

Good Afternoon,

My name is Kate Larose, and I serve as the statewide pandemic equity coordinator with the Vermont Center for Independent Living. I'm also joined here today by Krista Coombs, VCIL's Long COVID Advocate. At VCIL, we are people with disabilities working together for dignity, independence, and civil rights.

Our work includes assessing and responding to the current pandemic related issues Vermonters with disabilities are experiencing—including for COVID longhaulers—developing resources and community, and supporting people in advocating for equal access to education, healthcare, and civic life.

You may be asking yourselves “Why are we here today talking about COVID and Long COVID?” While we all wish that the pandemic were over, that is simply not the case. To frame our time together, I want to start with a few quotes.

In 2021 near the start of the pandemic, Dr Tedros Ghebreyesus, Director of the World Health Organization, said, “No one is safe until everyone is safe.” I believe this to my core, and suspect that those here today would say the same.

Shortly thereafter, the Harvard Public Health Review published an important piece entitled “Hiding in Plain Sight: Public Health, Eugenics, and COVID-19. Here is one excerpt I want to share:

“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.”

Less than a year later, CDC Director Rochelle Walensky came under fire by disability rights activists for her public stance on the disproportionate impact of harm of COVID to people with disabilities:

“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.”

A year later, in 2023, Dr. Anthony Fauci stated the following on a TV interview:

“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.”

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Instead of a decrease in death and disability, we've arrived at a perverse plateau in which the ongoing harms hold steady over time, instead of coming in waves. We are told this "normalcy" of harm to people with disabilities is a welcomed change.

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.

I'm a big context person. The more context the better. So before we delve in to Long COVID and the work of this committee, I want to share the briefest of historical overviews relevant to this current juncture.

When World War I ended in 2018, 224,000 U.S. soldiers returned home with a permanent disability.

From 1918 to 1919, the Spanish flu infected 33% of the world's population at the time. It killed about 50 million people globally, and 675,000 of those deaths were in the United States.

Concurrent with these events, encephalitis lethargica—sleeping sickness—assumed its most virulent form between 1918 and 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. No definitive cause was ever proven, no cure or treatment discovered, but it mysteriously went away in the 1930s. Decades later survivors were known to be impacted by other health conditions such as Parkinsons.

On June 2, 1920, President Woodrow Wilson signed the Civilian Rehabilitation Act into law. It created a federal, nationwide vocational rehabilitation program for all Americans with disabilities.

Now we're going to skip ahead a few decades to federal civil rights protections. Disabled people today have these rights because they were hard fought and won by disabled people.

Here are just a few of the individuals who helped secure these protections for us all:

- Judy Heumann, "Mother of the Disability Rights Movement"
- Ed Roberts, "Father of the Independent Living Movement"
- Justin Dart Jr., "Godfather of the ADA"
- Johnnie Lacey, Co-founder of America's first CIL and introduced intersectionality to our collective work

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- Paul Longmore, leading disability history scholar
- Sue Williams, co-founder of VCIL and fierce advocate for disabled Vermonters

One of the things all of these incredible leaders have in common is that they were polio survivors.

The history of disability rights in the United States—and in Vermont—is also the history of post-viral illness. This will continue to be the case in the decades to come and how systems effectively support or harm people with post-viral illness from COVID.

Let's skip ahead a bit more. This is where you come in! State Rehabilitation Councils were born out of the 90s and were established to provide a mechanism for people with disabilities to take an active role in shaping the vocational rehabilitation services available to them.

And here's the Vermont SRC mission:

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.

Effective and equal opportunities. I invite you to hold on to that mission for what I'm about to present next.

So here we are now in the present.

We know that the end of the public health emergency does not mean that the pandemic is over. It simply means that the burden of harm has now been shifted to those who are most vulnerable.

When our leaders tell us that COVID is something we should learn to live with, what they actually mean is that it is something some of us should just learn to die from.

And the tools that we are constantly told we have? They are burdensome to access or kept from us.

And we know—without a doubt—that the risk of complications increase with each subsequent infection, with the highest costs being paid by Vermonters who are older, disabled, Black, Indigenous, People of Color, rural, or low income.

We're also told over and over again that the only meaningful measure and data point in this pandemic is death. Even while millions of people are being robbed of their livelihoods and quality of life. Here are a few stats. These are old. These statistics were undercounts at the time. The full picture now is much, much worse but continually ignored.

And that 31 million Americans have or have had Long COVID.

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Brookings Institute estimated in 2022 that Long COVID is keeping 4 million Americans out of work. Completely.

And we know that at least 18% of people with Long COVID have been kept from work for over a year.

But what is Long COVID?

Let's start at the 10,000 foot view. According to Dr. Ziyad Al-Aly, clinical epidemiologist and one of the leading Long COVID researchers, we know that:

- "There is no long COVID without COVID."
- "There's almost no organ system long COVID doesn't touch."

Specific definitions vary. But here are two.

HHS states:

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

The World Health Organization states:

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.

CDC is currently stating that 1 in 5 currently have a health condition related to COVID.

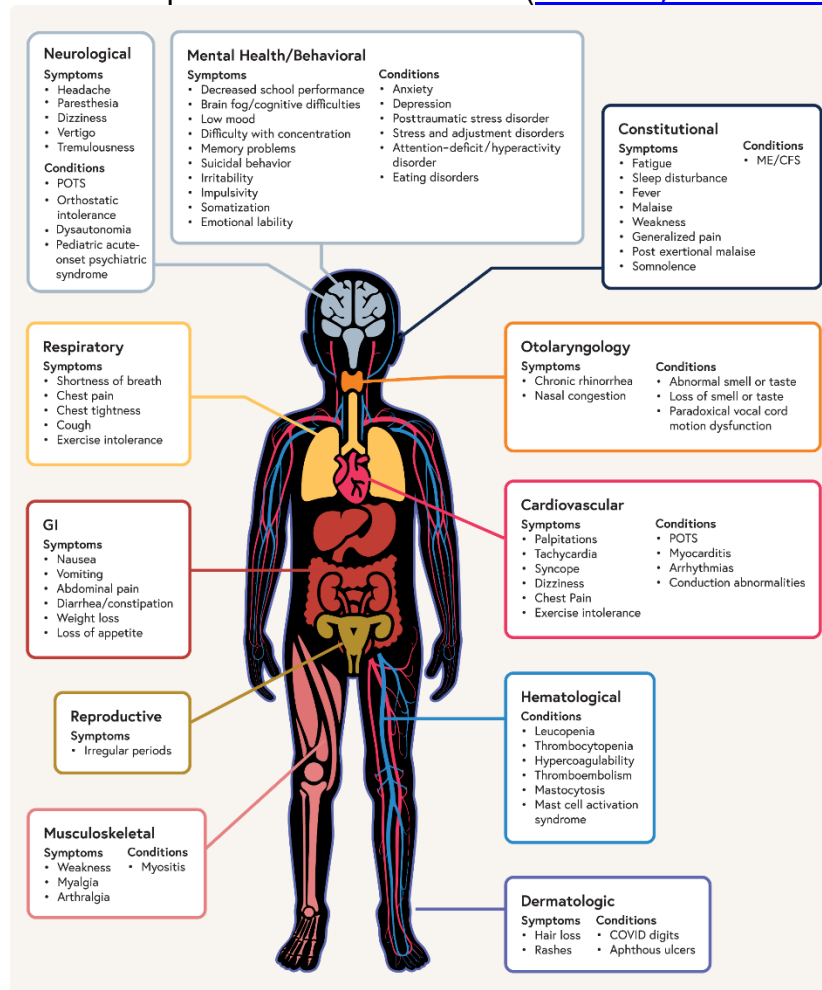
And even with over 200 different known symptoms so far, we also know that many Longhaulers are also commonly diagnosed with:

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

But it's not just adults!

According to a recent study published in the American Journal of Pediatrics, 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%. 5.8 million children are already impacted. 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."

Here are some specific examples of forms that takes. ([Full study available here.](#))



And we already know that they are not getting the needed supports they need from schools to access their education and—in fact—there is a push for an increase in educational neglect and truancy reports happening at the national and statewide levels.

And beyond the immediate harms of increased infections, hospitalizations, and deaths are the enduring impacts on the day-to-day lives of those being driven into isolation attempting to protect themselves in a society that no longer gives a damn about their lives.

VCIL just completed our annual survey of peers around the state. The results indicate that—while the majority of those we serve are continuing to take high levels of precautions to protect themselves—half have had COVID at least once, with the majority of those infections happening in year three of the pandemic when we no longer had access to protect ourselves outside of our homes.

We also asked about the impacts COVID continues to have in their daily lives. Many are still unable to safely visit with friends and family, go to the grocery store or pharmacy, access medical care and other necessary activities such as voting, and are being shut out of work, volunteerism, and education as a result of policy-based discrimination.

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%

Let's shift now and talk about known cures and treatments for Long COVID. Here's a list.

[Giant blank page.] This is it. This is the list.

Here's 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

Here's 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

Let's go back to Paul Longmore for a moment, polio survivor and disability rights scholar. He wrote:

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

Longhaulers and those at high risk of death or becoming longhaulers are asking you and our systems from being sentenced to social death.

Here's 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 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

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So what can the SRC and AOE do?

As a reminder, AOE Committee purview includes the following:

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.*

Here are a few ideas that come to mind for us of what you can do.

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?

Thank you!