

White Paper

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The Health Equity Collaborative

healthequitycollaborative.org

Healthcare Reform Proposals to Support Diverse Communities



HEALTH EQUITY COLLABORATIVE

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About the Author

The Health Equity Collaborative (HEC) is a diverse community comprised of dozens of national, public health, patient advocacy, and multicultural organizations that are committed to supporting equity and combating disparities experienced by underserved populations. HEC is a project of MANA Action, a 501c4 not-for-profit organization.

Introduction

Disparities in healthcare access, quality, cost, and outcomes in the United States continue to pose a significant challenge for policymakers and industry leaders. These disparities include systematic differences in health and healthcare between different populations or groups, often related to socioeconomic status, race, ethnicity, gender, sexuality, age, geographic location, or other social factors. Healthcare inequities are largely rooted in social determinants of health, such as poverty, discrimination, unequal access to education, and limited resources. They are also reinforced by both public and private sector policies that fail to account for diverse needs within the U.S. population.

Healthcare inequities manifest in various ways, including in unequal access to care, lower quality of care, disparities in outcomes, weaker patient-provider relationships, limited healthcare literacy and education, and insufficient representation of diverse populations in both the healthcare profession and in clinical medical trials. Disparities also exist in treatment options, diagnostic accuracy, prescribing of medication, and the provision of preventive services.

As a result of these disparities, we observe higher rates of chronic diseases, shorter life expectancy, and higher mortality rates among marginalized or underserved populations. Moreover, unequal power dynamics, implicit biases, and cultural insensitivity can negatively impact the patient-provider relationship, leading to disparities in communication, trust, and patient satisfaction. These factors may contribute to differential treatment recommendations and negative patient experiences within the healthcare system.

This paper summarizes several causes and manifestations of healthcare inequity. It then outlines policy options to better meet the needs of diverse communities, particularly through addressing rising healthcare costs, improving access, increasing representation, and supporting innovation that reflects and benefits diverse populations.

Healthcare Disparities and Challenges Facing Diverse Populations



OVERVIEW

Many individuals and communities in the U.S. face barriers to accessing healthcare services, insurance, and providers. Many also lack means of transportation or face financial constraints that force choices between healthcare and other necessities for themselves and their families. These barriers often lead to delayed or inadequate care, or no care at all, resulting in poorer health outcomes.

Lack of representation among healthcare professionals and in clinical trials for cutting-edge treatments further contribute to the growing inequality among socioeconomic groups. In addition to these factors, some communities in the U.S. are more likely to work in jobs that put their health at risk. For example, Pew found that 53% of Hispanics say that the prevalence of jobs with inherent health risks is a major reason for health disparities in their communities.¹

Ultimately, healthcare inequities carry enormous costs not only for individuals who are part of underserved communities, but for the entire U.S. healthcare system and population.

RISING COSTS

There are many structural causes to high healthcare costs in the U.S.

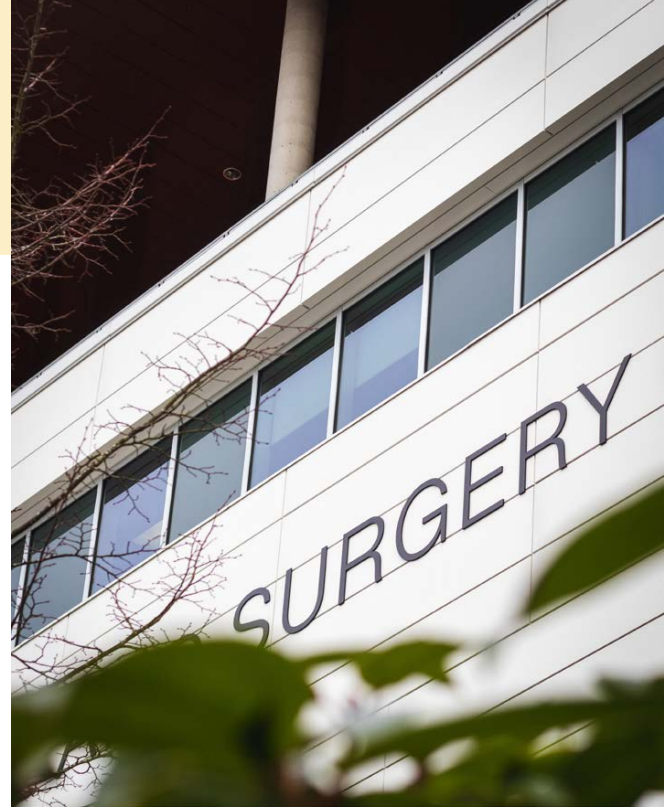
The U.S. healthcare system does not operate like a typical market. Pricing is often impossible to match for demand. For example, almost no one in America could afford the ‘real’ price of a new drug that treats a rare disease. In addition, hospitals prioritize surgeries and other procedures that maximize their revenues.²

The proliferation of rules, regulations, and non-overlapping systems has made competition and consumer choice rare or insufficient across the U.S. healthcare system. Laws governing the creation of new facilities and the production of medical supplies also stifle the innovation and disruption that could benefit the sector.³

Further, administrative costs in healthcare far outpace every other sector except government. Numerous factors drive these costs, including a lack of authoritative enrollment standards; the wide variety of available insurance options; government involvement in providing healthcare to some groups; the mixture of co-payments, deductibles, out-of-pocket costs, and private adjudicators; and adjusters governing varying tiers of insurance coverage.⁴

Finally, Medicaid cost limits result in healthcare costs being passed on to private insurers and individuals through processes that are not transparent.

Beyond these structural cost drivers of healthcare, below are certain sectors of the healthcare system that have an outsized impact on costs.



Hospitals

In the years following the enactment of the Affordable Care Act (ACA), the hospital sector began reporting profit margins in excess of 8%, far exceeding other healthcare sectors.⁵ Hospitals account for one-third of all healthcare spending, compared to 3% for medical equipment and 9% for pharmaceuticals. Hospital profits hold the potential to bring major investment to underserved communities, yet only a marginal portion of this investment goes to hospitals in neighborhoods representing underserved populations. This leads to significant disparities in care and can even create healthcare deserts in neighborhoods that lose facilities due to a lack of capital investment.⁶



Public Health Initiative Failures

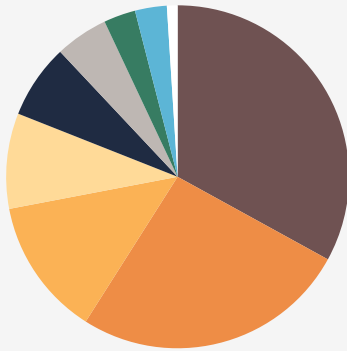
While public health initiatives hold great potential for long-term cost saving, they are too often used as public relations campaigns for politicians and corporations. As a result, they have failed to achieve their stated (and worthy) goals, such as education and prevention. According to a research project funded by the Robert Wood Johnson Foundation, public health initiatives have failed in specifically demonstrating a positive cost-benefit ratio when it comes to the actual health of the public. To be effective and

reduce rather than increase healthcare costs, public health initiatives – often aimed at helping underserved communities – should be evaluated based on their public benefit.⁷

Insurance

Today's insurance system leaves millions uninsured, with half of the uninsured being people of color.⁸ Some insurers even use gender-correlated factors when calculating premium costs. These are unjust and unacceptable realities that should be remedied.

Having millions of Americans without health insurance raises healthcare costs for society, including through taxpayer-funded emergency room visits, preventable diseases and conditions, lost productivity, and more.



NATIONAL HEALTH CARE EXPENDITURES BY TYPE

■ Hospital Care	33%	■ Investment	5%
■ Professional Services	26%	■ Medical Equipment and Products	3%
■ Nursing and Home Health	13%	■ Government Public Health Activities	3%
■ Prescription Drugs	9%	□ Government Administration	1%
■ Net Cost of Insurance	7%		

Source: 2018 data. Nunn, Ryan, et al. "A Dozen Facts about the Economics of the US Health-Care System." Brookings, Brookings Institute, 6 Apr. 2020.

Pharmacy Benefit Managers

While prominent in public and political debate, prescription drugs, in fact, comprise less than 10% of healthcare costs in the U.S.⁹ One reason for this, beyond political rhetoric, is that Americans have a more direct interaction with medicines and their costs than they do with many other healthcare system components. This relationship, however, does not reveal the billions of dollars invested in research and development to bring innovative medicines to market for their health benefits.

Still, the pain of high prescription drug prices is real and particularly acute for people living off a low or fixed income. Yet the pharmacy benefit manager (PBM) system created to ease the cost of prescription drugs for these Americans has strayed far from its intended goal.

PBMs work on behalf of insurance companies, negotiating large rebates from pharmaceutical manufacturers. These rebates, however, are not shared directly with patients, and these middlemen collect as much as half the spending on brand name medicines. The negotiated discounts, therefore, do not help vulnerable populations because they are not applied directly to consumers' out of pocket costs. In addition, a perverse incentive structure links higher priced drugs to larger rebates for the PBMs. This is particularly troubling since a large portion of PBM business is conducted with the federal 340B program, which was created to help hospitals that treat a disproportionately elderly or poor population.¹⁰

In May, Kaiser Family Foundation Health News reported:

*Drug manufacturers claim that exorbitant PBM demands for rebates force them to set high list prices to earn a profit. Independent pharmacists say PBMs are driving them out of business. Physicians blame them for unpredictable, clinically invalid prescribing decisions. And patients complain that PBMs' choices drain their pocketbooks.*¹¹

Even as prescription drug prices have risen, drawing massive attention and pharmaceutical company criticism, PBMs have remained largely unregulated. Savings from PBM drug price negotiations have skyrocketed, with little benefit trickling down to the patients in need of relief. The lack of regulation, oversight, and accountability in the current PBM system, therefore, has resulted in billions of dollars' worth of benefits not reaching the intended beneficiaries: patients.¹²



Medical Equipment

While spending on medical equipment currently accounts for just 6% of healthcare spending, its growth rate is double that of pharmaceuticals.¹³ The National Center for Biotechnology Medicine has warned the lack of competitive bidding in Medicare for medical equipment has contributed to higher healthcare costs.¹⁴ The Centers for Medicare and Medicaid reported retail spending on durable medical equipment increased by nearly 22% in 2021.¹⁵ Some medical equipment is often marked up 200%, 300% or more. Vulnerable Americans with chronic disease or long-term disability are at greatest risk from this trend, which directly threatens their ability to meet their basic daily needs.¹⁶

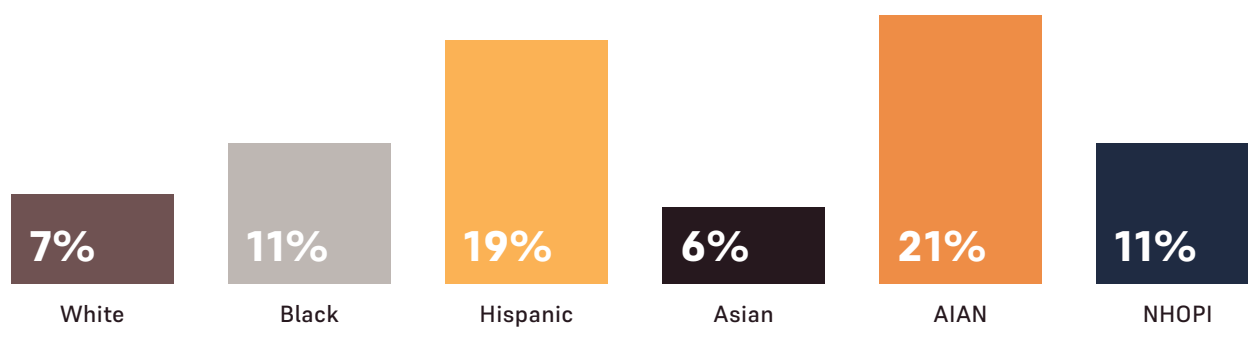
OBSTACLES TO ACCESS

More than a decade since the enactment of the Affordable Care Act, health insurance disparities persist, especially along racial lines.

According to a 2022 Kaiser Family Foundation (KFF) report, “Nonelderly American Indian and Alaska Native (AIAN) and Hispanic people had the highest uninsured rates at 21.2% and 19.0%, respectively, as of 2021. Uninsured rates for nonelderly Native Hawaiian and Other Pacific Islander (NHOPI) and Black people (10.8% and 10.9%, respectively) also were higher than the rate for their White counterparts (7.2%).”¹⁷

NONELDERLY UNINSURED RATE BY RACE AND ETHNICITY, 2021

NOTE: Includes individuals ages 0 to 64. Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic. AIAN refers to American Indian or Alaska Native. NHOPI refers to Native Hawaiian or Other Pacific Islander. Totals may not sum to 100 percent due to rounding. SOURCE: KFF analysis of 2021 American Community Survey, 1-Year Estimates.

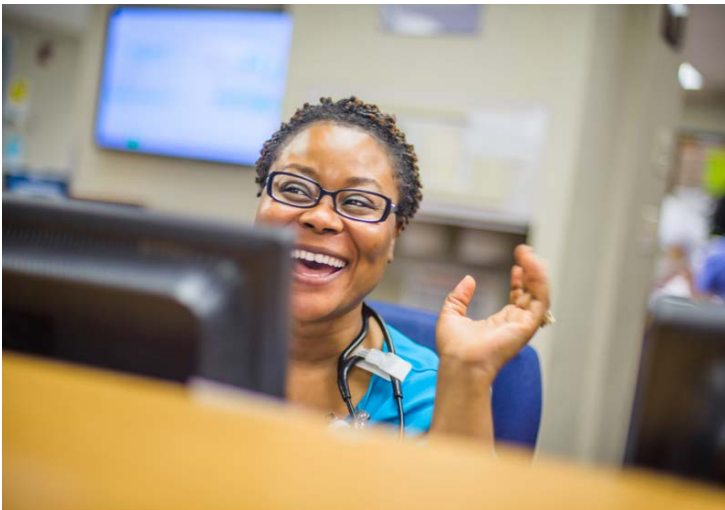


Uninsured rates for these groups dropped considerably from 2013 to 2016 as the ACA was implemented and many states expanded their Medicaid program eligibility. Rates since 2016 have generally remained stagnant, and with the recent end of the federal COVID-19 Public Health Emergency (PHE) declaration and the decision to scale back Medicaid eligibility, the number of uninsured may rise. Prior to the PHE declaration, coverage gains from the ACA had been slowly reversing for three consecutive years.¹⁸

Coverage disparities vary by state and region, determined in significant part by whether a state expanded its Medicaid coverage under the ACA. As noted in the KFF report, many southern states with large populations of Black people have not expanded Medicaid. As a result, many Black people do not qualify for Medicaid but also do not earn enough to qualify for premium subsidies for buying insurance through the ACA Marketplace. KFF estimates that nationwide, 2.2 million Americans found themselves in this coverage gap.

Citizenship status is also closely related to insurance access. According to Kaiser, 48% of uninsured Hispanic people in the U.S. were not citizens, as well as 40% of uninsured Asian people, and 35% of uninsured NHOPI people. Additionally, significant percentages of those uninsured populations are naturalized, not native, U.S. citizens.¹⁹

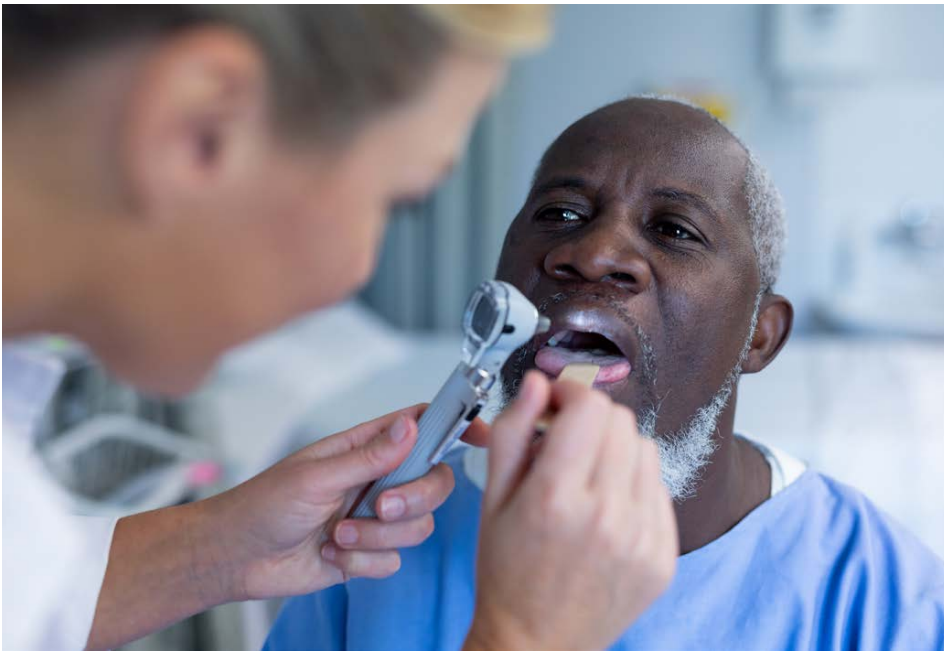
LACK OF REPRESENTATION



Despite efforts to increase diversity in the healthcare profession, Black, Latino, and Native American people remain severely underrepresented in healthcare professions ranging from doctors and nurses to pharmacists and therapists. Moreover, limited health literacy and educational opportunities among underserved communities continue to create barriers to understanding health information, making informed decisions, and navigating the healthcare system.

These disparities perpetuate health inequities by affecting individuals' ability to take control of their health and engage in preventive measures.

In addition to underrepresentation in the healthcare profession, the persistent lack of diversity of patients participating in clinical medical trials carries consequences not only for science but for ethics and society at large. Without a diverse participant pool, it is difficult to understand how different racial and ethnic, age, and gender groups will



respond to treatments. This limits the evidence-based guidance that healthcare providers may offer patients.²⁰

Further, because certain demographic groups may experience different responses to an experimental treatment, including side effects

and adverse interactions, lack of representation makes it difficult to identify potential risks or benefits specific to different subpopulations. Excluding diverse populations from trials impedes scientific understanding by limiting researchers' ability to fully understand diseases and treatments—a barrier that must be overcome to widely practice precision medicine.²¹

In recent years, however, there has been significant progress toward including diverse populations in clinical trials. In 2020, the FDA finalized guidance on enhancing the diversity of clinical trial populations, and similar work has been completed by a working group formed by the Multi-Regional Clinical Trials (MRCT) Center of Brigham and Women's Hospital and Harvard. In 2021, Pharmaceutical Research and Manufacturers of America (PhRMA) and its member companies established industrywide principles on clinical trial diversity. The National Academy of Sciences and the American Medical Association, too, have committed to and acted on increasing diversity in clinical trials.²²

Research practices now include considering the incidence, prevalence, and severity of the condition or disease in various populations, broadening eligibility criteria for a clinical trials, and selecting sites for trials that result in a more diverse group of participants. As Deloitte noted, PhRMA's more "patient-centric approaches can help improve the availability and quality of data that is representative of the population(s) most likely to use the drug. Study design, target enrollment population, endpoint selection, and recruitment and retention plans should be scientifically driven and responsive to the patient perspective."²³

Policy Options

ADDRESSING RISING COSTS

Pharmacy Benefit Manager Reform

For far too long, PBM middlemen have operated in a cloud of obscurity that allows them to enrich themselves by receiving enormous discounts on brand prescription drugs and refusing to pass their savings on to end consumers. While technically legal, this system harms those who should be its greatest beneficiaries—underserved communities and people on fixed incomes, more generally. Moreover, as PBM business continues to expand in areas like the federal 340B program for the poor and elderly, and into mail-order pharmacies, PBM transparency, oversight, and reform is a must if equity is to be achieved in the healthcare system.

Reform is on the horizon: the Federal Trade Commission is now looking into anti-competitive PBM practices (three companies control about 80% of the PBM market).²⁴ Congress, too, appears poised to finally create transparency and accountability for PBMs. The Senate Commerce Committee advanced five PBM reform bills in February. In May, the Senate Health, Education, Labor and Pensions passed four bills of its own. For instance, the Pharmacy Benefit Manager Reform Act (S. 1339), led by Chairman Sanders (I-VT) and Ranking Member Cassidy (R-LA), bans unjust PBM pricing schemes and requires that drug rebates be passed through to plan sponsors.²⁵

While The Pharmacy Benefit Manager Reform Act would bring some transparency and accountability, it does not ensure rebates are passed all the way through to patients. Instead, it requires rebates to pass through to employers and other prescription drug plan sponsors. The current legislation also does not end incentives favoring higher priced drugs. Meaningful PBM reform would bring real transparency to an opaque system, and ensure patients are the primary beneficiaries of negotiated drug prices.

“OUR COUNTRY CANNOT ALLOW GREEDY MIDDLEMEN TO SIPHON AWAY FINANCIAL BENEFITS INTENDED TO HELP UNDERSERVED POPULATIONS WITH THEIR HEALTHCARE COSTS. THOSE BENEFITS MUST REACH THE PATIENTS WHO NEED THEM.

Kevin Kimble, Esq., Southern Christian Leadership Global Policy Initiative (SCL-GPI)

Insurance

Two of the surest ways to contain or drive down health insurance costs are increasing competition and ensuring price transparency. The Federal Trade Commission has noted that “competition in healthcare markets benefits consumers because it helps contain costs, improve quality, and encourage innovation.”²⁶

Competition in Medicare Advantage is a case in point. According to America’s Health Insurance Plans (AHIP), Medicare Advantage Plans “provide far-reaching, long-term advantages, driven by robust competition among health insurance providers in the Medicare Advantage market. The result is lower costs, more choices, and better access to benefits for millions of seniors and people with disabilities.”²⁷

While competition in Medicare Advantage is successfully lowering costs and increasing quality, this lesson should be applied to the broader insurance market where it would lower average prices and reduce the burden on low-income Americans and disadvantaged communities.



Hospitals

One of the most significant drivers of healthcare cost increases is lack of hospital price transparency. A 2023 RAND Corporation study found that if “employers have access to the information on prices needed to be better-informed customers, they can do a better job shopping for healthcare on behalf of their employees.”²⁸

Current federal law requires hospitals to make publicly available their standard prices and negotiated discount rates for common health services. This law, which went into effect in 2021, is intended to encourage consumers to compare prices and to promote competition. And while hospitals may be in compliance with the law, many have been slow to comply and shortcomings remain due to the complexity of the data hospitals are providing, making it harder for consumers to shop and use competition to lower prices.

According to the Kaiser Family Foundation (KFF), “The complexity of using the data is largely due to a lack of standardization and specification in the reporting requirements.” The Foundation recommends making data both clearer and more standardized. In short, hospital transparency data must be more consistent and understandable for consumers to fully benefit from it.²⁹

INCREASING ACCESS

340B Reform

The federal 340B Drug Pricing Program was created to help eligible healthcare organizations, known as “covered entities,” access discounted prescription drugs to serve vulnerable and underserved populations. While well-intentioned, numerous reforms are needed to address design flaws in the program that have allowed it to veer from its mission and harm vulnerable populations.³⁰

First, covered entities now include organizations not directly related to serving underserved populations. New hospital eligibility criteria should be added to existing requirements to ensure the program is supporting true safety-net hospitals, including quantitative metrics that appropriately identify hospitals treating a disproportionately large share of low-income patients on an outpatient basis. Similarly, the current definition of a “patient” is overly broad and should be updated to ensure 340B program benefits remain focused on vulnerable populations.³¹

Second, the program is unclear in its guidance and reporting methods and uses weak enforcement mechanisms. Additional accountability is needed to ensure eligible hospitals are supporting underserved communities as true safety-net providers. 340B hospitals should have policies that increase access to affordable health services, and predatory practices should be clearly prohibited with rules that are enforced.

Third, contract pharmacies in the program should be in close proximity to the covered entities they serve. They should also be required to provide the same patient affordability assistance for 340B prescriptions as they do for other prescriptions.

Fourth, the savings generated from the 340B program should not be diverted for purposes other than the covered entity’s safety-net mission. Protections are needed to prevent for profit companies, like pharmacy benefit managers, from siphoning off 340B savings intended to help patients with lower drug prices. The savings from discounted drugs must be passed on to patients.

Finally, there must be strict reporting requirements that covered entities provide the HHS with their full acquisition and reimbursement, as well as an accounting of money spent to reduce patients’ out-of-pocket drug costs.

**“ WE MUST BRING TRANSPARENCY
AND ACCOUNTABILITY TO
PROGRAMS THAT ARE FAILING
TO ACHIEVE THEIR MISSION OF
MAKING AFFORDABLE, QUALITY
HEALTHCARE ACCESSIBLE TO
DISADVANTAGED COMMUNITIES.**

Joel Berrocal, Executive Director, National Puerto Rican
Chamber of Commerce

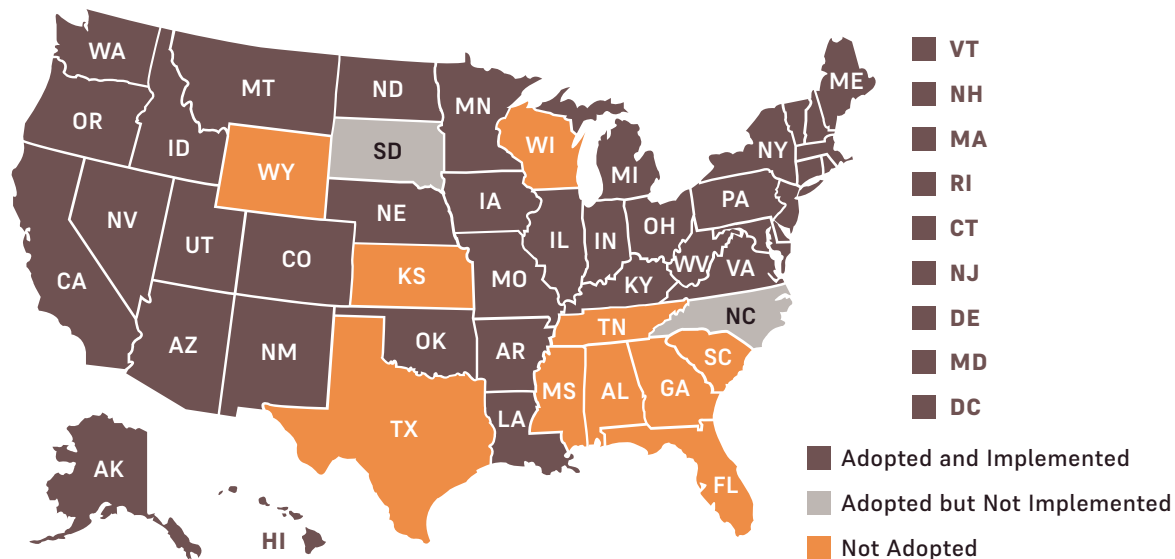


Expanding Medicaid

States that have not expanded Medicaid following the passage of the ACA have far higher uninsured rates for underserved populations than states that moved forward with expansion.

From a 2023 KFF report:

STATUS OF STATE ACTION ON THE MEDICAID EXPANSION DECISION



Although employer-sponsored and other private providers are primary sources of coverage across racial and ethnic groups, Medicaid helps to fill larger gaps in coverage for people of color, particularly children. Over time, gains in Medicaid coverage have helped reduce racial disparities in coverage, particularly following the expansion to low-income adults under the ACA.³²

Expanding Medicaid in the remaining 10 non-expansion states would tremendously increase health insurance coverage for people of color.

Many underserved communities will be negatively impacted by the unwinding of emergency, COVID-era rules maintaining coverage through continuous enrollment. It will widen health disparities as states conduct redeterminations for all Medicaid enrollees. According to KFF:

An estimated 17 million people could lose Medicaid coverage during the unwinding of this provision. Research shows that Hispanic and Black people are likely to be disproportionately impacted by this unwinding. The end of this provision may increase “churn,” the temporary loss of Medicaid coverage in which enrollees disenroll and then re-enroll within a short period of time. A recent analysis of churn rates among children found that while churn rates increased among children of all racial and ethnic groups following annual renewal, the increase was largest for Hispanic children, suggesting they face greater barriers to maintaining coverage.³³

To mitigate harm from the unwinding of continuous enrollment, states can improve outreach to Medicaid beneficiaries, simplify their renewal processes, and help individuals transition to other coverage. States can seek temporary waivers that help smooth the renewal process and minimize loss of Medicaid coverage caused only by procedural and bureaucratic inertia. States may also opt to provide continuous eligibility for certain populations.



“ WE NEED TO ADVOCATE FOR INNOVATIVE SOLUTIONS AT EVERY LEVEL OF THE HEALTHCARE SYSTEM TO CREATE A FUTURE WHERE LATINOS, AND OTHER UNDERSERVED COMMUNITIES, HAVE ACCESS TO THE CARE THEY NEED AND DESERVE.

Rosa Mendoza, Founder and CEO, ALLvanza



SUPPORTING INNOVATION

Healthcare innovations that improve prevention, diagnosis, and treatment of diseases often do not benefit everyone equally and so do not, by themselves, reduce health disparities. However, properly leveraged innovation holds the potential to be a force for equity. As University of Michigan professor of public policy and women and gender studies, Shobita Parthasarathy wrote in *Issues and Science and Technology*, “we need to think differently about expertise, innovation, and systems for ensuring access to crucial technologies.”³⁴

High prices and scarce supply are significant factors keeping the benefits of healthcare innovation out of reach for too many. Beyond these factors, however, many diseases disproportionately impact communities of color. These include some cancers, diabetes, and hepatitis, for example.

Research and development hold the potential to redress these inequities through innovations that cure or better treat such diseases. To start, policymakers, scientists, and engineers should understand the unique needs of the various underserved communities they seek to help. Experts should hold discussions with members of these communities to gain insight and knowledge that can guide policy and research.

Increasing the number of people from underrepresented communities on advisory committees that help steer research would be an innovative way to improve equity. This representation can be of great value to federal agencies such as the Patent and Trademark Office and the National Institutes of Health. As Parthasarathy wrote, “A more representative committee would provide the agency with a deeper understanding of the needs of the citizenry and specifically the health impacts of the patent system.”³⁵ Indeed, this method has proved successful before, in the case of women advocating for breast cancer research or people from Flint, Michigan playing an active role in addressing the community’s problem with water contamination.

Integrating social science, public health, and economics perspectives into the research process can help researchers better understand disease causation and better develop solutions that create more equitable health outcomes.

Requiring ‘equity impact assessments’ is yet another way to steer research and development toward more equitable innovation. This, too, would involve engaging people from marginalized communities to better understand both the effects of innovation and what the communities need. These assessments could fall under the purview of agency offices designated for community-focused innovation.



Finally, policymakers should be cognizant of monopoly-type situations that do not serve the public interest in promoting equity. While this would have implications for patents, incentive structures could be created in a fashion that drives research toward equitable results. One incentive, for example, could be financial rewards for innovators who develop cutting-edge technologies that enhance equity.

“ INNOVATION THAT ACCOUNTS FOR OUR DIVERSE POPULATIONS WILL HELP US BETTER UNDERSTAND DISEASES AND, THEREFORE, CREATE BETTER TREATMENTS AND CURES.

Brady Buckner, Co-founder and President, Partnership for Innovation and Empowerment

CREATING A REPRESENTATIVE WORKFORCE

People of color continue to be underrepresented in many healthcare professions. To redress this inequity, the human and societal benefits of diversity and inclusion must be recognized as central to creating a stronger, more efficient, and more equitable healthcare system.

To achieve a more diverse, inclusive healthcare workforce, people from disadvantaged communities should hold positions related to processing data on health disparities; engaging underserved communities and incorporating their wisdom; achieving equitable health outcomes; diversity training; assessing the effectiveness of diversity policies; and creating accountability to prevent circumventing health equity goals.










To grow and sustain a more diverse and inclusive healthcare workforce, changes in education and training are also required. Educational, mentoring, and networking opportunities must be more accessible to people from underrepresented communities. In some cases, there should be shortened training pathways, and technology should be leveraged to make distance learning possible. Assistance with childcare must be available, particularly for entry-level and middle-skill workers, and employers should be provided with support and education for recruiting diverse health workers.

The Urban Institute has made additional recommendations for the education system, which include funding mission-oriented programs in both the public and private sector; including for schools and students; developing guidance, including for K-12 schools in disadvantaged communities; and, creating diversity, equity, and inclusion mandates in medical and nursing education, as well as in healthcare settings.³⁶

REPRESENTATION IN RESEARCH

The enrollment of homogenous populations in clinical trials renders under-studied subpopulations unable to benefit from research. The clinical research community must commit itself to diversity and inclusion by implementing changes at the public policy, community, institutional, and interpersonal levels.

These changes include:

-  Creating standards and guidelines that guarantee research collects data on diverse populations that vary by race, ethnicity, and sexual orientation.
-  Considering the priorities of patients in underserved or underrepresented communities with relation to the health conditions being researched, when recruiting participants in clinical trials.
-  Conducting outreach to gain the trust of communities whose populations have been mistreated by research institutions in the past. This should include being transparent with data about any variations in treatment efficacy across diverse populations.
-  Ensuring the representation of diverse populations in research and development teams.
-  Increasing understanding of beliefs and attitudes about clinical research to better address barriers to diverse participation in clinical trials.
-  Ensuring heterogeneous population sample sizes are large enough for the research to be meaningful.
-  Focusing more research on diseases that disproportionately affect underserved communities, such as diabetes, heart disease, Alzheimer's disease, and cancer.



Diverse clinical trial participants can help increase the safety and effectiveness of new medicines, particularly racially and ethnically diverse communities. The outcomes of researching diverse populations can also enhance the understanding of certain diseases, which can improve prevention and treatment for all populations. Furthermore, clinical trial participants from underrepresented

communities can help improve public perceptions and build public confidence about drugs. Health equity may also be advanced by providing access to potentially lifesaving therapies and quality healthcare that might not otherwise be available.³⁷

The principles and goals laid out in recent years by the American Medical Association, PhRMA, the National Academy of Sciences, and others are leading to increased representation in research. They should be pursued rigorously to ensure better treatments and cures for diverse and vulnerable populations.

“ INCLUDING MORE DIVERSE POPULATIONS IN CLINICAL TRIALS WILL RESULT IN HIGHER QUALITY RESEARCH, BETTER TREATMENTS FOR UNDERREPRESENTED POPULATIONS AT HIGHER RISK OF CERTAIN DISEASES, AND MORE TRUST IN ONGOING RESEARCH.

Amy Hinojosa, President, MANA Action Fund

Conclusion

In its open letter to the Biden Administration and the 118th Congress, the Health Equity Collaborative (HEC) outlined priorities for advancing



health equity through confronting costs, improving access to quality care, supporting innovation, reducing disparities in health outcomes, prioritizing patient-driven outcomes, and addressing the lack of representation in both clinical trials and the healthcare workforce.³⁸ This paper provides more detail and options for policymakers and other healthcare leaders to consider and act on these priorities.

Policies should address areas of the healthcare system that are driving up costs for underserved communities, such as prescription drug middlemen, opaque hospital practices, and lack of transparency and competition in the insurance market. To increase access to healthcare, Medicaid should be expanded in non-expansion states, and there must be rigorous oversight of programs intended to benefit disadvantaged communities. Finally, diversity and inclusion must be high priorities both in cultivating the healthcare workforce and in the research and development of new drugs, with a strong focus on improving treatments for diseases that disproportionately affect people of color.

These policy changes will face resistance from entrenched interests that are benefiting from the status quo at the expense of disadvantaged communities. HEC stands ready to help any and all policymakers working to create a more equitable healthcare system. Their leadership is crucial to ensuring our communities can successfully address pervasive health disparities.

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