aft HEALTH CARE

A BIANNUAL JOURNAL ON HEALTH AND COMMUNITY WELL-BEING

RECOVERING TOGETHER BY:

+ INVESTING IN HEALTH EQUITY

+ EMBRACING CULTURAL HUMILITY

+ WELCOMING LGBTQ PATIENTS

+ CARING FOR FAMILIES

+ BUILDING A MORAL ECONOMY

Building Resilient Communities

AFT Settles Student Debt Lawsuit

Public Service Loan Forgiveness (PSLF) is a federal program that promised student loan borrowers that, if they went into public service and consistently paid their student loan bills, their remaining loans would be forgiven after 10 years. Until now, a shocking **98 percent** of all applications for loan forgiveness have been **rejected**—due to misleading information from servicers, forced loan consolidation into ineligible loan programs, and inane disqualifications.

The AFT has been working to address this student debt crisis for years. In a groundbreaking legal action, the AFT sued then-Secretary of Education Betsy DeVos for mismanaging the PSLF program. And on Oct. 12, **we reached a settlement**.

Millions of Americans will now have their loans completely forgiven, or they'll be properly enrolled in a forgiveness program crediting their years of past payments, putting them much closer to full forgiveness. The AFT's nurses and health professionals, educators, public employees, school staff and higher education staff will all benefit from these changes.

The AFT is committed to helping our members, our students and our communities thrive. With this settlement and our other student debt relief efforts, we have helped ensure borrowers will get the relief they were promised, demonstrating the strength of solidarity and the value of a union.

As your national union, we have partnered with a company called Summer to help borrowers navigate the complicated management of their student debt.

If you are a current AFT member who may be affected by this settlement:

The AFT will help you navigate the new PSLF process through our partner Summer. Working with Summer, AFT members already have saved $500 million on student loans. AFT members can sign up for a free account with Summer. Visit **meetsummer.org/pslf**.

If you are a borrower who works in public service and want help from a PSLF expert, **you can join the AFT as an associate member** now and access a Summer account for free. Visit aft.org/joinsummer.

Our Keys to Recovery

Accurate Information, Safe Staffing, and Higher Wages

RANDI WEINGARTEN, AFT PRESIDENT

FOR 22 MONTHS, nurses and other health professionals have been on the frontlines of COVID-19. They have been stretched dangerously thin as hospitals overflow. They've held phones at patients' bedsides as family members said their final goodbyes. They've cried in their cars after physically and emotionally draining shifts. They've pleaded with patients to educate themselves about this virus. Day after day, month after month, and now, year after year.

Throughout, the AFT has been fighting for these heroes and sheroes. Our union, which represents 200,000 nurses and health professionals, bought hundreds of thousands of respirators and other PPE for our locals facing the greatest shortages. We backed healthcare workers—like the members of the Backus Federation of Nurses in Norwich, Connecticut, and of St. Charles United in Bend, Oregon—when they went on strike. We advocated for free vaccines, funding for recovery that became the American Rescue Plan, and the transformational programs in President Biden's Build Back Better plan.

Vaccines are a real path to recovery. Unfortunately, misinformation, vaccine hesitancy, and the delta variant have slowed our progress. In recent months, a pandemic of the unvaccinated has once again overwhelmed hospitals in countless communities.

To emerge from this pandemic, we must address concerns about the vaccines, but at the same time we must solve the healthcare staffing crisis.

Health professionals must have the working conditions they deserve. In a recent poll of AFT healthcare members, fewer than one in three were satisfied with the conditions facing healthcare workers, and almost 60 percent said that conditions had worsened over the past five years. Inadequate staffing, stress, burnout, and turnover were severe before the pandemic; now they're at crisis levels. That is top of our agenda.

When it comes to safety, vaccination is the most effective tool to combat COVID-19. That's why I personally have been urging everyone who is eligible to get vaccinated and why the AFT's executive council unanimously approved a resolution to work with our employers on their vaccination policies and requirements, ensuring they're implemented fairly.

While voluntary vaccination is ideal, a mix of misinformation and understandable hesitancy has kept far too many people from the lifesaving jab. By listening to concerns, making personal connections, and answering questions, many health professionals have helped people choose to get vaccinated to keep themselves and their families safe—it's behind-the-scenes heroism.

In workplaces where vaccines are required, the AFT is engaged in impact bargaining. For example, an agreement negotiated by the Oregon Nurses Association required vaccination to be at convenient locations and provided time off for side effects; it also ensured that "personal, medical, and religious exemptions shall not be more restrictive than the influenza exemptions." Similarly, the University Health Professionals in Connecticut bargained for testing and on-site vaccinations during work hours, vaccine exemptions for medical or religious reasons, and testing and enhanced PPE for those granted exemptions.

We're fighting for everyone's safety and peace of mind.

In the October 7, 2021, episode of *Union Talk*, my new podcast,* I spoke with three nurses who have given their all throughout this pandemic. Their reality is a horror story: passing refrigerator trucks in the hospital parking lot because the morgue is full, never knowing when their shifts will end because of mandated overtime, and training traveling nurses who are being paid two, three, or more times as much as the dedicated regular staff.

For years, many hospital administrators have maximized profits while squeezing their staff. Nurses have sounded the alarm about unsafe staffing ratios putting patients at risk. The use of traveling nurses during the pandemic shows that money is available—and we're fighting for it to be invested in the professionals who live in and are committed to their communities.

We can solve the staffing crisis. As Joel Hernandez, RN, said on *Union Talk*, "Putting your employees before profit—it's as easy as that. Invest in your employees. Invest in their future. Invest in their happiness. And that will be paid back to your company two-, three-, fourfold."

Invest in their happiness. That's the standard our nurses and health professionals deserve. So we will fight for it—and we could start with a well-being index as part of hospital quality assurance measures.

Billboards that say thank you are not enough; our healthcare professionals must be respected, supported, and paid as the heroes and sheroes they are. ✚

> ## Inadequate staffing, stress, burnout, and turnover are at crisis levels.

*To listen, visit go.aft.org/j7v.

Moral Injury Among Nurses

Stories of Fractured Hearts and Wounded Souls

For far too long, the failings of our nation's healthcare system have fallen on nurses' shoulders—and hearts. The AFT launched a project to better understand, address, and prevent moral injury.

Have you experienced moral distress or moral injury?

The AFT is sponsoring research to gather nurses' experiences so we can identify and advocate for systemic solutions. Together, we can ensure that patients get the care they need and nurses have the fulfilling careers they deserve.

To learn about moral injury and self-care strategies, read the Spring 2021 issue of *AFT Health Care*: **aft.org/hc/spring2021**.

Visit **gwhwi.org/moralinjury.html** to share your story today!

Get Involved!

AFT Health Care is dedicated to ensuring that everyone has the freedom to thrive. It's about healthcare as a human right, systemic changes to put people above profits, and the social, economic, and environmental factors that affect individuals' and communities' health and well-being.

Apply to Become a Peer Reviewer

To publish the most relevant, trustworthy, and useful articles, we need to draw on your experience and expertise—so we're developing a peer review board. Please visit **aft.org/hc/peer-review** to learn more about becoming a reviewer and submit your application today.

Submit a Manuscript

We are interested in learning about your experiences during the pandemic and insights to prepare for future health crises. For details on submitting your manuscript on this and other topics, visit **aft.org/hc/article-submission-guidelines**.

BUILDING RESILIENT COMMUNITIES

When we learn from our history, invest in our communities, honor the expertise of those who are different from us, provide care with compassion, treat caregivers alongside children, and fight for equitable policies, we give everyone the opportunity to thrive.

What We're Reading: aft.org/hc/fall2021/wwr

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Investing In Our Future

Learning from Our History to Build a Healthier, More Equitable Society

By **Zinzi D. Bailey** and **J. Robin Moon**

Zinzi D. Bailey, ScD, is a social epidemiologist, faculty member at the University of Miami Miller School of Medicine, and associate director of the Robert Wood Johnson Foundation's Interdisciplinary Research Leaders. J. Robin Moon, DPH, MPH, MIA, is a social epidemiologist and faculty member at the City University of New York's Graduate School of Public Health and Health Policy, School of Medicine, and Institute for Health Equity.

Becoming a nurse was the obvious choice for Oliver Isleta.

The economy in the Philippines, his home country, was sluggish, and he wanted to make a better living abroad…. So after studying nursing in the city of Davao, he emigrated to the US in 2006 to take his board exams.

He lived first in Bridgeport, Connecticut, in a dormitory with other Filipino nurses, before moving to Fresno, into the granny flat behind his sister's house. Twelve-hour night shifts at Community Regional Medical Center left Isleta so tired he could barely walk on days off….

His salary flowed back overseas to relatives in Davao, where his wife and son Matthew counted down his once-a-year visits—timed to coincide with Matthew's April birthday—and hoped to … join him in California.

On September 1, [2020,] that future disappeared, when Isleta died from COVID-19 complications at Community Regional.[1]

Isleta's story is not unique. Filipino nurses specifically, and people of color generally, have been disproportionately put in harm's way throughout the pandemic—but also long before.

This article is about the weaknesses that structural racism creates in our nation, particularly in our approaches to healthcare and public health. If you're looking for recommendations for how to begin solving our longstanding challenges, jump to page 9. If you're interested in understanding the racial nature of our economy and of our disinvestment in public goods (including our political struggle to provide healthcare coverage for all), read on. The authors explore our society's dramatically different reactions to the crack (Black) versus opioid (white) epidemics and our colonialist journey to relying on nurses like Isleta. Along the way, they explain that both are rooted in racial capitalism, which systematically undervalues the labor, health, and lives of people of color, and they point to a path forward so that the cascading crises of the COVID-19 pandemic can be avoided in the future.

—EDITORS

The COVID-19 pandemic has had a disastrous impact on countries around the globe, and our collective responses have demonstrated—in glaring detail—the inequities embedded in our systems. Early in the pandemic, due to the country's slow, disjointed response, the United States quickly became the global epicenter of COVID-19. And yet what that meant for one's daily life varied enormously. From the teleworking professionals having their groceries delivered to the warehouse workers struggling to fulfill orders to the nurses caring for patients dying in hallways, the impact of this pandemic has been drastically different for each person depending on their place in our society. Two clear lessons quickly emerged: First, that COVID-19 cases and deaths disproportionately wreaked havoc in marginalized racial and ethnic groups. Second, that these inequities were, in large part, consequences of the structural racism embedded within the social fabric of the United States.

Despite progress made during the civil rights movements of the 20th century,[1] people of color remain disproportionately marginalized, overrepresented in segregated communities with crumbling infrastructure and severely limited opportunities. Historical and persistent disinvestment by public and private entities is so extensive that during the pandemic, basic public health recommendations of hand hygiene and self-quarantine have been challenging, if not impossible, to follow.[2] Substandard housing, crowded conditions,* and limited and/or unsafe water have hampered our collective ability to curb the spread of COVID-19.

Many of our most exposed and least visible "essential workers" are from these racially and economically segregated neighborhoods. Like most Americans, especially in states that rejected Medicaid expansion, these workers depend on anemic employer-sponsored health insurance[3] or must cut back on other basic needs to buy Affordable Care Act plans in order to get any level of routine care. And even if they have coverage, it is difficult to use because too often they do not have paid sick leave.[4] These same workers are far from grocery stores with affordable, fresh vegetables and close to polluters like bus depots and industrial zones; they also have higher rates of diabetes, heart disease, and asthma and are more likely to have healthcare services that are under-resourced and understaffed.[5]

These structural inequities do more than make us vulnerable as isolated communities—they make us vulnerable as a nation, reducing our ability to weather and recover from disasters. Our national housing crisis and food insecurity make us vulnerable to the next pandemic. Precarious, inequitable working condi-

tions and lack of paid sick leave make us vulnerable to the next pandemic. Our dependence on prisons and jails to deal with social and public health issues makes us vulnerable to the next pandemic. Our poorly coordinated, profit-focused health systems make us vulnerable to the next pandemic. Our immigration policies, systematic neglect of the elderly, and lack of early childcare and education make us vulnerable to the next pandemic. Deep structural inequities make us more vulnerable to the next pandemic.

It has taken the COVID-19 pandemic for some to see the inequities at work in our everyday lives, but this recognition now allows us the opportunity to course-correct. It's time to revive the idea of public goods and rekindle our commitment to our collective—not just our individual—well-being. Never in recent history has the need to dismantle the structural and institutional barriers to health equity been clearer.

Why Race Matters, Even When It Seems Irrelevant

The COVID-19 pandemic highlighted the many ways that health conditions do not operate on a level playing field. Virtually every health and social outcome is patterned by race and ethnicity. But why? As we will explain, at the heart of the many interwoven causes is the difficulty of dismantling racism within our society. Racism goes well beyond interpersonal discrimination; it "has a structural basis and is embedded in long-standing social policy."[6] When we describe racism as structural, we are referring to "the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice."[7] These systems prop up existing prejudices, values, and inequities in the distribution of resources. Structural racism itself can be hard to see, but its outcomes—like disparities in health insurance and access to preventive care—are not.

Many of us in the United States would like to put enslavement, Jim Crow, segregation, and racism behind us. Many people think that if we stopped talking about this history and approached each individual on their own merits, racial disparities would go away. We wish that were true. But our current conditions are the product of hundreds of years of cultural beliefs and policy decisions, and it will take a great deal of collective, concerted effort to make the United States the level playing field we aspire to be. Although we have made progress in recent decades, structural racism remains embedded within the social, economic, and political fabric of our country; it is most prominent in our low level of investment in public goods, like infrastructure, public health, and the social safety net (e.g., Medicaid, Medicare, Social Security, and affordable higher education).

Austerity regarding public goods began soon after the civil rights movement started opening our public

Deep structural inequities make us vulnerable to the next pandemic.

*For decades, government policies forced African Americans into substandard, crowded housing (while helping white Americans move into new, affordable homes). To learn about these policies and their ongoing impact, see "Suppressed History: The Intentional Segregation of America's Cities" in the Spring 2021 issue of *American Educator*: aft.org/ae/spring2021/rothstein.

goods to African Americans in the 1950s and 1960s. It has not only led to the country's overall structural vulnerability to major public health threats, like the COVID-19 pandemic—it has also been at the root of the struggles of the white working class.[8] The commitment to privatization and deregulation has been a serious problem since it began gaining momentum in the 1980s. Because of the legacies of enslavement and discriminatory immigration policies and then segregation of housing, employment, and services, people of color largely filled the lowest levels of our economic structure, and they felt the initial impact of these policies most strongly. In contrast, white working-class communities were mostly protected from feeling the impacts so long as the private sector was booming in white working-class communities. It took the Great Recession of 2008 and the COVID-19 pandemic to bring the full impacts of our highly unjust policies—in which the rich amass unimaginable wealth while governments are unable to pay for basic public goods like healthcare for all—to a broader swath of the middle and working classes.

Still, understanding the racial nature of seemingly nonracial policies can be very difficult. Here, we offer two case studies to examine what might appear to be race-neutral initiatives: our divergent reactions to the crack and opioid epidemics and our reliance on Filipino nurses. Along the way, we briefly explore the fading American dream and why America's version of *free market* capitalism is really *racial* capitalism.

Racialized Drug Policies

Modern drug policy goes back at least as far as the 1960s, when recreational drug use rose alongside countercultural "turn on, tune in, drop out" lifestyles and reports that 15 percent of American soldiers in Vietnam were addicted to heroin caused panic at home.[9] However, by the time President Richard Nixon declared a war on drugs in 1971, the dominant narrative in our society portrayed drug use as a criminal pathology inherent to urban, low-income Black and Latinx communities, one that could only be eradicated with aggressive

> **In 2003, more than 66% of crack users were white or Latinx, but 81% of defendants sentenced in federal court were Black.**

policing and harsh prison sentences. That narrative is well known. But not so well known is the political motivation for it: In a 1994 interview, John Ehrlichman, who had served as a domestic policy adviser to Nixon, said,

The Nixon campaign in 1968, and the Nixon White House after that, had two enemies: the antiwar left and [B]lack people.... We knew we couldn't make it illegal to be either against the war or [B]lack, but by getting the public to associate the hippies with marijuana and [B]lacks with heroin, and then criminalizing both heavily, we could disrupt those communities. We could arrest their leaders, raid their homes, break up their meetings, and vilify them night after night on the evening news. Did we know we were lying about the drugs? Of course we did.[10]

Given how successfully this narrative took root in the 1970s, it's no surprise that President Ronald Reagan doubled down on it in the 1980s as crack cocaine made its way onto urban streets. While crack was not relegated solely to urban Black and Latinx communities, the narrative around the crack epidemic was one of Black and Latinx men as gang members, fiends, and predators who deserved to be punished, and of Black and Latinx mothers as deviants whose pathological addictions condemned their children ("crack babies") to a life of permanent disadvantage. This new front in the war on drugs drove mass incarceration; it was concentrated in segregated Black and, to a lesser extent, Latinx communities.[11]

And yet, at the same time, Wall Street professionals and Hollywood stars were infamous for using powder cocaine—but rarely facing any consequences.[12] Biologically, there's little difference between cocaine and crack, which makes the racial nature of the so-called war on drugs especially clear. Under the Anti-Drug Abuse Act of 1986, the distribution of just 5 grams of crack carried a minimum federal prison sentence of five years, compared with 500 grams of powder cocaine for the same sentence.*

The only real difference between crack and powder cocaine was that crack was so much cheaper and

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*In 2010, the Fair Sentencing Act reduced but did not eliminate the discrepancy between sentencing for crack and powder cocaine; under this act, the distribution of 28 grams of crack triggers the same mandatory five-year federal prison sentence as for 500 grams of powder cocaine.[13] As of September 2021, legislation to eliminate the disparity was being considered.[14]

The New York Times Magazine

FEATURE

Children of the Opioid Epidemic

In the midst of a national opioid crisis, mothers addicted to drugs struggle to get off them — for their babies' sake, and their own.

were at play with the crack epidemic in segregated, disinvested neighborhoods. Addiction is a behavioral health issue that rears its head wherever there is a loss of purpose and hope, regardless of race or ethnicity. Two decades before the conceptualization of deaths of despair, renowned Black sociologist William Julius Wilson described a similar connection between the decline in work opportunities in urban Black communities and the rise of health and social issues.[20] Yet economic shifts by themselves need not lead to despair; it's the combination of economic change and the lack of public goods—lack of strong job-retraining programs and sufficient assistance to avoid family poverty while engaged in retraining, for example—that causes a person to lose hope. This loss of hope and purpose is a collective American problem—a symptom of the fading American dream.

more accessible to poor Americans, especially Black Americans in segregated neighborhoods suffering from decades of disinvestment. Still, people of color were targeted further through discriminatory policing and prosecution. In 2003—at the height of mass incarceration—more than 66 percent of crack users were white or Hispanic/Latinx, but they made up only 18 percent of defendants sentenced under harsh federal sentencing law, while Black people made up a whopping 81 percent.[15†] The impacts of this disproportionate enforcement of inequitable laws have not been limited to those who are locked up; families and communities have been torn apart—just as Nixon intended.

Now consider the very different narrative that has been constructed for the opioid crisis: media portrayals focus on opioid users as mostly rural and suburban white Americans who are victims of profit-seeking, predatory pharmaceutical companies.[17] Politicians demand treatments and lawsuits against the pharmaceutical companies, not harsh sentences for the opioid users. In a congressional hearing in July 2017, Brian Moran, Virginia's secretary of public safety and homeland security, said, "We cannot arrest our way out of the heroin and opioid addiction crisis."[18]

Now, as the impacts of our decades of disinvestment in public goods are being felt by white middle- and working-class Americans, we have a narrative focused on "deaths of despair"—gun-related suicides, drug overdoses, and alcohol-related deaths.[19] These deaths are linked rhetorically to places where manufacturing and other blue-collar jobs have disappeared, and where the communities that formerly supported these industries are experiencing high associated social costs.

In conversations about opioid addiction and deaths of despair, a big part of the explanation is the loss of purposeful employment and of hope more generally. Of course, these are the same mechanisms that

The promise of the American dream is that with enough hard work and determination, anyone can have a better life. The meaning of "a better life" varies, but one way to measure it is by comparing earnings across generations. While 92 percent of children born in 1940 went on to earn more than their parents did by the age of 30, that was the case for only half of children born in 1984.[21] What happened? Rising inequality. There's been plenty of economic growth, but it has not been distributed fairly (for details, see the article "Moral Policy = Good Economics" on page 38). The fruits of our labor have primarily accrued to those at the very top, especially in recent years.

Not surprisingly, this loss of upward socioeconomic mobility is also patterned by race and ethnicity. Data collected between 1989 and 2015 show that Black Americans and Native Americans have experienced lower rates of upward mobility and higher rates of downward mobility than white Americans.[22] These disparities feed intergenerational gaps in resources. According to data gathered between 2017 and 2019, for every dollar that white workers earned, Black workers earned 76 cents, Latinx workers earned 73 cents, and Native American/American Indian workers earned 77 cents[23]—not much better than the racial income gaps in 1978.[24]

Racial disparities in wealth (e.g., assets like savings accounts and home equity) are larger than those for income and education, and wealth makes an incremental contribution to health and health disparities over and above income and education.[25] For every dollar of wealth white households have, Black households have 10 cents and Latinx households 12 cents.[26] Because of our minimal public investments and weak social safety nets, Americans rely mainly on private, individual safety nets when emergencies like the COVID-19 pandemic arise; so the unequal distribution of private household reserves across generations further polarizes the experiences of the haves and the have-nots.

For every dollar of wealth white households have, Black households have 10 cents and Latinx households have 12 cents.

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†By 2020, the numbers hadn't changed much: white and Hispanic/Latinx people constituted 22.7 percent of defendants for crack distribution, while Black people constituted 76.8 percent.[16]

Together, what these results tell us is that we need to collectively reduce income inequality across neighborhood, class, and racial lines, while specifically emphasizing the upward social mobility of the people who have been systematically excluded from opportunities to rise.

Racial Capitalism

In order to address income inequality and social mobility across our population, we must confront the centrality of race in our social and labor hierarchies. This requires us to reconsider how we think about our economic system. Proponents of "free market" capitalism, a largely self-regulated economy that maximizes profit and minimizes government oversight and regulation, claim that it offers equal opportunities to everyone because free markets are rational, neutral, and unbiased.

However, we need to consider the context in which the US free market economy formed. Slavery was the first big industry in the United States, and the very bodies of the enslaved were the country's largest financial asset.[27] But even as the humanity of enslaved people has slowly come to be recognized, the American brand of capitalism has continued to make race a key factor in the value of labor. In effect, we practice *racial capitalism*, in which low-wage and high-risk work is concentrated among historically marginalized racial and ethnic groups.

The concept of racial capitalism recognizes the links between capitalism and colonialism. The development of race as an organizing principle within Europe several hundred years ago was largely a colonial process involving the invasion and settlement of lands possessed by Indigenous American, African, and Asian peoples, expropriation of natural resources, and establishment of a racial hierarchy that placed white Europeans at the top. But it didn't stop there. The history of anti-Mexican and anti–Central American immigrant sentiment is better known, but the waves of European immigrants to the newly formed United States in the 19th century were also subject to the racialized social, economic, and political systems established by European settlers. Irish, German, Italian, and Eastern European people, especially Catholics and Jews, were discriminated against as not truly white and struggled to find jobs and places to live.[28] The concept of racial capitalism helps frame everything from European explorers' treatment of Native Americans to slavery to anti-immigrant sentiment to the continued devaluing of people of color. One stark example within healthcare is our nation's dependence on nurses from the Philippines.

Racialized Nursing Policies

Filipino Americans play an outsized role in the US nursing workforce—including in COVID-19 cases and deaths. They are 1.1 percent of the US population but account for 4 percent of the nation's nursing workforce and about 25 percent of all COVID-related deaths among nurses. In California alone, where about 20

percent of nurses identify as Filipino (compared with 3 percent of the California population), they accounted for 23 of the 38 COVID-19 deaths in the profession as of February 11, 2021. This is because they are more likely to be assigned to critical care settings with highly infectious patients (intensive care units, emergency departments, nursing home bedsides), thus experiencing disproportionately prolonged exposure, in dangerous working conditions and without proper protection.[29] They are the frontline of the frontline healthcare workers.

Why? There is a century-long legacy of colonialism and discrimination. In 1898, after a US Navy ship sank in Havana Harbor, the United States entered into the ongoing Cuban War of Independence against Spain. Hostilities quickly extended to other arenas of war, including the Philippines and other Spanish colonies in the Pacific, launching the Spanish-American War. This three-month war led to US control of Puerto Rico, Guam, the Philippines, and, temporarily, Cuba. At the end of the war, President William McKinley issued a proclamation:

> We come not as invaders or conquerors, but as friends, to protect the natives in their homes, in their employments, and in their personal and religious rights…. Finally, it should be the earnest wish and paramount aim of the military administration to win the confidence, respect, and affection of the inhabitants of the Philippines … by proving to them that the mission of the United States is one of benevolent assimilation, substituting the mild sway of justice and right for arbitrary rule.[30]

This notion of "benevolent assimilation" was an extension of the US ideology of manifest destiny and the idea of the "White Man's Burden" popularized by British writer Rudyard Kipling: white colonizers had a duty to rescue Indigenous people from their supposedly primitive and uncivilized ways of life.[31]

Under US colonization of the Philippines, Filipino nurses were trained by Americans in Americanized nursing schools (and in English) so they could work in the United States. Adding to the handful of existing hospitals established by the Spanish regime, about 20 American hospitals and schools of nursing were established between 1906 and 1947, plus three colleges of nursing between 1946 and 1948. That's when the export of nurses began, as the United States had a post–World War II healthcare staff shortage to address and had launched an Exchange Visitor Program that made hiring foreign labor inexpensive and easy.

By the 1960s, nurses were migrating to the United States by the thousands because of an abundance of jobs created by the establishment of Medicare and Medicaid. In addition, the passage of the Immigration and Nationality Act of 1965 allowed a preferential approach to immigration; certain categories of immigrants, such as highly educated Asian scientists,

Filipino Americans make up 4% of the nursing workforce but 25% of all COVID-19 deaths among nurses.

engineers, and doctors, as well as Filipino nurses, were permitted to come to the United States in greater numbers. As of 2019, 1 out of 20 registered nurses in the United States was trained in the Philippines.[32]

Since the 1960s, 150,000 Filipino nurses have migrated to the United States for healthcare jobs. Like many other immigrant laborers in US history, they have often found themselves in demanding and dangerous work environments. From the 1980s to today, Filipino nurses have disproportionately cared for patients during America's HIV/AIDS, SARS, Ebola, and COVID-19 crises. Even when we are not facing a healthcare crisis, Filipino nurses suffer from exploitation, such as being assigned the less desirable shifts and the more precarious settings.[33]

To better understand the plight of today's Filipino nurses, we need additional historical context. The first group of immigrants to be barred from the United States was Asian. The 1875 Page Act was the first federal immigration law; it prohibited the entry of supposedly undesirable immigrants, including any individual from "China, Japan, or any Oriental country" who was coming to America as a contract laborer. In particular, the Page Act targeted Chinese laborers, who were depicted as filthy and unsanitary, a physical as well as a religious and moral threat to the Christian United States. Chinese women were perceived as a particular type of threat: they were stereotyped as prostitutes who spread sexually transmitted diseases.[34] Later laws continued in this vein, including the Chinese Exclusion Act in 1882 and the Asian Exclusion Act in 1924.

And yet, just four decades later, sociologist William Pettersen coined the term "model minority" in an article for the *New York Times Magazine*.[35] He attributed the apparent success of Japanese Americans, only 20 years after their incarceration in internment camps during World War II, to their cultural values, strong work ethic, family structure, and genetics. Numerous newspaper and magazine articles subsequently appeared describing the "successes" of various Asian American groups.

Pettersen's article can be considered in direct contrast to the 1965 Moynihan Report, which blamed Black culture and family structure for Black communities' socioeconomic problems.[36] The "model minority" analysis pitted Japanese Americans—and, later, all Asian Americans—against so-called problem minorities, putting wedges between Asian and Black communities[37] and masking the wide disparities among and within diverse Asian American and Pacific Islander groups in terms of income, employment, education, health, housing, and immigrant experience.[38] Perhaps most importantly, in suggesting inherent reasons that "model minorities" succeeded where "problem minorities" did not, it offered a distraction from examining the role of structural racism in understanding disparities between white and Black Americans.

In the last couple of decades, our postindustrial, service-based economy—with a minimum wage that's far too low to live on—has created marginal and inequitable opportunities for new immigrants and heightened economic hardships for native-born people of color. These conditions have been presented as new fault lines in race relations, beyond the civil rights era paradigm of white and Black relations. But such divisions among people of color only benefit the dominant group. While it is important to recognize the ways Asian Americans have benefited from anti-Black racism in the United States, for example, it is also important to recognize that the struggles for equity of Black Americans, Asian Americans, and other marginalized groups are, in effect, the same struggle against white supremacy. Conflict among racial and ethnic groups is a product of structural racism—and both can be dismantled if all of those who cherish equity stand together.*

We must face the reality that, by disinvesting in public goods, we have been smothering the American dream for decades. Attacks on "big government" as an excuse to cut public investments have largely translated into big corporations consolidating profit and political influence to the detriment of the American people. We can no longer reasonably ignore the realities of racial capitalism, structural racism, and the dangers of our divided, inequitable society.

We can see how our macroeconomic policy choices negatively impact our health and well-being simply by looking at life expectancy in the United States over the last 70 years. While life expectancy has increased since the 1950s, the rate of increase slowed beginning in the early 1980s, diverging from the upward trajectory of other wealthy nations. It actually decreased from 2014 to 2018 among all racial and ethnic groups, rising slightly through 2019 before dropping precipitously during the pandemic.[39] The decrease in life expectancy between 2018 and 2020 was 1.9 years, 8.5 times the average decrease in peer countries. The numbers are even starker for Hispanic populations and non-Hispanic Black populations: compared with peer countries, life expectancy decreased by 18 and 15 times the average, respectively.[40]

This decrease in life expectancy is shocking, but it's also highly predictable. Our social contract has been deteriorating for decades and needs renegotiating.

Public Health as a Public Good: Investing In Our Future

In order to act on the key lessons from the COVID-19 pandemic, we must reimagine our economy, ensuring human rights and human dignity by valuing our health and well-being as a shared common good.

If we want to address these problems, we must confront how central race is to the ways we organize our society.

*Today, the role of Asian Americans as a racial middle is critical. If Asian Americans buy into and strive to attain the privilege of white Americans, they will help perpetuate our racial economic system. Conversely, Asian Americans can help increase equity if they refuse to buy into racial hierarchy and strive to dismantle white privilege.

We must reimagine our economy, ensuring human dignity by valuing our health and well-being as a shared common good.

We find hope for this reimagining in the concept of *adaptive governance* grounded in grassroots civil society and public systems offered by 2009 Nobel laureate Elinor Ostrom.[41] Ostrom's early work emphasized the role of public choice in decisions influencing the production of public goods and services. Caring for the commons had to be organized from the ground up, shaped to cultural norms and based on a foundation of trust. Her recent work has documented how communities around the world—including in Guatemala, Kenya, Los Angeles, Nepal, and Turkey—have devised ways to govern public goods to ensure their survival and the survival of future generations. Essentially, success depends on a well-supported, active civil society engaging with the government. Robust community organizations strengthen local decision-making, promote mutual accountability, and galvanize joint progress, which engenders more support for shared public goods and long-term sustainability.

Local Investments

In the United States, we should invest in our *local* health departments as our boots on the ground, building a public health and social service infrastructure that employs community health workers who are paid a living wage and afforded occupational protections. We emphasize investment in local health departments because they are closest to the need, hold stronger relationships with community organizations, and are more likely to be held accountable for action and inaction.*

- In general, state health departments that are centralized—that is, whose decision-making is closely controlled and managed by governors at the state level—are slower and less effective at launching preventive measures, expediting hiring and purchasing, and receiving additional funds from the federal government during a public health emergency response.[42]
- More hierarchical state health departments are less likely to be prepared, have a comprehensive pandemic plan, or rapidly deploy resources during a pandemic.[43]
- Delayed public health responses may disproportionately impact historically marginalized racial and ethnic communities with more residential and occupational exposure to COVID-19 (and other diseases).

Federal Investments

Although we believe local investments are essential for improving public health, our local initiatives are far more likely to succeed if they rest on a strong foundation of federal investments.

Our federal investments should begin with a well-resourced Centers for Disease Control and Prevention (CDC) whose mission, mandate, and leadership extend beyond specific presidential administrations.

- Between 2008 and 2014, public health expenditures per capita decreased by 9.3 percent, and federal budget cuts compromised critical resources, including the pandemic unit of the US National Security Council in China, the CDC's emergency preparedness budget, and states' spending on public health programs.[44]
- The sidelining of the CDC in the COVID-19 pandemic response and the politicization of the role of its director has largely marred the credibility and reputation of the agency and reduced public trust in it as a public good.[45]
- The CDC's credibility and reputation must be rebuilt bit by bit, including by increasing transparency with the public, building stronger relationships with state and local health departments, and resisting the push to increase the number of political appointees and other lobbying forces in the agency.[46]

We should invest in Medicaid and healthcare for all. And we should invest in the Indian Health Service, not through annual congressional appropriations, but as an entitlement program for this land's first peoples.†

- There are still more than 30 million US residents without health insurance; these are disproportionately people who are Black or Latinx, are young, have low incomes, and/or live in states that have not expanded Medicaid.[47]
- Access to healthcare is a strong predictor of health; poor access to routine healthcare is associated with poorly controlled chronic disease.[48] (Importantly, a large percentage of COVID-19 deaths in the United States have occurred among patients suffering from chronic conditions, like hypertension, obesity, chronic lung disease, diabetes, and cardiovascular disease.[49])
- Potential healthcare costs prevent the timely testing, contact tracing, and treatment needed to curb the spread of COVID-19 and other infectious diseases.[50]

We must invest in workers' rights by ensuring safe work environments, mobilizing an independent Occupational Safety and Health Administration (OSHA), and supporting broadscale labor organizing efforts.

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*We do not focus on action on the state level due to high between-state and within-state variability and state governments' tendency to focus on politics instead of communities' strengths and needs.

†To read about how contact with US settlers has affected Native American health, read "Traditional Food Knowledge Among Native Americans" in the Fall 2020 issue of *AFT Health Care*: aft.org/hc/fall2020/segrest_hipp.

- Union organizing improves levels of compensation (in wages and fringe benefits) as well as quality of life for both unionized and nonunionized workers.[51]
- The federal government through OSHA should routinely mandate emergency safety measures for employees during public health emergencies, such that workers are not sacrificing their own and their families' well-being to maintain their employment.[52]
- Labor organizing has shown itself to be an opportunity for racial and ethnic solidarity. Rev. Dr. Martin Luther King Jr. advocated for unionism in human rights, environmental justice, and economic justice, not only as political participation but also as our moral obligation for the next generation.[53] A new study finds that white union members are less likely to have racist attitudes than white workers in similar industries who are not in a union. Additionally, becoming a union member, or even being a *former* union member, reduces white workers' racial resentment. Such lessening of racial resentment even translates to increased support for policies like affirmative action.[54]
- For our democracy to thrive and to rebuild the public good, we need to invest in and foster an active, unfettered, multiracial, and multiethnic civil society. The 21st century Poor People's Campaign led by Rev. Dr. William Barber II and Rev. Dr. Liz Theoharis lays out a comprehensive social movement whose moral policy agenda hinges on the right to democracy and equal protection under the law, the right to welfare and an adequate standard of living, the right to work with dignity, the right to health and a healthy environment, and the reprioritization of our resources toward these goals.[55] The movement has launched direct actions across the nation supporting a $15 minimum wage, equitable voters' rights, and government accountability across administrations and parties.

Given the structural inequities at play, we must address the root causes of health inequities by transforming the environments and policies that produce inequities. One critical place to start is investing in high-quality early childcare and education for working families.

- Childcare is beyond a family issue—it is part of the business infrastructure enabling parents (especially mothers) to work and is a major tool to level the playing field across classes and genders.[56]
- The CARES Act provided block grants to subsidize childcare; it also allowed for 12 weeks of paid sick leave for employees without access to childcare or school for their children. We now need to earmark funds for essential workers and independent contractors[57] and create a sustainable emergency childcare

system that can be deployed during subsequent public health crises.

We should invest in our public infrastructure to produce quality public schools, social services, and behavioral health rather than investing in the inequitable, punishment-focused prison industry.

- The environments of jails and prisons amplify health risks, including and beyond COVID-19.
- We can address the collective health vulnerability associated with mass incarceration by decreasing the number of people who are sentenced to correctional supervision and increasing investments in addressing the root causes of crime, namely by expanding education and economic opportunities equitably.[58]

Ties That Bind Us

While holding onto the virtues of liberal thought—respect for human rights, freedom of thought, freedom of assembly—we believe the United States would be stronger and better prepared for the next pandemic if we coalesced around a more collectivist approach to public policy.

We Americans have much in common, most importantly innovation, resourcefulness, and a desire to make our communities better. If we want the United States to become the equitable and just country we believe it can be, we must recognize the linked fates of our diverse communities and grow personal relationships and trust among community leaders and stakeholders from all backgrounds and walks of life. We need to continue promoting a culture of engagement and inclusion and recognize the need for cultural humility and an understanding of our unique history and how it has brought us to our present moment. Furthermore, we must demand that our economic system shift toward greater investments in shared public goods and in better wages and benefits for our least advantaged workers.

Throughout American history, when we have not planned with equity in mind, we have defaulted to inequity. It is up to us, individually and collectively, to recognize the ongoing impacts of structural racism and become a diverse, united group of anti-racist investors in American prosperity. We need to—must—do better, because our future depends on it. ✚

Investing in public goods will make our society healthier, more equitable, and better prepared for the next pandemic.

Editors' Endnote

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Article Endnotes

1. Lumen, "Expanding the Civil Rights Movement," Boundless US History, courses.lumenlearning.com/boundless-ushistory/chapter/expanding-the-civil-rights-movement; and V. Gosse, "Red, Brown, and Yellow Power in 'Occupied America,'" in *Rethinking the New Left* (New York: Palgrave, Macmillan, 2005), 131–51.

2. Z. Bailey and J. Moon, "Racism and the Political Economy of COVID-19: Will We Continue to Resurrect the Past?," *Journal of Health Politics, Policy and Law* 45, no. 6 (2020): 937–50.

Brave Spaces

Community-Driven Anti-Racism Partnerships

By **Ella Greene-Moton, Suzanne Selig,** and **Eugenia Eng**

Ella Greene-Moton is the administrator for the Community-Based Organization Partners (CBOP)–Community Ethics Review Board (CERB). Suzanne Selig, professor emerita of public health and health sciences, is the former director of the Department of Public Health and Health Sciences in the University of Michigan–Flint College of Health Sciences. Eugenia Eng is codirector of the Cancer Health Disparities Training Program and a professor in the Department of Health Behavior at the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill.

Imagine taking a course in public health and learning about the dangers of air pollution—but not about the historical and current structural and systemic racism and the resulting policies that drive racial segregation in housing and greatly increase the odds that major polluters (from bus depots to chemical plants) will be placed near communities of color. Imagine working for a hospital oncology department and noticing that, unlike white patients, Black patients tend to miss more appointments and have lower remission rates—and then seeing your colleagues nod in agreement as the department director says there is nothing the hospital can do about such disparities.

Unfortunately, these situations are not hard to imagine. They are common. They are, for the more privileged people involved, safe and comfortable. But what about the Black, Latinx, and Indigenous children having asthma attacks? And what about their parents and grandparents dying of cancer far too young? They need us to abandon our positions of relative comfort and to create brave spaces where we can acknowledge difficult realities and work toward solutions together.

Over the past two decades, we—along with many colleagues and community partners—have built spaces just like this, dedicated to dismantling inequities in our communities. Here, we explain our conceptual grounding in cultural competence and cultural humility, provide case studies summarizing our work, and then share lessons learned that we believe could be adapted across a wide variety of healthcare, public health, and educational settings.

Cultural Competence and Cultural Humility

In recent years, professionals in healthcare and public health (as well as many other fields) have recognized the importance of developing cultural competence. From understanding how patients' concerns are shaped by their cultural contexts to recognizing communities' strengths and creating environments in which patients feel safe sharing information, it's likely that the more health professionals know about the cultures of those they work with, the more effective they will be.[1] But with such great diversity in many communities across the United States, attaining competence in multiple cultures seems impossible.

While building as much competence as possible remains the goal, our experiences demonstrate that approaching others with *cultural humility* is an effective means of engaging despite the inevitable gaps in our cultural knowledge. Scholars have defined cultural humility as "a lifelong commitment to self-evaluation and critique, to redressing the power imbalances ... and to developing mutually beneficial and nonpaternalistic partnerships with communities on behalf of individuals and defined populations."[2] Cultural humility requires both introspection and collaboration; it remains hard, even after many years. It also remains well worth the effort and grows even more rewarding over time, as we hope our case studies show.

Our journeys began long before the cultural competence and cultural humility conversation began to pique the interest of health stakeholders or to take root

in community-level public health circles. More than three decades ago, pockets of public health enthusiasts were joining forces on local, state, and national levels to address health disparities.[3] Much of this work was collaborative, engaging a cross section of participants (i.e., from academic and clinical settings as well as from the community) in community-based public health; it laid the groundwork for universities, communities, and health departments to collaborate on research projects targeting local health disparities, in what is now known as community-based participatory research.[4]

The early literature indicated that when done well, this type of research tended to create relationship-oriented partnerships that were authentic, lasting, time consuming, layered, and ultimately beneficial.[5] Done poorly, community engagement had a very narrow scope and an even less articulated collection of shared expectations. Research projects that claimed community involvement usually issued a "statement of engagement" that had been drafted by researchers without community input and with little else to show for the process. There was no real, meaningful engagement. There was no real commitment. There was no real benefit, at least not for the community.

The need for true community participation became apparent—and that meant grappling with cultural differences so that everyone's expertise was tapped. Still, the notion of cultural competence caused some uneasiness, in part because of the growing understanding that we cannot ever become truly competent in another's culture.[6] Cultural competence is not something we achieve or fail to achieve; rather, it is a reminder to continue to strive to learn and know more about communities of all types, and especially those we work with or work to impact.[7]

In our experience, cultural competence and cultural humility together provide health professionals with some of our most important tools in working with diverse individuals, groups, and communities in today's complex world. Striving toward competence with humility is an exploration, constantly moving, constantly changing, and constantly expanding.[8]

As we hit our mental rewind buttons and reviewed our own journeys, several fundamental questions began to rise to the surface: What were some of the issues driving the early conversations that oftentimes became spirited debates? In what contexts did they arise? By whom were they sparked? How did we know that we, and our teams, were ready to have these conversations? And most importantly, why were these conversations necessary?

The specific answers to these questions are nuanced, but the broader view reveals one common factor: systemic racism. Without the trauma, fear, guilt, shame, and denial of racism, our pursuit of cultural competence with cultural humility would be stimulating, but not so challenging. The work would require energy, but not bravery.

One important catalyst in this work came in January 1991, when the Kellogg Foundation announced its Community-Based Public Health Initiative. Its aim was to strengthen the practice and teaching of public health by creating partnerships with an informed public. Together, these partnerships were to create sustainable models of a "new" public health through practice, research, and teaching.[9] This initiative planted a valuable public health seed that has taken root in several communities across the country and beyond. The two case studies presented in this article have common roots in being two of seven communities nationwide to receive generous funding from the Kellogg Foundation, which recognized the critical role of community engagement in the activities of local public health departments and schools/programs of public health. Several individuals in both of these projects shared experiences and goals, creating a synergy and cross-fertilization of ideas that further enriched each effort.

In the case studies that follow, we focus on our individual and shared journeys: the development of an anti-racism course for public health students at the University of Michigan–Flint (UM-Flint), where Ella Greene-Moton and Suzanne Selig have been collaborating for nearly 20 years, and the systemic transformation of oncology care delivery through the Greensboro Health Disparities Collaborative in North Carolina, in which Eugenia Eng has been a foundational partner.

Although our journeys are quite different, they are anchored in anti-racism and have been guided by the People's Institute for Survival and Beyond (PISAB), a nationally recognized anti-racism training program.[10] As explained in "Building the Foundation for Lasting Social Change" on page 14, PISAB's "Undoing Racism" framework delineates structures built into systems, such as healthcare, that obstruct transparency and accountability for racial equity. Because creating spaces for these conversations is so difficult, we highly recommend finding experienced partners like PISAB to offer guidance.

Case Study 1: Developing an Academic Course in Michigan

This case study, which looks back nearly four decades, describes a university-based anti-racism intervention and the partnership that has been essential to the intervention's development and sustainability. Today, that anti-racism intervention takes the form of a course, "Cultural Competence in Health Care," required by the UM-Flint Department of Public Health and Health Sciences for undergraduate health science students (enrolled in health education, health administration, pre-physical therapy, pre-medical, pre-pharmacy, and related degree programs) and master of public health students.

This anti-racism journey began in 1984, when Selig published the results from a five-year study of infant mortality in Genesee County, Michigan, in cooperation

Addressing health disparities requires creating brave spaces where we can acknowledge difficult realities and work toward solutions together.

with the local health department.[11] The purpose of the descriptive study was to better understand the dramatic disparity in infant mortality rates between white and African American babies. Selig and her partners identified geographic "hot spots" for infant deaths in which more prenatal care visits were associated with *higher* infant deaths. Further inquiries showed that pregnant clients with more visits had had more complicated pregnancies but raised questions about both the *what* and the *how* of service delivery. Could there have been something about the nature of the interaction between the pregnant clients and the providers or about the providers' settings that contributed to infants' deaths?

At that time, the conventional wisdom was that we needed to get clients into prenatal care sooner and that more visits were better. To facilitate this, and to overcome such barriers as cost and transportation, additional resources were allocated to lengthen clinic hours, open new clinics in areas with high infant mortality rates, and provide transportation. Despite these efforts, the racial disparity persisted.

Selig began to ask: Could implicit bias and racism be playing a role here? Were the clinical staff unknowingly creating an unwelcoming environment for these women? Were women treated respectfully at registration when they arrived late for an appointment? Did the clients who depended on public transit feel safe waiting for buses to attend the clinic? What neighborhood conditions might influence the low utilization of services and high rate of missed appointments?

> **Approaching others with cultural humility is a means of engaging despite gaps in cultural knowledge.**

The Genesee County Health Department invested more resources, including hiring additional staff, and organized a communitywide coalition to address the high infant mortality rate. In 1992, with support from the Kellogg Foundation, the Genesee County Health Department, the University of Michigan (UM), and the city of Detroit formed a public health partnership, bringing to the table faculty from the UM-Flint and UM-Ann Arbor campuses and leaders from local community-based organizations. (As a staff member of the Health Awareness Center, Greene-Moton joined the partnership in 1995.) The Genesee County group began meeting on a regular basis and coordinated with the parallel UM-Ann Arbor partnership with community leaders in Detroit.

The Genesee County partnership faced many challenges. The community group was largely African American, while the university faculty and health department staff members were largely white. It became clear early on that race and racism needed to be addressed for the partnership to be effective as the group struggled with how best to select and order agenda items, rotate meeting facilitators, allocate indirect costs, and foster group cohesion.

Fortunately, several exceptional individuals among the community partners, including Greene-Moton, assumed leadership roles in helping us navigate as we examined the unseen things that divided us. They guided us as we focused on the history of racism in our country and in our communities. We had multiple retreats grounded in the idea that we needed to

Building the Foundation for Lasting Social Change

If racism was constructed, it can be undone. It can be undone if people understand when it was constructed, why it was constructed, how it functions, and how it is maintained.[1]

–Ronald Chisom
Executive Director and Cofounder, People's Institute for Survival and Beyond, New Orleans

The work of the People's Institute for Survival and Beyond (PISAB) has been essential to the ongoing personal and community transformations described in this article. PISAB arose from decades of community organizing work by Ronald Chisom in New Orleans and Dr. James Norman Dunn in Ohio. Founded in 1980, PISAB's work focuses on community organizing for social change rooted in humanistic and anti-racist principles; underscoring all of them is the conviction that effective social change can only

happen when organizers understand the role of structural racism in perpetuating social inequality and commit to dismantling it. Since 1980, PISAB has brought its Undoing Racism/Community Organizing training to more than 2 million people in communities around the world.

In this interactive workshop that takes place over two and a half days, participants explore how they have been socially and culturally conditioned to think about race and racism by examining the power relationships in their own communities on both individual and institutional levels. This intensive process begins with each participant analyzing their own beliefs and experiences before considering larger structures of power and privilege. Over the course of the workshop, participants develop shared language for discussing racism, particularly institutional racism, and explore its historical context and present

impacts. They also explore how to create and sustain multiracial coalitions to engage in dismantling racism.

According to the Aspen Institute, "The program emphasizes humanistic values and recognizes the importance of bringing personal experience to understanding racism in order to counteract its dehumanizing effects. However, trainings remain focused on a structural analysis of racism rather than on emotional responses or the personal journey of anti-racism work.... It also prides itself on being rooted in and accountable to communities of color."[2] To learn more or to inquire about bringing the Undoing Racism workshop to your workplace, visit pisab.org.

–E. G.-M., S. S., and E. E.

Endnotes

1. I. Shapiro, *Training for Racial Equity and Inclusion: A Guide to Selected Programs* (Washington, DC: Aspen Institute, 2002), 7.

2. Shapiro, *Training for Racial Equity*, 11.

understand how racism structured our society and our conceptions of ourselves and communities before we could develop the kind of mutual trust and partnership needed to help our communities. The meetings were often tense and contentious—but we finally had hope after three years, when we were unearthing the root causes of the racial disparities in infant mortality (and so many other race-related health inequities).

Through focus groups and discussions with community members, a complex array of potential causes for high Black infant mortality was unearthed:

> Local residents attributed infant mortality to the government, parents, the health care system and its practitioners, poverty, and lack of insurance. Government programs were thought to be poorly designed and underfunded. Police were viewed as not doing enough to ... stem ubiquitous violence, which cheapens human life.... Parents were viewed as immature and irresponsible about sex.... The health care system was seen as providing insufficient preventive care, as not welcoming to the poor, and as requiring long waits for service. Practitioners were seen as spending too little time with patients, speaking in an incomprehensible technical language and jargon, and failing to make necessary referrals. They were also perceived as discriminatory and racist with a sole interest in the unborn baby to the exclusion of the parents. Local residents also noted that near-poverty leaves little money for insurance and a healthy diet.[12]

Failing to reduce African American infant mortality during the 1990s, the partnership realized that the true root cause was systemic, pervasive racism.[13] In turn, we grasped that in order to substantially reduce infant mortality (and tackle other health disparities), we would have to drive significant social changes.

Despite the termination of the Kellogg funding, which had been instrumental in bringing us together, we recognized that the partnership we had developed was too valuable to disband. Thus, our commitment to the partnership persisted and we continued to meet. When new funding from the Centers for Disease Control and Prevention (CDC) became available in 2000, we were poised to develop a successful multiyear grant application. We built upon the strength and authenticity of our partnership and our collective knowledge of the infant mortality challenges we faced to create an anti-racism campaign for Genesee County. The campaign included a series of PISAB's Undoing Racism trainings for local hospital administrators and their leadership teams, physicians and other clinic staff, and members of the larger community. Industry leaders and leaders of K–12 and higher educational institutions also participated.

With the work becoming more multifaceted to try to root out systemic racism, Selig, who remained the

UM-Flint representative throughout this initiative, proposed the development of a course to help UM-Flint health sciences students focus on self-awareness of their biases and how those biases had developed.* As the director of the Department of Health Sciences, she used her privileged position to achieve the adoption of this course in 2002. Aware of the lack of sensitivity within the university to directly confronting racism, she selected the less threatening title of "Cultural Competence in Health Care," rather than the more provocative "Racism in Health Care," with the hope of attracting as many students as possible. As many graduates of the health sciences programs go on to work in the local social service and health sectors, one core goal was for students to share their growing understanding of cultures, biases, and the impact of race with their coworkers and social networks, thus developing students as change agents within the larger community.

A portion of the CDC funding was allocated to UM-Flint, which used the money to hire and support an additional staff member whose primary task was to identify course materials, interactive exercises, and assignments for the students. It also provided funding for Selig to attend a five-day train-the-trainer cultural competence workshop at the University of California San Francisco early in the course development. The planning group determined early on that an African American community member—Greene-Moton—would team-teach the course with Selig.

Over the semester, students participated in many self-reflective exercises. For example, near the beginning of the course, we asked students to think about an early memory of when they felt different from those around them. Some students recalled that they had

Cultural competence and humility together are essential tools for working in our diverse communities.

*While the remainder of this case study focuses on the course, the anti-racism campaign in which this course is grounded is proving beneficial. Although there is still a disparity in Black and white infant mortality rates, those rates have been trending downward for several years[14] and our coalition of healthcare, public health, and community partners remains actively dedicated to strategies for addressing systemic racism.

Failing to reduce African American infant mortality during the 1990s, the partnership realized the true root cause was systemic racism.

felt different because of their brown skin, while others mentioned their body size or nonnormative gender behaviors (e.g., a girl who would only wear boys' clothes). Through this exercise, students realized that at some point in their lives everyone is viewed as different, or *othered*, and that this experience is often associated with some pain or embarrassment despite the passing of years. We also used an exercise we called "Who am I?" to emphasize that what we see when we first encounter another person is just the tip of the iceberg and that each of us has a multifaceted, complex identity. Each of these exercises was discussed in class in groups of three to five students who shared their reactions and reflections with each other. To deepen individuals' reflections, we required students to write weekly journal entries that were read only by the instructors. We provided feedback and asked thought-provoking questions like "Why do you think that discussion/comment made you uncomfortable?"

At the same time, students read Beverly Tatum's book *Why Are All the Black Kids Sitting Together in the Cafeteria?*[15] This easy-to-read book helped students to begin to understand the development of racial identity and the social meaning ascribed to skin color. Many of the students had day jobs, and they reported that reading this book during breaks often led to stimulating conversations with coworkers that might not have occurred otherwise. Throughout the term, most students expressed interest in the content of this book and became more confident engaging in conversations about these topics.

Still, as anticipated, we met resistance, mainly in the form of comments that there was too much focus on race and racism and not enough on other cultures. Some white students began to feel attacked as the cause of racism. This was particularly clear after we watched the documentary *The Shadow of Hate*, which relates the discrimination, persecution, and near extinction of nonwhite populations in the United States, beginning with Native Americans. It includes history and footage (both reenactments of distant events and real film of more recent events) of painful and difficult topics, includ-

ing slaughters of Indigenous communities, hangings of Black people in the South, internment of Japanese Americans and other groups during and following World War II, and other atrocities. Many students' high school history courses had glossed over much of the history of oppression in the United States, so this was the first time the students had been exposed to this information. They expressed both guilt and resistance. "Why has no one told me about this before?" was a common journal entry.

In class discussions, we presented students with models that convey cultural competency as a continuum[16] so they could plot their own progress. This, along with an initial in-class assessment, enabled students to mark where they were at that time relative to their knowledge, skills, and awareness. Most students rated themselves as more "competent" and anti-racist at the outset of the course than at the end—which we took as a strong sign of learning. During the course, most students realized how much of their assumed knowledge was inaccurate or incomplete. Students were required to write a final paper based on their previous journal entries, pointing to trends in the successive weekly entries that revealed their own resistance and progress. These papers often mentioned the "Aha!" moments we'd noted in their weekly entries.

With three sections offered per semester, this course has now been taken by over 3,000 students. Although a formal evaluation of this course has not been undertaken, we have much data from the students' weekly journals, postcourse assessments, and comments on course evaluations. We also have other anecdotal evidence from unsolicited correspondence we have received from students, sometimes many years after they completed the class and graduated. The most common comment is that "this should be a required course for all university students."

The success of this course is largely due to the solid, respectful, and trusting partnership we developed over many years prior to undertaking this intervention. We have the advantage of a faculty member (Selig), a highly competent staff member (Elizabeth Tropiano), and a community partner (Greene-Moton); each brought expertise, wisdom, history, and experience with racism to the course, giving authenticity to the content and processes. In co-leading the class—and in showing that we value the expertise of lived experience in the community as much as academic credentials—we practice the kind of partnership we hope our students will begin to build. We are also able to model interracial dialogue and express different perspectives in a respectful manner, which has proved invaluable for the students.

Case Study 2: Transforming a Healthcare System in North Carolina

This case study looks back over 25 years—across dozens of partners and processes—to describe the system change that transformed oncology care in Greensboro, North Carolina. Through a multiphase research

project in which many collaborators (including Eng) identified barriers to comprehensive care and made step-by-step changes in how patients and providers are supported, we achieved racial parity in cancer outcomes in two settings. Here, both the journey and the resulting oncology care model are shared.

In the mid-1990s, key leaders in Greensboro were eager to form alliances between under-resourced communities and well-established organizations. With the mayor calling for partnerships and a local college and foundation willing to commit to meaningful community-driven change, The Partnership Project (TPP) was formed. A nonprofit dedicated to resolving a wide range of issues related to racial health disparities, TPP remains grounded in Greensboro's communities. It now has a long history of offering workshops to build people's capacity to understand and address structural and institutional racism and of building coalitions and strategies to define and resolve specific problems.

Racial disparities in healthcare, well-being, and longevity were on TPP's radar from the beginning, but they hadn't gained much traction beyond some healthcare professionals and concerned community members attending workshops. Then, in 2003, inspired by the Institute of Medicine's report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*,[17] TPP approached the University of North Carolina (UNC) Gillings School of Global Public Health about tackling Greensboro's health disparities. Given the report's description of how racial hierarchies in the United States help explain inequities in the quality of healthcare provided to people of color, TPP's intent was to increase faculty involvement and engage Greensboro's communities in community-based anti-racism research that would enhance equity in race-specific health outcomes. More specifically, TPP interviewed three interested UNC faculty as potential collaborators and selected Eng for the planning grant submission that would eventually be called the Greensboro Initiative on the Institutional Dimensions of Racial and Ethnic Disparities in Health Care.

TPP was well prepared for this ambitious project. Since 1997, much of its work had been informed by the Undoing Racism training created by PISAB. The heart of the kind of anti-racism training offered in Undoing Racism is a powerful concept: "The world is controlled by powerful systems with historically traceable roots. Once people are shown how they benefit from or are battered by those systems, they can work together to change the systems."[18] PISAB fleshes this out by showing how structures built into systems, including healthcare, obstruct transparency about and accountability for racial equity.

Working together, TPP staff and UNC faculty quickly saw that PISAB's analytical approach could guide changes in cancer care. They realized that transparency in oncology and standard healthcare systems is obstructed by

- *technocratic protocols* that are applied widely to whole classes of patients regardless of their race, normalized by the system's stability and regular experience, and almost invisible because they seem so ordinary;[19] and
- *narrow knowledge*, which results from training providers and staff to play specialized roles and assigning them to "silos" of specialty divisions or units.[20]

They also saw that accountability in these areas is obstructed by

- *technical language*, such as medical jargon, code words, or euphemisms, that enables providers and staff to distance themselves emotionally from the impact of technocratic protocols on patients by disconnecting service delivery from a sense of right and wrong;[21] and
- *fragmented power* that inhibits the capacity of providers and staff to introduce systemwide reform and innovations.[22]

Based on this analysis, TPP staff and UNC faculty developed a three-phase proposal—consisting of (1) information gathering and anti-racism training, (2) a detailed examination of practices and development of new strategies, and (3) the implementation and evaluation of a new cancer care model—to be carried out over several years.

The local Community Health Foundation awarded TPP $127,573 to complete phase I from September 2003 to February 2005. Phase I established a community-academic-medical task force and engaged members in an anti-racism training; the goal was to form a research partnership that identified variables that appeared to be associated with disparate healthcare outcomes for Black patients in Greensboro and to design a study to determine whether and how these variables contributed to racial disparities in breast cancer care.[23] Critical to the success of this phase was the recruitment of 35 task force members (23 community leaders, 6 medical professionals, and 6 faculty), a process that took four months. Each member of this task force, which we called the Greensboro Health Disparities Collaborative, committed to an 18-month involvement with several components:

- Beginning with PISAB's Undoing Racism training to gain a common vocabulary and understanding of the history and culture of systemic racism in Greensboro and the United States;
- Attending monthly meetings to practice applying PISAB's racial power analysis to healthcare system change;
- Participating in study design and grant-writing activities to solicit external funding for a community-based anti-racism health disparities project focused on breast cancer care; and
- Deciding at the end of 18 months whether to continue with the work.

One goal of the course was for students to share their growing understanding of cultures, biases, and the impact of race.

In valuing experience as much as credentials, we model the partnerships we hope students will build.

During the final eight months of phase I, 17 sessions were led by the TPP-UNC team. We focused on the community-based participatory research approach, identifying factors that contribute to racial disparities in healthcare through a structured exercise of storytelling, analyzing the stories to develop potential research questions, selecting a funding mechanism, determining the healthcare outcome, and working in proposal writing subgroups and a proposal reading subgroup to develop our research project. All of the subgroups included at least one faculty member, at least one health professional, and several community members. The collaborative also convened two meetings with administrators at Greensboro's cancer hospital (Cone Health Cancer Center at Wesley Long) to elicit feedback and support for the study and request access to breast cancer registry data for the proposed community-based anti-racism cancer health disparities project.

We submitted the project, called the Cancer Care and Racial Equity Study (CCARES), to the National Cancer Institute (NCI) for funding in February 2005. The goal of CCARES was to investigate complexities of how breast cancer care was organized within Greensboro's cancer hospital, including the nuances of technical language and technocratic protocols, to help explain racial disparities in delay and discontinuation of breast cancer care.[24] While awaiting NCI's decision, the collaborative continued meeting monthly, promoting anti-racism training through outreach education, and developing bylaws so that we could be transparent about our decision-making processes and hold one another accountable in our pursuit of equity as a collaborative.

As phase I wound down, only one of the original 35 members of the task force decided not to continue (due to a budget disagreement). Those who continued crafted and signed a contract to indicate commitment to the collaborative's guiding principles and mission: to establish structures and processes that respond to, empower, and facilitate communities in defining and resolving issues related to disparities in health.

CCARES was funded in July 2006 by NCI, thus beginning phase II. In this phase, we reviewed the hospital's breast cancer registry data for 2001 and 2002, focusing on breast cancer treatment delivered to 853 Black and white patients, ages 40 and older, diagnosed with stage 1 or 2 disease. From this registry, 50 patients (46 percent Black, an intentional oversample) were randomly selected to complete two consecutive "critical incident technique" (CIT) interviews with collaborative members, who had been trained in CIT interviewing and analysis.

Here are several key findings that guided our work to develop a new cancer care model.

- Analyzing the registry data, we found racial differences in histological tumor grade, surgical outcomes, insurance status, and physician recommendation of hormone therapy, chemotherapy, and/or radiation therapy. We were not able to examine associations with racial differences in outcomes because cancer registry data did not record hormone receptor status, patient refusal of treatment, dates for initiating and discontinuing or completing treatment, or dates for discontinuing follow-up care.
- In our interviews, the 50 patients described a total of 861 specific encounters as having an impact, positive or negative, on their cancer care experience.
  - Both Black and white patients reported most frequently that encounters that contributed to their completing care involved having questions answered, verbally or in writing, by someone in the system.
  - For Black patients, encounters for managing side effects or complications from treatment had strong positive impact. For white patients, being satisfied with their interactions with doctors and staff had strong positive impact.
- Our interviews also revealed that 14 patients (4 Black) had delayed or discontinued their treatment or follow-up care, and they described 252 encounters related to these decisions.
  - The encounters reported most frequently by Black patients involved inattention to personal and emotional reactions to disease and treatment and minimal or no consideration for financial/insurance constraints.
  - White patients were most often negatively impacted by inadequate management of side effects or complications from treatment.

These findings revealed shortcomings in the cancer registry data related to which patients delayed or discontinued their breast cancer care. As to why, the CIT findings described subtle but important racial differences in impacts of patient encounters with the various systems of care. Overall, phase II pointed to the need for prospective studies that record patient encounters with the various systems of cancer care during treatment to identify systemic causes for less-than-optimal care for Black patients.[25]

Based on these findings, the collaborative began in June 2009 to design a healthcare system change intervention to reduce racial disparities in the quality and completion of early-stage cancer treatment. Collaborative members expressed two concerns: (1) by confining the study to breast cancer patients, the effect of racism could be eclipsed by sexism in the cancer care system; and (2) the cancer hospital in Greensboro is not attached to an academic center, which could limit the transferability of our study's findings. Hence, we decided to include early-stage lung cancer patients and to add a second site, the Hillman Cancer Center at

the University of Pittsburgh Medical Center (UPMC), where a postdoctoral fellow who had worked on CCA-RES had secured a faculty appointment.[26]

Phase III was the intervention trial, called Accountability for Cancer Care Through Undoing Racism and Equity (ACCURE). It was funded in June 2012 by NCI. This five-year study used information gleaned from patients in CCARES to develop a system-change intervention to address disparities in completion of care for white and Black breast and lung cancer patients with stage 1 and 2 diagnoses. The additional site allowed us to compare an academic research cancer center (UPMC) in a large northern city with a regional cancer center (Cone Health) in a small southern city. If found effective in both locations, the intervention might have transferability to other healthcare systems.

The collaborative followed the community-based participatory research approach and used anti-racism principles of accountability and transparency to design the ACCURE intervention; community, academic, and medical partners shared power in every step of the process so that academic and community perspectives and priorities were carefully integrated.[27] As displayed in the ACCURE Conceptual Model diagram below, this anti-racism intervention focused on improving the quality and completion of care in these systems for all patients, regardless of their race.

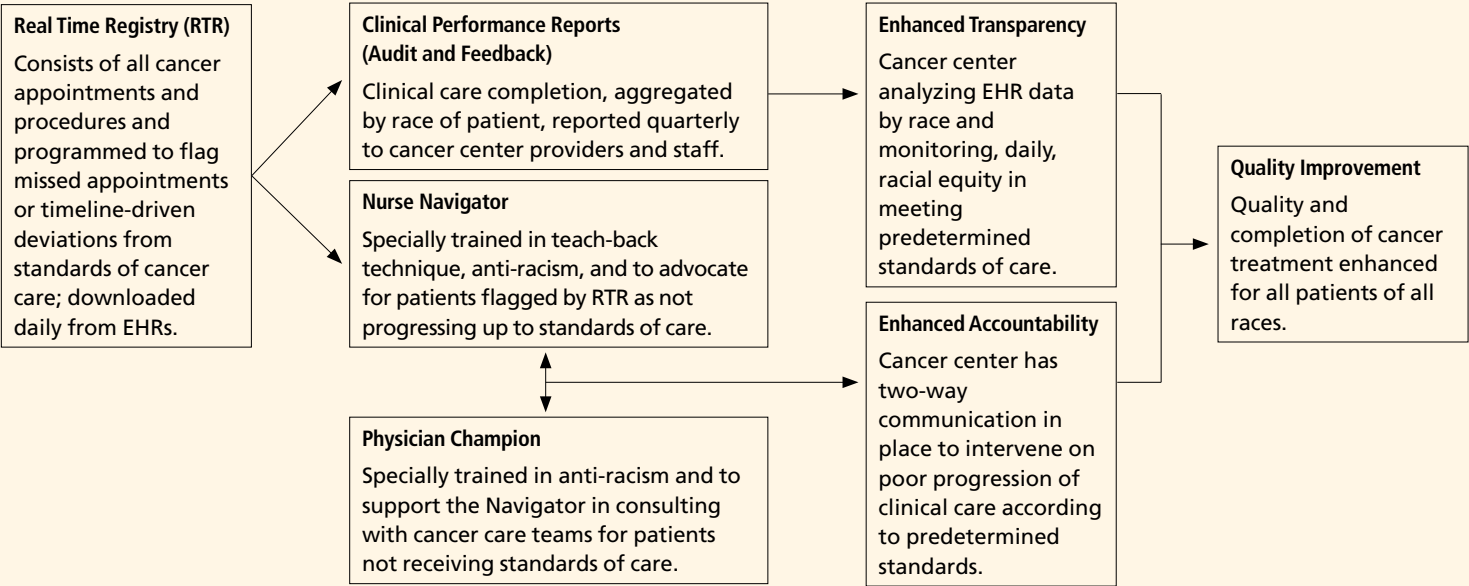The intervention had four specific components:

- Real Time Registry: ACCURE applied meaningful use of electronic health records (EHRs) to the sys-tem's problem of incomplete data. We developed a real-time warning system derived from EHRs, downloaded at the end of each day, to identify patients who missed appointments and those who were not on schedule to reach anticipated milestones in standards of care. The next morning, when the ACCURE nurse navigators (described below) logged into the real-time registry, they would be able to see which patients the system had flagged for follow-up.

- Clinical Performance Reports: To ensure that EHR data were analyzed by race, the ACCURE physician champions (described below) distributed quarterly clinical performance reports about patients' missed appointments and treatment milestones, broken down by race, to clinical teams.

ACCURE Conceptual Model

Real Time Registry (RTR)

Consists of all cancer appointments and procedures and programmed to flag missed appointments or timeline-driven deviations from standards of cancer care; downloaded daily from EHRs.

Clinical Performance Reports (Audit and Feedback)

Clinical care completion, aggregated by race of patient, reported quarterly to cancer center providers and staff.

Nurse Navigator

Specially trained in teach-back technique, anti-racism, and to advocate for patients flagged by RTR as not progressing up to standards of care.

Physician Champion

Specially trained in anti-racism and to support the Navigator in consulting with cancer care teams for patients not receiving standards of care.

Enhanced Transparency

Cancer center analyzing EHR data by race and monitoring, daily, racial equity in meeting predetermined standards of care.

Enhanced Accountability

Cancer center has two-way communication in place to intervene on poor progression of clinical care according to predetermined standards.

Quality Improvement

Quality and completion of cancer treatment enhanced for all patients of all races.

- Nurse Navigators and Physician Champions: To improve communication between and among patients, nurses, and doctors, each site had an ACCURE nurse navigator and physician champion specifically tasked with advocating for patients. They completed PISAB's Undoing Racism workshop and were specially trained in particular systemic barriers and beliefs that can limit care for Black patients; they were also trained on how to use the real-time registry.
- As the ACCURE model was being implemented, six equity education and training sessions were held with medical and administrative staff. These sessions allowed the ACCURE team to report progress, including preliminary findings, and elicit feedback. These sessions also covered anti-racism concepts such as implicit bias and institutional racism.[28]

Community, academic, and medical partners shared power so that each group's perspectives and priorities were integrated.

The ACCURE study was a pragmatic trial designed to provide results that could be applied to real-world clinical practice. It was community-based, used broad enrollment criteria, involved treatment by usual care providers in typical cancer care settings, and used study tools and personnel that could easily fit routine clinic workflows. ACCURE also included an embedded randomized controlled trial. Results showed both higher rates of completion of care among Black and white patients and success in closing the gap in completion of care for Black and white patients. At baseline, 87.3 percent of white patients had completed cancer treatment as compared to 79.8 percent of Black patients, which was statistically significant. After the intervention, 89.5 percent of white and 88.4 percent of Black patients completed treatment, which was not statistically significant (indicating parity).[29]

Phase III was completed in March 2018. The collaborative continues to work with both sites to sustain the ACCURE intervention so that it can be applied to the entire cancer center population, adapted for treatment of other cancers that require more modalities and steps, and expanded to more chronic conditions (such as anti-estrogen therapy in breast cancer) and

to the management of other chronic diseases. The collaborative also continues to advocate for system changes to eliminate impacts of racism in other ways.

Lessons Learned

From these two cases of community-driven anti-racism partnerships, we draw the following five lessons, which we believe are transferable to other settings, populations, and public health issues.

Remain community focused and value all participants' expertise. When the intention is to guide the development of a collaboration to document and address the impacts of systemic racism, consider following the principles of community-based participatory research:[30]

- Design interventions with the community to enhance knowledge and promote change in ways that benefit the community;
- Establish norms of partnership that emphasize mutual respect and recognition of the knowledge, expertise, and resource capacities of all partners in the process; and
- Be committed to engaging in open communication.

In Michigan, one of the main objectives of the academic course was to prepare students to be change agents in communities to promote anti-racism initiatives. A member of the local African American community (Greene-Moton) brought her community knowledge and lived expertise into the classroom in her role as co-instructor, which added to the authenticity of our interracial dialogue. In North Carolina, the Greensboro Health Disparities Collaborative explicitly employed community-based participatory research principles regarding decision-making power and governance when developing its bylaws and when proposing, designing, and implementing its anti-racism research project.

Create a brave space, in which cultural humility is practiced and nurtured, by anticipating and embracing disagreements and recognizing that conflict is necessary for meaningful change to occur. After the members of the North Carolina collaborative's phase I task force developed and signed a Full Value Contract documenting their commitment to the collaborative's mission, that process continued annually. By signing, collaborative members indicated their commitment to the partnership's 15 core values: conflict, humility, mutual respect, a willingness to stay at the table, speaking from our own experience, perseverance, teamwork, humor, critical listening, accountability to team members and to the team, fun, honesty, a willingness to be uncomfortable, confidentiality, and acknowledgment of people's strengths. These values were an explicit reminder of how to accomplish the goals that we set

together. The Michigan partnership practiced cultural humility and encouraged respectful conflicts within the classroom. Although the specific issues vary with each group of students, every time the course is taught the students are engaged in developing ground rules for open, civil discussions of disagreements.

Establish and work from a common vocabulary of anti-racism to enable discussions of structural racism and white supremacy. Members of the partnerships in both Michigan and North Carolina completed anti-racism workshops conducted by the People's Institute for Survival and Beyond. For the collaborative, the rationale was that in order to study the historical origins and current manifestations of systemic racism, members needed to gain a common language and vocabulary. For health disparities researchers and practitioners, studying racism is as essential as studying biology is for medical scientists and clinicians. To this day, completing anti-racism training is required for new members to join the collaborative. For the Michigan course, the planning team found the Undoing Racism workshops invaluable for thinking through both the content of the course and the most respectful processes for encouraging discussions of highly charged topics. In addition, students in the course have been invited to complete anti-racism training to deepen their understandings and, thereby, reduce resistance to concepts such as white privilege and internalized racial inferiority.

Elevate the community voice to leadership roles within the partnership; recognize community partners' needs and make the work sustainable, while holding all partners accountable. For the course, a community member was (and still is) a paid co-instructor serving as a liaison between the instructional team and community partners. For the collaborative, the bylaws stipulate that the chair position can be filled only by a community partner, and all committees (e.g., outreach, membership, publications, social media, and ad hoc) must include community partners.

Recognize that these partnerships are fluid and dynamic, reflecting continual changes in membership and requiring orientation and reorientation while also necessitating institutionalization of processes. As the demand for the Michigan course increased, new instructor pairs were hired. The selection process included an orientation to ensure that the instructors had the experience and commitment to fulfill the objectives of this course. The North Carolina collaborative amended its bylaws to establish a "Friends of the Greensboro Health Disparities Collaborative" membership category for those who experienced a life course transition, such as retirement or illness, and could no longer be fully active. Friends still receive collaborative minutes and mailings. For new members, the collaborative's Membership Committee developed an orientation video on the partnership's history and a "buddy program" to pair each new member with a current member.

We began this writing journey recognizing an opportunity introduced through the Community-Based Public Health Initiative in 1991, which planted enduring seeds in our communities. These models advocated for an engagement between academia, public health practitioners, and communities, brokering relationships that would inevitably grow into lasting partnerships. We found that these partnerships were most often formed and bounded by deliberate practices and guidelines developed and adopted by all the participants in those groups, based on shared language and agreed-upon values. The synergy that resulted was the product of our hard work and our commitment to the partnership, which were possible because we recognized that "we are stronger and better when we work together."[31] ✦

When all participants commit to doing hard work together, lasting partnerships can form and communities can begin to heal.

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Improving Care of LGBTQ People of Color

Lessons from the Voices of Patients

By **Stephanie Bi, Scott C. Cook,** and **Marshall H. Chin**

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I n a recent interview, Vita—who identifies as Black, trans, nonbinary, mentally disabled, pansexual, demisexual, and femme—powerfully highlighted how living in a world that is structured against her has harmed her health.

One of the ways I think being a Black pansexual trans woman affects my hypertension directly is stress.... I hadn't had super high blood pressure until I came out.... It's a mental exercise to leave the house now, you know, and to feel confident enough that you would get from point A to point B and back to point A safely.... On a racial level, there's a societal stigma that Black people aren't intelligent.... I've noticed a very real sense of entitlement in medical health professionals and mental health professionals around hypertension, around STI [sexually transmitted infection] prevention.... "I'm a doctor. I know more than you, period. So here's what you're going to take."

For Vita, her Blackness and transness are necessarily intertwined, and both affect how she navigates through the world. During the interview, she also noted that she knows a great deal about her own lived experiences and needs, which contributes to her frustration when clinicians unilaterally decide they know what is best for her. They fail to understand who she is, what she knows, or how to help her.

Vita's experience is too common. Few care team members have received training in how to care for lesbian, gay, bisexual, transgender, and questioning and/or queer (LGBTQ) people of color. All too often, LGBTQ people of color receive poor-quality care and have negative experiences interacting with the healthcare system.[1] Not surprisingly, they may delay or avoid care, and many may feel unsafe disclosing their sexual orientation or gender identity to health providers.

Having long been marginalized, LGBTQ people tend to carry greater burdens and to endure greater power imbalances in society at large and with their care teams. As a result, they have higher rates of many conditions—including mental health disorders, suicidal behaviors, substance misuse, HIV, and diabetes—compared with their heterosexual peers, and they need competent, high-quality care.[2] LGBTQ people of color often face the highest rates of these conditions

(due to how society reacts to their intersecting identities, leading to greater marginalization); they are less likely than white LGBTQ individuals to seek preventive care, have a regular health provider to help them manage chronic health conditions, or have health insurance.[3]

The onus should not be on patients to effectively navigate a complex healthcare system that, all too often, does not welcome their multifaceted identities. LGBTQ patients of color like Vita deserve our full attention and need our best efforts. As healthcare providers, we should educate ourselves about the issues they face and strive to improve our care. Fortunately, Vita and her peers give us a starting place: listening to them. By sharing their stories and recommendations, Vita and her peers also remind us that they are resourceful, strong, and capable individuals who have the lived experience and expertise to help us improve the healthcare system.

Our group at the University of Chicago has been studying how to improve shared decision making between clinicians and LGBTQ people of color through our Your Voice! Your Health! project.* We have performed and analyzed individual interviews and focus groups with more than 200 LGBTQ people of color. Our article shares the voices and experiences of these individuals and draws heavily from the lessons learned from this work. After a brief history and some terminology, we describe what we have learned about shared decision making. In sidebars, we also suggest ways to make the clinical environment more welcoming and offer training resources for clinicians, including opportunities to become advocates.

A Brief History of LGBTQ People of Color in the United States

The movement for LGBTQ rights and well-being began as early as 1924, when the Society for Human Rights was established in Chicago, the first gay rights organization in the United States. Like the civil rights movement focused on reducing anti-Black racism and dismantling Jim Crow, the gay rights movement in the United States grew in the years after World War II as LGBTQ people faced increasing hostility from the government and the medical establishment; thousands of people lost their jobs, and many others were imprisoned, committed to institutions, or forced to endure "treatments" such as castration and electric shock therapy.[4] LGBTQ people of color, subject to not only racial but also sexual and transgender discrimination, faced even greater barriers to acceptance than their white peers.[5]

There is a significant history of nonviolent protest and civil rights advocacy by LGBTQ individuals in the 1950s and 1960s. In many ways, these pushes for equality were quite similar, but the challenges were so great that the movements did not publicly unite. For example, Bayard Rustin was an essential leader for several decades in the fight for racial equity. He was an advisor to Rev. Dr. Martin Luther King Jr. and an organizer of the March on Washington for Jobs and Freedom (among many other accomplishments). But as a gay man, he was kept in the background out of fear that his sexuality would detract from the racial justice cause. People of color were similarly sidelined in the gay rights movement; the leaders of the largest organizations were predominantly white, and the focus on decriminalizing homosexuality centered on images of white men, ignoring the disproportionate effects of police brutality and other violence experienced by LGBTQ people of color.[6] Still, roughly parallel progress was made, often with advocates for gay and trans rights adopting strategies successfully pioneered by Black activists in the fight for racial justice.[7]

Not long after landmark civil rights legislation passed, the LGBTQ movement gained significant momentum with the 1969 Stonewall Uprising in New York City, when people protested the police raiding the Stonewall Inn, a gay club in Greenwich Village. Such raids were frequent throughout the country at locations where LGBTQ people gathered. The names of those arrested were often published in newspapers, resulting in many individuals losing their jobs. Marsha P. Johnson, a Black transgender woman, and Sylvia Rivera, a Latina transgender woman, were two of many pivotal leaders of color in the Stonewall Uprising and the broader gay liberation movement.[8]

Today, there is broader recognition of how these struggles are connected as the fights for racial, sexual, and gender equity continue.[†] Although President Biden signed an executive order expanding protection for LGBTQ individuals against discrimination in employment to also include domains of healthcare, housing, and education,[9] multiple states continue to attempt to pass anti-LGBTQ legislation,[10] and discrimination and violence against LGBTQ persons of color are all too common. For example, at least 44 transgender or gender nonconforming individuals, largely Black and Latinx transgender women, were murdered in 2020, with likely more deaths unreported. According to the Human Rights Campaign,

> Some of these cases involve clear anti-transgender bias. In others, the victim's transgender status may have put them at risk in other ways, such as forcing them into unemployment, poverty, homelessness and/or survival sex work.

"I hadn't had super high blood pressure until I came out.... It's a mental exercise to leave the house now."
—Vita
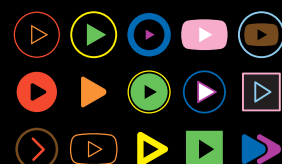
Watch Vita, Don, Reyna, Sam, and Aurora tell their stories by going to go.aft. org/tri and downloading the videos in the Appendices box on the right side of the page.

While the details of these cases differ, it is clear that fatal violence disproportionately affects transgender women of color—particularly Black transgender women—and that the intersections of racism, sexism, homophobia, biphobia, transphobia and unchecked access to guns conspire to deprive them of employment, housing, healthcare and other necessities.[11]

LGBTQ Terminology and Concepts 101

I think it's important on multiple levels for my healthcare provider to know about my gender identity and gender expression.... What would be more important to me is that they have a context for that.... Rather than it being on me to disclose that, ... doctors and providers [should] already have an awareness around issues.... I would want a doctor to understand that there's ... a spectrum.... Not all trans masculine people are going to identify as traditionally masculine.

—Sam (Asian American, Taiwanese American, biracial, queer, pansexual, trans, transmasculine, genderfluid, genderqueer)

To provide high-quality care for LGBTQ people, it is important to understand basic definitions and concepts related to sexual orientation and gender identity.* The table on page 25 introduces widely used terms and essential concepts. Keep in mind that aspects of sexual orientation and gender identity will change for some people over the course of their lives, including later stages of life. Some people may also experience one or more periods of exploring, or being unsure about, different aspects of their sexual orientation or gender identity.

Intersections of Race, Ethnicity, Sexual Orientation, and Gender Identity

Rooted in Black feminist theory and drawing upon earlier work by Anna Julia Cooper, W. E. B. Du Bois, and others, law professor Kimberlé Crenshaw describes *intersectionality* as how multiple identities and systems of oppression (e.g., racism, sexism, homophobia) interact, giving us an understanding of individuals and their multifaceted identities that we could not gain by examining each identity or system of oppression on its own.[12] For example, a Black lesbian person may navigate the world in a different way than a Black straight woman or a white lesbian person, and in an altogether different way than a white straight woman or man.

Intersectional theories state that failure to recognize and address the powerful effects of structural racism, discrimination grounded in cultural norms for

*This video (go.aft.org/fp8), created by the New York City Health and Hospitals Corporation, explains why knowing about a patient's sexual orientation and gender identity is as important for their care as knowing their blood pressure and temperature.

gender expression, or other systemic forms of oppression of marginalized populations prevents clinicians and healthcare systems from providing the best care to LGBTQ people of color.[13] Consider the challenges that Aurora and Don face.

The only thing I had out there to go to ... [were] nightclubs or bars; and the bars that were available, they were predominantly white.... In the Latino community, ... you're a female or a male, and you do certain things a certain way as a male or a female. You look a certain way as a male or a female, and I bend all those rules.

—Aurora (Mexican American, Latina, lesbiana, lesbian)

Being African American has been the predominant identity in my life—not just for me, but in terms of the way people identify me and interact with me.... Race is really a very strong determinant of my interactions in society. I have been aware of mortality and threats to life for a long time, everything from lynching to neighborhood shootings; there's a constant threat to life and safety for African American men.... I have never been, in the LGBT community, just *a gay man. I have always been a* Black *gay man. And that has determined in most cases how people interact with me. For a very long time, Black men were generally not particularly welcome on the strip, on Halsted Street, in the center of the geographic [Chicago] gay community.*

—Don (cisgender, profeminist, gay, single-gender-loving man of African descent)

Different identities can vary in importance and can vary by context. Aurora identifies as Latina, but she has struggled to find a Latina lesbian community and to be accepted in the broader Latinx community. Don states that being African American has been his most predominant identity, and that he has experienced racism in both heterosexual and homosexual communities. As a healthcare provider for Aurora or Don, how would you seek to understand their lived experiences in all of their complexity? How would you help reduce the stressors they face?

Clinical Best Practices for Shared Decision Making

There is so much stigma associated with being trans, especially a trans woman of color, and a lot of times they [healthcare providers] push that stereotype upon you. The biggest one, obviously, is HIV in our community as trans-identifying people, especially trans women of color.... It's a terrible thing when you go into an office and they are giving you all these little signs and you're internalizing them, and you're like, they think I'm positive. Or they're just already assuming that I'm HIV positive as a trans woman ... or that we're completely infected with every STI available. They put the gloves on right away.... They don't think we see that—we do. It's a big reason why [there is] a lot of distrust in the medical field.... It's insulting.

—Reyna (Latina, transsexual)

Basic LGBTQ Terms and Concepts

Sex	Sex assigned at birth, typically conceptualized as male, female, or intersex (not fitting the typical definitions of male or female bodies).
	Intersex is an umbrella term for differences in sex traits or reproductive anatomy. Intersex people are born with these differences or develop them in childhood. There are many possible differences in genitalia, hormones, internal anatomy, or chromosomes, compared with the usual two ways that human bodies develop. Sometimes you will see the acronym LGBTQI. The "I" refers to intersex people.*
Sexual Orientation	An individual's attraction, behavior, and identity related to sexual desire.
	The attraction component of sexual orientation consists of the sexes and genders of the people we find attractive. The behavior component consists of the sexes and genders of people with whom we have sex. The identity component consists of the way that we describe our sexual orientation to others.
	Terms to describe sexual orientation include but are not limited to asexual, bisexual, lesbian, gay, queer, pansexual, demisexual, and straight.
Gender Identity	A person's internal sense of their gender.
	Everyone has a gender identity. Most people have an internal sense of gender that aligns with their sex assigned at birth. Some people experience their internal sense of gender as neither male nor female, but something in between. Some people have an experience of their gender that shifts or changes over time. And others report feeling no internal sense of gender.
	Terms to describe gender identity include but are not limited to man, woman, trans, transgender, genderqueer, genderfluid, gender nonconforming, and nonbinary.
Gender Expression	How an individual presents their gender identity (speech patterns, clothing, mannerisms, hairstyle, etc.).
	There are spoken and unspoken cultural norms regarding how people express their gender. Clothing, hairstyles, leisure activities, vocations, and body language are often associated primarily with binary male or female gender. Family and community members often respond negatively, from mild nonverbal expressions of disapproval to assault or homicide, when individuals do not conform to expectations regarding gender expression.
	Terms to describe gender expression include but are not limited to masculine, feminine, femme, butch, androgynous, and nonconforming.

Transgender	Describes an individual whose gender identity does not align with their sex assigned at birth.
	For example, someone who was assigned female sex at birth but has a gender identity of male might describe himself to others as a transgender male or man, or trans male or man, or transmasculine. This term is not to be used as a noun (e.g., "the transgenders" is inappropriate).†
Cisgender	Describes an individual whose gender identity aligns with their sex assigned at birth.
	For example, someone who was assigned female sex at birth and has a gender identity and expression of female (i.e., whose internal sense of gender and gender expression aligns with cultural norms for femininity) might describe herself as cis or cisgender.
Queer	Queer is a complex concept. There are many ways that people use the term queer to describe one or more aspects of their identity. For some, queer can be an umbrella term for sexual and gender minority people (i.e., people who are not part of the cisgender and/or heterosexual numerical majority). For others, queer can be a sexual orientation or gender identity distinct from other terms such as gay or lesbian. Some people may use the term in yet other ways.
	Of note, the term queer has historically been used as a slur. However, many in the LGBTQ community have reclaimed the term and use it in an affirming way to describe their gender and/or sexual orientation. For some, the use of the term can help them avoid stereotypes held by others regarding terms such as gay, lesbian, and bisexual. Others may use the term to affirm aspects of their identity that are nonbinary or may shift over time.
	If you have a patient who identifies as queer, you can respectfully ask them what it means for them personally, if you need to know in order to provide them with high-quality healthcare (and not just for your own curiosity).
	Do not assume that every LGBTQ patient will identify as queer or will welcome people who do not identify as queer using the term. For example, some patients may react negatively to being referred to as queer due to past or current bullying, abuse, or assault by others who used the term to degrade and dehumanize them.

*To learn more about intersex people, visit the InterACT website: interactadvocates.org/faq.
†The National Center for Transgender Equality has a user-friendly resource hub called "About Transgender People" where you can learn more: transequality.org/about-transgender.

"Some trans women don't see a doctor until they're practically dying."
–Reyna

Pause for a moment to imagine your first encounter with Reyna. What assumptions have you made based on her appearance—and how can you let go of them? What is your body language conveying? Are you ready to listen to Reyna, to appreciate her humanity, and to engage with her as an equal partner in making choices about her health?

Shared decision making is a patient-provider communication tool that takes into account a patient's needs and preferences and supports their participation in decisions about their care.[14] It has been conceptualized as having three domains: information sharing (the clinician and the patient share information with one another about the health condition and illness), deliberation (the clinician discusses different treatment options and elicits the patient's preferences, needs, support structures, and goals), and decision making (the clinician and the patient make decisions together on the approach to health and treatment). Disparities in how well clinicians engage LGBTQ patients in making decisions about their health may contribute to the difficulties LGBTQ people of color face in accessing care and obtaining appropriate treatment for physical and mental health conditions.

We have drawn upon our Your Voice! Your Health! project and our prior papers to develop the following suggestions to help clinicians improve their communication and shared decision making with LGBTQ people of color.[15] Most of the lessons come directly from the LGBTQ people of color we interviewed about their experiences receiving healthcare. We cover (1) educating clinicians, (2) establishing safe spaces, and (3) asking questions. In addition, the table on page 27 provides specific advice with examples.

Educating Clinicians

One of the best ways to improve the quality of care you provide to LGBTQ people of color is to learn more about them and get to know them. For examples of steps you or your healthcare organization can take, see the table on page 27. In general, attempt to take on your patients' perspectives, keeping in mind their intersecting identities. Learn to look for and recognize your personal responses, thoughts, and feelings regarding sexual and gender minority patients of color that are based on stereotypes. And remember that many LGBTQ people, and many people of color, have experienced discrimination and culturally incompetent healthcare. Some LGBTQ people, especially transgender patients, have been abused in healthcare settings.[16] Gaining the trust of LGBTQ people of color who have been discriminated against or abused in healthcare settings is especially challenging—but that makes it all the more important.

The LGBTQ people of color we interviewed asked that healthcare providers:

- Learn the basics of care of LGBTQ persons.

"Well she knows what gay means, and she knows what like bisexual means ... [but not queer]. Do I really want to go to a therapist where ... I have to spend half the time trying to teach them ... [about] my issues?" (Korean/Korean American gay/queer trans male)

- Recognize the heterogeneity within LGBTQ people of color communities.

"Understand that the LGBTQ community is just not under one umbrella.... I mean, a queer Asian man is going to have a different experience from a queer Black female." (Queer multiracial Asian man)

"It's one thing to be identified as Asian American, but there are still differences between like Southeast Asian, South Asian, and everything else as well too. So it's not a one size fits all." (Filipino American gay male)

- Be cognizant of intersecting identities.

"It's not like I'm choosing to be Black on this day and I'm choosing to be gay on this day, but both are facets of who I am." (Black gay male)

"The South Side, where I grew up, it's very homophobic.... We're really into the church and condemnation about homosexuality.... I had an aunt that told me ... 'I don't mind you people being gay, but why do you have to march in that parade where everybody can see you?' ... If you are gay, you have to keep it in the closet and act like a straight man." (Black gay man)

- Be aware of implicit and structural biases.

"They [providers] automatically assume that all gay men ... receive anal sex. Some people assume that gay men are just so promiscuous, and we're just out here doing any and everybody." (Black gay man)

"As somebody with ... a Mexican last name and as a Mexican person, I think folks ... will raise their eyebrow about ... the fact that I'm bringing in a passport [as a form of identification]. Like, is this a cover up? Is this somebody who's ... using a false document? ... Which is funny because ... my motivation to use it is actually about my gender identity!" (Latinx transgender man)

"My provider would make assumptions about me just because of my race and my being transgender. Like, 'Oh, so are you a sex worker? Are you this, are you that?'" (Black transgender woman)

"You have more of a positive image tied to you as a white trans person than a Black trans person ... because of how Black trans people are portrayed so often. We're always seen as like the worst possible versions of ourselves." (Black transgender woman)

Recommendations for Healthcare Teams

Advice	Examples
Reflection, Empathy, and Partnership	
Understand how marginalization and discrimination may have affected your patients	• Some patients have experienced sexual abuse, rape, or other violence or trauma perpetrated by others in response to their sexual orientation or gender identity. • Some patients have had prior discriminatory healthcare experiences that affect their current fears and expectations of your healthcare team. • Do not focus on sexual orientation or gender identity if it is not relevant to your patient's presenting health concerns. • Family, friends, and spiritual organizations may have rejected, ostracized, or abused patients due to their sexual orientation or gender identity.
Understand intersecting identities; avoid assuming that different subgroups of sexual and gender minority populations have similar life experiences and healthcare needs	• Many sexual and gender minority patients hold multiple marginalized identities that affect their status in society generally and their healthcare experiences and outcomes specifically. • Do not expect gender and sexual minority patients to have similar beliefs, values, needs, or life experiences. • Terms describing sexual orientation and gender identity can vary by race, ethnicity, socioeconomic status, or other demographics and can change over time. • Symbols of acceptance and pride in sexual and gender minority communities can also vary in importance and meaning for different racial and ethnic groups and different individuals.
Recognize and reduce personal and team biases	• Interact directly with sexual and gender minority individuals and groups and approach these interactions with humility, knowing you have much to learn. For example: 　▪ Invite people with minority sexual and gender identities to give presentations on how to provide culturally competent and relevant healthcare for them. 　▪ Partner on a healthcare or research project with sexual and gender minority individuals and encourage them to take a leadership role.* 　▪ Attend a conference on sexual and gender minority health and engage in active discussion with sexual and gender minority attendees. 　▪ Spend time in activities or organizations where heterosexual/cisgender individuals and sexual and gender minority individuals relate with each other cooperatively, interactively, and as equals (e.g., sports teams, community volunteering). • Interact indirectly with sexual and gender minority individuals and groups. For example, discuss a book or documentary that positively and empathetically portrays sexual or gender minority individuals. • Avoid attempts to be "colorblind" or to see everyone as the same. Instead, seek specific information about individual patients or community members.
Language, Knowledge, and Environment	
Strive to become culturally competent and sensitive with terminology and language	• Patients sometimes reject labels. Allow them to choose their own terms to describe their sexual orientation, gender identity, and partners. • Transgender patients should be identified with preferred names and pronouns, even when they are not present. • Avoid language that makes assumptions about sexual orientation or gender identity: 　▪ Instead of "Do you have a husband?," ask "Are you in a relationship?" 　▪ Instead of "How may I help you, ma'am?," ask "How may I help you?" 　▪ Instead of "She is here for her appointment," say "The patient is here for their appointment." 　▪ If you are unsure about a patient's name or pronouns, say "I would like to be respectful. What name and pronouns would you like for me to use?" 　▪ If you accidentally use the wrong term or pronoun, say "I'm sorry. I did not mean to be disrespectful." 　▪ If a patient's name does not match insurance or medical records, you can ask "Could your chart/insurance be under a different name?" or "What is the name on your insurance?" • Pay attention to your body language and facial expressions.

Adapted from S. C. Cook, K. E. Gunter, and F. Y. Lopez, "Establishing Effective Health Care Partnerships with Sexual and Gender Minority Patients: Recommendations for Obstetrician Gynecologists," *Seminars in Reproductive Medicine* 35, no. 5 (2017): 397–407, copyright © 2017 by Thieme Medical Publishers, Inc., www.thieme.com (reprinted by permission).

*For more on the importance of cultural humility in partnering with communities to address health disparities, read "Brave Spaces: Community-Driven Anti-Racism Partnerships" on page 12.

"Whiteness in general carries a certain amount of benefit of the doubt. So I think there would be less doubt about the validity of my identity in general [if I were white]." (Latinx masculine gender-nonconforming person)

- Avoid using patients as learning tools.

"They're using me as a way to learn for themselves.... Especially first-year residents.... 'How does a guy put a penis in another guy, doesn't that hurt?' These aren't appropriate questions.... It's basically irrelevant questions ... either about my racial identity or my sexual identity." (Mixed Filipino queer cis man)

Establishing Safe Spaces

Before healthcare providers can effectively create safe spaces (i.e., spaces in which patients will feel good about sharing their identities), they must grasp the cultural diversity that exists within LGBTQ populations. For example, within the Latinx LGBTQ population, here are several key factors that may affect care for some but not all patients:[17]

- limited English proficiency and/or undocumented immigration status
- family stigma and lack of social support (e.g., around issues such as cultural expectations of masculinity or femininity)
- interest in using alternative therapies, such as visiting curanderos or botánicas offering herbal and folk remedies[18]
- traditional perceptions of the clinician-patient relationship that rely on patients' deference to medical authorities, which may hinder open communication and shared decision making
- strong religious beliefs

And here are some related and some unique factors that may affect some Asian American LGBTQ patients:[19]

- new or recent immigration, limited English proficiency, and/or varying levels of acculturation
- family stigma and conflicts with family and community about cultural norms related to sexual orientation and gender identity
- stereotypes related to race, ethnicity, and gender (e.g., model minority; perpetual foreigner; emasculated Asian man; exoticized, submissive Asian woman)*
- invisibility of Asians in the United States, predisposing them to institutionalized, personally mediated, and internalized racism

*Visit these sites to learn more about the history of anti-Asian racism and the model minority (go.aft.org/mdb), perpetual foreigner (go.aft.org/njw), emasculated Asian man (go.aft.org/2sq), and exoticized, submissive Asian woman (go.aft.org/m1y) stereotypes.

"There's ... a spectrum.... Not all trans masculine people are going to identify as traditionally masculine."
–Sam

Although this is just a small sample of the cultural knowledge clinicians need to cultivate, we hope it shows how cultures impact lived experiences and thus healthcare needs. Still, while it is helpful to be aware of common threads across patients, healthcare professionals must individualize care to specific patients, avoiding stereotypes.[20] In addition, it is our responsibility to reform systems of care delivery to better meet patient needs rather than putting the onus of responsibility on, or blaming, the patient (e.g., complaining that a patient has limited English proficiency or cultural norms that differ from our own).

With this understanding of the groundwork that clinicians need to do, here are some suggestions from the LGBTQ people of color we interviewed:

- Take the initiative to be welcoming.

"[The provider could say], 'I'm open about your sexual identity. It's an open space, and we're not going to feel pressured if you don't want to talk about it.'" (Chinese gay male)

"We already ... have issues with healthcare providers.... A lot of people are just uncomfortable disclosing ... their sexual identity." (Black gay man)

- Be aware of the bidirectional implicit biases and fears that may exist between clinician and patient.

"I chose someone with an Asian American background, because I think there's some commonalities among Asians in terms of lived experience." (Asian Pacific Islander gay male)

"Well if the doctor is Filipino, I would generally avoid [talking about] the whole [LGBTQ] identity, because even though they're supposed to keep everything confidential, the reality is ... being Filipino is a small world, at times.... Somehow it ... gets back to my family." (Filipino American gay male)

"It's so rare to have a provider that's a person of color that I fear alienating that person. So it feels easier to just pass and maybe connect with that person from that one identity and wait to see how safe it is before disclosing the other identity." (Latinx masculine gender-nonconforming person)

- Understand that the clinician does not need to be a member of the LGBTQ population or a person of color to establish trust and rapport.

"I wouldn't say that I necessarily need to have a doctor that looks like me. But ... I need to be able to have a provider that empathizes with that I'm a person of color and that I'm transgender at the same time. That ... one doesn't cancel out the other." (Transgender woman)

"I don't care if you're Black, white, or whatever. As long as you understand the trials and tribulations

of the trans woman of color, I'm cool with you." (Latinx transgender woman)

- React appropriately.

"When I finally disclosed that I was gay, usually their body language, how they reacted towards me, did change." (Asian American LGBTQ individual)

"If I were a healthcare provider, [I] would be like: 'Yeah, we should check in with our patients more about those things [HIV risk, HIV prevention, gender identity, and sexual orientation] and hopefully that can remove the stigma a little bit.'... If we treat them as very common things that we can take care of, because human beings are human beings and this is a part of who they are, ... then maybe people would want to talk about it more often." (Black trans woman)

- Do not ignore intersecting identities or default to issues you find more comfortable.

"[The mental health provider], she'll kind of reroute back to ... it not having to do so much with identity and having to do more with like, 'Oh, well, maybe you're feeling this thing because, you know, this person just wasn't being that great of a friend to you.'... She won't use the frameworks that I have come at her with to offer something helpful back to me.... She won't reference me being queer or a person of color or a biracial person to help me understand any of what I'm coming to her with, which is strange." (Biracial queer female)

Asking Questions

Although our studies focus on many different populations, across the board LGBTQ people of color wish for clinicians to educate themselves about the history, culture, and oppression that underlie their communities. Some persons emphasized the need for providers to do this work before the clinical encounter so that the responsibility doesn't fall on the patient to explain their identities, which could erode trust in their relationship. Still, each person is unique and it's crucial to avoid stereotyping or making assumptions—so asking open-ended questions is essential.

Improving the Care Environment

I had a terrible accident, and I was just traumatized.... The [healthcare provider's] receptionist looked at me and said, "How can I help you, sir?" The pain went away and the only thing that I had was anger. I was furious that this person decided to be so blatantly disrespectful to me in a time of need.... Some trans women don't see a doctor until they're practically dying.
　　　　　　–Reyna (Latina, transsexual)

You have opportunities to help LGBTQ patients feel accepted and supported long before they enter an exam room: the physical environment, training and education of staff, and infrastructure play key roles.[1]

Physical Environment

- Display stickers or symbols (e.g., LGBTQ rainbow flags) in your rooms and on your website. Consider artwork or photos of prominent local or national leaders who are LGBTQ people of color.
- Provide pronoun pins, stickers, or tags for patients and ask staff to wear them as well. Pronouns could include she/her, he/him, they/them, or a blank space to fill in.
- Provide intake forms that are LGBTQ-inclusive (e.g., including spaces for sex assigned at birth, gender identity, and pronouns).

- Provide reading materials (e.g., in a waiting room or consultation rooms) for issues related to common LGBTQ-specific health concerns (e.g., PrEP [HIV pre-exposure prophylaxis], safer sex, hormone therapy, and mental health).
- Provide resource sheets listing community organizations that serve LGBTQ people of color.

Training and Education

- Ensure that all staff—including receptionists, interpreters, and physicians—are trained about and familiar with LGBTQ issues, as well as racial and cultural issues, such as using patients' correct pronouns and fighting for equity across their multifaceted identities. Consider partnering with community organizations led by LGBTQ people of color to conduct these trainings.
- Participate in continuing medical education on LGBTQ, racial, and cultural issues through attending conferences, workshops, etc.
- Provide clinicians with training about shared decision making with LGBTQ people of color.

Infrastructure

- Hire a workforce that is diverse in terms of race and ethnicity, sexual orientation, gender identity and expression, ability/disability, age, and more—a workforce that reflects the patients being served.
- Obtain patient feedback by maintaining a community advisory board and surveying patients about their experiences—and then make sure that feedback is taken into account.
- Consider performance-based financial incentives for reducing health disparities for patients who are LGBTQ people of color.
- Allow patients to dictate which parts of their identities they feel comfortable being documented by providers in the electronic health record.
- Use the electronic health record, as permitted by patients, to collect data about sexual orientation and gender identity, and do not be surprised if some patients shift their gender identity over time.
　　　　　　　　–S. B., S. C. C., and M. H. C.

Endnote

1. R. DeMeester et al., "A Model of Organizational Context and Shared Decision Making: Application to LGBT Racial and Ethnic Minority Patients," *Journal of General Internal Medicine* 31, no. 6 (2016): 651–62; and S. Cook, K. Gunter, and F. Lopez, "Establishing Effective Health Care Partnerships with Sexual and Gender Minority Patients: Recommendations for Obstetrician Gynecologists," *Seminars in Reproductive Medicine* 35, no. 5 (2017): 397–407.

Study participants emphasized how important they found agency in the shared decision making process, whether that related to a treatment or screening decision or setting their own priorities for a particular clinical visit. We encourage providers to empower their patients with knowledge of options and provide space for mutually respectful, bidirectional conversations—including asking questions about patients' goals, preferences, and values. The heterogeneity of LGBTQ people of color highlights the need for providers to listen to and communicate with each patient as a distinct individual who may have experiences and beliefs that align with or deviate from themes presented in the research here or elsewhere.

- Ask for the patient's pronouns; apologize if you accidentally misgender the patient.

"[After] slipping [pronouns] up, … they would just blame it … [on being] a legal thing…. [It] really deterred me from even wanting to be within any type of healthcare." (Pacific Islander, Asian queer male)

- Ask what the patient would like to talk about and address during the visit.

"I guess a lot of it is timing in terms of … shared decisions…. What I struggled with is when I have a lot of things going on, whether it's family, my partner, or identities, … [I don't know] which to focus my energy towards for that day. I can't tackle it all at once. And in terms of making those decisions with my therapist, … they are very aware." (Mixed Filipino queer cis man)

- Ask about mental health.

"At the point where your physician knows that your sexuality is different, … I would like the physician to really push the envelope and then check in more often about mental health. Because the fact of the matter is, I do feel that being these minority identities, that we do face more challenges more often." (Asian American LGBTQ individual)

- Ask if there are cultural issues to be aware of.

"The very few times [the provider] ever addressed the family issue, it's always been like, 'Why do you care what your family thinks?' … They didn't really understand or grasp how deep [family's] influence was. It was always like, I felt, especially in Asian cultures, it's like family is a very strong influence in our lives…. I was like, 'Do you not get it?'" (Asian American gay/queer male)

- Strive to understand and validate the patient's lived experience.

"You [the provider] have this training, … this expertise. But if you're looking at a human being and telling them that the things they feel and experience aren't valid all the time, then they are not going to trust you. There could be things that they don't

> "In the Latino community, … you're a female or a male, and you … look a certain way…. I bend all those rules."
> —Aurora

know about and it's your responsibility to inform that patient without contradicting them and making them feel like shit." (Black trans woman)

It's long past time to end the marginalization of LGBTQ people of color. Too often, they receive inadequate, low-quality care, and for far too long, they have endured serious health disparities. We have shared the voices of LGBTQ people of color to provide insights into the issues affecting their health and the safe spaces they need. Clinicians have exciting opportunities to make a difference—to improve their communication and shared decision making with patients, enhance the way their clinics are organized and care for LGBTQ people of color, and transform how they teach their colleagues and advocate for their patients. ✦

Endnotes

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2. US Department of Health and Human Services, "Lesbian, Gay, Bisexual, and Transgender Health," Office of Disease Prevention and Health Promotion, healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health; H. Hafeez et al., "Health Care Disparities Among Lesbian, Gay, Bisexual, and Transgender Youth: A Literature Review," *Cureus* 9, no. 4 (April 2017): e1184; and J. Krehely, *How to Close the LGBT Health Disparities Gap: Disparities by Race and Ethnicity* (Washington, DC: Center for American Progress, December 21, 2009), cdn.americanprogress.org/wp-content/uploads/issues/2009/12/pdf/lgbt_health_disparities_race.pdf.

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Providing Better Care to LGBTQ People of Color: Training and Advocacy

We have developed and made freely available* teaching materials for healthcare professionals to offer trainings, including slides and lecture notes on LGBTQ terminology and health disparities, video interviews of the five LGBTQ people of color featured in this article, example questions for discussion sessions, and a table to help guide adaptation of these teaching materials and approaches to different local contexts.[1] We hope these materials will help a broad array of clinicians and trainers feel more comfortable teaching about these topics. The lessons come from LGBTQ people of color themselves; the major roles of the trainer are to present basic definitional material and concepts and to facilitate discussions based on the patient videos.[†]

For additional educational resources, we also recommend "Practical Lessons for Teaching About Race and Racism: Successfully Leading Free, Frank, and Fearless Discussions."[3] That paper shares 12 lessons centered around ground rules (e.g., suggestions for establishing a psychologically safe space), language and communication (e.g., start with stories, not numbers), key concepts (e.g., social constructs, intersectionality, bidirectional biases), and structural racism, solutions, and advocacy.

Advocacy for LGBTQ People of Color

Clinicians can advocate for their LGBTQ patients of color in many ways. As previously described, they can improve their communication and shared decision making skills when caring for individual patients, help make their clinics better organized and structured to provide high-quality care to LGBTQ people of color, and teach their colleagues how to provide better care to these patients. They can become familiar with the cultural competency of local healthcare and community-based organizations that they may use for referrals and develop formal or informal partnerships with organizations that serve LGBTQ persons, including people of color.[4] Providers could form relationships with organizations that serve LGBTQ communities to better understand and support the community's lived experiences outside of healthcare. They can ensure that the voices of LGBTQ people of color are heard in improving clinical care through surveys and a community advisory board.[5]

As a result of tireless advocacy by LGBTQ people and their allies, the University of Chicago Medicine improved its care of LGBTQ persons, including people of color, through several actions and an ongoing commitment to this goal. One of the most significant early activities was participating in the Healthcare Equality Index survey, a national benchmarking tool that evaluates healthcare facilities' policies and practices related to the equity and inclusion of their LGBTQ patients, visitors, and employees.[6] Students at the University of Chicago's Pritzker School of Medicine and a small group of LGBTQ employees lobbied leadership for several years to gain their buy-in to participate in the survey. Other changes include adding sexual orientation and gender identity to the organization's nondiscrimination policies; expanding the definition of "family" in visitation policies to include LGBTQ people and relationships; establishing an employee resource group program, with an LGBTQ-focused resource group serving as the pilot; beginning a series of one-time and ongoing LGBTQ cultural competency training programs; offering Safe Space training;[7] and establishing the infrastructure necessary to begin collecting patient-level sexual orientation and gender identity data.

Advocacy for LGBTQ people of color can also occur in the legal and political realms.[8] After choosing a particular area to focus one's advocacy, providers should develop skills such as writing, teaching, and speaking and then take political action by voting, meeting with legislators, signing petitions, and/or attending and organizing marches and rallies. Providers can be advocates in many ways. Everyone can find the niche that is comfortable for them and that builds on their healthcare expertise and their personal experience caring for LGBTQ people of color.[9]

—S. B., S. C. C., and M. H. C.

> **Providers have many opportunities to use their expertise and experience to advocate for LGBTQ people of color.**

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*Visit go.aft.org/eiz.
[†]We taught our workshop to 90 first-year medical students. Here are a few outcomes of note: Students' "somewhat/complete confidence" in defining intersectionality increased from 57 to 96 percent, in identifying barriers to care for sexual and gender minority patients increased from 62 to 92 percent, and in asking sexual and gender minority patients about their identities from 33 to 81 percent.[2]

Boosting Child _and_ Caregiver Health

The Benefits of Preventive, Team-Based Care

By **Sarah MacLaughlin, Shay-Lee Perez,** and **Rahil D. Briggs**

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In the United States today, some groups of people are at higher risk for poor health and are less likely to have access to preventive medical care.[1] With low income being a major risk factor for poor health, it should be a grave concern to all health professionals that as many as two in five babies are born to families with incomes at less than twice the federal poverty line, and that Hispanic and Black infants and toddlers are, respectively, more than two and three times as likely to live in poverty as their white counterparts.[2] By nearly every measure, children living in families with low incomes and children of color face the biggest obstacles to good health, such as low birth weight, unstable or crowded housing, and limited access to early learning experiences.[3] Although these complex problems have many causes, primary among them are systemic racism, along with other forms of marginalization and discrimination, and resulting wealth disparities—all of which are longstanding and still occurring.[4] The COVID-19 pandemic exposed and exacerbated these disparities and structural barriers, which have harmful, life-altering effects that begin before birth and too often result in premature illness and death. Now more than ever, attention is needed to ensure that high-quality preventive physical, mental, and behavioral healthcare is provided to young children and their parents and caregivers.*

Understanding and Addressing Health Inequity

Some of the factors that exert the greatest impacts on health across the lifespan are healthy pregnancies, adequate housing, good nutrition, family stability, quality education, steady jobs with adequate wages, safe communities, and other social determinants of health (SDOH).[5] To tackle health inequity, we must pivot toward wellness and prevention with an explicit focus on young children and their caregivers. Pediatric primary care† is the only system in the country that reaches nearly all young children and their families regardless of race or class, creating an opportunity to provide support as early as possible in the life of a child.[6] Because not all babies, toddlers, or preschoolers attend early learning and childcare settings—or even have access to these settings—pediatric primary care is the way to most universally reach these children before kindergarten. No other system has the same consistent and positive connection to families, their young children, and their communities or stands to make the kind of broad-scale influence on our collective prosperity. This connection provides a unique opportunity to understand and support the holistic needs of the family—especially when visits to the pediatric provider are intentionally nonstigmatized and families feel safe sharing nonmedical concerns.

To be comprehensive, pediatric primary care requires providing services to young children and their caregivers with a two-generation lens. While this may initially appear to be outside the scope of pediatrics, consider a visit focused on sleep training: the ideal focus of the intervention is the whole family, not just the infant, because an infant who doesn't sleep impacts the whole family, and because the infant will not be following the sleep training guidance independently. Pediatric practices should promote wellness and well-being by providing preventive education and

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*Although we use the terms _parent_ and _parenting_ throughout the article, we also use _caregiver_; our assertions are intended to be inclusive of everyone who fulfills the role of bonding with and raising a child.

†Pediatric primary care includes both pediatrics and family medicine practices.

referring to early intervention or other services for the child, caregivers, and the family, mitigating the need for more intensive and costly interventions—not to mention preventable suffering—later in life. These family-oriented services are the bedrock of high-quality pediatric primary care and set the most vulnerable children on a healthy life trajectory.

The frequency of primary care use by young children and their caregivers (12 to 13 well-child visits in the first three years of life) provides an early port of entry into a strengths-based partnership between families and providers. The American Academy of Pediatrics urges pediatricians to screen for maternal depression, behavioral and developmental risks, and SDOH such as food and housing insecurity; they also recommend addressing these issues through a care team—which includes nurses, therapists, community partners like social workers and educators, and the family itself—as an innovation to improve pediatric care.[7]

Although primary care providers largely recognize the importance of screening for SDOH, they may not always carry it out. A 2014 survey of pediatric screening and referral practices among families with low incomes showed that pediatricians were less likely to screen if they felt it was not feasible at their clinics or if they felt unprepared to address families' social needs. Pediatricians were more likely to screen for SDOH and make resource referrals if someone in their clinic was responsible for connecting families to services.[8] Still, even when pediatric practices do screen for risks, families cannot necessarily access important resources and services. According to the 2018–2019 National Survey of Children's Health, among families with young children (0–5 years old) who needed help arranging or coordinating their children's care among different doctors or services, only 29.3 percent said they received that support.[9] This lack of follow-up and support further cements health inequities and limits a child's ability to thrive.

Preventive, team-based care offers a remedy, allowing pediatric and family medicine practices to take steps toward two-generation universal screening and early intervention follow-up. Team-based care is a delivery model in which patients' health-related needs are addressed as coordinated efforts among multiple providers and across settings of care, including helping with housing and nutrition. The impact of this model is significant for both patients and the care team: "If team-based care is thoughtfully implemented and fully supported, each team member's contribution to the overall well-being of the child is valued…. When clinicians feel connected to their patients and receive personal satisfaction from their work, they are more engaged and are less subject to burn out. Highly engaged and satisfied members of the care team have a positive effect on patient care and outcomes."[10]

The remainder of this article describes Healthy-Steps—a model of preventive, team-based care focused on infants, toddlers, and their caregivers—and outlines essential common elements for this and other models to effectively ameliorate health inequities. Achieving comprehensive coordinated care is not easy, so we also address major barriers to implementation and the benefits of alternative payment models that value a broad picture of health and thus support preventive, team-based approaches.

What Is HealthySteps?

As a team-based, preventive-care model, Healthy-Steps, a program of ZERO TO THREE, brings focus to the important array of skills, knowledge, and connections needed for families to foster healthy child development and lifelong well-being. When implemented to fidelity, HealthySteps leads to improved outcomes, especially in areas where there have been persistent inequities for families of color or those with low incomes.[11] HealthySteps has eight core components designed to provide positive parenting guidance, connect families to community resources to meet children's and caregivers' needs, and foster caregiver-child relationships that nurture children and buffer them from the effects of toxic stress.[‡]

To ensure delivery of the core components, a skilled child development professional known as a Healthy-Steps Specialist (HS Specialist) is integrated into the pediatric primary care team. HS Specialists have the time and training to support both common and complex child and family problems, including (but not limited to) feeding and nutrition, behavior, sleep, attachment, maternal depression, social needs, and adapting to life with a baby or young child. An emphasis on building healthy relationships—between caregivers and children, between families and healthcare providers, and among healthcare professionals—is one of the model's guiding principles. HealthySteps thus builds on and enhances the trust caregivers have in pediatric primary care providers.

HealthySteps practices aim to help all children from birth to three years of age,[§] as well as their families, by employing a three-tiered approach based on family needs and risk factors. In the first tier, child and family screenings and access to a child development support line are offered universally. In the second tier, families with mild to moderate concerns receive short-term consultations on development and/or behavior, along with referrals to needed services, care coordination, positive parenting guidance, and early learning resources. In the third tier, families with the greatest risk factors and/or needs receive a series of team-based well-child visits coordinated and guided by a HS Specialist. Some universal services (such as screening) are provided by front-desk staff, medical assistants, nurses, and other

Pediatric primary care is the only system in the country that reaches nearly all young children and their families.

[‡] For details on the model, visit healthysteps.org/the-model.

[§] Some family medicine practices enroll prenatally, and some practices go up to age 5.

team members so that doctors and HS Specialists can focus on families with the most needs. This approach allows practices with a single HS Specialist to serve up to 2,000 children and their caregivers annually.[12]

Essential Principles of Preventive, Team-Based Care

The essential principles of effective, evidence-based models like HealthySteps are relationship-based care, a two-generation approach, a focus on SDOH, developmental and behavioral screening and follow-up, and trauma-informed care. Together, these elements provide a constellation of services that can work to prevent child health inequity from occurring in the first place, while also intervening when needed, as early as possible.

Relationship-Based Care

Relationships are at the heart of the HealthySteps model. Fundamentally, nurturing, warm, and responsive relationships between caregivers and their children help lead to healthy and positive child development. Parenting can be difficult and regular access to trustworthy parenting guidance scarce. By providing open access to a child development specialist, such as a HS Specialist, effective models give families resources and support to address common parenting concerns and identify atypical behavior early.

HS Specialists cultivate relationships with families and, as part of the pediatric team, can help build relationships between the family and the pediatric clinic. When pediatric practices consider that there are three perspectives in the room—the provider's, the caregiver's, and the child's—the family's voice is more fully represented. Further, there is often a parallel process occurring when practice staff interact with families. The way that providers and other staff communicate with caregivers impacts how they feel (and what they will share and ask) in that moment and how they might interact with their children later. When providers engage reflectively—paying full attention when caregivers are speaking, using body language to convey interest, and managing their own emotional response to what is being shared—they model how caregivers can interact with their babies and toddlers.

Patient engagement is an area of growing interest in healthcare as providers seek to understand why recommended treatment plans are not always followed.* Research highlights the importance of person-centered care in creating positive patient-provider relationships.[13] These relationships are vital for creating partnerships with families with young children that produce positive results. For example, a multisite evaluation found that families in HealthySteps practices were significantly more likely

Family-oriented pediatric primary care services set the most vulnerable children on a healthy life trajectory.

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*For more on how to help patients understand and follow treatment plans, see "Improving Communication and Care: How Clinicians Can Increase Health Literacy and Equity" in the Spring 2021 issue of *AFT Health Care*: aft.org/hc/spring2021/roberts.

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than those in regular pediatric practices to report that practice staff went out of the way for them, and mothers in HealthySteps practices were more likely to rely on practice staff for advice than a relative, book, or other source.[14] In another study, families rated their HealthySteps provider as more competent and caring and were significantly more likely to believe that the healthcare team cared about them.[15] Across a group of practices with the HealthySteps model in place, when surveyed 30 months after adopting HealthySteps, clinicians noted four times the odds (compared to baseline) of being satisfied with their ability to provide quality supports to caregivers.[16]

Two-Generation Approach

Caregivers' wellness is necessary for children to thrive because it directly affects children's health and well-being. In a two-generation model, the quality of attachment between a caregiver and child can be continually observed and supported. Improving awareness, providing parenting education, and conducting mental health screenings enhance the likelihood that caregivers will get the support they need as early as possible. When caregivers receive timely support and other needed services, physical, mental, and behavioral health outcomes for children can improve. If caregivers build positive, loving relationships with their children, they create buffers that can protect their children, interrupting stressors that perpetuate intergenerational cycles of challenges and reducing the impact of trauma. HealthySteps' two-generation approach aligns closely with existing, widespread child abuse and neglect prevention efforts as well as efforts to improve caregiver mental health.

Untreated maternal depression and anxiety affect caregiver-child attachment and the healthy development of young children. The Centers for Disease Control and Prevention estimates that postpartum depression affects 11 to 22 percent of mothers in the first six months after giving birth, with American Indian/Alaska Native, Asian/Pacific Islander, and Black mothers being at the higher end of that range and white and Hispanic women at the lower end.[17] Several studies have found that among women living in poverty, postpartum depression is two to four times more common than among women in middle- or upper-middle-income households; socioeconomic status is considered the most dependable predictor.[18] Despite this high risk, one study found that women with public insurance (a proxy for low income) had lower postpartum screening rates than women with private insurance (56 percent versus 68 percent, respectively) and that African American and Hispanic women had lower postpartum screening rates than white women (49 and 56 percent versus 67 percent, respectively).[19]

HealthySteps and other integrated, two-generation care programs ensure more frequent screenings, create more opportunities for prevention, and support treatment of perinatal mood and anxiety disorders. As part of a quality improvement project at a practice in
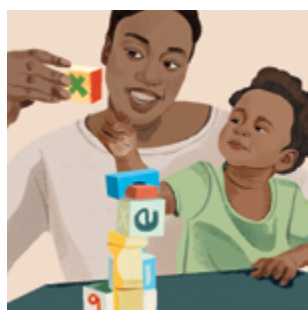
rural Arizona, HealthySteps increased the screening rate for maternal depression from 41 percent to 92 percent over five months.[20] This practice serves more than 300 Native American families from the Hopi, Navajo, San Carlos Apache, and White Mountain Apache nations among its patient population. Importantly, in HealthySteps practices, mothers experiencing depression reported significantly fewer symptoms after receiving care and noted that symptoms decreased at a faster rate than comparable mothers.[21]

Attention to Social Determinants of Health

As noted above, a focus on SDOH as upstream drivers of inequity is critical to enhance family wellness. An integrated care model can identify SDOH early and connect families with timely services. Screening for SDOH can be complicated because most current tools focus on individual areas; there is a need for more comprehensive, validated screening tools. Fortunately, the Centers for Medicare & Medicaid Services recently released a screening tool and guidance for practices to determine families' health-related social needs.[22]

Before this tool was available, HealthySteps developed the Family Needs Questionnaire to screen for key SDOH and other risk factors that may affect families served by HealthySteps practices. Five essential needs were identified (these were consistently found across existing screening tools): food, housing, utilities, transportation, and safety. HealthySteps added questions about tobacco and substance misuse (alcohol and other drugs) to capture a more comprehensive picture of family needs using a single screening tool. To address concerns related to language and literacy accessibility, questions were selected from validated screening tools, with literacy levels ranging from sixth to ninth grade, and versions are available in English and Spanish. Annual screening for SDOH using either the Family Needs Questionnaire or another adequate tool is required at all HealthySteps practices.

HealthySteps in Action

Although we described each of the essential principles of HealthySteps—or any effective care model—the real key to comprehensive preventive care is integration. No one element can reduce health inequity or change a family's trajectory from trauma to well-being, but well-coordinated, multifaceted care can do just that. Here, we share a few examples from HealthySteps practices to show the benefits of integration and coordination.

Team-Based Care

With team-based care, everyone benefits. Caregivers', babies', and children's health and well-being are attended to more comprehensively, and staff share the potential stresses of supporting families, which reduces the risk of burnout.

In one HealthySteps practice, the teen parents of a baby, both of whom had a history of trauma, needed extra supports. Instead of one point person, the whole care team collaborated to meet their needs. At weekly meetings, the care team shared relevant information so that all members would be up to date on the care plan and delegated tasks, ensuring everyone had a discrete, defined role. The community health worker helped with fundamentals like diapers and immediate access to food. The social worker guided the couple in navigating waves of paperwork so they could obtain their birth certificates, Social Security cards, and food benefits. Meanwhile, the HS Specialist shared parenting skills and approaches, helped them understand their own histories of trauma better (including how trauma affected their parenting), and taught conflict resolution strategies for the couple to use with each other.

Care Coordination

When complex or considerable needs arise—or even dire situations—hands-on and comprehensive support for families can be particularly effective. But too few pediatric practices are prepared to meet significant or dire needs. Consider this family: A newly immigrated, Spanish-speaking, single mother of two children—one with an autism diagnosis—was living in the Bronx, New York, with relatives. After the relatives deemed her autistic son's behavior too loud and disruptive, she and her children spent the night on a park bench. In the morning, she got an appointment at the only place she could think to go: her pediatrician's office. Through the HealthySteps team, she learned of a local family shelter, started the intake process, and got a temporary room that day. She then received support with public assistance and special education for her son and learned about a back-to-work program to help with employment. Through another referral, she started taking English as a second language classes, began the certification process to become a home health aide, and placed her children in an afterschool program. She even received immigration assistance with her green card (which had been sent to her relative's home but not forwarded to her).

Early Screening and Intervention

When it comes to early intervention, the earlier the better. This is particularly true with autism spectrum disorder. At one HealthySteps practice, a family's 2-year-old was not yet talking; the primary care provider had made several referrals for early intervention, but the parents had not followed up. The community health worker met with the mother to discuss the difficulty in moving forward and found that the early intervention service coordinator did not speak the family's primary language. The community health worker arranged for translation services, helped the family with the necessary paperwork, and provided additional supports such as advocating for the family to insist on bilingual practitioners for autism spectrum disorder treatments.

Once a HealthySteps practice is well established, teams may choose to partner with other programs to further enrich the lives of children and their caregivers. For details on several complementary programs, such as Incredible Years and Reach Out and Read, see "HealthySteps: Transforming the Promise of Pediatric Care," which is available for free at go.aft.org/168, and scroll to the "Synergy with Other Models" section.

–S. M., S.-L. P., and R. D. B.

Team-based care coordinates across settings to address health-related issues, including housing and nutrition.

Of course, screening is only the first step; once needs are identified, families need to receive appropriate referrals and be connected to the relevant services.[23] To help make those connections and thereby more comprehensively address SDOH, some HealthySteps practices add community health workers to the team. Preliminary research suggests that in a group of urban HealthySteps practices, referrals made with HS Specialist support were successful in 74 percent of attempts at connecting families with the appropriate services.[24] This is well above recent studies looking at referral rates in pediatric medical settings to community services (which hover around 61 to 64 percent). When a community health worker was added to the team alongside a HS Specialist, successful referrals were even higher: 96 percent.

Developmental and Behavioral Screening and Follow-Up

For years, the American Academy of Pediatrics has recommended that pediatricians routinely use validated screening tools to identify risks to development in every child as effectively and as early as possible.[25] Despite this recommendation, US screening rates remain consistently low. Only 36.4 percent of parents responding to a national survey reported having completed a developmental screening tool when their child was between 9 and 35 months of age.[26] When children receive primary care in a medical home—care that is coordinated, family centered, accessible, continuous, and comprehensive[27]—the number of children screened rises to only 43.5 percent.[28]

HealthySteps requires annual, universal screening for development. This allows for tracking of developmental milestones and lays the groundwork to address challenges early by connecting families and children to services. Without clear referral and follow-up protocols, many families cannot access the services they need. Studies have found stark income- and race-based disparities in early intervention services:

- Among babies who had been in neonatal intensive care, those in single-parent households waited an average of 24 days longer than those in two-parent households to start receiving prescribed intervention services; parents of color and single parents reported putting forth greater effort to find services.[29]
- Children from families making $20,000 or less per year were 13.6 percent less likely to receive physical therapy and 10.4 percent less likely to receive occupational therapy than children from higher-income families.[30]
- Black children were five times less likely to receive early intervention services than white children at 24 months of age.[31]

HealthySteps works to successfully connect families to early intervention services by understanding family concerns (e.g., those who have experienced racism and pervasive bias may be particularly wary of special education diagnoses and systems) and ensuring that the systems of care are well coordinated with each other and that all are centering the family.

Narrowing specifically on one element of development, we know that early diagnosis and treatment leads to more positive outcomes later in life for people with autism spectrum disorder (ASD). Yet, children of African American, Hispanic, and Asian descent, and children living in families with low incomes, are less likely to receive an early diagnosis of or early intervention for ASD than white children, despite similar prevalence of ASD across racial/ethnic groups.[32] HealthySteps facilitates timely screenings and referrals for ASD by screening all children. One HealthySteps practice with integrated behavioral care offers a strong model: of children who screened at the high-risk level, 90 percent received a developmental evaluation, and the median age of ASD diagnosis was two years earlier than the national median (26 months versus 52 months).[33]

Trauma-Informed Care

Research on childhood adversity has demonstrated that child abuse and neglect can disrupt a child's developing brain, negatively influencing behavioral, educational, economic, and health outcomes for decades and even generations. Trauma-informed pediatric care that is culturally competent, reflective, and focused on families' strengths empowers families to interrupt intergenerational transmission of trauma and can help to mitigate secondary trauma in providers.[34]

HealthySteps enables practices to identify children and families most at risk for child abuse and neglect and address their needs to prevent nascent concerns from escalating. The trusting and longstanding relationships that HS Specialists establish with families during these early years allow sensitive subjects to be addressed in a safe setting and to be monitored through frequent appointments. A recent study noted that children of mothers with a history of childhood trauma scored better on a social-emotional screening after receiving care in a HealthySteps practice than comparable children who were not in the program.[35] Another study found that HealthySteps parents were less likely to resort to using harsh forms of punishment (threatening, yelling, spanking with hand) or severe discipline (face slap, spanking with objects) than comparable non-HealthySteps parents.[36] A longitudinal analysis showed that parents who participated in HealthySteps noted fewer behavior problems among children 16 to 37 months old and showed greater attachment security.[37]

The benefits of preventive, team-based care focused on young children and their caregivers are clear. However, current policy and payment landscapes do not allow for this kind of programming to be the expectation rather than the exception. As we seek

to ensure such services are available to all families, changes will need to occur.

Barriers to Integrated Care

Despite the many benefits of preventive, team-based care models, there are barriers to sustaining integrated programs built into our medical health insurance reimbursement policies. Here are three of the most common obstacles.

1. *Behavioral or mental health visits are not allowed on the same day as a medical visit.* In some states, medical insurance carriers may only reimburse for one type of visit on a given day (known as *same-day billing*). The lack of financial acknowledgement of both visits on a given day creates a barrier to rendering high-quality care. Typically, the families most in need of integrated services are those least able to make multiple visits spread over different days. Therefore, doing what is best for the family threatens the financial viability of the team-based practice.

2. *Restrictions on behavioral health licensures eligible for medical insurance reimbursement.* While a robust team of providers with varied backgrounds and experiences benefits a diverse patient base, restrictions around insurance prevent payment for certain providers. Not all behavioral and mental health professionals are recognized for medical insurance reimbursement. Licensures eligible to file medical claims for the services they have rendered are restricted in many states. One example is that some states do not recognize community health workers' care coordination for separate reimbursement.

3. *Many preventive services are not recognized for medical insurance reimbursement.* Services such as positive parenting guidance and information, child development support lines, and ongoing preventive team-based well-child visits are not recognized for separate reimbursement in many states. Maternal depression screenings rendered during well-child visits are also not recognized for separate reimbursement in some states. The diagnosis requirement precludes almost all behavioral health and developmental prevention services from being paid. This, in turn, makes early intervention less likely and results in much suffering and far higher costs—most of which could have been prevented.

Fortunately, shifts in reimbursement for the coordinated-care model are occurring. For example, California's Medicaid system, Medi-Cal, reimburses for California's family health benefit, which focuses on preventive two-generation supports via family psychotherapy and is geared toward preventing mental health conditions in children with specified risk factors. These services can be rendered by any licensed behavioral health clinician and are unlimited for patients under the age of 21 with approved risk factors. These risk factors are associated with SDOH for the child and/or for the caregiver. In addition, Medi-Cal will reimburse for up to five sessions when a mental health diagnosis is suspected, giving clinicians valuable time to assess whether a diagnosis is warranted and to plan for treatment. While such advances are welcome, a more radical change in our payment policies is needed to reap the full potential of preventive, team-based care.

Developing an Alternative Payment Model

A child- and caregiver-focused alternative payment model could help increase focus on the early years as the foundation for a healthy life and incentivize providers to address child and caregiver needs well beyond physical health. In addition, such holistic and equitable supports for caregivers in the context of their young children's pediatric visits would drive cost savings.[38] Given the frequency of primary care use by young children, an alternative payment model that includes services to caregivers and allows multiple types of care in each visit would encourage primary care providers to deliver preventive high-quality services, including integrated behavioral health services and health-related social needs supports. Providing these interventions in the context of pediatric primary care has the potential to drive significant improvements in health outcomes and to reduce total cost of care for the family unit (and, ultimately, for our nation). A well-designed alternative payment model should aim to achieve value-based care, meeting the quadruple aim of improved patient experience of care, improved health of the population, improved clinical experience, and reduced cost of care.[39]

As the COVID-19 pandemic continues to unfold, there are many unknowns about the long-term impacts on the physical and mental health of children and adults. Data already show declines in children's and caregivers' well-being. Between March and June 2020, "27 percent of parents reported worsening mental health for themselves, and 14 percent reported worsening behavioral health for their children."[40] Such increased physical and behavioral health needs, paired with ongoing or new family needs, including sudden job loss and food and housing insecurities, have the potential to add significant costs to state Medicaid and cross-system partner agencies. This is in addition to the negative impact of ongoing inequities experienced by communities of color.[41] These are serious health challenges calling out for integrated, team-based care. An alternative payment model could encourage providers to offer critical comprehensive services to children and caregivers in the pediatric primary care setting, addressing needs in a timely manner while bending the cost curve in an era when health expenditures are on the rise.

When caregivers receive timely support and services, children's health outcomes can improve.

Moral Policy = Good Economics

By **Rev. Dr. William J. Barber II, Shailly Gupta Barnes, Josh Bivens, Krista Faries, Thea Lee,** and **Rev. Dr. Liz Theoharis**

A Closer Look at America's Inequality

For a detailed examination of several of the most crucial problems facing working families, see the online version of this article. It has graphs showing the rise of inequality, explanations of the policy choices that created today's challenges, and strategies for increasing equity, opportunity, and health. Visit and share: go.aft.org/i45.

When the coronavirus pandemic arrived, the United States was already deeply unequal. Before the pandemic, 140 million Americans were poor or near poor, living just one emergency above the poverty line, and approximately 250,000 people died annually from poverty and income inequality. This human tragedy is largely ignored, which allows inequality to grow unchecked and does not make good economic sense.

When we fail to meet basic needs for food, housing, and healthcare for everyone, and when we fail to invest in education, safe communities, and fair elections, the health and well-being of our entire nation is compromised. In today's severely unequal economy, economic growth is slower, downturns are more severe and painful, and our economy fails to reach its full potential.

No single piece of legislation did this; instead, it was the accumulation of dozens, if not hundreds, of choices made in the form of legislation, regulatory changes, and administrative and judicial decisions over several decades that consistently allowed the wealthy to reap the vast majority of the benefits of economic growth. As corporations and employers have been prioritized over communities and employees, anti-poverty programs have been consistently underfunded. These choices were only possible because our democracy has been weakened by voter suppression. To fight back, a multiracial democracy must rise up to demand better economic and social policies.

Transformative Policies

Because policy and fiscal choices have been used to perpetuate and deepen inequality, they can also be used to usher in an era of greater equality and equity. We offer 10 policy changes that would be transformative, especially for the 140 million people who were facing significant challenges even before COVID-19.

1. Prioritize "high-pressure" labor markets, in which unemployment is very low, to change the bargaining dynamic between workers and employers, increasing workers' leverage over wage negotiations.
2. Raise the federal minimum wage to $15. If the federal minimum wage had kept up with productivity since its inception, it would be over $23 per hour today.
3. Uphold the right to form and join unions. Passage of the Protecting the Right to Organize (PRO) Act would reform our nation's labor law so that private-sector employers are no longer able to intimidate workers seeking to unionize or stall union elections and contract negotiations.
4. Reform unemployment insurance to greatly expand the share of the unemployed who receive benefits in normal times while also making these benefits significantly more generous.
5. Provide universal healthcare, which not only would have profound effects on the economic security of households but also could boost wages and jobs.
6. Provide universal access to vital goods and services, such as high-quality child and elder care and early childhood and higher education.
7. Create a new federal poverty measure (reflecting what it takes to have a decent standard of living today) and expand social welfare programs, including programs to guarantee adequate incomes, housing, food, water, and other human needs.
8. Invest in safe communities by focusing on health, education, and opportunity for people in chronically under-resourced neighborhoods.
9. Tax the rich and corporations to help finance needed public investments and safety net spending and to reduce the incentive for privileged economic actors to rig the rules of the market to tilt more gains their way.
10. Protect and expand voting rights, especially for poor people and poor people of color. Voter suppression laws continue to proliferate across the states; pushing back begins with restoring the full power of the Voting Rights Act.

If America does not address the problem of inequality by making visionary social and economic choices, the health and well-being of the nation will continue to decline. We need long-term policies, enshrined in law, that establish justice, promote the general welfare, reject decades of austerity, and build strong social programs that lift society from below. ✚

Investing In Our Future

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Boosting Child and Caregiver Health

As the single most commonly accessed system in early childhood, pediatrics is the ideal setting to provide comprehensive, coordinated care, with supports to meet each family's needs. At the time when children's brains are developing most rapidly, integrated care programs like HealthySteps foster healthy child development and lifelong well-being, leading to improved outcomes especially in areas where there have been persistent inequities for families of color and those with low incomes. The need is apparent and the knowledge exists; now is the time to remove payment barriers and bring high-quality, preventive, two-generation, team-based care to scale. ✚

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