Health Equity Guidelines for the 118ᵗʰ Congress and Biden Administration

An Open Letter

Dear 118th Congress and the Biden Administration,

We, the undersigned organizations, that represent diverse communities across the country, are committed to improving healthcare for underserved patients. Our communities are too often excluded and underrepresented in the policymaking process. This lack of inclusion reflects a distressing reality about the current state of our nation's healthcare system: diverse communities experience higher rates of poor health and are less likely to receive quality care.

As policymakers, your leadership is crucial to ensuring our communities can successfully address pervasive health disparities. Working alongside community-based organizations and public health advocates, we can develop solutions to measurably improve health equity and address social determinants of health. We urge your consideration of the following information and guidelines as you and your colleagues pursue future healthcare initiatives. The priorities we outline below enjoy broad support and are directly responsive to the issues that affect diverse communities in America today.

Confront the Rising Cost of Healthcare

The rising cost of healthcare in the United States translates into higher insurance costs, under-resourced hospitals, and a lack of quality healthcare access for marginalized communities. To truly lower costs and achieve better outcomes for every patient, all healthcare stakeholders must be held accountable for the rising cost of care. Predatory practices such as surprise and unfair medical bills, exploitation of federal program loopholes, and rampant profiteering by middlemen in the drug supply chain must end. Rising out-of-pocket costs and the lack of competition in healthcare markets—particularly the growing concentration between insurers, hospitals, and Pharmacy Benefit Managers (PBMs)—are also distressing trends that must be addressed.[1] Increased government oversight and fundamental reforms are necessary to curb existing waste, fraud, and abuse and lower costs for every patient.

Improve Access to Quality Healthcare Among Vulnerable Populations

Despite historic gains in recent years, more needs to be done to reduce the coverage gap among diverse communities and ensure access to treatments and services that meet the needs of all patients. The end of the nation's public health emergency is fostering uncertainty across the country as millions of Americans are poised to lose their existing coverage.[2] In many cases, patients will be left uninsured or compelled to enroll in private coverage that charges higher premiums and out-of-pocket costs. According to a recent report from the Kaiser Family Foundation, most uninsured people are nonelderly adults, in low-income working families, and six in ten are people of color.[3] When uninsured populations decide to seek care, they often face unaffordable medical bills that help to exacerbate poverty and income inequality. To improve coverage among vulnerable populations, we must seek to better inform our communities of the real cost of insurance plans through easily accessible out-of-pocket cost information in their primary language before enrollment.

Support Breakthrough Medical Technologies and Innovation

The COVID-19 pandemic has served as a catalyst for innovation in healthcare. The race to rapidly develop preventative and therapeutic interventions to combat the virus as well as the widespread adoption of super-regional health systems vis-à-vis broadband telehealth and virtual care exemplify this acceleration of innovation. While the pandemic is coming to an end, the work of public and private stakeholders to advance our healthcare system is far from over. Smart innovation policies that strengthen our intellectual property system and promote equitable broadband access are vital to combating future health crises. The Biden Administration and Congress must foster an innovation ecosystem capable of combating pervasive challenges to health and well-being. There is a great need for research and development of treatments directed towards sickle cell disease, cancer, Alzheimer's, asthma, and other diseases greatly impacting diverse communities. Infrastructure must be put in place to ensure all Americans have access to the latest advancements in healthcare technology. We urge lawmakers and private industry actors to remain committed in their pursuit of new treatments as more innovation and further medical breakthroughs are needed.

Reduce Health Disparities

Health disparities are a pervasive problem for ethnic communities in the United States who consistently suffer from higher mortality rates, chronic conditions, and infectious diseases.[4] Communities of color are also less likely to have access to mental health services, less likely to utilize community mental health services, and more likely to depend on inpatient hospitalization and emergency departments for primary mental healthcare.[5,6] Acknowledging these staggering disparities for racial/ethnic, gender, and sexual minorities and empowering greater participation in the stakeholder process through civic engagement and education is the first step toward achieving health equity. Elevating culturally competent care, preventing obesity, reducing needless pregnancy-related deaths, and keeping families together are also universally beneficial objectives. In addition, greater attention must be given to social determinants of health (SDOH) including the deep inequities in education, housing, and financial insecurity. Historic underinvestment and a lack of coordination have hindered real progress in SDOH areas that impact opportunity and health. For example, there is limited understanding about how SDOH affects high risk diseases among Asian Americans—one of the fastest growing immigrant populations in the U.S.[7] Prioritizing SDOH as a national imperative means a government-wide commitment to enhanced coordination and standardization of policies and practices as well as increased funding for research and program interventions to address SDOH.

Modernize Value-Based Treatment and Clinical Care

When it comes to healthcare, one size does not fit all. Lawmakers and industry stakeholders must provide meaningful tools and personalized services to meet the needs of underserved populations. Putting our patients and communities first depends on steering the healthcare industry towards consumer-focused and consumer-driven solutions, including the utilization of value-based contracts to improve patient access and reduce out-of-pocket costs. However, discriminatory assessments from outside entities, or other countries, that put arbitrary numbers

on patient lives should not be used. Our infrastructure for providing home and community-based services (HCBS) can also be improved to better meet the needs of disadvantaged communities. Currently, too many low-income older adults and people with disabilities are forced into institutional settings to receive the care they need, particularly women, communities of color, and individuals with cognitive disorders. Conventional metrics to measure value to patients, such as the Quality-Adjusted Life Year (QALY) metric, should also be revisited to ensure these tools are not contributing to increased racial disparities.

Address the Underrepresentation of Diverse Communities in Clinical Trials and Data Collection

The timely collection, analysis, and distribution of disaggregated data by public health agencies is paramount to addressing the unique health issues faced by underserved communities. Having rich data on diverse communities and strong representation in medical research and clinical trials ensures that the treatments developed meet the various needs of patients. Yet, communities of color are traditionally disproportionately underrepresented within medical research, and data collected on these populations is limited.[8] Disaggregated data broken down by race, ethnicity, primary language, sex (including sexual orientation and gender identity), disability status, age, and other sociodemographic characteristics is critical for understanding health challenges faced by underserved communities. Unfortunately, such data is often incomplete with many instances of chronic undercounting. Also in clinical trials, underrepresentation is even true among diseases and illnesses that disproportionately impact people of color, including diabetes, heart disease, Alzheimer's disease, and cancer.[9] Such gaps endanger potentially significant public health advancements and undermine the value of clinical trials. To address these issues, we must work with trusted messengers to increase awareness and develop educational programs that help to encourage engagement from communities of color. Physicians must also have access to trained medical interpreters to ensure diverse populations receive the highest quality of care in the language that is most comfortable to them.

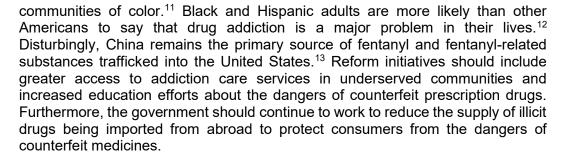## Promote a Diverse Healthcare Workforce

Increasing the diversity of America's healthcare workforce is essential to gaining diverse communities' trust and ensuring all segments of our society receive quality care. While there is some progress, the current number of medical school matriculants does not mirror the population of black and Hispanic persons in the US.[10] A culturally competent and diverse workforce leads to improved access to high-quality care for all Americans. Pro-diversity policies, such as establishing nationwide recruitment and support for pipeline training programs and STEM diversity initiatives to remove socioeconomic barriers for minorities and people with disabilities seeking careers in healthcare, are essential to building a healthcare workforce that draws on the strengths of all segments of our society.

Improve Access to Addiction Care and Safe Medicines

Throughout our communities, we have witnessed a growing number of overdoses and deaths and the use of fentanyl-laced counterfeit medicines. Monthly drug overdose deaths rose during the pandemic and are disproportionately impacting

communities of color.[11] Black and Hispanic adults are more likely than other Americans to say that drug addiction is a major problem in their lives.[12] Disturbingly, China remains the primary source of fentanyl and fentanyl-related substances trafficked into the United States.[13] Reform initiatives should include greater access to addiction care services in underserved communities and increased education efforts about the dangers of counterfeit prescription drugs. Furthermore, the government should continue to work to reduce the supply of illicit drugs being imported from abroad to protect consumers from the dangers of counterfeit medicines.

Sincerely,

Health Equity Collaborative

ALLvanza

American Muslim Health Professionals (AMHP)

ASPIRA Association, Inc.

Association of Black Cardiologists, Inc. (ABC)

Black, Gifted & Whole Foundation

Black Women's Health Imperative

Center for Black Equity

From the Bottom Up Foundation

GLMA: Health Professionals Advancing LGBTQ+ Equality

HEAL Collaborative

HealthHIV

Hispanic Federation

Hispanic Health Network

HTTP/Hispanic Technology & Telecommunications Partnership

Latino Coalition

Latino Commission on AIDS

LatinoJustice PRLDEF

League of United Latin American Citizens (LULAC)

MANA, A National Latina Organization

Mental Health America (MHA)

National Alliance for Caregiving (NAC)

National Association of Councils on Development Disabilities (NACDD)

National Association of Hispanic Federal Executives (NAHFE)

National Black Nurses Association (NBNA)

National Caucus and Center on Black Aging, Inc. (NCBA)

National Coalition for LGBTQ Health

National Consumers League (NCL)

National Council on Independent Living (NCIL)

National Disability Rights Network (NDRN)

National Grange

National Hispanic Caucus of State Legislators (NHCSL)

National Hispanic Medical Association (NHMA)

National LGBT Chamber of Commerce (NGLCC)

Partnership for Innovation and Empowerment

SER: Jobs for Progress National, Inc.

South Asian Public Health Association (SAPHA)

Southern Black Policy & Advocacy Network

Southern Christian Leadership-Global Policy Initiative (SCL-GPI)

The Balm in Gilead, Inc.

The Hispanic Institute

The National Partnership for Healthcare and Hospice Innovation (NPHI)

The National Puerto Rican Chamber of Commerce

U.S. Pan Asian American Chamber of Commerce (USPAACC)

United Spinal Association

United States Hispanic Chamber of Commerce (USHCC)

United States Hispanic Leadership Institute (USHLI)

UsAgainst Alzheimer's

Women Impacting Public Policy (WIPP)

[1] https://www.ama-assn.org/system/files/prp-pbm-shares-hhi.pdf

[2] https://www.urban.org/sites/default/files/2022-12/The%20Impact%20of%20the%20COVID-19%20Public%20Health%20Emergency%20Expiration%20on%20All%20Types%20of%20Health%20Coverage_0.pdf

[3] https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/

[4] https://www.americanprogress.org/article/health-disparities-race-ethnicity/

[5] https://link.springer.com/article/10.1007/s40615-022-01284-9

[6] https://www.frontiersin.org/articles/10.3389/fpubh.2021.641605/full

[7] https://pubmed.ncbi.nlm.nih.gov/35216607/

[8] https://www.fda.gov/consumers/minority-health-and-health-equity-resources/clinical-trial-diversity

[9] https://www.sciencedirect.com/science/article/pii/S0146280618301889

[10] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7387183/

[11] https://nida.nih.gov/research-topics/trends-statistics/overdose-death-rates

[12] https://www.pewresearch.org/fact-tank/2022/01/19/recent-surge-in-u-s-drug-overdose-deaths-has-hit-black-men-the-hardest/

[13] https://www.dea.gov/sites/default/files/2020-03/DEA_GOV_DIR-008-20%20Fentanyl%20Flow%20in%20the%20United%20States_0.pdf