

Senate Health Committee & Special Committee on Pandemic Emergency Response

March 9, 2022

Thank you, Mr. Chair and Members of the Committee, for inviting me to speak today. My name is Jennifer Stark and I am the Managing Attorney of Disability Rights California's Mental Health Practice Group. I am here to speak about my personal experiences with Long Covid and the importance of affording disability accommodations and protections to those who are negatively affected by it.

Personal story: Almost two years ago to the day I became sick. At the time, I was on parental leave and barely leaving the house because I needed to care for my four month old daughter and I was already concerned about the virus. Had the State's lockdown orders gone into effect one week prior, I likely would have been spared the virus and its continuing toll.

I was sick for approximately three weeks. While all of my symptoms tracked those of COVID, I never received a positive test because tests were not available to people like me. I could barely leave my bed, but I did not require hospitalization.

Long Covid: In the weeks after having COVID, I felt extraordinarily grateful for having recovered and moved beyond such a frightening experience.

However, approximately two and half months later, I developed breathing problems again. I wondered whether I might have COVID a second time – a prospect that seemed nearly impossible since I had not left the house for over two months. I got tested for COVID and for COVID antibodies. Both came back as negative. Doctors had not explanation for me; they merely advised me to take an antacid. Several well-meaning friends and family expressed disbelief that I had ever had COVID or anything related to COVID.

- They wondered whether the extreme fatigue I was experiencing—which was akin to having Mono--was simply due to having a newborn.
- They questioned the seriousness of my symptoms—the recurring low-grade fevers, short-term memory loss, brain fog, difficulty breathing, racing heart beat, digestive problems, anxiety, depression. According to them, because I was managing to keep working as a litigator and I didn't complain too often. I seemed fine. I was merely exaggerating or being a hypochondriac.
- When I went to a doctor to express concern about swollen toes that had turned purple and made it difficult to walk, I was advised just not to wear flip flops.

This was the beginning of weeks, months, and now years of people disbelieving me and my experiences simply because science has not yet caught up to the lived experiences of people with Long COVID.

- **Ongoing symptoms and challenges in getting treatment:** Since March of 2020, I have had recurring waves of symptoms that we now recognize as emblematic of Long COVID. These wide-ranging symptoms have affected me from head to toe and I have spent

months trying to get doctors' appointments with specialists in what feels like a game of whack-a-mole.

- After waiting more than three to four months to see a neurologist, my symptoms moved from my brain to my lungs.
 - By the time I got an appointment with a pulmonologist, my symptoms had moved to my joints, and so on.
 - I requested referrals to see the one Long Covid unit at UCSF, but initially didn't qualify because I was never hospitalized. I am now on the list for an appointment, which I scheduled nine months ago and UCSF has already canceled once. I am still waiting.
 - I have been living with Long Covid for almost two years and have yet to meet with any multi-disciplinary doctors who can help me to understand the effect that Long Covid is having on my body and what, if anything, I can do to treat it.
- **Long term Impact:** The impact that having Long COVID has had on my mentally and physically is hard to quantify. While I feel comparatively lucky – many people with Long COVID have experienced far more debilitating effects and have not been able to work at all – this has taken a toll on my family and I have needed to take far more sick leave than ever due to unexpected and ever-changing symptoms and to attend doctor's appointments. I have opted out of certain career opportunities out of concern that symptoms might return and I might be unable to perform as necessary.
 - Despite these setbacks, I have been able to keep working because I have a job that offers flexibility and makes reasonable accommodations for people with disabilities. If I were in a different workplace that refused to offer these accommodations, I may have needed to quit several months ago.
 - Open questions about whether my 6 year old son has long covid.
 - **Disabling event:** There is no question that this is one of the most disabling events in United States History.
 - **Disproportionate Impact:** And the disproportionate impact that COVID-19 has had on underserved communities and communities of color, especially the Black, Latinx, and American Indian communities—makes the need to respond to this disabling event in a way that squarely addresses socio-economic inequality absolutely vital.
 - **Policy Recommendations:**
 - Based on my own experiences and the work that I have done at DRC, there are many steps that California must take to address this crisis. As but a few examples—building on what several other panelists have already said--there needs to be:
 - **Clear recognition that** Long Covid can be deemed a disability under the Americans with Disabilities Act, which triggers the need to provide accommodations.

- Despite the often invisible nature of this condition, it must be made clear to businesses, schools, and employers that people whose long COVID qualifies as a disability must be afforded the same protections from discrimination and reasonable accommodations as any other person with a disability under the ADA and the Rehabilitation Act.
- **There also needs to be:**
 - **More research on Long COVID**, with a specific focus on underserved communities, communities of color, and people with disabilities and underlying health conditions.
 - **As Dr. Deeks and Ms. Vazquez mentioned, there is a need for Expanded Treatment Options** that include multi-disciplinary treatment teams (centers of excellence) and a **reduction of Unnecessary Barriers to Treatment and Reimbursement** (such as eliminating the need for prior hospitalization or proof of a positive COVID test)
 - **A continuous feedback loop with leading representatives of the patient communities informing research and policy decisions.**

Conclusion:

While many of the problems that people with Long Covid are not new to the disability community, this is a newly political problem given how many more people are now going to be impacted.

For me, the scariest part of all of this is that we have no idea what the future may hold. While I am (thankfully) only experiencing what seem to be minor Long Covid symptoms right now, I have no idea what tomorrow, next month, or next year might bring. Whether Long Covid will become a lifelong chronic condition or lead to early mortality. Whether my time with my two young children will be cut short or my ability to build a meaningful career will be halted. No one knows. I hope that others do not have to continue to navigate these terrifying questions in the way that I have – largely alone.