

Liza Fisher
Long COVID Patient advocate
February 3, 2022

Health Subcommittee Hearing on Bridging Health Equity Gaps for People with Disabilities and Chronic Conditions

Hello, my name is Liza Fisher from Houston, Texas. Thank you to the committee for having me here today. I'd like to tell you my story as it represents the experiences of many people from the chronic illness community, the post COVID community, and the disabled community

In June 2020, I became sick with what I thought was a sinus infection until one day I woke up feeling like a truck hit me. I was having respiratory symptoms, headache, fatigue, and sore throat. I had been struggling to breathe, but things turned really bad when an invisible elephant started sitting on my chest. A few days later, I ended up in an emergency room with my feet turning blue, gasping for breath, with an uncontrollably high heart rate. My chest X ray came back with a spotted pneumonia and a few days later, my PCR test came back positive.

I was told to go home and try to recover. "You're young and healthy. It should be a rough two weeks, but you'll get better." I had thought the same. However, the next week I was back at the emergency room. I felt like I was dying.

I ended up at a hospital that was treating COVID positive patients. I was seen in a tented facility in the hospital parking lot, then sent to an isolated COVID wing where I waited for hours. I was told again to go home and drink Gatorade. I explained my situation and continued to beg for treatment. I was told that there was a two day wait for hospital beds and "it just wasn't going to happen. go home and try to tough it out."

When I was leaving, I saw a shirt that said 'I can't breathe.' I'm a biracial female being turned away from a hospital and in that hospital waiting room, all I saw was brown and black folks. And the only person I saw who walked through 'the plastic zippered area' was a white male.

After being turned away from the hospital, I found a practitioner who would see me virtually for the next few weeks as I continued to get worse and develop neurological symptoms. Again, my provider told me to go to the emergency room. About 5 weeks after my initial infection, they admitted me to COVID ICU, I spent a week in the hospital and then was released to a rehab hospital. Within 10 days, I started to develop severe tremors, neuropathy and lost my ability to walk.

While I was in the hospital, everyone had told me that I needed to start applying for disability. I struggled with that concept, because I just didn't identify with it. But in 2020, I started the process of applying for disability. In June 2021, I was approved, and my doctor was so excited because we would finally be able to get the medications I needed without having to struggle and fight with insurance in order to receive them. However, we were both surprised when I found out that I had to wait an additional 24 months before receiving the health care portion being Medicare that came with it.

I talked to the social worker, and found out that the waiting period wasn't 24 months from when you are considered disabled. But it's 24 months from when you were approved for disability. So, that added another five months for me. For me, this gap in coverage caused my family to spend our retirement savings. For others, this gap in coverage can be even more catastrophic.

At this point, I'd like to note I had been unable to work since June of 2020 and I was paying for COBRA insurance. I survived with the help of my friends, family and co-workers that had started a GoFundMe while I was in the hospital. Too sick to work, when I started to look at different insurance options, none of the options allowed me to see all of my specialists, and cover all of the medications that I was on, some of those being very important, like my heart medication, and my asthma medications.

I thought, Wow, this system is really meant for you to fail and never get better.

This situation has been catastrophic to my life. Not only am I still using mobility devices, including being in a wheelchair, but I am still having to relearn to walk. But my family has been affected too. My mother had to move in with me. She no longer works.

Overall, my story is a little bit of a roller coaster, but these experiences reflect what many people face every single day. So although you only hear my voice right now, it is the voice of many. ***The Solve Long COVID Initiative estimates that before omicron between 15 - 30 million Americans have experienced Long COVIDⁱ. The COVID-19 Longhailer Advocacy Project recently wrote to President Biden that “the current estimated total income lost by COVID Longhailers is approximately \$88.8 billionⁱⁱ.”*** We're about to see a mass disability event from post-viral illness, something that has been ignored for too long.

And in summary, I just really urge you to consider removing the waiting period for Medicare, because it would make it such a tremendous impact on so many lives. And please consider the huge number of long covid and post-viral illness patients that need support and equal access to coverage and care. Thank you.

Liza Fisher

Member of the Long COVID Alliance (www.longcovidalliance.org)

ⁱ Adapted from “Range of Potential U.S. Long Covid Cases,” pg 8. by Solve Long Covid Initiative (solvelongcovid.org). The Solve Long Covid Initiative. Retrieved January 29, 2022 from https://solvecfs.org/wp-content/uploads/2022/01/Kotok_12.9.21-LCI-Presentation.pdf

ⁱⁱ Bisoff, Karyn et al (January 10, 2022). “An Open Letter to President Biden, Cabinet and Congressional Leadership and Key Government Agencies” COVID-19 Longhailers Advocacy Project. Retrieved January 29, 2022 from <https://www.longhailer-advocacy.org/open-letter>