**BODY POLITIC**
**PATIENT-LED RESEARCH COLLABORATIVE**

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# *Body Politic and Patient-Led Research Collaborative Applaud Federal Long COVID Disability Rights Guidance on Anniversary of Americans with Disabilities Act*

**"Many disabled and chronically ill people still face barriers fighting for their rights under the ADA and IDEA, and while hundreds of thousands of Long COVID patients have already joined and will continue to join their ranks in what is shaping up to be the one of the largest mass disabling events in modern history, we hope today's guidance helps pave the way for better disability protection and services under the law for our Long COVID community and other chronically ill people."**

**"Today's important announcement sets the stage for future policy actions by Congress that will help secure essential resources and funding for Long COVID patients, such as the Social Security reforms in progress and Representatives Beyer's and Bergman's Long Haulers Act."**

**NEW YORK --** Body Politic COVID-19 Support Group and Patient-Led Research Collaborative (PLRC) celebrate the 31st anniversary of the Americans with Disabilities Act today by applauding the Biden Administration's announcement that Long COVID patients living in the US are entitled to disability rights and resources under federal law, including the Americans with Disabilities Act (ADA). The Administration released a package of guidance and resources to support people with Long COVID, with guidance from the Department of Health and Human Services (HHS), Department of Justice (DOJ), Department of Education (DOE), Department of Labor (DOL), and the Administration for Community Living (ACL) that will help Long COVID patients navigate barriers in the workplace, school, doctor's office, and community.

One of the most important results of today's announcement and guidance may be the awareness it brings to Long COVID patients who now know that they may be considered disabled under the ADA and the Individuals with Disabilities Education Act (IDEA) and therefore may be entitled to accommodations and services that make everyday life activities, work, and school more accessible. The guidance issued by HHS along with DOJ states: "Put simply, they [disabled Long COVID patients] are entitled to full and equal opportunities to participate in and enjoy all aspects of civic and commercial life." Likewise, in the guidance issued by DOE, Katherine Neas, Acting Assistant Secretary for the Office of Special Education and Rehabilitative Services noted "[local educational agencies] need to ensure that children who are living with impaired development or health due to long COVID that is a disability are identified and are provided the appropriate services and supports covered under IDEA."

**"Today's guidance will help relieve some of the self-advocacy burden on Long COVID patients in navigating accommodations and services, as the guidance published today will help provide**

**credible instruction to institutions, workplaces, schools, and the community regarding how they can support people with Long COVID. Many disabled and chronically ill people still face barriers fighting for their rights under the ADA and IDEA, and while hundreds of thousands of Long COVID patients have already joined and will continue to join their ranks in what is shaping up to be the one of the largest mass disabling events in modern history, we hope today's guidance helps pave the way for better disability protection and services under the law for our Long COVID community and other chronically ill people." - Lisa McCorkell, Long COVID Patient-Researcher, Patient Led Research Collaborative**

More broadly, these efforts from the federal government today set an example for the international community -- Long COVID is real; patients, including school-aged children, may be disabled by it; and they are entitled to the same protections and benefits other citizens with disabilities have. The guidance lists common symptoms as cited by the Centers for Disease Control and Prevention (CDC): tiredness or fatigue, difficulty thinking or concentrating (sometimes called "brain fog"), shortness of breath or difficulty breathing, headache, dizziness on standing, fast-beating or pounding heart (known as heart palpitations), chest pain and more.

The guidance collectively helps to clarify that Long COVID patients can meet the definition of disability (under ADA, Section 504 or Section 1557, or under Part B or C of IDEA) and lists common examples of how Long COVID substantially limits activities. It is particularly attuned to the needs of Long COVID patients, as the DOL guidance notes that even with fluctuating symptoms that make the impairment come and go, it still is considered disability. Additionally, the impairment does not have to be "severe, permanent, or life-long" which reduces the burden on Long COVID patients who do not know how long their impairment will last.

While Body Politic and PLRC would have liked to see explicit recognition of the testing access issue that many Long COVID patients face, it's important to recognize that neither the guidance from HHS and DOJ nor from DOE requires any history of positive COVID-19 lab results to determine Long COVID disability for protection under federal law.

**"Disability determination under Social Security is a separate policy issue and eligibility determination remains complicated and challenging for Long COVID patients seeking disability benefits. Still, today's important announcement sets the stage for future policy actions by Congress that will help secure essential resources and funding for Long COVID patients, such as the Social Security reforms in progress and Representatives Beyer's and Bergman's Long Haulers Act." Angela Meriquez Vázquez, MSW, Vice President, Body Politic; Long COVID Patient**

Lastly, while Body Politic and PLRC recognize this as a win for the Long COVID community, they acknowledge that many people in the chronic illness and disability communities such as those living with ME/CFS, chronic pain, Lyme Disease, dysautonomia and many others have longed for recognition of their disease and the barriers they face in having their disabilities acknowledged by their employers, communities, and even the medical system. The success that Long COVID advocates celebrate today are built on the previous efforts of disability activists and patient advocates.

Today's announcement reflects over a year of volunteer labor by Body Politic and PLRC, whose patient-leaders have met with the President of the United States' COVID-19 Health Equity Task Force on several occasions to represent people living with Long COVID, in addition to their numerous meetings with the CDC, National Institutes of Health, Substance Abuse and Mental Health Services Administration, Office of Personnel and Management, and other federal partners. They have presented data from PLRC's peer-reviewed publication, told their stories of living with Long COVID, and reported on the barriers this population faces with navigating the medical system, employment, benefits, and everyday life in their communities. Without the diligent work of patient advocates from organizations like Body Politic and PLRC, the presidential announcement and guidance published today by federal agencies would not contain the Long COVID patient-centered perspectives they do.

Body Politic is a grassroots health justice organization at the forefront of the patient-led movement for Long COVID with one of the largest COVID-19 support groups in the world, serving more than 20,000 members globally. Body Politic's research partner, Patient-Led Research Collaborative (PLRC), is a self-organized group of Long COVID scientists, data analysts, and other experts working on patient-led research around the Long COVID experience and has published the groundbreaking peer-reviewed paper "Characterizing long COVID in an international cohort: 7 months of symptoms and their impact".

*Quick Links for Long COVID Patients:*

- Guidance on "Long COVID" as a Disability Under the ADA, Section 504, and Section 1557
- Long COVID under Section 504 and the IDEA: A Resource to Support Children, Students, Educators, Schools, Service Providers, and Families
- Department of Labor compilation of resources on COVID and Long COVID including:
    - COVID-19 Long Haulers and the Americans with Disabilities Act
    - Your Accommodation Request Was Denied. What Now?
    - Adopting an Integrated Telework Policy for Employees With and WIthout Disabilities
- How ACL's Disability and Aging Networks Can Help People with Long COVID
- Body Politic: Long COVID Disability Claims with Body Politic x Springer Ayeni Law
- Body Politic Slack support group for COVID-19 patients and their caregivers for the #financial-and-legal channel: https://www.wearebodypolitic.com/support-group

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