CHRONIC INJUSTICE:
CENTERING EQUITABLE HEALTH CARE
AND POLICIES FOR COVID-19 AND
OTHER CHRONIC CONDITIONS
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Partner Organizations

- Center for HIV Law and Policy, https://www.hivlawandpolicy.org/
- Coalition for the Homeless, https://www.coalitionforthehomeless.org/
- Health People, https://www.healthpeople.org/
- #MEAction, https://www.meaction.net/

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EXECUTIVE SUMMARY

No infectious disease epidemic in history has ever been so clearly fueled by chronic disease as COVID-19. And yet, over a year from the COVID-19 pandemic’s onset, city, state, and federal leadership have no clear plan or processes in place to properly implement the many well-proven, community-led, and evidence-based practices to significantly prevent and control chronic diseases that have been exacerbated or caused by COVID-19.

Further, there is inadequate discussion and planning for the massive influx of chronically ill patients into strained and fractured systems of care already rife with inequities.

There is now abundant evidence that like other viruses such as poliovirus, SARS-associated coronavirus, and Epstein-Barr, SARS-CoV-2 can trigger chronic disease, often called Long COVID by people experiencing it and now referred to as post-acute COVID-19 syndrome (PACS) or post-acute sequelae of SARS-CoV-2 (PASC) by the National Institutes of Health (NIH). At the same time, COVID-19 infections and the massive societal disruptions brought about by the pandemic have worsened conditions and outcomes for people with pre-existing chronic conditions.

New York will emerge from the pandemic with our residents facing an even more significant, potentially lifelong, and racially disproportionate burden of disease; physical, mental, and emotional health challenges; and a potential deluge of nonmedical suffering associated with chronic conditions that have been created or worsened by COVID-19, including stigma, isolation, and economic devastation.

To honor those we have lost and those who remain in harm’s way, we must not accept an “end” to this crisis that consists solely of mass vaccination, a return to prior rates of in-person schooling, and the reopening of non-essential workplaces.

‘After COVID-19’ is Just for Some, and ‘Normal’ Never Was: We Need Equity

It is only through transparent and comprehensive efforts for genuine equity—particularly economic and racial equity—that we can truly “end” the impact of the COVID-19 pandemic, while addressing the ongoing harms of fragmented and insufficient systems for care of chronic conditions.

While this report focuses on New York City and state, we also urge the development and full funding of equity-based policies and programs—including essential community-led services—across the country and around the world, knowing that there are no true borders in our interdependence as a human society.

An equitable approach that can reach equitable outcomes must encompass all aspects of COVID-19 prevention, testing, acute care, chronic care, and the myriad societal impacts of the pandemic—including a comprehensive restructuring of care and support for all chronic conditions—and be assessed with appropriate and clear indicators, developed in true collaboration with those most affected.
RECOMMENDATIONS:

• Recognize COVID-19 as a chronic condition or trigger of chronic condition for New Yorkers and accept that vaccination alone will not address or undo the damage of COVID-19.

• Restructure and finance health care and support systems—including community-driven and adequately funded delivery of support, self-care, and prevention services—for all people with chronic health conditions, including chronic mental health conditions.

• Meet expanded long-term services and supports (LTSS) needs, including addressing long-standing underpayment of workers (read more in “A Closer Look: Home Care and Support Services” on page 16).

• Specifically include mental health considerations in all aspects of the COVID-19 response (read more in “Mental Health Must Be Considered in All COVID-19 Policies” on page 19).

• Build a foundation of equity and trust with communities by being trustworthy.

• Confront the structural drivers of suffering and disease—such as systemic racism and economic inequality (read more in “Heed Four Key Lessons from the HIV Epidemic” on page 8).

• Treat metabolic diseases—including through community-led efforts and access to healthy foods—to prevent the impact of many conditions that they can cause (read more in “Highly Avoidable Diabetes Deaths” on page 10).

• Enact equitable economic policies in order to achieve sustainable funding for vital work to address long-term consequences of COVID-19.

• Center meaningful, compensated collaboration with members of communities most affected by Long COVID and other chronic conditions.

• Develop and use a central Equitable Access Framework (EAF), such as the Equity Lens Tool created by Human Impact Partners on behalf of the Big Cities Health Coalition, for care during and beyond the COVID-19 pandemic.

• Conduct data collection for reporting, planning, and evaluating health and policy interventions in authentic consultation with disproportionately affected communities.

• Shift the stigmatizing belief that chronic illness or disability or mental health challenges are a lessening of human worth and potential, through the aforementioned steps and systematic public education/communications.

• Create, scale up, and sustain a network of wrap-around services in New York City and state, promoted through a multilingual public education campaign, on the many facets of Long COVID/PACS, including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

• Support all people experiencing physical or mental post-COVID symptoms, illness, conditions, or disabilities in these wrap-around services, regardless of insurance status, ability to pay, pre-existing conditions, or history of COVID test results (read more in “Will Recognition of Long COVID/PACS Bring Equity?” on page 12).

• Recognize housing as health care: Provide thousands of single-occupancy hotel rooms; support and enact statewide rental assistance legislation, including Home Stability Support and Housing Access Vouchers; and support a broader federal housing relief package (read more in “Housing is Health Care” on page 20).

If anything is “normal,” it is the very human realities of illness and disability across the life span; it is the disabling structures of society that isolate and disregard those among us who are living with them.
A CALL FOR PRINCIPLED ACTION: HEALTH JUSTICE AND HEALING, THROUGH EQUITY

Preventing COVID-19, as well as addressing acute and chronic care needs of people with COVID-19 and Long COVID, calls for fundamental changes in our society related to the structure of health care delivery and financing, the management of data, the stigmatization of marginalized populations, and the inappropriate imposition of policing and criminalization in public health.

For the foreseeable future, we will face a sustained, complex, and acute health crisis, falling most heavily on elders; Black and Brown people; Indigenous peoples; people living with chronic conditions and disabilities; and people in congregate living, including shelters, nursing homes, jails, prisons, and immigrant detention.

In the city, state, and nation, COVID-19 infection and death rates reveal harsh realities of interdependence without equity. A recent assessment of disproportionate impacts on mortality by race/ethnicity predicts that:

- COVID-19 will reduce US life expectancy in 2020 by 1.13 years. Estimated reductions for the Black and Latino populations are 3 to 4 times that for Whites. Consequently, COVID-19 is expected to reverse over 10 years of progress made in closing the Black–White gap in life expectancy and reduce the previous Latino mortality advantage by over 70%.

These blatant disparities of the pandemic, alongside an uprising for racial justice and a drastically changing political landscape, are a mandate for a rapid, sustained shift to equity and health justice.

As we face lasting consequences of COVID-19 as a city and state, New York must create and sustain a decisively equitable system of community-accountable, integrated care for all with chronic care needs, using the hard-won lessons from previous pandemics and ongoing health challenges. To mitigate this pandemic, and to prevent or minimize the next ones, we must create and sustain truly accessible, comprehensive structures of health care, rooted in community accountability and genuine measures of equity.

1. Kat Aaron, a post-election commenter on the How to Survive the End of the World podcast, paraphrased a powerful Twitter posting, noting that what was called the coronavirus “lockdown” consisted of “middle-class people hid[ing] while poor people brought them things.”
An equitable approach that can reach equitable outcomes must encompass all aspects of COVID-19 prevention, testing, acute and chronic care, and the myriad societal impacts of the pandemic—including a comprehensive restructuring of care and support for all chronic and mental health conditions—and be assessed with appropriate and clear indicators, developed in true collaboration with those most affected. To do so, we need to:

- **Recognize COVID-19 as a chronic condition or trigger of chronic condition for New Yorkers and accept that vaccination alone will not address or undo the damage of COVID-19.** Plan for an equitable, community-led, comprehensive and long-term response centered on addressing the chronic health conditions that created vulnerability to the pandemic, or that were triggered or worsened by COVID itself—establishing, funding, and evaluating a new model of care that ensures quality, accessible care for all who have these conditions.

- **Restructure and finance health care and support systems**—including community-driven and adequately funded delivery of support, self-care, and prevention services—for all people with chronic and mental health conditions. Systems must be developed and evaluated through an equity-based framework (read more on page 7) and the wisdom of affected communities, including but not limited to people living with Long COVID/PACS, HIV, ME/CFS, diabetes, disabilities, and mental health conditions; marginalized communities most affected by COVID, including Black, Indigenous and people of color (BIPOC) and immigrants; low-paid and frontline workers; and people living in congregate settings (including jails and prisons), overcrowded housing or who are homeless/ unstably housed.

- **Meet expanded long-term services and supports (LTSS) needs** by eliminating or increasing the “global cap” on Medicaid spending, investing in the home care workforce; and reimbursing providers for telehealth visits.

- **Specifically include mental health considerations in all aspects of the COVID-19 response**, including a meaningful increase in support for grassroots organizations to provide mental health care, e.g., NYC’s Connections to Care program. Specifically support the mental health needs of health care providers, incarcerated, and homeless populations.

- **Build a foundation of equity and trust by being trustworthy**: centering the rights and leadership of members of the most marginalized communities harmed by COVID-19, police violence, and poverty, including Black, Brown, and Indigenous people living with chronic physical and mental health conditions.

- **Confront the structural drivers of suffering and disease**—such as systemic racism and economic inequality—and ensure access to housing, income, food, education, and broadband internet, as well as freedom from police/Immigration and Customs Enforcement violence as fundamental components of health.

- **Recognize and treat metabolic diseases**—including through community-led efforts and access to healthy foods—to prevent the impact of many conditions they can cause. Most of the chronic diseases linked to COVID are, in fact, metabolic diseases, which means they are fueled by excess sugar and overprocessed food.

- **Enact equitable economic policies**, including state taxes on the ultra-wealthy and on fiscal transactions and federal funding that will avoid greater future costs, in order to achieve sustainable funding for this vital work, including support for workers excluded from other relief plans.

- **Center meaningful, compensated collaboration with members of communities most affected by COVID-19 and other chronic conditions**—including those often marginalized from decision-making and public policy because of linguistic, cultural, legal, health, or accessibility barriers—as essential experts in developing strategies, setting policies, and advising and running programs. We must harness their collective wisdom through truly meaningful involvement.
• Develop and use a central Equitable Access Framework (EAF), such as the Equity Lens Tool created by Human Impact Partners on behalf of the Big Cities Health Coalition, for care during and beyond the COVID-19 pandemic. Cutting across all chronic conditions, this will be a powerful tool for ensuring attention to key areas of policies and programs as we confront the challenges ahead.

• Conduct data collection for reporting, planning, and evaluating health and policy interventions in authentic consultation with disproportionately affected communities on issues of (1) data transparency; (2) enhanced data collection capacity in collaboration with community-based partners; (3) routine communication regarding both efforts and outcomes; (4) attention to reducing unintended consequences of data dissemination; and (5) clear application of data to policy, programs, and milestones.

• Shift the stigmatizing belief that chronic illness or disability or mental health challenges are a lessening of human worth and potential, through the aforementioned steps and systematic public education and communications. Even before COVID-19, six of every ten people in the United States had at least one chronic condition. If anything is “normal,” it is the very human realities of illness and disability across the life span; it is the disabling structures of society that isolate and disregard those among us who are living with them.

• Housing is health care. Provide thousands of single-occupancy hotel rooms for all homeless people living in congregate shelters, living on the streets, or sleeping in the subway, facilitating appropriate social distancing, with access to private bathrooms and showers, as well as the safety of an indoor place in which to isolate and recover. Support and enact statewide rental assistance legislation, including Home Stability Support and Housing Access Vouchers. Support a broader federal housing relief package including robust investments in affordable housing (thereby enabling job creation) and universal access to housing vouchers for those who are homeless or at risk of losing their homes.

DEFINING EQUITY IN HEALTH CARE

In 2003, ministers of health from Chile, Germany, Greece, New Zealand, Slovenia, Sweden, and the United Kingdom met to further action on equitable access to good quality health care. They sought a shared, specific definition for “equitable access” in order to plan and evaluate their efforts. In response, Drs. Adam Oliver and Elias Mossialos of the London School of Economics published a definition of equity in health care with the aim of “turning the principle into a useful, operational policy objective,” explaining that equity in health care must be addressed in four aspects:

• Equal access to health care for those in equal need of health care.

• Equal utilization of health care for those in equal need of health care.

• Equal (or, rather, equitable) health outcomes (as measured by, for example, quality adjusted life expectancy).

• Equal access for equal need requires conditions whereby those with equal needs have equal opportunities to access health care (that is, horizontal equity), and, as a corollary, those with unequal needs have appropriately unequal opportunities to access health care (that is, vertical equity).

For the purpose of mitigating the harms of COVID-19 and addressing ongoing crises of unmet care needs for those with chronic conditions, we must also consider the social determinants of health—defined by Healthy People 2030 as “the conditions in the environments where people are born, live, learn, work, play, worship, and age”—as factors that can ease the way or block access to equitable health care.
COMMUNITY MEMBERS ARE ‘CRITICAL PARTNERS IN ALL EFFORTS’ FOR HEALTH EQUITY

“The participation and leadership of people living with, vulnerable to, and affected by HIV has been a hallmark feature of the response since the start of the epidemic. Beginning with the earliest report of AIDS, community leaders demanded that the voices of people living with the disease and their communities be heard by decision makers and fully considered in all areas of funding, research, public policy, and prevention and care service delivery. Indeed, community members—most of whom lack formal medical, legal, public health, or health care systems training—have continually proved to be critical partners in all efforts to sensitively and effectively address disparities, improve outcomes, and control the spread of HIV.”


We call for an Equity Access Framework (EAF) for COVID, recognizing that even our best intentions may produce unintended consequences. A framework that requires us to work with all potentially affected stakeholders—and to consider both intended and unintended consequences—is a transparent and ethical way to confront long-standing and novel problems alike.

New York must create, launch, monitor, and adapt the EAF in true partnership with affected communities. And whenever possible, New York should invest in solutions that communities can provide for themselves with adequate resources and support. But CWG-NY has noted that the response to COVID-19 in the city and state has lacked transparency, particularly at the state level, and there is a lack of commitment to ongoing, meaningful involvement across communities most affected by COVID-19.

An Equity Lens Tool: In late 2020, Big Cities Health Coalition (of which New York City is a member) commissioned Human Impact Partners to create Ensuring Equity in COVID-19 Planning, Response, and Recovery Decision Making: An Equity Lens Tool for Health Departments. This tool provides an excellent foundation in COVID-19-related planning and evaluation. It centers core questions and can be accessed as a fillable “pocket guide” worksheet. Although it focuses on pandemic-era COVID-19, it can and should be used for longer-term planning, including that which addresses the social determinants of health, care for chronic conditions, and Long COVID.

Adapting it for use in New York will require identification of specific ethnic, racial, and/or linguistic groups—such as Haredi Jews—as communities, which the tool defines as those people who are most likely to be affected by the decision at hand and/or by COVID-19. In addition, people with chronic conditions must be centered in the tool as communities affected by potential policies.
INTERSECTIONAL HEALTH CARE LESSONS FOR CURRENT ISSUES:
PRINCIPLES AND PRACTICES FOR HEALTH EQUITY IN THE COVID ERA

We know that applying the knowledge base and practices from other long-term health challenges—including diabetes, HIV/AIDS, home care and nursing care services, housing access, ME/CFS, and mental health conditions—can and should substantively inform our pandemic response. And conversely, we’ve seen how ignoring the vital principles of equitable access (even when they are grounded in constitutional rights, as we have seen with incarcerated people) risks limiting or delaying our progress against COVID-19.

In order to end the COVID-19 pandemic and ensuing health crisis, to prepare for future crises, and to confront long-standing health inequities, we must center equitable access to health care.

We must learn both from our successes and our failures with chronic conditions in a society full of inequities—and be steadfast in following key principles to insist on equity to move forward in this time of crisis.

Members of the CWG-NY Healthcare Access subcommittee have contributed to the following case studies and reports on current issues in early 2021. We provide these as historical and current examples of lessons learned or overlooked and as an indication of some of the work to come. We do not suggest that these are the sole references from decades of health justice work on chronic conditions nor the only priorities for COVID-19-related health equity.

As the COVID-19 Vaccines Roll Out, Heed Four Key Lessons from the HIV Epidemic

By Sarit A. Golub, PhD, MPH

The first weeks of the year brought, among other things, recognition of the tremendous and complicated task of rolling out COVID-19 vaccination in the United States. Almost immediately, there were reports of inequities in vaccine distribution and lack of access for the hardest-hit communities. Sadly, for those of us who work in HIV, these findings come as no surprise: Almost every time a new public health intervention is introduced, its implementation exacerbates health inequities.

When HIV antibody testing became available, it was disproportionately accessed by White, wealthier individuals. Rollout of antiretroviral therapy, which transformed HIV from a fatal diagnosis to a chronic illness, was associated with a marked increase in relative death rates for people of color and those with less money. The first effective preventive medication, pre-exposure prophylaxis (PrEP), has been disproportionately accessed by White, wealthy gay men, resulting in dramatic reductions in new diagnoses that have not been experienced by communities of color.

Disparities in COVID-19 illness and death rates are attributable to underlying inequities in our health care system and to racism in our social structure. But we have the power to reduce—rather than exacerbate—these disparities as interventions to fight the new pandemic emerge.
Our blueprint is four key lessons from our past failures to address similar disparities in the HIV epidemic.

- **Remove financial barriers to receiving coronavirus-related vaccines, testing, and treatment.** In the absence of universal health care, we must employ innovative strategies. Coronavirus testing, treatment, and prevention should be on the list of interventions and medications provided with no co-pay as part of the Affordable Care Act. The federal government should develop an analog to the AIDS Drug Assistance Program, which provides U.S. states and territories with funding to provide free HIV medications to people with limited or no insurance coverage.

- **Bring coronavirus interventions to high-priority communities, rather than waiting for them to access centralized care or distribution centers.** Health care utilization and vaccine acceptability is lower among lower-income communities and among people of color. Lower-income people and households encounter significantly more barriers to accessing health care and support services. Black and Brown patients are less willing to seek care given experiences of discrimination and mistreatment compounded by our nation’s history of unethical medical/research practices among these communities. In order to overcome mistrust, our health care system must act in a way that is trustworthy. We need to meet people where they are by bringing coronavirus vaccines to community centers, settlement houses, food pantries, public housing projects, prisons and jails, and homeless shelters. HIV prevention and care programs that have used this approach have been the most successful in reducing health inequities in distribution and uptake.

- **Develop clinical protocols that remove unnecessary barriers to care.** When HIV antibody testing was introduced, counseling and testing procedures were onerous. It was only when these restrictions were relaxed, and testing became universalized, that disparities in HIV testing rates began to decrease. Similarly, when logistical hurdles to receiving HIV treatment and prevention are minimized (e.g., same-day prescriptions, allowing telemedicine visits), access is increased and inequality lessens. Clinical guidelines for vaccine eligibility and distribution must be developed without erecting artificial barriers that limit access.

- **Guard against stigma and blame that limit individuals’ willingness to engage in coronavirus intervention programs.** In some cases, the outrage about disproportionate COVID-19 rates in Black, Brown, and poor communities has already transformed into racist or xenophobic blaming of “those people” for perpetuating the epidemic. In HIV, we have seen individuals and groups labeled as “vectors” of transmission and have witnessed horrifying homophobic and transphobic screeds—and policies—that have limited our ability to effectively reach and engage the people who most need testing, prevention, and care. Our education and messaging about coronavirus must be clear, consistent, and careful. Using people-first language; recognizing structural determinants of transmission; and proactively fighting racist, classist, and xenophobic language will be fundamental to ensuring that individuals and communities are willing to access the services that are available to them.

Our experience with the HIV epidemic shows us how to create a more equitable future. The question is whether we are willing to prioritize this knowledge and experience as we develop structures, systems, and policies to address a new epidemic.
Highly Avoidable Diabetes Deaths, Disability, and Community Trauma During COVID-19

By Chris Norwood, Executive Director, Health People, The Bronx

New York City experienced a 356 percent increase in excess diabetes deaths during the first wave of the COVID-19 pandemic,\(^2\) the most of any urban area in the nation, and the rest of New York state had the largest increase of any state. This appalling reality confirms the real price of the state’s absolute, studied refusal to confront the diabetes epidemic with evidence-based strategies that could significantly improve self-care and prevention—improving the basic health of people with diabetes and those at risk of diabetes.\(^3\)

By February 2020, peer-reviewed reports of the clinical characteristics of COVID-19 in China revealed high rates of severe disease in people with diabetes and noted that “individuals with diabetes are at risk of infections, especially influenza and pneumonia. This risk can be reduced, though not completely eliminated, by good glycemic control.”

As the pandemic approached New York, it was already clear that people with diabetes—especially low-income and minority populations—would be incredibly vulnerable to COVID-19, with devastating financial and personal costs. New York City has 1 million residents living with diabetes and the state has 2 million, including 600,000 state Medicaid recipients. Before the crisis, the state was already paying the highest excess costs in the nation for Medicaid patients with diabetes: $15,366 a year more for a patient with diabetes than without diabetes.\(^4\)

This money has poured into procedures (one above-the-knee amputation can easily cost $250,000 the first year), complications, and frequent hospitalizations of people with uncontrolled diabetes. Even as diabetes costs grew to be so overwhelming that they constituted a major part of the state’s huge Medicaid deficit, New York would not pay the quite modest costs to bring effective self-care education directly to the highest-need communities.

The U.S. Centers for Disease Control and Prevention notes that the Diabetes Self-Management Program (DSMP) (provided by Health People in the South Bronx), a six-session course for people with type 2 diabetes, is proven to reduce blood sugar and a number of diabetes complications. With the consequent savings in emergency room visits, hospitalizations, and other medical expenses, it saves $2,220 per participant in just the first year after completion.

**FLATTENING THE A1C CURVE IN PEOPLE WITH DIABETES**

During the onrush of COVID-19, if the state had supported a coherent, cost-saving effort to bring self-care education to high-risk communities, a lot of people would not have become sick or died.

By August 2020, international studies\(^5\) had made it clear: It was not precisely diabetes itself that was driving these deaths, but excess blood sugar. When people with diabetes had good blood sugar control, their risks for death and complications and poor outcomes from COVID-19 were not significantly worse than those of people without diabetes.

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3. Unless otherwise specified, the term “diabetes” in this case study refers to type 2 diabetes, which represents 95 percent of diabetes cases.
4. It’s important to note that this system and “commoditization” of patients is as disrespectful to frontline medical personnel, who constantly struggle to help patients without the tools, as it is brutal to patients.
The A1C is a blood test that measures average blood sugar over the previous few months. The pre-diabetes range is 5.7–6.4%, while 6.5% and above starts the diabetes range, 7.5% is widely considered the outer limit of acceptable blood sugar control, and 7.6% and above shows increasingly poor control.

Generally, COVID-19 complications and death appeared to measurably increase when people with type 2 diabetes had an A1C of 7.6% or more. A public health campaign focused on reducing sugar use would have been perhaps the single immediate effort that most clearly had a chance of reducing complications most associated with COVID.

Additionally, the situation was exacerbated by the longtime neglect of community-based solutions for diabetes management, in favor of the commodification of people with diabetes for expensive medical procedures resulting from uncontrolled diabetes.

For a few years, Health People had special federal funding—now ended—to widely provide the DSMP in the South Bronx. We trained community members who had diabetes or pre-diabetes to become peer leaders to facilitate the course. They engaged almost 2,000 people with type 2 diabetes on Medicaid in the DSMP by taking it to a range of community sites—such as churches, day mental health programs, homeless shelters, and community centers. This was a record for community-delivered self-care education in New York state—and probably the nation—and they did it themselves. Reducing the impact of one disease regularly means reducing the impact of others. For example, the DSMP not only reduces heart complications worsened by diabetes, but participants also have a 90% reduced incidence of new kidney disease in the first year after completing the course.

As we prepare to enter the second year of the pandemic, New York City and state, like multiple jurisdictions around the nation, have seen our low-income and Black and Brown communities suffer the most. But the city and state have left the large populations of people with diabetes in these communities needlessly vulnerable to more episodes of mass suffering and mortality in the second wave, as well as subsequent, often multisystem, illness or challenging recoveries after acute COVID-19 illness.

What can we do to change these perverse priorities and long-standing harms? How can we help these communities recover from setbacks to sustained control of their diabetes? Three measures that can start to turn this around are:

- **Communities must be given the resources to fight rampant chronic disease themselves.**

- **Reducing chronic disease requires nutrition education and confronting the food supply crisis.** A major example is plant-based nutrition, a way of eating that can reduce the impact of a range of chronic disease—and outrightly reverses diabetes for a majority of participants. The sole public hospital plant-based program in New York, which offers educational and supportive counseling as well as monitoring for clinical improvements at Bellevue, has such a long waiting list that it had to cut off the list.

- **Recognizing and treating metabolic diseases—including through community-led efforts and access to healthy foods—will prevent the impact of many conditions that they can cause.** As discussed in a recent expert webinar, most of the chronic diseases linked to COVID are, in fact, metabolic diseases, which means they are fueled by excess sugar and overprocessed food.

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Will Recognition of Long COVID/PACS Bring Equity to Care for Complex Chronic Conditions?

By JD Davids, #MEAction and The Cranky Queer Guide to Chronic Illness

As the COVID-19 pandemic approached the United States, the media reported that illness would cease after two weeks. Most people, it was said, would have “mild” illness.

But as the difficult months of 2020 progressed, people began to find each other online, sharing stories of long-term COVID symptoms and new health challenges weeks or months after the acute illness was seemingly resolved. They shared stories of disbelief from medical providers and shaming from family members who had heard that COVID-19 was a two-week illness—painful gaslighting experiences familiar to generations of people, often women, living with ME/CFS, fibromyalgia, and other complex chronic illnesses whose experiences were dismissed as hysteria, depression or laziness.

**What is ME/CFS?** Myalgic encephalomyelitis (ME) or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex chronic disease that presents with symptoms in multiple body systems. An estimated 15–30 million people live with the disease worldwide, including between 1.7 million and 3.38 million Americans prior to the COVID pandemic. An estimated 75–85% of them are women. Eighty to ninety percent of them are undiagnosed. Learn more at MEAction.net

It is now abundantly clear that the physical and mental suffering caused by SARS-CoV-2 infection can last months and may be chronic or permanent. Long COVID—a working term that may change as we learn more—is appearing at high rates regardless of the results (or lack) of COVID-19 test results, or of the mildness or severity of initial illness.

The NIH’s Dr. Anthony Fauci estimates that 25–35% of those with COVID-19 will face long-term effects and recognizes myalgic encephalomyelitis (ME, also known as ME/CFS, referencing the former name of chronic fatigue syndrome) as a likely post-viral syndrome.

As the year wore on, many people passed a six-month threshold of symptoms that could lead to an ME diagnosis. Fauci affirmed at February’s International AIDS Society conference that “what we’re finding is that there’s a certain percentage of people, and we don’t know what that percentage is yet, we need to do cohort studies, who have varying degrees of duration, anywhere up to several months or more, where they have a constellation of syndromes, some of which [are] quite similar to what has been referred to as myalgic encephalitis/chronic fatigue syndrome. And it is, you know, rather consistent: profound fatigue, muscle aches, temperature dysregulation like dysautonomia, sleeplessness, and then something that people refer to as brain fog.”

As so often is the case, affected communities led the way from gaslighting to patient-led research. Patient-Led Research for COVID-19 published the first report on Long COVID in early May, having found each other in the Body Politic support group for “long-haulers.”

Patients with Long COVID report prolonged multisystem involvement and significant disability. Most had not returned to previous levels of work by 6 months. Many patients are not recovered by 7 months, and continue to experience significant symptom burden.

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8. The UK’s National Institute for Health Research has developed a working description of four types of ongoing COVID-19 suffering: the after-effects of intensive care; post-viral fatigue; lasting organ damage; and fluctuating symptoms that move around the body.
Their extensive second study, involving 3,762 survey respondents from 56 countries, was released as a pre-print in December 2020 while awaiting journal publication. It concludes that “patients with Long COVID report prolonged multisystem involvement and significant disability. Most had not returned to previous levels of work by 6 months. Many patients are not recovered by 7 months, and continue to experience significant symptom burden.”

On average, the symptoms of their study participants crossed over more than nine organ systems; the most frequent after six months included fatigue, post-exertional malaise (a key characteristic of many cases of ME), and cognitive dysfunction.

This groundbreaking research makes it clear that millions will newly face a fragmented, faulty chronic care system and join those already struggling to access care and support. A massive cohort of people (some of whom already had chronic conditions) now have perplexing and shifting constellations of multisystemic symptoms, including dangerous and sometimes fatal complications like heart attacks and often trivialized, difficult-to-measure symptoms such as fatigue and brain fog. Many may have had milder experiences with initial COVID illness and were not hospitalized but now face chronic, complex, and disabling multisystem issues from which they are not recovering.

The impact of the pandemic on health care and public health workers and systems has been and remains vast, horrifying, and largely unaddressed. And now, in a chronic care system already rife with inequities, Long COVID looms large—but has been barely discussed in myriad plans and debates about the pandemic.

By the first week of April 2020 in New York City, it was shown that the novel coronavirus was killing Black and Latinx people at twice the rate of White people, with the mayor admitting that it reflected “long-standing and persistent economic inequalities and differences in access to health care.” How will the same systems that undergird such inequities address a large-scale challenge in chronic care?

In June, New York City announced that three “COVID-19 Centers of Excellence” would open in communities of color that have been hardest-hit by the COVID-19 pandemic; the first opened in November. The CWG-NY applauded this move but recommended other activities to comprehensively address the chronic disease impact of the pandemic, including:

• Public data tracking of COVID-19 chronic disease impact: Enhance or develop systems for public health surveillance to monitor COVID-related chronic conditions (including diagnoses and key metrics).

• Clinical guidance: The city’s Department of Health and Mental Hygiene (DOHMH) and the state’s Department of Health (DOH) (through their clinical guidelines committee) should collaborate with community partners to research, develop, and publish clinical guidelines for the assessment, diagnosis, monitoring, and treatment of post-COVID-19 symptoms based on the best available evidence-based clinical knowledge.9

• Clinical education: DOHMH should offer comprehensive clinical education with continuing education credits on post-COVID-19 conditions (including ME/CFS), the impact of the SARS-CoV-2 virus on those with chronic illnesses, and clinical management of both.

• Comprehensive chronic disease control and prevention: We urge DOHMH to undertake a robust program of evidence-based chronic disease prevention and control that particularly engages the most affected communities in implementing proven strategies.

9. As noted in a recent Lancet Comment, “Comprehensive long COVID guidelines are essential to prevent an epidemic of long-term, chronic disease as a result of early mismanagement of pathology, and the potential implications of such an epidemic for health systems and economies.” Ultimately, federal and global guidelines are needed, but it is imperative that the city move forward with due haste to develop interim guidelines that can immediately inform local practices and resource allocation.
• Development of consumer outreach and education materials, created in collaboration with community members; comprehensive peer support and education programs in each center; and telehealth services providing access to necessary home technology as well as the services themselves.

However, much more is needed. To address the scope and scale of the challenges, New York City and the state must:

• Create, scale up, and sustain a network of wrap-around services promoted through a multilingual public education campaign on the many facets of Long COVID/PACS, including ME/CFS. The network must bridge community organizations and medical care systems to guarantee accessible, comprehensive, and culturally relevant care and support to all people experiencing physical or mental post-COVID symptoms, illness, conditions or disabilities, regardless of insurance status, ability to pay, pre-existing conditions, or history of COVID test results. This network must be planned, implemented, and evaluated through an equitable access framework, with deep community involvement at all levels.

• Redesign chronic care. In order to provide health care equitably, the DOHMH and the DOH must approach Long COVID through a fundamental redesign—constructed with meaningful involvement of those affected—of all chronic care to integrate services, reduce fragmentation, eliminate barriers, and create genuine access for the large and diverse cohort of people facing complex chronic illnesses with overlapping and debilitating symptoms like fatigue and cognitive challenges.

• Prohibit restriction of care and services to those without positive COVID-19 tests. Given vast barriers in accessing tests that can reflect provider bias, obstacles to care, and other inequities, funding must support community-based organizations and community-collaborative medical providers to offer case management, peer navigation, mental health providers and social workers to assist people with any form of Long COVID, chronic conditions that increase COVID risk, or other conditions that can be the sequelae of COVID infection.

• Ensure comprehensive clinical and public education on Long COVID and the connection to post-viral illnesses, risk of heart attacks, and other emerging dangers.

• Insist on equitable access to Long COVID research and care to avoid repeating the pattern in the rollout of HIV treatment, where gains in survival and reductions in suffering lagged far behind for Black and Brown people with HIV even as White people found renewed health and longevity. Research must address the understudied symptoms of many complex chronic conditions, including fatigue and cognitive challenges.
How Not to Survive a Plague: Righting the Wrongs of ME/CFS to Confront Long COVID and Other Complex Conditions

While some answers about ME and Long COVID could ultimately emerge from $1.15 billion in NIH research for long-term COVID research earmarked by Congress in December, the history of ME is a cautionary tale for the diagnosis, care, and support for people with complex post-viral illnesses. Programs and policies addressing possible ME and other post-viral illnesses in those who had COVID must rapidly scale up, using lessons from the history of ME, including:

- **Believe patients:** People with ME seeking a diagnosis and care are often disbelieved outright or told their illness is solely a manifestation of a mental health condition. In 2019, researchers (who also found that dismissal from providers was more common among female patients) recommended that “a patient-centered, empathetic, informed treatment approach would likely be beneficial to improving the doctor-patient relationship, which has been fraught with perceived delegitimization due to a predisposition to psychological diagnoses and treatment approaches.”

- **Provide information and correct misinformation, particularly on diagnosis and on ineffective therapies:** ME organizations, including #MEAction, an international network of people living with ME and their allies, have strived to bring information and resources to people with Long COVID, their friends and families, and a wide range of medical providers. These kinds of efforts should be rapidly expanded for Long COVID and taken up by public health authorities, professional medical organizations and the media, and they should include messaging for family members and friends who can find it hard to accept sudden, profound, and lasting health changes in loved ones.

- **Educate health care providers:** There is a drastic shortage of clinical specialists in ME, even for those who have the benefits of private medical insurance or the wealth needed for out-of-pocket payment for providers who do not accept insurance. The lists of providers posted online by ME advocacy groups are too slim to accommodate the number of patients with ME even before COVID.

- **Increase coordinated, collaborative federal efforts, including research:** The NIH funded three collaborative research centers (CRCs) that have started to contribute invaluable research on ME/CFS, but they are nearing the end of their grant period, and the pandemic has greatly disrupted their research plans in 2020. It is critical that the NIH not only ensures the continuation of their work past 2021, but expands it as well, and creates meaningful structures of community guidance as seen in HIV/AIDS research structures. Across federal agencies, there must be coordinated efforts to improve epidemiological work to study ME/CFS prevalence and to address the mounting clinical care crisis through improving and scaling up medical education and outreach, as well as ensuring ME/CFS integration in Long COVID/PACS studies.

- **Provide immediate economic and social support so people can rest and recover:** While exercise has been shown to cause harm in people with ME, there is data showing that rest and pacing can help. It is imperative that those who exhibit signs of potential ME and/or Long COVID, including fatigue, post-exertional malaise syndrome (PEMS), or cognitive challenges, are immediately able to access income and social supports, including home care, help with family responsibilities from trusted community members as well as trained providers, case management, and legal assistance for disability claims, in order to heal and prevent perhaps irreparable damage.
The needs and challenges faced by people receiving home- and community-based long-term services and supports (LTSS)—and the caregivers providing these services—have been seriously ignored in the COVID pandemic. Providing comprehensive, high-quality LTSS is a disability, gender, racial, and economic justice imperative.

Older adults and disabled people, including people with chronic health conditions, rely on home- and community-based LTSS to keep them healthy and independent in their own homes, as opposed to institutional settings like nursing facilities. Not only do people overwhelmingly prefer to age in place at home, but under the Supreme Court’s Olmstead decision, which found that the unjustified institutionalization of disabled people violates the Americans with Disabilities Act, states have an obligation to provide community-based support. Home- and community-based services are also less expensive than institutional care, and the COVID-19 pandemic has made it even more obvious that homes are safer and healthier than nursing facilities, which have seen widespread outbreaks with high fatality rates.

What are long-term services and supports (LTSS)?

LTSS is a broad but person-centered basket of services, based on the physical, cognitive or chronic health conditions that prevent a person from performing tasks on their own. They include, but are not limited to, home health care services (such as cooking, bathing, dressing, and housekeeping), private-duty nursing, transportation, medical respite, and adult daycare programs, as well as assistance provided by a family caregiver. Care planning and care coordination services help beneficiaries and families navigate the health system and ensure that the proper providers and services are in place; these services can be essential for LTSS beneficiaries, who often have substantial acute care needs as well.

In the U.S., the majority of LTSS is provided by unpaid caregivers: mostly women age 50 and over who care for a parent for at least one year while still maintaining outside employment. Caregiving can be rewarding, but it can also be challenging, resulting in significant stress, health problems, and disruption for the caregiver’s life. This is even more true during the COVID-19 pandemic. When a person’s care needs become more intensive, when there is not family support available, or simply because of personal preference, paid LTSS provided by direct support professionals may be required. However, the cost of LTSS is out of reach for most families across all the states. The high cost of care can all too often cause people, even in middle-income families, to exhaust their savings.

Medicaid is the primary funder of LTSS in the United States. Medicare typically provides only limited short-term home care after a hospitalization, and there are few affordable options in the private insurance market.

Medicaid is a large part of New York’s budget. In the state, over 7 million people receive Medicaid-eligible services through a network of more than 80,000 health care providers and more than 50 managed care plans. And the costs of this care are rising. Aging populations are one factor: New York state’s population of people age 65 and older grew by 23.7% over the past decade, outpacing the national average of 15% growth, and it is expected to continue to grow. The need for paid LTSS will only continue to increase. The older population is also becoming more diverse. In particular, the Hispanic/Latinx population age 65 and older is projected to quadruple from 2015 to 2050—thus, culturally competent care is also key.

New York has a relatively generous LTSS package—for example, people can receive 24-hour home care, including private-duty nursing, and there are no waiting lists or cost caps on home care. The AARP’s 2020 State Scorecard ranks New York’s LTSS system 11th out of the 50 states and Washington, D.C. However, navigating the managed care system is difficult for consumers and families, especially for those with limited English proficiency or cognitive difficulties. Plans too often resist providing high numbers of home care hours (24 hours) because of the expense. Assessments are also able to better capture physical and medical needs, rather than cognitive challenges. Therefore, people with dementia or other cognitive challenges, but no physical needs, can fall through the cracks.

HOME CARE AND LABOR JUSTICE

Lastly, home care is a labor justice issue. Despite the essential nature of the services that home care workers provide (which has been highlighted by the COVID-19 pandemic), they experience poor job quality, which contributes to the high turnover in this field. The average annual salary for home care workers in New York is $24,810. That’s so low that about half live in or near poverty, relying on public benefits to make ends meet. In addition to wages, problems with transportation, especially in rural areas; uneven and erratic scheduling; lack of career advancement opportunities; and lack of benefits.

The average annual salary for home care workers in New York is $24,810. That’s so low that about half live in or near poverty, relying on public benefits to make ends meet.

12. Medicaid is a federal-state health insurance program, so it varies from state to state. It is run by state and local governments within federal guidelines. It serves low-income people of every age.
14. Medicare is a federal health insurance program for adults over age 65, whatever their income, and some younger disabled people and dialysis patients. It is basically the same everywhere in the United States and is run by the Centers for Medicare & Medicaid Services, an agency of the federal government.
21. NY Caring Majority, Platform, https://www.nycaimingmajority.org/platform; see also CUNY Graduate Center, The Case for Public Investment in Higher Pay for New York State Home Care Workers (Executive Summary), https://static1.squarespace.com/static/58fa6c032e69cfe88ec0e99f/t/6022ae8312cfd1015354dbee/1612885635936/Executive+Summary+CUNY+REPORT.pdf
contribute to the challenge of recruiting and retaining workers.\textsuperscript{22} The majority of New York’s home care workforce are women of color, and almost 40\% are immigrants.\textsuperscript{23,24,25,26}

All of these challenges and injustices related to LTSS have significantly worsened in the time of COVID.\textsuperscript{27} LTSS is, understandably, a very personal, and in-person, endeavor. No matter the intensity of care—whether a visit of a few hours from a niece or 24-hour paid care by a home care worker—it requires the sharing of space, of time, and often, of physical contact. This can be difficult in the best of times, and even more challenging during COVID because of fears of infection. Yet the LTSS ecosystem—people receiving care, caregivers (whether paid or unpaid), service provider agencies, and insurance plans—received little attention during the pandemic.

Public data on these issues is limited, if it exists at all, so most of our understanding comes from anecdotal reports of users and providers of LTSS. We have heard that:

- Some users of home care did not want home care workers to come to their home due to the risk of infection.
- Others wanted their home care aides to come but were terrified and frustrated that personal protective equipment (PPE) and testing were not available.
- The LTSS system was neither prioritized for PPE nor provided sufficient funding to purchase PPE privately.
- Home care schedules were disrupted because of workers testing positive for COVID themselves or needing to quarantine after an interaction with a person who tested positive. Some reported that their aides transmitted COVID to them.
- Some care and assessments could be replaced by telehealth visits; however, not everyone has the technological ability for such a visit, nor were insurance companies and provider agencies reimbursed for telehealth visits.
- Insurance companies and provider agencies faced great difficulty deciding when and how to return people with COVID to their homes (or hotels or other sites) after hospitalizations.

To meet expanded LTSS needs in New York, we must:

- Eliminate or increase the “global cap” on Medicaid spending in New York.
- Invest in the home care workforce: Increase worker pay to 150\% of minimum wage.
- Plan to address home health care issues as part of long-term effects of COVID—especially for marginalized communities.
- Reimburse provider agencies and insurance companies for telehealth visits.
- Increase federal funding directly for LTSS.

\textsuperscript{22} Caring Majority, 2019 One Pager, https://static1.squarespace.com/static/5a982d25a9e028f76c7bf46b/t/5d951f04a6d33b435 761644d/1570053894204/New+York+Caring+Majority+2019+One+Pager.pdf.
\textsuperscript{23} Migration Policy Institute, Immigrant Health-Care Workers in the United States (May 14, 2020).
\textsuperscript{26} Campbell Robertson & Robert Gebeloff, How Millions of Women Became the Most Essential Workers in America, NY Times, Apr. 18, 2020, https://www.nytimes.com/2020/04/18/us/coronavirus-women-essential-workers.html (“Of the 5.8 million people working health care jobs that pay less than $30,000 a year, half are nonwhite and 83 percent are women.”)
“The COVID-19 pandemic has had a major effect on our lives,” opens the CDC web page on coping with stress in a nation with over half a million COVID-19 deaths by the third month of 2021. Indeed, the mental health challenges of the COVID-19 pandemic are intense, complex, and visible in every facet of the pandemic.

Families—particularly those in Black, Brown, and Native American/Alaskan Native communities—are experiencing multiple losses of loved ones while bearing the strain of isolation, unemployment, looming threat of eviction, risks to undocumented immigrants, and an intense political climate surfacing White supremacy and racial injustice.

People with diagnosed or undiagnosed clinical conditions such as anxiety, obsessive-compulsive disorders or depression may face escalation of symptoms in isolation, while some may lose access to providers if they become unemployed and lose health insurance or lack funds for out-of-pocket care.

Health care providers, some who have newly shifted to emergency or intensive care duties to meet the escalating need for COVID-19 care, speak of exhaustion and the burden of overwhelming grief and trauma.

The 25–35% of people who experience COVID-19 as a long-term condition may struggle with loss of autonomy and stigma, alongside the terrifying nature of COVID disease that does not resolve, often includes intense neurological symptoms, and has no existing standards of care. Long COVID itself can bring cognitive effects: In a large international sample, over half of people with Long COVID had symptoms ranging from brain fog to intense memory loss to psychosis.

Across the spectrum of mental health impacts of COVID-19, there is one common thread: There are many people with unmet needs. And as with other aspects of the pandemic, these challenges fall upon a nation with intense health disparities. As explained by the National Black Leadership Commission on Health:

The Black community is 20% more likely to experience serious mental health problems than the general population. Common mental health disorders among the Black community include depression, ADHD (attention deficit hyperactivity disorder), suicide (particularly among young Black men) and post-traumatic stress disorder (PTSD). However, only about 1 in 3 Blacks who need mental health care will get it. This is because of insurance barriers, stigma, lack of awareness, and distrust of the medical community.

Others at greatest risk for COVID-19 infection, severe disease, and death who have higher risk of mental illness include Latinx people, older adults, people who are homeless or incarcerated, and people with chronic illnesses.

We must rapidly scale up accessible mental health services that will reach all of those in need, including:

• Meaningfully increasing local, state, and national funding for campaigns directly focused on supporting grassroots organizations to provide mental health care, e.g., New York City’s Connections to Care program.
• Creating supportive infrastructure that connects people with COVID-19 and other chronic illnesses to mental health care through patient navigation services, easy referral processes, and provision of care by members of their own communities.

• Implementing policies that support health care providers’ mental health care, such as standardized time off and funding for peer mental health support programs.

• Implementing policies for ongoing unemployment relief expansion and eviction prohibitions that do not bring the threat of eviction or unachievable rent repayment after their expiration.

• Providing protections and mental health care for those experiencing incarceration and homelessness.

• Ending the criminalization of mental illness.

Housing is Health Care: A Life and Death Reality Underscoring the Urgency of Equity in Interventions to Fight COVID-19 in New York City

by Shelly Nortz, Deputy Executive Director for Policy, Coalition for the Homeless

Because of systemic racism and persistent inequities, New Yorkers of color are both more likely to experience homelessness and more likely to succumb to COVID-19 than White New Yorkers. Approximately 57% of heads of household sleeping in New York City (NYC) shelters are Black, 32% are Hispanic/Latinx, 7% are White, less than 1% are Asian-American or Native American, and 3% are of unknown race/ethnicity.

One study on the early impact of the pandemic in NYC documented that Black and Latinx communities suffered disproportionately higher rates of hospitalization and death; our research shows that such disparities have continued throughout the pandemic.

The type of shelter setting and prevalence of risk factors among homeless people affect their exposure to the novel coronavirus and vulnerability to COVID-19. As of the end of October, the age-adjusted mortality rate (AMR) for sheltered families with children (who generally have private units with bathrooms and kitchens) was 227 per 100,000 people, roughly the same as the NYC general population (231 per 100,000 people), while the rate for sheltered adult families without minor children was 53% higher than the general city population, at 353 per 100,000 people, and the rate for sheltered single adults was 79% higher at 413 per 100,000 people. Moreover, from May through October, the mortality rate due to COVID-19 for all of NYC increased by 22%, and for sheltered single adults during the same time period, it increased by 47%.

A significant proportion of homeless New Yorkers are at higher risk of serious illness or death due to COVID-19, including seniors as well as adults and children with underlying health conditions such as chronic obstructive pulmonary disease (COPD), sickle cell disease, chronic kidney disease, type 2 diabetes, cancer, heart ailments, compromised immunity, and others.

NYC calculates the AMR among racial and ethnic groups, showing the disproportionate impact that COVID-19 has had on Black and Hispanic/Latinx communities. Nearly 90% of single adults and family heads in NYC shelters are Black or Hispanic/Latinx.
Lack of a private living space creates a heightened risk of exposure to the coronavirus, particularly in congregate shelters and facilities with shared dining and/or bathrooms, which typically serve homeless single adults and some adult families without children. It is therefore no surprise that:

- the AMR at the end of October for single adults (413 per 100,000) and adult families (353) in Department of Homeless Services shelters surpassed those of Black and Hispanic/Latinx New Yorkers (249 and 266 per 100,000, respectively);

- the AMR for homeless families with children in shelters, who generally have private dwelling units, kitchens and bathrooms, was about the same as the overall NYC rate; and

- the AMR for sheltered single adults was 222 percent higher than White New Yorkers overall, underscoring the vast inequities that place this group in such grave danger of death due to COVID-19.

In order to address the disparate impact COVID-19 has had on homeless people, including people of color, the city and state must take immediate and comprehensive action, grounded in the principles of public health and human rights. The city and state must also act on medium- and long-term recommendations, ensuring ongoing support for the duration of this pandemic.
We must address the following immediate, medium, and long-term needs:

Immediate Needs:

• Provide thousands of single-occupancy hotel rooms for all homeless individuals living in congregate shelters, living on the streets, or sleeping in the subway, facilitating appropriate social distancing, with access to private bathrooms and showers, as well as the safety of an indoor place in which to isolate and recover.

• Continue free, widespread, voluntary testing for all homeless New Yorkers and those serving them, and increase the frequency of systemwide testing to at least every two weeks.

• End the criminalization of street homelessness by (1) reversing subway closures from 2 a.m. to 4 a.m. and (2) ceasing all street sweeps.

• Ensure that unsheltered people have access to basic hygiene supplies and facilities, including masks and face coverings, hand sanitizer and wipes, clean clothing and socks, blankets, handwashing stations, restrooms, showers, and laundry facilities. Our recommendations for public restroom access during the pandemic can be read here.

• Publish detailed COVID-19 statistics on infection, hospitalization, and mortality among homeless New Yorkers, including family composition, age, shelter status and type, race, and other relevant demographics, including risk factors.

• Engage community health centers, including Health Care for the Homeless and street medicine providers, in the Test & Trace Corps to ensure that the communities most isolated from mainstream health services are reached in that effort.

• Ensure that shelter residents, unsheltered people, and the staff who serve them are offered immediate access to available vaccines, including informed consent and clear, consistent, culturally competent, and accessible information.

Medium- and Long-term Needs:

• Advocate that the federal government provide $100 billion for emergency rental assistance in the next stimulus package in order to provide rent subsidies for New Yorkers experiencing homelessness and those at risk of losing their homes.

• Support a broader federal housing relief package including robust investments in affordable housing (thereby enabling job creation) and universal access to housing vouchers for those who are homeless or at risk of losing their homes.

• Support and enact statewide rental assistance legislation, including Home Stability Support, and Housing Access Vouchers.

• Establish medical respite and supportive housing with on-site medical services in lieu of nursing homes for homeless people in need of nursing/personal care services who cannot live safely in a shelter but do not require inpatient care.

• Prioritize the production of permanent supportive housing in the city and state budgets.

• Initiate the redesign of emergency shelter facilities with (1) the expectation that the risk of exposure in future pandemics will require the provision of private rooms and bathrooms for each person or household and (2) attention to the principles of safety, public health, and individual autonomy.
CONCLUSION

We must address the following immediate, medium, and long-term needs:

Going forward, we ask that government officials develop an approach that reaches equitable outcomes by addressing all aspects of COVID-19 prevention, testing, acute care, chronic care, and the myriad societal impacts of the pandemic, including a comprehensive restructuring of care and support for all chronic conditions. This thorough strategy should be developed in true collaboration with those most affected, and its effectiveness assessed with appropriate and clear indicators.

- Recognize COVID-19 as a chronic condition or a trigger of chronic conditions for New Yorkers and accept that vaccination alone will not address or undo the damage of COVID-19.
- Restructure and finance health care and support systems – including community-driven and adequately funded delivery of support, self-care, and prevention services – for all people with chronic and mental health conditions.
- Center meaningful, compensated collaboration with members of communities most affected by Long COVID and other chronic conditions.
- Develop and use a central Equitable Access Framework (EAF).
- Create, scale up, and sustain a network of wrap-around services in New York City and NY state, promoted through a multilingual public education campaign on the many facets of Long COVID/post-acute COVID-19 syndrome (PACS), including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).
- Recognize housing as health care: Provide thousands of single-occupancy hotel rooms, support and enact statewide rental assistance legislation, including Home Stability Support and the Housing Access Voucher Program, and support a broader Federal housing relief package.
March 2021

For more information on the COVID-19 Working Group please visit www.covid-19workinggroupnyc.org