COVID-19 & ACHIEVING HEALTH EQUITY:

Congressional Action Is Necessary To Address Racism And Inequality In The U.S. Health Care System

SEPTEMBER 2020 – DEMOCRATIC STAFF REPORT
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Introduction

On January 20, 2020, the first domestic case of COVID-19 was identified in Snohomish County in Washington State. Since then, the virus has spread throughout neighborhoods in every region of the country. From mid-January to now, at least seven million people in the United States have been sickened and more than 200,000 have died from COVID-19. The virus has significantly altered life as we know it, changing the way we approach health care, education, the workforce, and the economy.

While no one has gone untouched by the pandemic, Black, Latinx, Tribal communities, and other communities of color are getting sick and dying at particularly high rates.\(^1\) Across all age groups, and in all regions of the country, people of color have higher rates of COVID-19 infection and are more likely to die from the disease if they do become infected. This is particularly true for people of color who have a disability, are older adults, have preexisting conditions, are LGBTQIA+, or are low-income workers.

Among many tragic lessons, the COVID-19 pandemic is an appalling reminder of the deep inequities entrenched in our country. The high rates of infection and mortality in communities of color are driven by health and economic systems that were built on foundations of abuse, discrimination, racism, and neglect that continue to hurt communities of color today. And while no family or community has been spared, high- and middle-income families have a greater ability to work and learn from home and have more access to testing and health care when they are sick or exposed to infection. Too many other families lack these options. These inequities did not start with the COVID-19 pandemic, nor will they end when the virus is contained.

This Health, Education, Labor, and Pensions (HELP) Committee Democratic staff report examines the intersection of the COVID-19 pandemic, inequality in infection rates and health outcomes, and structural racism within the health care system. It describes the impact of COVID-19 on the health of communities of color and discusses a few of the factors that have contributed to inequality in health outcomes, including exploitation of communities of color, segregation, discrimination, and bias within the health care system, lack of access to high-quality care, and social determinants of health. Throughout, the report conveys the impact COVID-19 has had on communities of color using data and individual storytelling.\(^2\) This review is meant to be illustrative rather than complete; the factors that contribute to systemic racism and inequality in health outcomes are complex and are not all included in this document. The report concludes with initial steps Congress can take to begin to address inequality and systemic racism within the health care system.

While this report is primarily limited to the health care system, the unfortunate reality is that racism, inequality, and the disproportionate impact of the pandemic on communities of color are

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\(^1\) Committee staff chose to use the term Latinx unless referring to a particular study, in which case Committee staff used the term used by the researcher. As such, the terms used throughout the report differ.

\(^2\) The report includes summaries of interviews of patients, families, and practitioners that are meant as examples of how people of color are experiencing COVID-19. In some instances, personal information has been altered in order to protect the privacy of the people involved.
not. The same communities who have experienced the worst health outcomes during the COVID-19 pandemic have also disproportionately suffered from other interconnected adversity, including high rates of job loss, lack of access to options for high-quality education, and discrimination and harassment. As the country grapples with a pandemic, health and economic disparities, police brutality, and systemic racism, we should recognize these challenges as well as the vast opportunities for improvement and make sustained commitments to achieve equity in health care and beyond.

COVID-19 in Communities of Color

People of Color are Getting Sick and Dying at Disproportionately High Rates

People of color are becoming infected, getting seriously ill, and dying from COVID-19 at disproportionately high rates. The data is stark:

- COVID-19 has had a disproportionate impact on Black people across urban, suburban, and rural communities.\(^1\) As of September 2020, Black people were nearly 3.5 times as likely to die from COVID-19 as white people when age is accounted for.\(^2\)

- Latinx people have experienced some of the highest rates of infection from COVID-19 in the country. As of June 2020, counties where more than a quarter of the population is Latino saw infection rates increasing at higher rates than in counties with smaller Latino populations,\(^3\) and as of July 2020, the infection rate among Hispanic patients was more than three times the rate among white patients.\(^4\) Over the same time period, Hispanic patients were hospitalized at a rate that was more than four times higher than white patients,\(^5\) and COVID-19 accounted for approximately one in five deaths among Hispanic people.\(^6\)

- Data on the health outcomes for Asian patients are reported less consistently by states and do not typically include information about more specific Asian communities such as South Asians, Asian Indians, and East Asians, which can obscure disparities for subgroups at higher risk and mask trends.\(^7\) However, the data that is available suggests there are significant disparities in outcomes for Asian patients. For example, when socioeconomic factors like age, sex, and underlying health are controlled for, Asian patients have the highest rates of hospitalization and death from COVID-19 compared to white patients as of July 2020.\(^8\)

- There is also less data available on Native Hawaiian and Other Pacific Islander and American Indian or Alaska Native people compared to other communities of color, but the data that does exist suggest that both populations also see substantially poorer health outcomes than white people due to COVID-19.\(^9\) A July 2020 analysis of Washington state residents showed that Native Hawaiian and Other Pacific Islander patients were ten times more likely to be hospitalized and three times more likely to die from COVID-19 than white people.\(^10\) As of July 2020, the Navajo Nation had more COVID-19 related deaths per capita than any state,\(^11\) and as of September 2020, American Indian or Alaska Native patients were being hospitalized at more than four times the rate of white people.\(^12\)
The racial disparity in death rates is evident across all age groups, even among younger adults and children. While only about 38 percent of children in the United States are Black or Hispanic, as of September 2020, Black and Hispanic/Latino children account for more than 70 percent of cases of Multisystem Inflammatory Syndrome in Children (MIS-C), a rare but serious inflammatory disease that develops in some children who have been infected with COVID-19. And while age increases the risk of severe COVID-19 for people of all races and ethnicities, the risk is even more elevated for older adults of color. As of September 11, 2020, 80 percent of deaths in the United States from COVID-19 have been adults age 65 and older, and the most recent data from the COVID-19 – Associated Hospitalization Surveillance Network (COVID-NET) reveal that adults ages 50 to 64 are about twice as likely to be hospitalized as adults ages 18 to 49. The rate of hospitalization for older people of color is even higher – American Indian or Alaska Native patients ages 50 to 64 are more than six times, and Hispanic or Latino patients more than five times more likely to be hospitalized than white patients of the same age. Nursing homes that have higher numbers of residents of color are significantly more likely to have cases of COVID-19, even among facilities with high quality ratings. And an analysis of Centers for Disease Control and Prevention (CDC) data found older Black adults aged 65 to 74 died of COVID-19 five times as often as white adults in the same age group.

Factors such as income level and disability status are also highly correlated with increased risk of serious illness or death from COVID-19 and may compound racial and ethnic disparities. Several studies have found individuals with higher incomes face less risk of becoming infected with COVID-19 than individuals at other income levels. While very few states are disaggregating data related to COVID-19 by disability status, an independent analysis showed as of June 2020, people with intellectual disabilities and autism in Pennsylvania were twice as likely to die from COVID-19, and people with developmental disabilities in New York were 2.5 times as likely to die compared to COVID-19 patients without disabilities. Another independent study found that individuals with developmental disabilities between the ages of 18 and 74 had a death rate from COVID-19 of nearly twice that of their same-age peers without disabilities.

Poor-Quality Data Limits Our Understanding of the COVID-19 Pandemic

While it is clear COVID-19 is hitting communities of color harder than white communities, available data is incomplete and inconsistent. The lack of quality demographic data makes it more
difficult for policymakers to fully understand the nature of health disparities and to respond appropriately. The failure to effectively prioritize collection of demographic data surrounding COVID-19 is apparent at all levels, from providers to states and localities to the federal government.

Data collection starts with providers and testing sites, which are responsible for collecting initial information about patients. Too often, providers and testing facilities have failed to provide complete information about the race and ethnicity of individuals who are tested.\textsuperscript{22} Many health care providers are hampered by an outdated public health infrastructure and have been overwhelmed by the number of patients and hasty efforts to stand up testing sites — especially during the early response to the pandemic — making complete data collection difficult.\textsuperscript{23}

States have also failed to consistently collect and report the data they receive from providers, labs, and localities. Initially, some states released racial and ethnic information only for cases, but not deaths, while others failed to report race and ethnicity data at all.\textsuperscript{24} States that did collect data varied widely in consistency; as of September 2020, in Vermont, nearly 100 percent of cases included information about race and ethnicity, compared to just 53 percent of cases reporting race data and 39 percent reporting ethnicity data in Alaska and less than 10 percent of cases in Texas reporting either race or ethnicity.\textsuperscript{25} Some states do not disclose the percent of reported cases that include race or ethnicity information, making it challenging to infer the cases missing and get a clear picture of potential disparities.\textsuperscript{26} Months after the COVID-19 outbreak began, the Department of Health and Human Services (HHS) finally issued guidance requiring laboratories to report demographic data on race, ethnicity, sex, age, and other factors to the CDC with their COVID-19 test results; as of September 2020, all states report some race and ethnicity data.\textsuperscript{27}

Data quality issues present particular challenges to understanding the impact of the pandemic on Asian American and Pacific Islander (AAPI) communities. Despite improvements in data collection for some racial and ethnic groups, the impact of COVID-19 on AAPI communities is not well known.\textsuperscript{28} Some entities reporting COVID-19 data have not standardized the definitions for AAPI communities, while others have reported them all together, and federal and state governments have not disaggregated data by race and ethnicity using standard definitions.\textsuperscript{29} Although the Office of Management and Budget has defined and disaggregated some communities, it has not disaggregated groups by national origin within the “Asian” category.\textsuperscript{30} Similarly, there is little available information about other critical populations, including people of color who identify as LGBTQIA+.\textsuperscript{31} The failure to set a federal standard for data collection for these populations has meant there is limited collection or distribution of any targeted information about the prevalence of infections for LGBTQIA+ people of color.\textsuperscript{32} In May 2020, Pennsylvania became the first state to track information on LGBTQ COVID-19 patients; California began collecting data on sexual orientation and gender identity in late July.\textsuperscript{33}

Without addressing gaps in initial data collection at the provider or testing facility level, there will continue to be gaps in understanding the disparate impacts of COVID-19 by demographic factors. Despite the critical need for accurate and complete information, the Trump Administration has failed to prioritize understanding the role of demographic factors in the COVID-19 pandemic and to tailor its response appropriately. The Paycheck Protection Program and Health Care
**Enhancement Act** (Pub. L. 116-139) required the Trump Administration to submit reports to Congress on COVID-19 testing that include available data on demographic characteristics and information on the number and rates of cases, hospitalizations, and deaths as a result of COVID–19. HHS has submitted five reports so far. Although the reports have improved since the initial four-page document that was simply a compilation of public sources, the Administration has not demonstrated that it is using this demographic COVID-19 testing data to inform its response.

**Several Factors Likely Contribute to the Higher Rates of Illness and Death in Communities of Color**

High rates of illness and death from COVID-19 in communities of color are linked to a number of factors caused by inequality in our health system. These factors place people of color at higher risk of infection and serious health outcomes. Policymakers have long known that people of color, on average, experience worse health outcomes, have less access to health insurance, and are less likely than white people to have the workplace health and safety protections that have proved critical to keeping communities and families safe during the pandemic. While the pandemic is still far from over, and much more information needs to be gathered to fully understand how health and economic systems contribute to individual illness, there is strong evidence these key factors contribute to the disproportionate burden of COVID-19 on patients of color.

**Underlying Health Conditions**

There are a number of underlying medical conditions that place adults at an increased risk of serious illness or death from COVID-19, and due to systemic inequality described later in this report, these conditions are more prevalent among communities of color. According to the CDC, severe illness from COVID-19 is correlated with type 2 diabetes, chronic kidney disease, sickle cell disease, and obesity, among other diseases and conditions. People of color are more likely than white people to have each of these medical conditions. For example, Black people experience higher prevalence of diabetes, kidney failure, and sickle cell disease than white people; Hispanic people are more likely to have diabetes or kidney failure compared to non-Hispanic white people; and American Indian and Alaska Native people are almost three times more likely to be diagnosed with diabetes and 1.6 times more likely to be diagnosed with chronic liver disease compared to white people. LGBTQIA+ people also experience high rates of certain diseases—including asthma and diabetes—that place them at risk of getting COVID-19 or experiencing poorer outcomes related to the virus.

Tobacco use has been shown to be a risk factor for COVID-19 complications. The World Health Organization (WHO) and public health researchers have determined people who smoke are more likely to develop COVID-19 and experience complications if they do contract the disease; the risk of serious COVID-19 disease in people who smoke was nearly double that of people who do not smoke; and exposure to secondhand smoke may result in worse outcomes from diseases associated with COVID-19, such as pneumonia. American Indian and Alaska Native populations report smoking at higher rates than other racial and ethnic groups, with nearly double the smoking rate of white people. Black children are more likely to be exposed to secondhand smoke than any other racial or ethnic group, and Black people are more likely to get sick and die from tobacco-
caused disease than white people, despite generally starting smoking at a later age, being more likely to make a quit attempt, and smoking fewer cigarettes per day.47

A Lack of Adequate Insurance

At the same time Black and Latinx people and people from Tribal communities are more likely to have underlying conditions that place them at higher risk for severe COVID-19 outcomes, due to policy choices from federal, state, and local officials, they are also more likely to be uninsured compared to white people.48 People of color generally experience high rates of uninsurance: an analysis by the Kaiser Family Foundation of nonelderly individuals found 22 percent of American Indian and Alaska Native people, 19 percent of Hispanic people, 11 percent of Black people, and nine percent of Native Hawaiian and Other Pacific Islander people lacked insurance coverage in 2018.49 Women of color uniformly experience higher rates of uninsurance compared to white women.50 According to 2017 data, about 21 percent of American Indian and Alaska Native women, 20 percent of Latina women, and 14 percent of Black, Native Hawaiian, and Pacific Islander women were uninsured.51 LGBTQIA+ people are also more likely than non-LGBTQIA+ people to lack access to insurance and affordable medical care.52 Under the Trump Administration, the number of Black people and women who are uninsured has risen, and coverage gains following the passage of the Affordable Care Act (ACA) have stagnated for Hispanic people.53 A lack of adequate insurance can make it harder for individuals to access care to treat their underlying health conditions that may contribute to serious COVID-19 outcomes.

Being uninsured can also prevent people from accessing testing and care for COVID-19. People who are uninsured face challenges in getting appointments with private primary care providers; more than half of uninsured people report not having a regular source of medical care.54 Those who can obtain appointments may be unable to afford them.55 Although Congress has taken steps to provide free testing, including for uninsured patients, people without insurance may still be
reluctant to get COVID-19 testing or care for fear of cost.\textsuperscript{56} An April 2020 Gallup poll found 22 percent of people of color would not seek care if they or a member of their household had a fever and dry cough and 14 percent would avoid treatment for suspected COVID-19 infection for fear they could not afford it.\textsuperscript{57}

The Trump Administration has refused to take steps to address uninsurance among people of color and others who desperately need access to better coverage during the pandemic. Typically, people are only eligible to sign up for ACA marketplace coverage during the end-of-year annual enrollment period or when they qualify for a special enrollment period (SEP) because of a qualifying life event, such as marriage, loss of employer-based coverage, or the birth of a child.\textsuperscript{58} In order to address the impact of lack of insurance during the pandemic, many state-run marketplaces have created COVID-related SEPs to allow their residents to obtain coverage, but the Trump Administration continues to refuse calls for a SEP on the federally-run marketplace.\textsuperscript{59} As a result, residents in the 32 states that use the federal marketplace remain unable to enroll in coverage, unless they experience a qualifying life event.\textsuperscript{60} This refusal builds upon years of efforts by President Trump and Republicans in the federal and state governments to sabotage the health care system, undermine critical protections for people with preexisting conditions, and restrict opportunities to enroll in quality, affordable health coverage.\textsuperscript{61}

\textit{Increased Likelihood of Exposure to COVID-19 at Work}

One reason for the higher rates of COVID-19 infections in communities of color is the increased likelihood that Black and Latinx workers are exposed to the virus on the job. Workers of color are overrepresented in many frontline jobs, particularly in certain industries, including those that have faced high levels of COVID-19 infections.\textsuperscript{62} For example, workers of color make up 53 percent of home health care workers, over 54 percent of bus service and urban transit workers, over 56 percent of building cleaning service workers, and nearly 60 percent of warehousing and storage workers.\textsuperscript{63} Black and Latinx workers also report being less likely to be able to work from home than white workers.\textsuperscript{64}

Working on-site, especially in crowded workplaces with extended periods of close contact with coworkers, increases workers’ risk of exposure to COVID-19.\textsuperscript{65} The potential danger of essential work without sufficient health and safety measures has been tragically illustrated by the meatpacking industry. In April, President Trump issued an Executive Order requiring processors of beef, pork, and poultry to continue operating during the pandemic, despite concerns about whether workers are adequately protected.\textsuperscript{66} In April and May of 2020, more than 16,200 workers in meatpacking plants were infected with COVID-19, 87 percent of whom were people of color.\textsuperscript{67}

Similar concerns have been raised about the safety of workers in airports,\textsuperscript{68} transit workers,\textsuperscript{69} long-term care workers,\textsuperscript{70} home health care workers,\textsuperscript{71} and workers in numerous other frontline jobs that disproportionately employ people of color.\textsuperscript{72} Moreover, emerging evidence suggests that even within industries with higher exposure rates, workers of color are more likely to become infected than white workers who have the same job. For example, one study found health care workers of color are more likely than white health care workers to lack adequate access to personal protective equipment (PPE) and face a higher risk of becoming infected with COVID-19.\textsuperscript{73}
At the same time workers of color are more likely to be exposed to COVID-19 they are also less likely to have jobs that provide critical workplace protections that allow them to keep their families and communities safe when a worker gets sick. The importance of paid sick and paid family and medical leave has never been clearer than during the pandemic: if workers cannot afford to take time off without risking their jobs, they face an untenable position of having to choose between their livelihoods and the health of themselves, their families, and their communities. Congress has failed low-wage workers by not extending paid leave. Currently, only about 30 percent of workers in the industries with the lowest wages have paid sick leave compared to 90 percent of the highest-wage workers. Latinx workers, in particular, are substantially less likely than white or Black workers to have access to paid family and medical leave; more than half of Latinx workers do not have access to paid sick leave.

Finally, when workers of color do get sick, it may be harder for them to avoid exposing members of their families and communities, including older relatives, to disease. More than a quarter of Asian, Black, and Hispanic families live in multigenerational homes. Black and Latinx families are also more likely to live in more crowded homes with more people sharing the same space; in a study of overcrowded households with at least one worker in a job that requires close proximity to other workers, nearly half were headed by a Hispanic person. As a result, when one family member is exposed to COVID-19 on the job, their families and other members of their communities may be at greater risk of catching the disease.

Abuse, Bias, and Discrimination in Health Care Have Contributed to Disparate Health Outcomes

Neither the disproportionate impact of COVID-19 on communities of color, nor the higher prevalence of underlying conditions, lack of adequate insurance, or greater risk of COVID-19 exposure, is a coincidence. Rather, inequality within the American health care system is driven by a long history of exploitation, bias, and discrimination, lack of health care access, and other
interrelated factors. Some of these longstanding, systemic factors are explored in more detail in the section below.

**Historic Exploitation and Discrimination Have Caused Mistrust in the Health Care System**

The American health care system has a shameful legacy of racism and exploitation that is often unacknowledged. While most medical professionals are deeply devoted to their patients, it is important to recognize that others participated in the abuse of people of color by experimenting on their bodies, denying or providing treatment without consent, stealing genetic information, and more. History is rife with examples, including:

- Dr. J. Marion Sims was dubbed the “father of modern gynecology” in the 19th century for his critical advances in gynecological medicine, which he developed by experimenting on enslaved Black women. Dr. Sims performed the experiments that led to new gynecological treatments on fourteen enslaved people without their consent. Dr. Sims was not the only physician to receive acclaim for his medical accomplishments after experimenting on enslaved people.

- For four decades, the Public Health Service purposely denied Black men treatment for syphilis to study the course of the disease. Starting in 1932, the federal government and the Tuskegee Institute tracked 600 Black men, about two-thirds of whom had syphilis. The men were told they were being treated for “bad blood” and purposely given ineffective treatments, even after penicillin became known as a treatment for the disease and was widely available. The participants were never informed of the real purpose of the study, nor that they were denied effective medications. The Tuskegee Study ended in 1972 after the mistreatment was exposed.

- When Henrietta Lacks, a Black woman, received treatment at Johns Hopkins Hospital for cervical cancer in 1951, a doctor took a tissue sample from her tumor without informing her or obtaining her consent. Her cells, which became known as “HeLa” cells, are among the most important scientific discoveries of the last century as the first immortal human cell line, and have been extraordinarily valuable to the medical community as a research tool – generating millions of dollars in profits and contributing to many medical breakthroughs over the past several decades. The Lacks family learned about the HeLa cells from a social encounter with a cancer researcher more than 20 years after Henrietta Lacks died. The family did not receive any compensation for the unauthorized use of the cells, and while the National Institutes of Health (NIH) and the Lacks family reached agreement in 2013 to allow researchers controlled access to HeLa cells, there are continued controversies about the family’s lack of ownership of the cells and lack of compensation from research involving the cells.

- From the 1920s through the 1970s, it was disturbingly common for women of color, people of color with disabilities, and low-income women to undergo coerced sterilization or be sterilized without their consent. A number of states passed compulsory sterilization laws linked to the then-popular eugenics movement. North Carolina’s Eugenics Board was
responsible for the sterilization of about 7,600 people, an estimated 40 percent of whom were people of color. In California – which conducted about 20,000 compulsory sterilizations – Latina women were about 60 percent more likely to be referred for sterilization than white women. And in the 1970s, the Indian Health Service sterilized thousands of American Indian women without their consent. There are still allegations of forced sterilizations in the United States today.

The legacy of these outrageous and unethical practices still reverberates today. People of color report high rates of mistrust of the medical system and medical professionals. For example, one study of patient relationships with doctors in twenty cities found that Black and Hispanic patients, particularly low-income patients, were more likely to mistrust their doctors than white patients with higher incomes. This lack of trust is driven at least in part by the history of racism and exploitation in the medical community; Black patients often cite the Tuskegee experiment as an example of why they mistrust the medical system and are reluctant to participate in medical research.

Unfortunately, as mistrust of the medical community leads patients of color to delay or choose not to seek care, patients experience poor health outcomes that, in turn, may lead to higher death rates from COVID-19. Studies have shown that high levels of mistrust cause some Black men to avoid going to the doctor, which delays the preventive care important to prevent chronic disease and other underlying conditions. Other reports have linked medical mistrust to reluctance to getting treatment for specific conditions including tuberculosis, HIV, and prostate cancer. In fact, one study found lower life expectancy for Black men can be traced directly to avoidance of medical care spurred by the Tuskegee experiments.

Explicit and Implicit Bias Still Pervade the Health Care System

Unfortunately, bias and discrimination are still prevalent within our health care system. Patients of color may face outright discrimination, battle inaccurate stereotypes, find their pain or illnesses are not taken seriously, and they are rarely treated by providers of the same race or ethnicity. Such issues are exacerbated for patients of color who may face bias or discrimination because of multiple aspects of their identities, such as patients of color with a disability, who identify as LGBTQIA+, or who are English language learners. Our health care system fails to meet the needs of many patients of color, contributing to worse health outcomes generally, and in turn, worse outcomes during the pandemic.

Patient Care and Provider Interactions

Today, patients of color and other underrepresented populations report bias and mistreatment from health care providers that can lead to under-treatment and misdiagnoses, which subsequently impact the long-term health of these communities. Adults in underrepresented groups, including people of color, LGBTQIA+ adults, and adults with disabilities, are more likely to report being disrespected or judged unfairly by a provider or their staff. As a result, patients of color receive less effective care than white patients, which contributes to the high rates of underlying conditions that put communities of color at risk for severe COVID-19 outcomes.
Patients of color report lower quality of patient-physician interactions compared to white patients, which are associated with lower overall satisfaction with the health care system. Research has shown that implicit bias results in clinicians speaking more slowly and using less patient-centered dialogue with Black patients. Almost a quarter of Native American patients report being discriminated against when they seek medical care.

For example, providers are more likely to underestimate their Black patients’ level of pain and Black and Hispanic patients in emergency rooms are substantially less likely than white patients to receive medication to ease pain. Research suggests that mental health providers are more likely to incorrectly diagnose mental health conditions for people of color. From 2012 to 2016, white patients were substantially more likely to be prescribed buprenorphine for opioid use disorder than Black patients, even though deaths from opioid use disorder rose faster for Black people over the same time period. Notably, Black women and their babies are substantially more likely to die from complications during pregnancy or childbirth than white women and children. A study of more than 2,000 women in California found Latina mothers were more likely than white mothers to report being treated unfairly during hospital stays and feeling unsupported by medical staff during childbirth.

Transgender patients of color also experience additional barriers to accessing adequate care. The 2015 U.S. Transgender Survey found about one-third of respondents reported being uncomfortable while seeking medical care at least once over the past year, including incidents ranging from having to educate their own doctors about transgender people to being denied care. Almost one-third indicated that they had not disclosed being transgender to their medical providers, and one in four respondents avoided seeing medical providers because they were worried about being mistreated. The Trump Administration has exacerbated these issues by revoking protections against discrimination for transgender people seeking health care.

Like other underrepresented groups, people with disabilities report feeling uncomfortable in health care settings. A 2016 survey showed about 24 percent of adults with disabilities reported feeling disrespected by their doctors, compared to about eight percent of adults without disabilities. Compounding these issues, many medical
facilities remain physically inaccessible for people with disabilities, for example lacking accessible transportation and parking, exam tables, and equipment.\textsuperscript{124} People of color with disabilities may experience particular difficulty; for example, among people who are deaf, women of color – and particularly Black women – have greater challenges accessing care compared to white women.\textsuperscript{125} As a result of these physical and attitudinal barriers, people with certain disabilities may be less likely to seek and receive appropriate care. As just one example, studies have found that women with disabilities are less likely to receive recommended breast cancer screenings,\textsuperscript{126} and those with early-stage breast cancer have lower rates of some treatments and higher rates of mortality than other women.\textsuperscript{127}

Finally, English language learners also report receiving low-quality care from many providers. In one study, patients who did not speak English as a primary language reported being less satisfied with the emergency care they received and were more likely to report overall problems with that care than English speakers.\textsuperscript{128} Another study showed Spanish-speaking patients, in particular, reported lower satisfaction with a health care visit when providers do not speak Spanish or do not provide trained interpreters.\textsuperscript{129} The pandemic has only exacerbated this longstanding issue. For example, language barriers may have contributed to an outbreak at a meat processing plant where workers spoke 40 different languages, yet critical information about COVID-19 was provided in only English.\textsuperscript{130} The lack of access to translation services has been a consistent barrier to non-English speaking patients getting adequate COVID-19 care.\textsuperscript{131}

As the health care system embraces technology to help providers make care decisions, algorithms that purport to be objective may perpetuate and further systematize biases and disparities in medical care between white patients and patients of color.\textsuperscript{132} Physicians use diagnostic algorithms that may adjust their recommendations based on a patient’s race or ethnicity in a way that may result in directing care and resources to white patients over patients of color.\textsuperscript{133} Even algorithms that intentionally exclude race as a factor can include other variables, such as patient health care costs, that may lead to racially biased outcomes that exacerbate health disparities.\textsuperscript{134} Research shows that using race-based algorithms to guide care decisions lead to worse care for people of color, including, for example, admitting fewer Black and Latinx patients who presented at the emergency department with heart failure to the hospital than white patients and being less likely to evaluate for kidney stones in Black patients.\textsuperscript{135} Biased algorithms can also amplify and reinforce provider bias when they underlie decisions about who needs care and what care to provide,

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**CHRISTLE**

Christle is a first-year internal medicine and pediatrics resident in Baltimore. She is a first-generation American; her family was born in Nigeria and many of her family members are nurses. At the hospitals where Christle works, there are strict limitations about visitation during COVID-19 to protect patient and provider health. However, this has left some of her patients feeling especially isolated. Patients who do not speak the language of their providers have limited access to translators, and their family or community members are not able to provide in-person translation. Her patients no longer have visits from family members or a prayer group to look forward to. While some patients have turned to video calls, that has been difficult for older patients who may not be as familiar with technology. These unanticipated aspects of the COVID-19 response have left some patients – even those uninfected by COVID-19 – with even more barriers to overcome.
furthering unequal access to necessary care and unequal health outcomes, including higher rates of underlying conditions, for people of color.

**Physicians of Color**

One way of decreasing bias among health care professionals is to increase the diversity of physicians. Research has shown that when patients of color are treated by doctors with similar backgrounds, they tend to have better outcomes. For example, a study of Black male patients in Oakland, California, showed they were more likely to seek preventive care and talk about health issues when their doctor was also a Black man. Another study of Florida hospital births showed the mortality rate for Black newborn babies cared for by Black physicians is half that of Black newborns cared for by non-Black physicians. Other research has found Hispanic patients similarly are more satisfied with their health care overall when treated by Hispanic physicians. In contrast, bias among white doctors may lead to inadequate care; a disturbing study from 2016 found that about half of the white medical students and residents surveyed held inaccurate beliefs about physical differences between Black and white people.

People of color face barriers in entering in and advancing in medical professions, leaving many patients of color lacking access to doctors from communities of color. As of 2019, only 5.8 percent of physicians identified as Hispanic, five percent identified as Black or African American, 0.3 percent identified as American Indian or Alaska Native, and 0.1 percent identified as Native Hawaiian or Other Pacific Islander. Only two percent of physicians identified as Black women. The percentage of medical school graduates of color is similarly low; of 2019 graduates, only 5.3 percent were Hispanic or Latino, 6.2 percent were Black, 0.2 percent were American Indian or Alaska Native, and 0.1 percent were Native Hawaiian or Other Pacific Islander.

Black and Latinx medical students and doctors also report high rates of incidents of discrimination throughout their medical careers, with women of color reporting even higher rates of discrimination than men of color. Recent medical school students of color, female students, and students who identify as LGBTQIA+ report more incidents of mistreatment, including harassment and discrimination, than their peers. Evidence suggests that doctors of color continue to experience bias as they enter their professional careers; after interviewing Black, female physicians, the New York Times found that they frequently faced situations where their credibility or authority was questioned.

Since the spread of COVID-19, Asian medical professionals have faced increasing rates of bias and discrimination on the job. Incidents of harassment against AAPI people ranging from racist insults to outright physical attacks have skyrocketed and have been linked to untrue stereotypes and perceptions that people of Asian descent are responsible for the spread of COVID-19. Doctors, nurses, and other medical professionals helping to treat COVID-19 patients have experienced harassment even as they work to save lives during the pandemic.
Widespread bias and discrimination against people of color, especially women of color, are also prevalent in the scientific and medical research community. This manifests both as bias against funding for research conducted by researchers of color and bias against funding for research topics that particularly affect people of color. A 2011 report studying the NIH Research Project Grant Program (R01) found that Black applicants were about 10 percent less likely than white applicants to receive a funding award after controlling for factors such as the applicant’s training, educational background, and employer. Another study found that white researchers receive funding for new and renewal R01 applications at a rate about 1.7 times higher compared to Black researchers. NIH is working to implement changes designed to reduce bias in the grant awards process, but there is much more work to be done.

In addition to bias against researchers of color, evidence suggests that, at least in some instances, diseases that primarily impact people of color have been underfunded and received less public and private support than other diseases. For example, an analysis of funding found that sickle cell disease, which disproportionately impacts Black people, has been underfunded by both the federal government and private foundations compared to less prevalent diseases. Research involving health disparities, which is more likely to be proposed by Black researchers, is also less likely to be funded compared to topics proposed by white researchers.

Additionally, female researchers, particularly women of color, experience high rates of harassment both as students and later in their careers. In 2018, a National Academies of Science, Engineering, and Medicine (National Academies) report found disturbingly high numbers of women in academic medicine and other academic researchers experience harassment. In fact, workers at academic institutions have the highest rates of sexual harassment outside of the military; the National Academies found that more than half of female faculty and staff experienced harassment. Between 20 and 50 percent of female students also experience sexual harassment.
and the rates of gender-based harassment were more frequent in academic medicine than in other fields. The rates of harassment are even higher for women students and faculty of color, who experience both racial and sexual harassment; LGBTQIA+ people also experience higher rates of sexual harassment than heterosexual women. These experiences can impede women’s careers and health in numerous ways, including resulting in women dropping out of the academic profession, seeing reductions in productivity, and feeling negative impacts on mental and physical health.

**Clinical Trials**

The pharmaceutical industry is the largest sponsor of clinical trials, which have generally failed to include a representative sample of people of color in their patient populations. For example, despite Black people comprising 13 percent of the U.S. population, they accounted for less than five percent of the patients enrolled in clinical trials for 24 of 31 cancer drugs approved since 2015, and have even been underrepresented in trials for drugs that were meant to target diseases with disproportionately high incidence in Black communities. In particular, clinical trials for three drugs recently approved by the U.S. Food and Drug Administration (FDA) for treatment of HIV-1, manufactured by Merck, ViiV Healthcare, and Gilead Sciences, included between 21 and 29 percent of Black or African American patients, although more than 40 percent of new HIV diagnoses in the United States are among Black adults and adolescents.

Similarly, despite the fact that people of color are bearing the heaviest burden of the pandemic, they are severely underrepresented in current COVID-19 vaccine clinical trials. While week-by-week enrollment in Moderna’s Phase 3 COVID-19 vaccine clinical trial is improving for some populations of color, data released as of September 2020 makes it difficult to assess the total number of enrollees as a share of the total population, particularly for people who identify as American Indian or Alaska Native, Hawaiian or other Pacific Islander, or more than one race. As of September 14, 2020, Pfizer’s Phase 2/3 vaccine trial had also enrolled far fewer people of color in the United States compared to their share of the overall population. The NIH’s COVID-19 Prevention Trials Network, which was created to recruit participants and conduct Phase 3 clinical trials...
clinical trials for COVID-19 vaccines and monoclonal antibody therapies, has struggled to recruit substantial numbers of volunteers from communities of color.\textsuperscript{168} As of mid-August 2020, only 10 percent of the 350,000 volunteers who had signed up for COVID-19 clinical trials through the online registry identified as Black or Latino.\textsuperscript{169}

Clinical trials assess the potential benefits and risks of experimental treatments; unless trials represent all demographics of potential patient populations, researchers and drug developers lose an important opportunity to understand the effects of the treatments for all populations.\textsuperscript{170} Although there is limited data, research has found that some drugs tested mainly on white, male adult patients may be less effective for Black patients and women; conversely, this suggests trials that do not include enough patients from underrepresented groups may overlook drugs that could work for these populations.\textsuperscript{171}

A number of systemic factors influence this lack of representation. As described above, patients of color are more likely to have comorbidities, which can make drug trials potentially less safe; providers may fail to make patients aware of clinical trial opportunities; and people of color may feel reluctant to participate given the length of the trial and the cost of participation.\textsuperscript{172} Additionally, the historic exploitation of patients of color and resulting mistrust of the medical community mean people of color may be less inclined to volunteer for trials.\textsuperscript{173}

**Patients of Color Lack Access to High-Quality Medical Care**

In addition to facing explicit and implicit bias and discrimination from health care providers, communities of color have less access to high quality, affordable health care than white communities, contributing to inequality in health outcomes. Our system of medical care is highly segregated; patients of color are more likely to be treated at facilities that see large numbers of patients of color, and they are less likely to have access to high-quality facilities than white patients. The market-based system of health insurance also contributes to segregation and inherently discriminates against people of color, particularly low-income people of color, making care more expensive and, accordingly, less accessible.

**Hospitals and Other Medical Facilities are Highly Segregated**

Patients of color and white patients have long had separate and unequal medical care. Prior to the 1960s, many health care facilities participated in state-sanctioned discrimination against patients of color.\textsuperscript{174} Like schools and restaurants, medical facilities in states with formal segregation served only patients of one race or had separate wings for white patients and patients of color.\textsuperscript{175} In some states, the blood supply was even separated to ensure that white patients received blood only from white donors.\textsuperscript{176} In states without formal segregation, the health care system found informal ways of separating patients by race. Black doctors were often denied admitting privileges to white hospitals, and Black patients were sent to traditionally Black hospitals or doctor’s offices, even if those were not the closest facilities to their homes.\textsuperscript{177}

Federal civil rights legislation finally forced medical facilities to integrate. When Congress created Medicare in 1965, shortly after the Civil Rights Act, the Johnson Administration made clear it would enforce federal prohibitions against using federal funding to discriminate, allowing only
hospitals that integrated to be eligible for federal funds. Federal inspectors were sent to health care facilities to determine whether they were segregated and, therefore, ineligible to receive federal Medicare dollars. Rather than lose access to the large amount of new federal funding, health care facilities complied; 98 percent of the nation’s hospitals integrated in just a few months.

Despite the progress made during the 1960s, some medical facilities still primarily serve patients who are white and higher income, while others are more likely to treat low-income patients of color. One study found care for Black patients is concentrated in a very small number of hospitals: nearly half of all elderly Black patients receive care in the five percent of hospitals with the highest volume of Black patients. Another study found 80 percent of African American and Hispanic patients admitted to skilled nursing facilities for post-acute care were concentrated in under 28 percent of all facilities.

Several interrelated factors contribute to the ongoing segregation within the medical system. Housing patterns, in part driven by overt discrimination, have created segregated neighborhoods, resulting in white people tending to live near the same hospitals and doctors as other white people. Patients of color are also more likely than white patients to be treated at safety net hospitals, because people of color are less likely to have private insurance and more likely to have Medicaid or Medicare as their main insurance. And evidence suggests that ambulances take Black and Hispanic patients to different hospitals than white patients from the same zip code, whether because of bias, patient choice, or other factors.

The Medical Facilities That Primarily Serve Patients of Color are Lower Quality

The medical facilities that disproportionately treat patients of color tend to underperform and provide worse patient experiences compared to facilities that treat primarily white, affluent patients. A recent analysis demonstrated that the most prestigious hospitals in the United States serve a patient population that is primarily high-income with good insurance. Facilities that treat higher proportions of people of color tend to have higher rates of infection for infants born with very low birth weight, higher patient-to-nurse ratios, fewer technological resources, and medical professionals with less training and experience. They are also more likely to close than hospitals in affluent white neighborhoods. Similarly, nursing homes with more patients of color had characteristics associated with a lower quality of care; they are larger, are more likely to operate for profit, and have higher resident-to-staff ratios compared with nursing homes serving more white residents.

This gap in quality is driven in part by disparities in resources among medical facilities. Patients of color disproportionately receive care in under-resourced hospitals. Many of these are safety-net hospitals that serve a larger proportion of Medicaid and uninsured patients, which means they likely provide more care that is not compensated or fully reimbursed, operate on thinner financial margins, and have lower financial performance. The most recent annual report by American’s Essential Hospitals revealed that while the operating margin for U.S. hospitals is 7.6 percent on average, many essential hospitals operate on margins of only 2.5 percent; the margin would be negative 1.6 percent without Medicaid disproportionate share hospital payments. Another study found total capital assets – the value of land, buildings, and equipment – held by hospitals serving
mostly white patients were around 60 percent higher than total capital assets held by those serving mostly Black patients and close to 44 percent higher than those serving mostly Hispanic patients.\textsuperscript{196} Compared to white patients, patients of color are also more likely to lack access to high-quality behavioral health services and treatment for substance use disorders.\textsuperscript{197} Limited financial and physical resources at hospitals that serve people of color have been shown to significantly contribute to lower hospital quality and poorer health outcomes, including higher mortality rates for a number of conditions.\textsuperscript{198} For example, studies have shown Black patients are more likely to undergo surgery at low-quality hospitals and have worse outcomes as a result,\textsuperscript{199} and Hispanic and Black babies have higher rates of morbidity and mortality in part because they are more likely to be born in lower-quality hospitals with inferior neonatal intensive care units.\textsuperscript{200}

There is emerging evidence that access to poorer quality medical care may also impact outcomes from COVID-19 in low-income Black and Latinx communities. The New York Times highlighted this dynamic in two New York hospitals: a hospital that treats primarily low-income patients who are immigrants has resorted to using plastic tarps and duct tape to create barriers between patients in the intensive care unit, while a wealthy private hospital used private planes to fly in N95 masks from China.\textsuperscript{201} Nursing homes have seen similarly disparate outcomes for people of color; those with a higher proportion of Black and Latino residents were twice as likely to have COVID-19 cases in the initial months of the pandemic.\textsuperscript{202}

\textbf{Our Market-Based Health Insurance System Creates Barriers to Care for People of Color}

One of the factors contributing to health care segregation, lower quality care, and worse outcomes in communities of color is that high-quality, affordable care and coverage is out of reach for some low-income people of color. People of color are substantially more likely than white people to be uninsured or underinsured and left to shoulder the full cost of their care. About half of uninsured people in the United States are people of color,\textsuperscript{203} including about 25 percent of Hispanic and American Indian and Alaska Native people ages 19 to 64, compared to nine percent of white people.\textsuperscript{204} There are also disparities in the types of insurance most accessible to certain communities; for example, in 2017, about 80 percent of white adults between the ages of 19 and 64 had private insurance, compared to 56 percent of Hispanic and 63 percent of Black adults in the same age range.\textsuperscript{205} Without high-quality health insurance, patients of color may not be able to access the care they need.

By relying on a system that is heavily market-based, significantly more so than in many other industrialized nations, the U.S. health care system has created significant barriers to obtaining affordable insurance and health care.\textsuperscript{206} These barriers, in turn, disproportionately affect communities of color and magnify historic racial inequities in access to health care and health outcomes in general.\textsuperscript{207} The U.S. system, with its greater emphasis on market-based delivery, is the product of more than half a century of policies adopted by Congress and state governments, many of which favor middle- and high-income families, who are disproportionately white.\textsuperscript{208} While Congress has adopted policies that have expanded access to care and lowered costs, in many other cases, it also has made policy decisions that were driven by profit-seeking and other considerations of special interests rather than improving access to medical care for all patients.
In the American system, private sector insurance premiums and the price of health care services are set primarily by private actors, including large, for-profit companies. Policies that encourage profit-seeking limit policymakers’ ability to control rising costs. Insurance companies then turn to the limited, blunt tools available for them to compete on price, including increasing out-of-pocket costs and limiting benefits. Insurers also seek to cut costs by restricting patients’ choice of providers to narrow networks; patients who then seek out-of-network care are often forced to pay higher out-of-pocket costs. As a result, patients’ use of care declines as provider networks narrow and cost sharing obligations rise, too often leading people with the worst health to forgo desperately needed care. This reduction in care-seeking shifts care from the sick and poor to the healthy and wealthy—a system that means communities of color are most often those going without high-quality, consistent care.

The health care system in the United States has relied heavily on employer-based health insurance for decades, in the process favoring high-income workers who are disproportionately white and amplifying inequality within the workforce. The employer-based health insurance system was driven by tax incentives for employers to cover health insurance premiums. Employer-based health insurance systems provide better options for families with higher incomes who get a greater tax benefit from employer contributions to health insurance premiums. The low-income workers who are less likely to have access to quality, affordable employer-sponsored health insurance are disproportionately people of color. The latest data show that 66 percent of white, nonelderly people have employer-sponsored coverage, with 46 percent of Black people, 41 percent of Hispanic people, and 36 percent of American Indian and Alaska Native people having such coverage. Prior to the passage of the ACA, researchers found that lack of access to employer-sponsored insurance and overrepresentation in low-wage jobs were key reasons for the high uninsurance rates for Black and Hispanic people.

Enacting the ACA was a significant step forward—bringing affordable, comprehensive insurance coverage to millions of people, including communities of color, who previously faced barriers to coverage—but the highest financial burden of health care still falls on low-income families and families of color. Even under the ACA, patients can have substantial out-of-pocket risk through deductibles and copayments. These costs are more burdensome for low-income people and can discourage patients who cannot afford those costs from seeking care. Similarly, Medicare imposes regressive cost-sharing measures on the entire health care system; uninsured individuals—who are disproportionately low-income and persons of color—do not benefit from insurers’ negotiating leverage and, as a result, are charged the highest prices.

While Medicaid expansion has proven to be an effective tool for improving equity in coverage and access to care, many people live in states that still have not expanded access to coverage through Medicaid expansion. Forty-six percent of Black adults and 36 percent of Hispanic adults live in the 15 states that have not yet implemented Medicaid expansion as of January 2020—a much larger share than national averages. Additionally, the Latinx community continues to experience the largest disparities in access to coverage, in part due to Trump Administration health care sabotage and in part because undocumented immigrants have limited access to coverage through their jobs and are prohibited from enrolling in Medicare, Medicaid, the Children’s Health Insurance Program, or ACA marketplace coverage. Despite the lack of national-level policies
to provide coverage to undocumented immigrants, several states use state-only funds to provide Medicaid coverage to some undocumented immigrants.\textsuperscript{228}

**Factors Outside of the Health Care System Impact Health Outcomes for People of Color**

While this report is primarily focused on the issues within the health care system that create and exacerbate health disparities between communities of color and white communities, it is important to acknowledge again that there are many challenges outside the health care system that contribute to these disparities. These additional factors outside the health system, or “social determinants of health,” are defined by the WHO as “the conditions in which people are born, grow, live, work and age.”\textsuperscript{229} Health People 2030 identifies five key areas that can influence health outcomes including: (1) economic stability, (2) education access and quality, (3) social and community context, (4) health care access and quality, and (5) neighborhood and built environment.\textsuperscript{230} The legacies of slavery, Indian removal, segregation, and anti-immigrant policies have produced longstanding systemic barriers that mean communities of color tend to have greater hurdles to overcome across the social determinants of health compared to their white peers.\textsuperscript{231} The following few examples illustrate some of those barriers:

- Communities of color experience high rates of unemployment and poverty. The unemployment rate among Black, Asian, and Latinx people is higher than the unemployment rate for white people; this remains true among every age group and for both men and women.\textsuperscript{232} Black, Hispanic, and American Indian and Alaska Native people and people who identify as multiple races all experience poverty at higher rates than the national average.\textsuperscript{233}

- Students of color are more likely than their peers to have less access to high-quality schools and early childhood learning opportunities. The graduation rate among white public high school students is 89 percent, with Hispanic students at 81 percent, Black students at 79 percent, and American Indian and Alaska Native students at 74 percent.\textsuperscript{234} White students are also more likely to earn advanced degrees at public and non-profit four-year institutions than are Black or Hispanic students; Black and Hispanic students represent a much larger portion of the student bodies at for-profit institutions.\textsuperscript{235}

- People of color also experience discrimination, which itself can be a social determinant of health.\textsuperscript{236} Since the first comprehensive reviews of discrimination and health were conducted nearly 30 years ago, a significant body of work has been developed showing how experiencing racial discrimination in and of itself can lead to adverse health outcomes and place people of color at higher risk for negative health conditions.\textsuperscript{237}

- Communities of color are incarcerated at higher rates than white people. Black and Latinx people are represented in far higher rates in the U.S. prison population than they are in the share of the U.S. population as a whole: in 2017, Black people were 12 percent of the U.S. population but 33 percent of the sentenced prison population, and Hispanic people were 16 percent of the U.S. population but 23 percent of inmates.\textsuperscript{238} By contrast, white people were 64 percent of the U.S. population but 30 percent of the prison population.
Communities of color face higher rates of pollution and other environmental hazards than white communities. Black and Hispanic people are more likely than white people to live in counties with higher levels of air pollution. Of the more than nine million people who live within approximately 1.9 miles of toxic waste facilities, more than half are people of color. Finally, the risk of lead poisoning is higher for Black and Latinx communities than for white communities; Black children having elevated lead levels at triple the rate of white children, and Latinx children are more likely to experience asthma and lead positioning than white children. Native Americans are more likely to experience threats to their fish and other food sources than other demographic groups.

Social determinants of health can negatively impact health starting from childhood through adulthood, and some experiences or exposures early in life may not manifest in negative health outcomes for years. Social determinants of health are also influenced by other aspects of a person’s identity, in addition to race and ethnicity, including disability status, sexual orientation and gender identity, and age, reflecting that one factor alone may not explain health outcomes. Despite the importance of social determinants of health, Congress and the CDC designate almost no funding to programs that target social determinants and alter the conditions that lead to disparate health outcomes for communities of color. In addition to reforms within the health care system, effectively addressing social determinants of health will require sweeping changes, potentially encompassing issues such as affordable housing, environmental justice, and other broad reforms to combat structural and institutional racism.

Recommendations

The Democratic staff of the Senate Health, Education, Labor, and Pensions (HELP) Committee make the following recommendations to HELP Committee members and to Congress. These recommendations respond both to the disproportionate impact COVID-19 is having on communities of color as well as the longstanding systemic issues described in this report. These recommendations are just a few of the immediate things that Congress should consider in order to address inequality, underinvestment, discrimination, bias, and lack of access to care – and are primarily limited to the HELP Committee’s jurisdiction.

Congress Must Take Immediate Action to Support Black, Latinx, Tribal, and Other Communities with High Rates of Illness and Death During the Pandemic.

There is no question that Black, Latinx, and Tribal communities are experiencing disproportionately high rates of morbidity and mortality from COVID-19. Every moment wasted without a comprehensive federal response that recognizes these disparities means more sickness, pain, and death for families of color. Congress must take immediate steps to provide unprecedented support to the nation’s public health infrastructure and community resources and ensure assistance is reaching those communities that need it the most. Congress should:
- **Provide significant new funding, resources, and support to communities of color and others disproportionately impacted by the pandemic.** All future pandemic relief legislation must include dedicated resources for communities of color, including but not limited to resources to ensure access to testing and therapeutics, enhanced public health infrastructure, and material supports for isolation and quarantine. This funding should include support for organizations that represent and serve these communities.

- **Require the Trump Administration to plan for equitable vaccine distribution and administration, with a particular focus on reaching communities of color.** The Trump Administration must develop and implement a sufficient, comprehensive national vaccine plan that addresses all aspects of a successful vaccination campaign and work toward making that plan a reality. Although the Trump Administration has outlined some elements of a vaccine distribution plan, much more information is required to address equitable allocation of safe and effective COVID-19 vaccines to ensure they are cost-free to everyone, targeted to the most vulnerable, and available through providers in underserved communities. The Trump Administration must also work with communities to build vaccine confidence, especially in communities of color.

- **Fund expanded testing and contact tracing efforts in communities of color.** In order to mitigate the spread of COVID-19, the federal government must support the efforts of state, local, Tribal, and territorial governments to scale up testing and contact tracing initiatives that aim to reduce the spread of COVID-19. Resources should be targeted to ensure these efforts are effective in communities of color.

- **Protect workers from exposure to COVID-19 on the job.** Congress must require the Department of Labor and CDC to issue robust, detailed, industry-specific, and evidence-based guidance and workplace standards about the steps employers need to take to protect workers from exposure to COVID-19. This effort must include the Department of Labor issuing an enforceable Occupational Safety and Health Administration (OSHA) standard for infectious disease so that workers, including the workers of color who hold a disproportionate number of the essential jobs that put workers at higher risk for COVID-19 exposure, can hold employers accountable for creating safe workplaces.

- **Create a federal right to paid sick days and paid family and medical leave.** The pandemic has clearly and dramatically demonstrated the necessity of paid leave for both workers’ and their families’ economic security and public health. Without paid leave, workers may fall into an untenable position of choosing between their jobs or staying at home to protect their communities and families from COVID-19—particularly workers in low-wage, essential jobs, many of whom are workers of color. Congress should pass legislation to expand and make permanent the federal right to paid sick and paid family and medical leave, including the FAMILIES Act, the Healthy Families Act, and the PAID Leave Act.

- **Support the aging network to better serve the needs of older adults of color.** Older adults, and especially older adults of color and those residing in long-term care facilities, are being disproportionately impacted by COVID-19. Congress should ensure the aging
network, including state and local area agencies on aging and programs authorized under the Older Americans Act, has adequate resources to respond to the pandemic and address the health care needs of older adults. This effort should include significant funding for nutrition services, family caregiver supports, case management services, programs to combat the impact of social isolation, and other supportive services. Additionally, Congress should provide resources to public health departments to build aging expertise and promote older adult health and well-being during and following the pandemic.

- **Support comprehensive and accurate COVID-19 data collection.** In order to fully understand the impact of COVID-19 on communities of color, we need timely, complete, consistent, and accurate data collection. Long-term investments to modernize the public health data system are crucial to inform and enable comprehensive system change to reduce and eventually eliminate disparities. In the immediate term, Congress should require improved data collection and reporting and provide a short-term funding surge to assist state, local, Tribal, and territorial governments and other entities with data reporting and collection tools to better understand and mitigate the impact of COVID-19 across communities of color. Congress should also require CDC to create a plan to collect disaggregated data on COVID-19 among people with disabilities, AAPI communities, as well as on LGBTQIA+ people, when appropriate.

- **Establish a task force to better understand and respond to COVID-19 related racial and ethnic disparities.** Congress should establish a task force comprised of government officials, experts, and representatives from community-based organizations addressing racial and ethnic inequality in health care, with the mandate to focus specifically on COVID-19 related disparities. The task force should provide ongoing recommendations for targeted resource allocation, ensuring inclusion in clinical trials, and policies to reduce the disparities experienced by communities of color.

**Congress Must Work to Reduce Bias and Discrimination in the Health Care System.**

Since the 1960s, Congress has taken steps to address racism and bias in the health care system by passing landmark legislation including the Civil Rights Act of 1964 and the Affordable Care Act, both of which included explicit prohibitions against discriminatory conduct in health care settings. Unfortunately, the legacy of exploitation and discrimination continue to shape the way our systems are built today. Too often, implicit and explicit stereotypes, bias, racism, sexism, ableism, and other forms of discrimination impact the quality of care that patients receive and the ability of health care workers of color to do their jobs. This is particularly true for people of color who are women, who have a disability, who are LGBTQIA+, and others who may experience multiple forms of discrimination.

Congress should pass comprehensive legislation to reduce inequality and bias faced by people of color and others when they seek or provide medical care. Such efforts could include:

- **Reduce discrimination against patients of color in the health care system.** Congress must ensure no person is discriminated against in the health care system because of their
race, color, national origin, sex (including sexual orientation and gender identity,) age, or disability. While some of these protections were included in Section 1557 of the Affordable Care Act, the Trump Administration has revoked these protections and made it harder for patients to enforce their rights. Congress must make clear that such discrimination is prohibited and strengthen enforcement and accountability measures to ensure patients can hold providers accountable for bias and discrimination.

- **Strengthen workplace protections to prevent discrimination in health care settings.** Congress should pass legislation to make it easier for health care workers to hold employers accountable for providing workplaces free of harassment and discrimination. Currently, too few workplaces offer adequate policies and training for staff, and courts have created barriers making it too difficult for workers who are discriminated against to successfully bring claims. Moreover, many workers, including independent contractors, are left out of federal nondiscrimination protections. Passing legislation such as the Be HEARD in the Workplace Act will help to address these issues, including for workers of Asian descent who are facing a resurgence of anti-Asian discrimination, as well as other workers of color, workers with disabilities, women, LGBTQIA+ workers, and older workers.

- **Require anti-racist and anti-bias training for health care professionals and across health care systems.** Health professionals, including public health officials and health care providers, and any health care staff interacting with patients, should undergo anti-racist and anti-bias training to identify and reduce instances of implicit bias and explicit bias against people of color, including those with disabilities and English language learners. Additionally, Congress should support systems of review and accountability to ensure training and other tools for reducing bias and racism are actually working to improve quality of care and health outcomes for patients.

- **Provide support to Black, Latinx, Tribal, and other underrepresented people to train and pursue careers in public health and as health care providers.** Resources should be allocated to encourage, recruit, and retain people of color, including those who are LGBTQIA+, people with disabilities, women, and others often underrepresented in health care fields, to pursue and maintain careers in health care. These investments would help to shape a health care workforce that not only reflects the demographics of the overall population, but may also lead to better care for patients and ensure priorities for improving health care reflect the needs of these communities. For example, Congress should increase investments for the area health education centers (AHEC) program to further enhance health care education and training networks within communities of color.

- **Ensure clinical trials are inclusive of people of color.** People of color and their health care providers need to have sufficient information about the risks and benefits of medical products to make informed decisions about patient care. Ensuring sufficient enrollment of underrepresented populations in clinical trials means designing trials to address barriers to participation. Congress should encourage the implementation of inclusive trial design criteria whenever feasible by all agencies that sponsor or oversee clinical trials and provide sufficient funding for trial sponsors to conduct necessary community engagement. Congress should also support campaigns that raise awareness of the availability and
importance of clinical trials among potential participants through culturally aware, multilingual outreach efforts.

- **Invest in researchers of color and research that serves communities of color.** Congress should require research funding agencies, such as the National Institutes of Health, to increase spending that will target researchers of color, as well as Historically Black Colleges and Universities (HBCUs) and research centers that predominantly serve communities of color. Congress should also require federal agencies to provide technical assistance and funding support to build grant management capacity at HBCUs.

- **Reduce disparities in research funding rates and eliminate harassment in the sciences.** Congress should require NIH to develop specific goals and metrics through which the agency will reduce racial, ethnic, and gender-based funding gaps in research awards, with an aim to increase equitable distribution of funding to researchers of color and female researchers. Congress should also require NIH to examine how it can bolster funding for research on health conditions that disproportionately impact communities of color. Additionally, NIH should continue to build on its existing work combating harassment and make concrete commitments to eliminate all forms of harassment within the research enterprise.

- **Authorize and fund grants for interpretation and translation services, and ensure rights to access information are enforced.** For federal resources to effectively address racial and ethnic disparities in health care, they must be accessible to all people. Information about health care services must be widely available in formats accessible to English language learners and people with disabilities to ensure they can fully understand their rights and the resources available to them. Congress should provide grants to state, local, Tribal, and territorial governments, and community-based organizations to assist with interpreting and translation services. Congress should also ensure the Trump Administration responds to violations of the Americans with Disabilities Act when information is not provided in an accessible format for people with disabilities.

- **Authorize and fund grant programs to improve health equity for people of color with disabilities.** Action is needed to improve health equity for people of color with disabilities, including training of health care professionals in reducing bias and providing appropriate care, increasing the number of health care professionals with disabilities to improve representation, and increasing tax credits to ensure health care buildings are accessible. Congress should also authorize a study to assess the current accessibility of health care facilities for people with disabilities.

- **Authorize and fund a CDC grant program to fund a Health Equity Officer in state and local public health departments.** Achieving health equity will require a response from all levels of government, but under-resourced state and local health departments are struggling to keep up, let alone make progress against longstanding structural inequality. Congress should fund, through CDC, grants to state and local health departments for the creation and support of a Health Equity Officer. Health Equity Officers must be fully integrated across departments and empowered to work with social service agencies and
organizations to better address social determinants of health and support integration of solutions into the health care system. This official will be responsible for pulling together a comprehensive, cross-cutting strategy to achieve health equity in their community.

Congress Must Ensure Families of Color, Particularly Low-Income Families, Have Access to Affordable, High-Quality Health Care.

The current health care system, with its over-reliance on the market to deliver goods and services essential to physical, mental, and social wellbeing, is largely failing communities of color. Congress must consider comprehensive and expansive reforms to address this tragic history of neglect and longstanding failures, including reforming our patchwork system of health insurance coverage to simplify and democratize access for all. There are a number of options to reform and greatly expand access to affordable, high-quality health care and make the system more accountable to voters— including through the creation of a single publicly accountable payer, the expansion of existing publicly administered payers like Medicare and Medicaid, or the creation of a new public option.

We must consider reforms to the practice of medicine in a market-based system that too often targets the wealthiest patients and seeks the highest profit margin— rather than serving patients who need care to achieve the greatest social gain. Additionally, Congress should consider the following steps to increase access for families of color:

- **Make insurance more accessible and affordable.** Congress should build on the Affordable Care Act to significantly expand the availability and accessibility of health insurance coverage. A Special Enrollment Period (SEP) would widen access to health insurance coverage in the short term for those who need it and who have too often lost coverage as a result of the pandemic’s disruption of the economy. Beyond the context of the public health emergency, increasing the value of Advance Premium Tax Credits (APTCs) for those already eligible, and lifting the cap on APTC eligibility for households with incomes above 400 percent of Federal poverty, would help more patients and families afford comprehensive coverage. Congress should also close gaps in the system that raise costs for families— for example, by fixing the “family glitch,” which locks families out of affordable coverage and by limiting APTC amounts to be paid back if income rises, especially for vulnerable groups.

- **Strengthen and stabilize state-based individual insurance markets.** Congress should fully fund efforts to states to establish state-based health insurance marketplaces in all states and territories. Congress should also provide states with funding to establish reinsurance programs to stabilize insurance markets and reduce premiums. Finally, Congress should ban the sale of short term “junk” plans and rescind waivers that undermine protections for people with pre-existing conditions and weaken standards for essential health benefits.

- **Provide full Federal matching funds to states that expand Medicaid.** Millions of Americans fall into a coverage gap in that they do not qualify for either Medicaid or APTC on the marketplace. Congress should pass legislation to close the coverage gap by
providing states that expand Medicaid after 2014 full Federal matching funds. Closing the coverage gap would also have the benefit of making millions of enrollees in those states’ marketplaces eligible for Medicaid, and likely reducing their premiums and out-of-pocket costs.

- **Protect existing Medicaid and CHIP beneficiaries from coverage gaps.** Congress should mandate that all Medicaid and CHIP beneficiaries receive 12 months of continuous coverage after initial enrollment and Medicaid-eligible new mothers remain enrolled for at least 12 months post-partum. Congress should enact mandatory screening of Medicaid eligibility for individuals transitioning out of incarceration and require all eligible individuals to be enrolled prior to release.

- **Fund programs to connect communities of color, Tribal communities, people with disabilities, English language learners, and other uninsured or underinsured groups with coverage.** Congress should increase funding for outreach and enrollment activities to encourage enrollment by providing appropriate information to consumers about their health insurance options, including eligibility for APTCs, Medicaid, and CHIP, and explaining key insurance terms such as deductibles, co-pays, and coinsurance. Outreach materials should also be tailored to target key underserved populations, including those who may not speak English.

- **Expand coverage eligibility for immigrant communities.** Congress should expand Medicaid and CHIP eligibility to DACA recipients and remove the existing five-year waiting period for Medicaid and CHIP for lawful permanent residents. Congress should also support expanded coverage for undocumented people, including by enabling them to purchase coverage on the ACA marketplaces and benefit from tax credits and cost-sharing reductions if they are eligible. Congress should also restore Medicaid eligibility for COFA (Compact of Free Association) migrants.

- **Provide robust investments in primary care programs and support the expansion of the health care workforce in communities of color.** Congress should provide robust, long-term investments for primary care programs, including community health centers, teaching health centers, the National Health Service Corps, family planning clinics, and other safety net and Health Resources and Services Administration programs to make sure affordable, quality health care is available to those most in need. These critical programs are essential in providing health care services to underserved communities, including communities of color, as well as fostering the expansion of the health care workforce.

### Congress Must Make New Financial Investments in the Health of Communities of Color.

This report and its recommendations focus almost exclusively on issues within the health care system, but Congress and policymakers at all levels must recognize the interconnectedness of health with the other factors that relate to the way people live, work, and engage in their communities. Long-term efforts to address health disparities will ultimately be unsuccessful if
they do not also address underlying structures that prolong and entrench racist systems and discriminatory behaviors.

Addressing these social determinants of health outside of the health care system will require non-clinical interventions, such as removing toxins from living environments, removing barriers to safe, affordable housing, providing reliable transportation options, or improving access to nutritious foods. Programs to address these issues should be tailored to better respond to and address inequality that harms communities of color.

Congress should take action to improve public health and ensure communities of color have the opportunity to address their health care needs, including by taking the following steps:

- **Bolster public health departments’ capability to address racial and ethnic disparities.** Congress should create a robust, sustained, mandatory investment of $4.5 billion annually in public health infrastructure that bolsters health departments’ capability to correct health inequities. Sustained, long-term investment in the nation’s public health infrastructure is critical to strengthen foundational public health capabilities, bolster the current COVID-19 response, and prepare for future public health emergencies. These investments are critical to strengthening the work of state, local, Tribal, and territorial health departments to better understand and address racial and ethnic inequality.

- **Support community health workers in communities of color.** Community health workers can assist in connecting individuals and communities with the health care system and other social services. For example, community health workers can help to reduce barriers to accessing necessary health care, including providing education and resources to individuals without internet or with mobility or language access challenges. Congress should support programs that utilize community health workers and other community-driven efforts.

- **Increase support for mental health care for people of color.** Systemic racism and increased risk of contracting COVID-19 can lead to increased anxiety and other mental health challenges for communities of color. Additionally, while Congress has supported many efforts to reduce and respond to substance use disorder (SUD), communities of color are still experiencing SUD at higher rates and often have fewer options when it comes to treatment for opioid use disorder. Congress should provide additional resources for culturally sensitive mental health care providers in communities of color to ensure everyone has access to the mental health care and substance use disorder treatment they need.

- **Authorize programs to improve access to nutritious food within communities of color.** Nutrition is an important aspect of positive health outcomes. Congress should support efforts to improve access to nutritious food in current food deserts through strengthened public health programs, public-private partnerships, funding for community-based agriculture and farmers markets, and support for good nutrition in child care and school settings. Congress should enact stricter requirements for food marketing to children, which often targets children of color, and require the Dietary Guidelines for Americans to
consider recommendations related to addressing disparities in the incidence of preventable, diet-related diseases.

- **Strengthen regulation of tobacco products.** The disproportionate impact of tobacco products on communities of color has contributed to shortened life expectancy and increased health care costs, particularly for Black Americans. Congress should strengthen laws to prevent tobacco companies from targeting a new generation of kids and getting them addicted to tobacco products – beginning with banning the use of all flavors in tobacco products, including a prohibition on flavors in e-cigarettes unless or until a thorough FDA review shows they benefit public health, and bolstering investments in culturally and linguistically competent tobacco use prevention and cessation programs. Action to prohibit the use of flavors in little cigars and to prohibit menthol in cigarettes is particularly important in order to address the disproportionate impact of tobacco on Black Americans.

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5. Id.


34 Pub. L. 116-139.


46 “Adults Who Report Smoking by Race/Ethnicity,” Kaiser Family Foundation (2018), https://www.kff.org/other/state-indicator/smoking-adults-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D.


80 Id.


85 Id.

86 Id.

87 Id.


90 Id.

91 Id.


Id.


See Lisa Rapaport, Nonwhite patients get less pain relief in U.S. emergency rooms, Reuters (July 2, 2019), https://www.reuters.com/article/us-health-analgesia-race/nonwhite-patients-get-less-pain-relief-in-u-s-emergency-rooms-idUSKCN1TX2IJ; Paulyne Lee et al., Racial and ethnic disparities in the management of acute pain in U.S


115 Pooja A. Lagisetty et al., Buprenorphine Treatment Divide by Race/Ethnicity and Payment, 76(9) JAMA Psychiatry 979-981 (May 9, 2019), https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2732871.


120 Id.


152 Travis A. Hoppe et al., Topic choice contributes to the lower rate of NIH awards to African-American/black scientists, Science Advances (Oct. 9, 2019), https://advances.sciencemag.org/content/5/10/eaaw7238.


154 Faheem Farooq et al., Comparison of US Federal and Foundation Funding of Research for Sickle Cell Diseases with Cystic Fibrosis and Factors Associated with Research Productivity, 3(3) JAMA Network Open (March 27, 2020), https://jamanetwork.com/journals/jamanetworkopen/fullarticle/276306

155 Id.

156 Travis A. Hoppe et al., Topic choice contributes to the lower rate of NIH awards to African-American/black scientists, Science Advances (Oct. 9, 2019), https://advances.sciencemag.org/content/5/10/eaaw7238.


159 Id. at Ch. 5.

160 Id. at 65.

161 Id. at Ch. 9.

162 Id. at Ch. 6


169 Elizabeth Cohen and Dana Vigue, Covid-19 vaccine trials have been slow to recruit Black and Latino people -- and that could delay a vaccine, CNN (Aug. 16, 2020); https://www.cnn.com/2020/08/16/health/covid-19-vaccine-trial-black-minority-recruitment/index.html.


179 Id.


184 See David Barton Smith, Eliminating Disparities In Treatment And The Struggle To End Segregation, The Commonwealth Fund (Aug. 2005),


“Employer-Sponsored Coverage Rates for the Nonelderly by Race/Ethnicity,” Kaiser Family Foundation (2018), https://www.kff.org/other/state-indicator/rate-by-raceethnicity-2/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22Location%22%7D.


