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Report Seeks Equitable Health Care and Social Policies Guided by New York’s Vulnerable Communities Facing High Rates of Coronavirus Illness, Long COVID, and Death

The Health Care Access Sub-committee of the COVID-19 Working Group of New York Highlights Growing Concern that an Inequitable and Fractured Health Care System is not Equipped to Prevent and Address Acute and Chronic COVID-19 Illnesses

The Report, “Chronic Injustice, Centering Equitable Health Care and Policies for COVID-19 and other Chronic Conditions” includes Recommendations for Creating an Equitable Response to Help Chronically Ill New Yorkers and Underserved Communities Impacted by the Pandemic


Chronic Injustice highlights how the pandemic is causing people to face an even more significant, potentially lifelong, and racially disproportionate burden of disease; physical, cognitive, and emotional health challenges; and a deluge of associated suffering created or worsened by COVID-19, including stigma, isolation, and economic hardship.

Expert partners provided recommendations based on proven, community-led, and evidence-based practices that have significantly prevented and controlled chronic diseases like HIV/AIDS and diabetes.

“Disabled people and people living with chronic illnesses - including those of us affected by post-viral conditions like Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) - hold vital expertise, perspectives and potential solutions for the challenges we face. But we were largely ignored as the pandemic approached a year ago, and
continue to be sidelined, even as our ranks have swelled with the formerly 'able-bodied' who are now facing Long COVID,” explained JD Davids, principal author of *Chronic Injustice*, person living with ME/CFS who has had COVID-19 twice, #MEAction board member, and founder of the Cranky Queer Guide to Chronic Illness. “Our lived experiences with HIV, ME/CFS, diabetes and other chronic conditions show us that fragmented, inequitable systems of care and support must be swiftly and fundamentally transformed to address the growing need, even as we fight to abate the acute pandemic.”

“By limiting the current COVID-19 narrative to discussions about vaccines and questions about when life can return to “normal,” we are naively underestimating the long road to recovery following the pandemic, particularly for those with new COVID-19 related or pre-existing chronic health conditions. *Chronic Injustice* seeks to expand our focus and emphasize the needs of individuals living with Long COVID, ME/CFS, diabetes, HIV, mental illness, homelessness, and other long-term health conditions for whom the present crisis will exist long after we reach herd immunity,” said Jeremiah Johnson, HIV Project Director, Treatment Action Group, principal editor, and sub-committee co-coordinator.

“The need for true health equity - informed by racial and economic equity – has never been more obvious and urgent as it is right now, a year into this devastating global pandemic,” said Kimberleigh J. Smith, Senior Director for Community Health Planning and Policy at Callen-Lorde Community Health Center. “The chronic conditions that have been exacerbated or created by COVID-19 are disproportionately impacting communities already greatly burdened – including Black and Brown, LGBTQ, disabled people and people living with chronic conditions, elders and those living in congregate settings. *Chronic Injustice* is not only an indictment of our city, state and nation’s inadequate response to addressing COVID-19 pandemic’s impact on chronic conditions. It issues a searing call to action to reset, and endeavor to repair, our fragmented and inequitable systems of care and support.”

"COVID-19 has unveiled for the public the disparities that many of us have been fighting to address for years- disparities around race, ethnicity, socioeconomic status, neighborhood, and more. Black/African Americans face disproportionate burdens around chronic illness and often face additional barriers when accessing appropriate healthcare. It is critical that we take bold actions on ways that we can improve health equity, and this report is a valuable resource to providing a pathway for achieving what must be done,” said C. Virginia Fields, President & CEO, National Black Leadership Commission on Health.
“As a Black woman I have often been told explicitly and implicitly to minimize how I am feeling for the sake of others. I have been in doctors’ offices where it was clear they weren’t listening to me and where I walked out feeling stupid for even going in the first place,” said Charly Evon Simpson a Brooklyn-based writer and teacher who has coped with Long COVID for the past year, including fatigue, trouble breathing and a racing heart. “It took months (and a positive antibody test) for me to say the words ‘I can’t move as fast’ or ‘this feels really hard for me to do’ even to the people I love and who knew I had the virus. It saddens me that I know I am not alone in feeling this way, and I hope this report encourages people to advocate for themselves and share how they’ve been feeling post-COVID and I hope it encourages those in healthcare to set up systems of care that are dedicated to the long-term response those affected need.”

“COVID-19 has taken a devastating toll on homeless New Yorkers, and if we are to recover in a way that promotes equity, our elected officials must protect underserved communities and ensure they have access to the all-encompassing resources needed to help them survive the pandemic and support them on the sometimes long road to health and recovery. For those experiencing homelessness, survival begins with stable permanent housing: Housing is health care, and the pandemic has exposed the vulnerability of those living without the security and privacy of a home. Long-standing inequities, like the lack of affordable and supportive housing, have exacerbated this pandemic and it will take a substantial, ongoing commitment to enact meaningful solutions grounded in equity and built to scale to address this crisis and prevent future ones,” said Shelly Nortz, Deputy Executive Director for Policy with the Coalition for the Homeless, and contributor to the report.

“New York City experienced a 356 percent increase in diabetes deaths during the first wave of the COVID-19 pandemic, the most of any urban area in the nation,” said Chris Norwood, Executive Director of Health People and contributor to the report. “As we underscore in Chronic Injustice this high rate of deaths - and an accompanying high rate of complications - were completely unnecessary. They occurred largely among people with diabetes whose blood sugar was in poor control, but both New York State and New York City are responsible for this appalling occurrence. Both have refused for years to support community-delivered self-care education proven again and again to help people with diabetes drive down their blood sugar levels.”

Chronic Injustice asks 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. The report advises that this thorough strategy should be developed in true collaboration with those most affected, and its effectiveness assessed with appropriate and clear indicators.
Key Recommendations

- 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.

To see the full report and comprehensive list of recommendations, click here; for the testimonial provided by Charly Evon Simpson, click here.

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