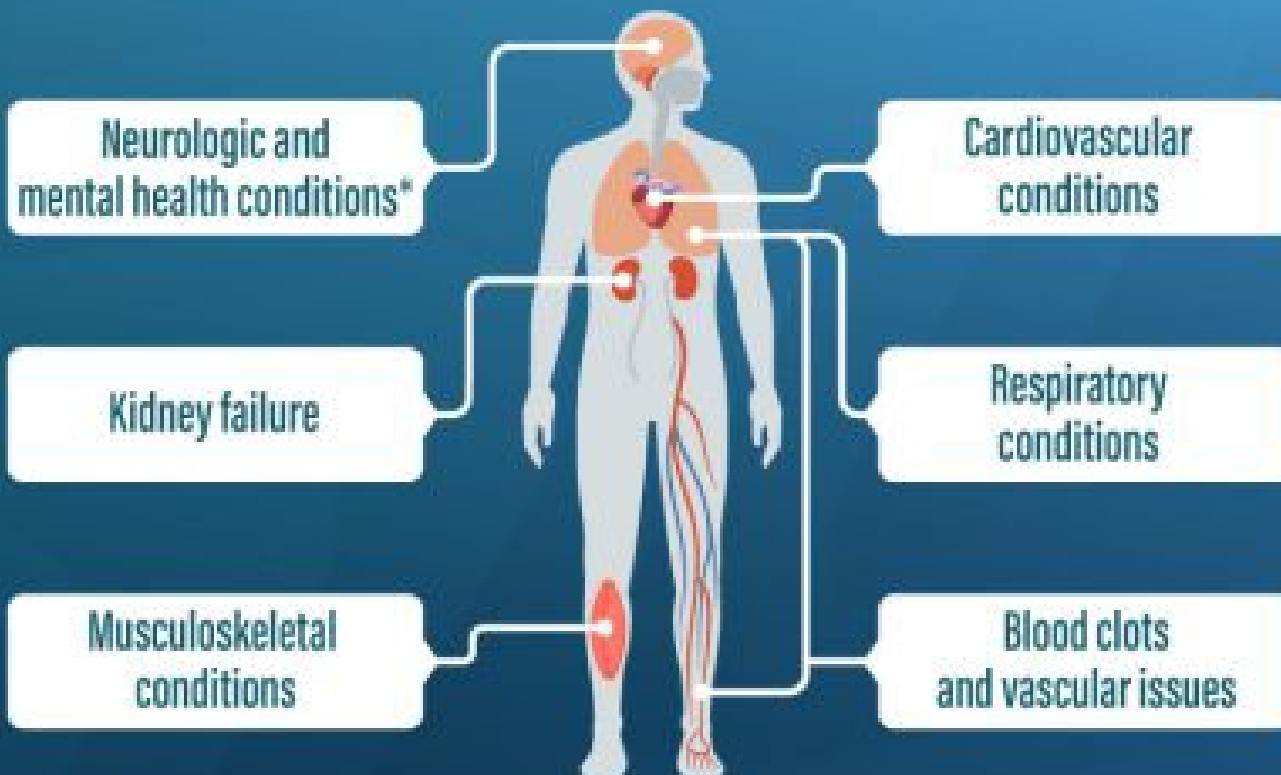
Post COVID-19 Condition, commonly known as long COVID, can affect anyone exposed to SARS-CoV-2, regardless of age or severity of original symptoms.

It is defined as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

While common symptoms of long COVID can include fatigue, shortness of breath and cognitive dysfunction over 200 different symptoms have been reported that can have an impact on everyday functioning.

Studies show that around 10–20% of people infected by SARS-CoV-2 may go on to develop symptoms that can be diagnosed as long COVID.

Approximately  
**1 in 5 adults**  
ages 18+ have a  
health condition  
that might be related to  
their previous COVID-19  
illness, such as:



**Talk to your health care provider  
if you have symptoms after COVID-19**



[bit.ly/MMWR7121](https://bit.ly/MMWR7121)

MAY 24, 2022

\* Adults aged 65 and older at increased risk

**MMWR**

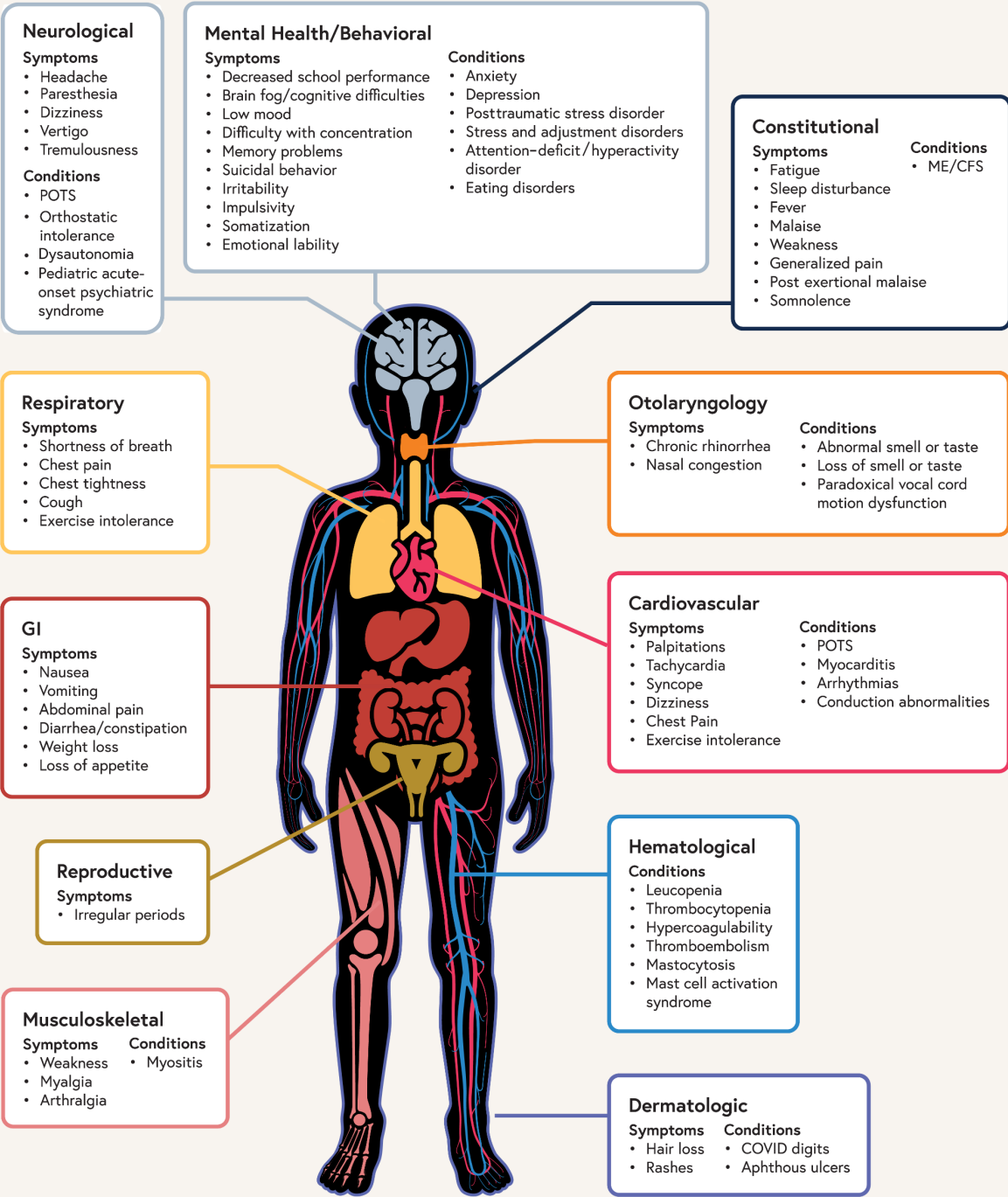
Over 200 different symptoms, but we also know that many Longhaulers are also commonly diagnosed with:

- ME/CFS (43-90% meet criteria)
- Dysautonomia (66% have moderate or severe)
- Neuropathic pain (34%)



## Postacute Sequelae of SARS-CoV-2 in Children

“Given that ~20% of COVID cases in the United States are in children, and that current pediatric postacute sequelae of SARS CoV-2 (PASC) prevalence estimates are 10% to 20%, PASC is estimated to affect up to **5.8 million children**, representing a significant community impact. The scientific community has acknowledged an urgent need to understand more about PASC in children. Although PASC can affect any individual, populations deserving specific focus include children with intellectual and developmental disabilities, children with medical complexity, and those with prolonged debilitating symptoms.”



**Neurological**

**Symptoms**

- Headache
- Paresthesia
- Dizziness
- Vertigo
- Tremulousness

**Conditions**

- POTS
- Orthostatic intolerance
- Dysautonomia
- Pediatric acute-onset psychiatric syndrome

**Mental Health/Behavioral**

**Symptoms**

- Decreased school performance
- Brain fog/cognitive difficulties
- Low mood
- Difficulty with concentration
- Memory problems
- Suicidal behavior
- Irritability
- Impulsivity
- Somatization
- Emotional lability

**Conditions**

- Anxiety
- Depression
- Posttraumatic stress disorder
- Stress and adjustment disorders
- Attention-deficit/hyperactivity disorder
- Eating disorders

**Constitutional**

**Symptoms**

- Fatigue
- Sleep disturbance
- Fever
- Malaise
- Weakness
- Generalized pain
- Post exertional malaise
- Somnolence

**Conditions**

- ME/CFS

**Respiratory**

**Symptoms**

- Shortness of breath
- Chest pain
- Chest tightness
- Cough
- Exercise intolerance

**Otolaryngology**

**Symptoms**

- Chronic rhinorrhea
- Nasal congestion

**Conditions**

- Abnormal smell or taste
- Loss of smell or taste
- Paradoxical vocal cord motion dysfunction

**GI**

**Symptoms**

- Nausea
- Vomiting
- Abdominal pain
- Diarrhea/constipation
- Weight loss
- Loss of appetite

**Cardiovascular**

**Symptoms**

- Palpitations
- Tachycardia
- Syncope
- Dizziness
- Chest Pain
- Exercise intolerance

**Conditions**

- POTS
- Myocarditis
- Arrhythmias
- Conduction abnormalities

**Reproductive**

**Symptoms**

- Irregular periods

**Hematological**

**Conditions**

- Leucopenia
- Thrombocytopenia
- Hypercoagulability
- Thromboembolism
- Mastocytosis
- Mast cell activation syndrome

**Musculoskeletal**

**Symptoms**

- Weakness
- Myalgia
- Arthralgia

**Conditions**

- Myositis

**Dermatologic**

**Symptoms**

- Hair loss
- Rashes

**Conditions**

- COVID digits
- Aphthous ulcers

STUDENT WELL-BEING

# Thousands of Students Will Face Long COVID. Schools Need to Plan Now

Need for accommodations likely to rise, experts say

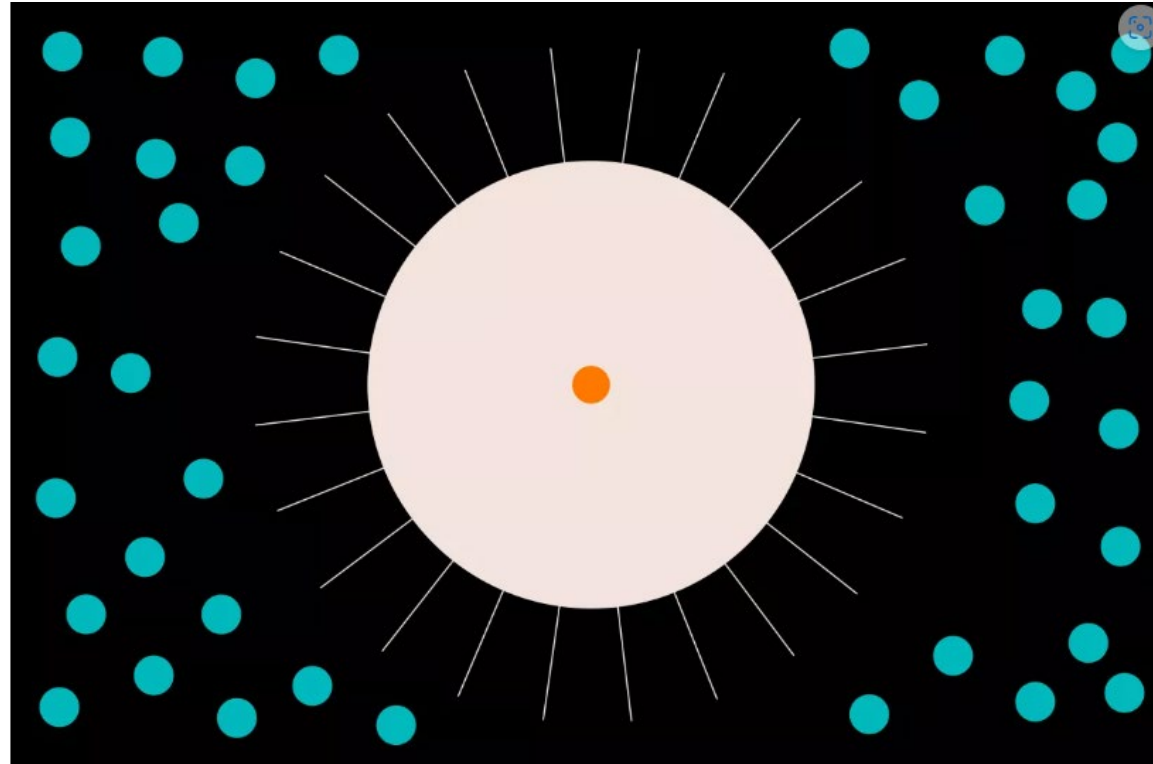


By [Catherine Gewertz](#) — June 20, 2022 ⌚ 7 min read

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# Los Angeles Times

The loneliness of being immunocompromised in the age of COVID-19



# In the past year, have you limited any of the following activities as a result of COVID concerns?

In person visits with friends or family	76%
Going to grocery store or pharmacy	63%
Medical or dental care	45%
Other necessary activities (voting, visits to post office or DMV, pet care, car care, etc.)	43%
Work or volunteer hours	21%
Education/schooling	12%



# **Known Cures and Treatments for Long COVID**



**What We Know**

**\*Doesn't\***

**Work**

- Attempting to motivationally interview someone out of being disabled
- Attempting to exercise therapy someone out of being disabled
- Telling people to ignore/push through symptoms to un-disable themselves

**What We Know**

**\*Is Very\***

**Harmful**

- 1) Getting re-infected
- 2) Being gaslit by medical providers, case managers and support workers, family, and friends
- 3) Being told to accept mass death and disability/further disability as “living with the virus”
- 4) Social death



“The systematic denial of the chance to work, joined with restrictions on education...and most forms of social intercourse, have entailed what amounts to... social death.”

-Paul Longmore, 2003

# **What Longhaulers are Telling Us They Want**

# Long COVID Competent Providers

- Medical providers who diagnose instead of dismiss
- Social service workers who are supportive

# ADA Accommodations

ADA accommodations in healthcare, employment, education and government services so they can fully and equally access life

- Reinfection prevention measures
- Tele and home based options
- Accessible forms and processes

# Funding Support

Stand-alone funding streams for direct support for:

- Housing
- Utilities
- Food
- Healthcare (including co-pays, specialists, supplements, wheelchairs, compression devices, etc.)
- Safe childcare/respite

# Programmatic Support

Programmatic support from service providers such as:

- Case management support (benefits applications, scheduling medical visits and paperwork)
- SSDI application support
- Legal consultations to get accommodations in employment, healthcare, and public life
- Expertise in helping students secure school-based supports and accommodations
- Creation of referral lists for medical and mental health providers who will not gaslight longhaulers

# **What Can the AOE and SRC Do?**



# AOE Committee

The Advocacy, Outreach and Education Committee plans and recommends to the full State Rehabilitation Council activities to be undertaken in the name of the SRC that:

- Advocate for issues that affect the mission of HireAbility Vermont and the people that it serves
- and-
- Educate the general public and specific audiences about vocational rehabilitation and HireAbility issues.

# A Few Ideas

Recommend broad training and technical assistance on topics such as:

- ADA and reasonable accommodations requests as they pertain to COVID and Long COVID
- How to “do no harm” and examples of universal design in services and supports during an ongoing pandemic

Active outreach and support to ensure needs of those who have been harmed are being met (e.g., don’t wait for longhaulers and those needing to protect themselves from infection/reinfection are going to come to you...go to them with salient and responsive offerings)

Ensure you are not perpetuating harmful narratives reflective of eugenics values (e.g., “The vulnerable will fall by the wayside but most of us will be okay”, “Living with the virus”, “Gotta live your life”, “The new normal”, etc.)

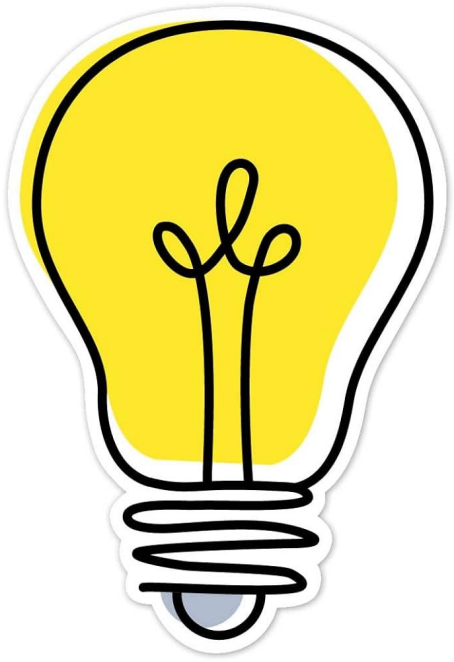
**NOW,**

**IT'S**

**YOUR**

**TURN**





**What Ideas and  
Questions Does this  
Provoke for You?**