

The logo banner features a yellow background on the left and a light blue background on the right, separated by a wavy purple line. The text "Long COVID Justice" is in dark blue on the yellow background, and "a project of Strategies for High Impact" is in dark blue on the light blue background.

Long COVID Justice

a project of
Strategies for High Impact

Community-led solutions & movement building for health justice – lessons from Long COVID Justice

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Long COVID Justice NYC

Long COVID Justice NYC, a project of Strategies for High Impact, is a volunteer-run advocacy group. We strengthen networks of people with Long COVID and associated diseases (LCAD). Our work is done by and for chronically ill and disabled people, our families and communities.

We are leading grassroots, collective efforts to confront the Long COVID crisis, while centering racial, social, economic and disability justice. Our work includes conducting community needs assessments, as well as advocacy with state and city officials and public health leaders.

Long COVID: What is it?

Long COVID, also known as long Term COVID or post-COVID conditions,.

Long COVID is an ongoing public health crisis.

In the Household Pulse Survey, the U.S. Census defines Long COVID as **“any symptoms lasting 3 months or longer that you did not have prior to having COVID-19, or that got worse after having COVID-19.”**

Long COVID: Where Are We Now?

Did you know...?

- 1 in 10 New Yorkers experience Long COVID/post-COVID conditions.
- DOHMH data: Up to 30% of people who have had COVID-19 may experience Long COVID.
- In NYC, around 2.9 million people have been infected with Covid-19, meaning that around 870,000 may be experiencing Long COVID.
- Every time someone gets COVID-19 – even if they had it before – they are at risk of getting new or worsened Long COVID.

Long COVID Symptoms

Long COVID is an ***infection-associated chronic condition (IACC)***. IACCs affect the body in many ways and manifest in a variety of chronic conditions.

Long COVID can include many long-term and multi-organ symptoms, affecting the nervous, digestive, and respiratory systems.

There is no one specific test to show whether someone has Long COVID. Many medical providers do not know much about the condition.

Long-term symptoms may include:

- Tiredness or fatigue, or inability to exercise;
- Difficulty thinking or concentrating, forgetfulness, or memory problems (sometimes referred to as 'brain fog');
- Difficulty breathing or shortness of breath;
- Joint or muscle pain;
- Fast-beating or pounding heart (also known as heart palpitations);
- Chest pain;
- Dizziness on standing;
- Changes to your menstrual cycle, or
- Changes to taste/smell.

LONG COVID ESSENTIALS

a new series from
THE SICK TIMES and
LONG COVID JUSTICE

30+ RESOURCE SHEETS

designed by & for
**PEOPLE LIVING WITH
LONG COVID &
ASSOCIATED DISEASES**

The Sick Times x **LONG COVID JUSTICE**

PRINTABLE RESOURCES!

**STILL FEEL UNWELL AFTER COVID-19?
HERE'S WHAT YOU NEED TO KNOW
ABOUT LONG COVID.**

LONG COVID ESSENTIALS: A SERIES BY

If you still feel sick or unwell weeks or months after COVID-19 can lead to a disease called Long COVID that affect every part of the body. People in all age groups can get Long COVID.

For some people, their symptoms never resolve and can last for weeks or months later. These symptoms

**HAVING TROUBLE SLEEPING
AFTER COVID-19?**

LONG COVID ESSENTIALS: A SERIES BY The Sick Times x **LONG COVID JUSTICE**

Having trouble falling or staying asleep after COVID-19? Do you still feel tired when you wake up? You're not alone. As many as four in five people with Long COVID experience

**WHY YOU SHOULD BE
CAREFUL ABOUT ACTIVITY &
EXERCISE AFTER COVID-19**

LONG COVID ESSENTIALS: A SERIES BY

After having COVID-19, it's important to get as much rest as you can at the pace your body can tolerate.

For some people, routine activities that were okay before COVID-19, but affects an estimated 80%

* **WHAT COUNTS AS EXERCISE OR**

**DIZZINESS,
LIGHTEADEDNESS, AND
RACING HEART AFTER COVID-19
IT COULD BE DYSAUTONOMIA**

**"BRAIN FOG," MEMORY
PROBLEMS, AND OTHER
NEUROLOGICAL ISSUES AFTER
COVID-19**

SERIES BY The Sick Times x **LONG COVID JUSTICE**

a condition called **dysautonomia**, in which the body does by itself, like heart beating) are one form seen commonly in Long COVID syndrome."

LONG COVID ESSENTIALS tiny.cc/LCE

a series by The Sick Times x Long COVID Justice

LONG COVID ESSENTIALS

A NEW SERIES BY THE SICK TIMES
& LONG COVID JUSTICE

30+ RESOURCE SHEETS on topics like:

- * **GETTING HELP**
- * **CONDITIONS & COMPLICATIONS**
- * **SYMPTOMS & TREATMENTS**
- * **LC IN PEOPLE LIVING WITH HIV
& TRANSGENDER PEOPLE**
- * **LC IN CHILDREN & YOUTH**

designed by & for **PEOPLE
LIVING WITH LONG COVID
& ASSOCIATED DISEASES**



 **VIEW OR PRINT:** tiny.cc/LCE

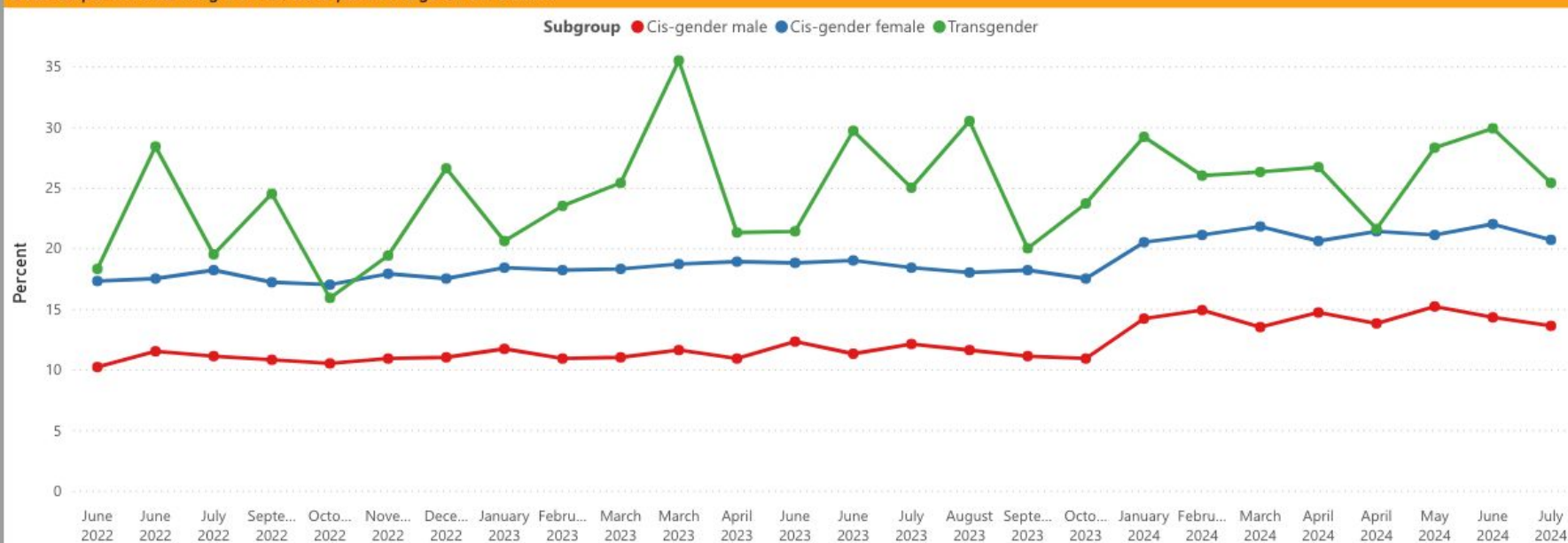
Long COVID: Disparities in Prevalence

Long COVID, like COVID itself, has an **outsized impact on marginalized communities**, including low-income communities, transgender people, people living with HIV, people with diabetes, African American and Black people, and people of Hispanic/Latino heritage.

- The Household Pulse Survey (HPS) found “particularly high odds of developing long COVID for Hispanic females, Black non-Hispanic females, Hispanic college graduates, Black college graduates, and multiracial/other college graduates.”
- HPS also reported that that 17.3% of transgender people in the United States are currently experiencing Long COVID compared to 5.0% of cisgender men and 8.4% of cisgender women.
- A positive HIV status was associated with two to four times higher odds of having Long COVID.
- Occupational factors play a role in Long COVID risk, with workers in public-facing positions, such as teaching, education, transportation, and caring and leisure services, at higher odds of experiencing Long COVID (Kromydas et al., 2023).

Long COVID Rates in Trans People in the US

Ever experienced long COVID, as a percentage of all adults

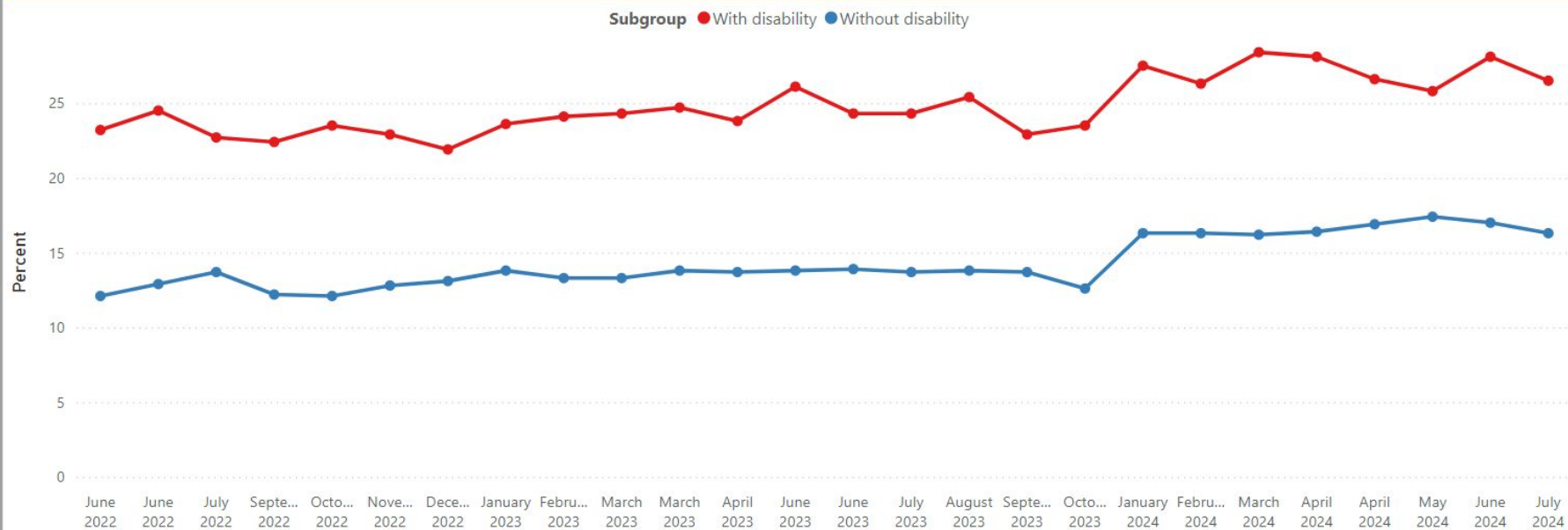


NOTE: All estimates shown meet the NCHS standards of reliability. See Technical Notes below for more information about the content and design of the survey.

SOURCE: U.S. Census Bureau, Household Pulse Survey, 2022-2024

Long COVID Rates in Disabled People in the US

Ever experienced long COVID, as a percentage of all adults



NOTE: All estimates shown meet the NCHS standards of reliability. See Technical Notes below for more information about the content and design of the survey.

SOURCE: U.S. Census Bureau, Household Pulse Survey, 2022-2024

According to the United Nations:

“[P]ersons with disabilities are often at higher risk of exposure to HIV. Additionally, there is a growing understanding that persons living with HIV or AIDS are also at risk of becoming disabled on a permanent or episodic basis as a result of their condition.”

People living with HIV
are 2 to 4 times more likely
to develop Long COVID,
which often is disabling

Prevention
and
treatment as prevention
are imperative regarding
HIV and COVID

Needs Assessment Action Project (NAAP)

Our discussion today may inform the findings of our **Needs Assessment Action Project (NAAP)**, a pilot program assessing the needs of people living with Long COVID in NYC.

- The NAAP will focus on three priority populations who have been disproportionately overlooked or impacted by Long COVID, including transgender people, people living with HIV, and/or children and youth.
- By understanding the needs of the Long COVID community in NYC, we can help determine effective solutions, raise awareness among affected individuals, and activate the systems that are, or could be, resourced to respond.

Findings from this project will inform an **action plan** and **informational materials** about Long COVID.

This will inform a **policy agenda** and **further advocacy**.

Thanks to the **New York Health Foundation** for supporting this work!

ARE YOU EXPERIENCING LONG-TERM SYMPTOMS AFTER A COVID INFECTION?

WE WANT TO HEAR FROM YOU!

Long COVID Justice NYC has a new survey on post-COVID conditions. The survey focuses on groups that have been especially affected by Long COVID:

- Trans or nonbinary people;
- People living with HIV; and/or
- Children and youth (parents or caregivers will fill out survey)

If you're experiencing long-term symptoms following a COVID infection and belong to the above groups, you may be eligible for this survey!

**\$25
GIFT
CARD**

Everyone who completes the survey will receive a \$25 gift card as a thank you for your participation.

**TAKE
THE
SURVEY**

Learn more and take the survey-
Go to tiny.cc/naap-survey or scan this code:



QUESTIONS? naap@s4hi.org

**LONG COVID
JUSTICE NYC**

HIV & Long COVID small support group:

A support group for people living with HIV and Long COVID led by

When: every other Thursday beginning October 24 through December 5 of 2024.

Where: on Zoom

Time: 6:30pm-8:00pm Eastern Time

Facilitated by: Gabriel San Emeterio, LMSW – gabriel@s4hi.org

thank you!

**LONG COVID
JUSTICE**

STRATEGIES FOR
HIGH IMPACT