



## **Testimony of Long COVID Justice NYC**

### **Submitted to the New York State Legislature**

#### **Testimony in Support of Reforming Temporary Disability Support A84/S172**

**February 26, 2025**

Long COVID Justice NYC thanks the Legislature for the opportunity to testify in support of the expansion of New York’s temporary disability benefits pursuant to A84/S172.

Long COVID Justice NYC (“LCJ-NYC”) is a group of New Yorkers living with Long COVID and associated diseases. The group’s mission is to improve and expand related policies and programs through advocacy, media efforts, education and cultural events. LCJ-NYC is currently undertaking a pilot needs assessment in New York City, funded by the New York Health Foundation, to examine the needs of people with Long COVID, centering often-overlooked yet disproportionately impacted groups. LCJ-NYC is also advocating for similar efforts on the city and state level.

#### **Long COVID and Associated Diseases Background:**

Long COVID (or post-acute sequelae of SARS-CoV-2) is an illness that can develop in children, adults, and seniors after a probable or confirmed case of COVID-19, and can last months or even years. Long COVID can occur following infection of SARS-CoV-2 regardless of severity of acute presentation, including in people who were asymptomatic, and in those who have been vaccinated. Almost 50% of people with Long COVID meet the criteria for ME/CFS, a disabling neuroimmune disease characterized by extreme fatigue and symptom exacerbation following physical, cognitive and/or emotional exertion (known as post-exertional malaise (“PEM”) or post-exertional symptom exacerbation (“PESE”)). Approximately 200,000 people were already disabled with ME/CFS prior to the pandemic.

According to the most recent Household Pulse Survey<sup>1</sup> conducted by the National Center for Health Statistics in conjunction with the Census Bureau, almost 15% of all adults in New York State have experienced Long COVID, including over 23% of all adults who have ever had COVID. Many New Yorkers are experiencing activity limitation as a result of Long COVID: Of all adults living in New York, almost 4% (approximately 620,000 people) are currently experiencing activity limitation, and 1.7% have significant activity limitation (almost 275,000 people). Note that the survey results include a note that the percentage of adults self-reporting a COVID infection is lower than scientific estimates, which may suggest that Long COVID symptoms are going miscategorized by those who do not believe they have had COVID. The New York State Insurance Fund reported in spring 2023 that “Long COVID has harmed the work force”<sup>2</sup>, noting that approximately 71% of workers compensation claimants with Long COVID were unable to work for more than 6 months or required ongoing medical treatment.

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<sup>1</sup> <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

<sup>2</sup> <https://www.nytimes.com/2023/01/24/health/long-covid-work.html>

## Commentary:

Respectfully, LCJ-NYC urges the Senate to pass S172 and, critically, ensure that any paid medical leave program and/or temporary disability benefit update includes the right to *intermittent* leave.

For too long, New Yorkers have had to make the almost impossible choice between their health and their financial security, due to the state's inadequate temporary disability benefits. Without appropriate support, New Yorkers risk permanent damage and decline, particularly if they continue to work beyond their energy capacity without adequate, scheduled rest or forgo ongoing medical treatments and appointments due to inadequate leave, as is often the case for people with Long COVID, ME/CFS and other energy-limiting chronic diseases ("LCAD").

Intermittent leave is explicitly allowed through New York's paid family leave program ("PFL") albeit in daily increments, and through federal unpaid family and medical leave ("FMLA"), but not under New York's temporary disability program. Thus, as it currently stands, a New Yorker in need of routine intravenous immunoglobulin infusions to address their LCAD, like someone receiving chemotherapy for cancer, could *potentially* use unpaid FMLA, but only their accompanying family member could rely on job-protected paid leave to attend that appointment. Similarly, for some people living with LCAD, radical rest is medically indicated to manage symptoms and avoid further decline. Thus, if a New Yorker with an energy-limiting disability needed a temporarily reduced schedule, such as "Wednesdays off" to allow for focused, radical rest between two two-day work blocks, to manage their PEM and migraines, their family member could rely on job-protected paid leave as a caregiver but the individual would have to choose between their health and job.

Implementing intermittent paid medical leave would improve the ability of more New Yorkers with LCAD to participate in the workforce while respecting their needs and energy limitations. For example, one LCJ-NYC advocate was able to increase their hours worked over an extended period by utilizing *private* disability benefits to work a reduced hours and "Wednesdays off" schedule that allowed them to rest on Wednesdays and throughout the day, while also attending medical appointments. The payments available under private disability benefits significantly replaced their lost income and allowed them to work, and subsequently increase, their reduced hours at a pace guided by their physician rather than their wallet. This arrangement was mutually beneficial to the employee and employer - it provided financial security and needed rest to the employee while keeping a valuable employee available to the employer. In the alternative, if the employee had been required to take their private disability benefits in one lump, the employee would not have been able to safely resume full time activities without risk of permanent damage and decline, and the employer would have risked losing that employee permanently. LCJ-NYC, as a disability-centered organization, has a four-day "no Friday" workweek in order to respect its employees' energy limitations. All New Yorkers, not just those with private benefits or especially supportive employers, deserve *adequate, intermittent* benefits.

Once again, LCJ-NYC thanks the Senate for the opportunity to testify regarding the expansion of paid medical leave and temporary disability benefits. This expansion is an important first step to acknowledge and protect people with LCAD, as well as the three million New Yorkers with disabilities. The number of New Yorkers with disabilities continues to rapidly grow, as people continue to develop LCAD in the ongoing COVID crisis, so change cannot come soon enough.