

KELLY REPORT 2015

HEALTH DISPARITIES IN AMERICA

Congresswoman Robin L. Kelly represents Illinois' 2nd Congressional District. Her district includes parts of Chicago as well as suburban and rural areas and represents a microcosm of the health disparities facing communities across the country. As chair of the Congressional Black Caucus Health Braintrust, she compiled this report to examine nationwide health disparities and lead policymakers and medical thought leaders in a meaningful direction in improving health outcomes in the United States. This report is dedicated to the basic human right of all Americans to a healthy life and to the medical professionals working on the front lines of the health equity movement to forge a healthier future for us all.

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FOREWORD

CHERYL R. WHITAKER, MD, MPH, FACP



I applaud Congresswoman Kelly for keeping focus on the important health issues that impact communities in ways that extend beyond healthcare.

The *2015 Kelly Report* will walk us through the disparities that continue to persist in communities of color since the publication of the *Report of the Secretary's Task Force on Black and Minority Health* (also known as the *Heckler Report*) 30 years ago. Since then, our country has taken several steps to improve access to research funding for health disparities and for outcomes research that digs deeper into the reasons for health disparities.

Indeed the journey towards health equality will take time to reverse, but alas there is action and progress. The *Kelly Report* calls attention to complementary programming that has been supported by federal policies that recognize the value of diverse faculty and providers as a part of the disparities improvement equation. Programs that improve the diversity of students in STEM and in health/clinical fields that have sprung up across the country. Programs that fill the pipeline with students from diverse backgrounds who have academic talent and interest have shown fruit. This work must continue.

This report also examines the potential of leveraging the closing of the "Digital Divide" to improve public health outcomes. Minority communities have access to smartphones on par with majority communities. How do we take this access to the Internet to influence and support the healthcare needs of these communities?

And while the Affordable Care Act is only five years old, we now have a solid infrastructure to complement some of the prevention and access issues that defined much of the earlier narrative around disparities. While its ultimate impact on the health of communities of color remains to be seen, we are hopeful in light of the immediate progress that we have witnessed since its inception.

I congratulate Congresswoman Kelly and her team on establishing a new narrative at the intersection of medical research, private sector innovation, and community and federal action, which will serve as a "recipe" in healing our nation. We look forward to this second official *Kelly Report*, and all reports to follow.

Sincerely,

Cheryl R. Whitaker, MD, MPH, FACP

The 2015 Kelly Report calls attention to complementary programming that has been supported by federal policies that recognize the value of diverse faculty and providers as a part of the disparities improvement equation.

WELCOME

ROBIN L. KELLY (IL-02)
 CHAIR, CONGRESSIONAL BLACK CAUCUS HEALTH BRAINTRUST



When Benjamin Franklin and Dr. Thomas Bond created the nation's first public hospital, The Pennsylvania Hospital, in 1751, they established the promotion of public health as a core American value. Nearly 300 years later, the Affordable Care Act (ACA) cemented healthcare as a fundamental right for all Americans. This year, the U.S. Supreme Court reaffirmed this right.

Yet today, we find ourselves at a crossroads in healthcare. Health disparities in communities of color continue to be intractable hurdles in the quest to achieve health equity in America.

African Americans are infected with HIV at a rate that is eight times that of White Americans. While White women are more likely to have breast cancer, African American women are 40 percent more likely to die from the disease. African Americans, Latinos, Asians and Pacific Islanders, and Native Americans are diagnosed with lupus two-to-three times more frequently than Caucasians. More than 13 percent of African Americans aged 20 or older have diagnosed diabetes. And people of color are two-to-four times more likely than Whites to reach end-stage renal disease. This grim snapshot illustrates that, despite the gains of the ACA, we have much ground to cover in closing the health equity gap. Your ethnicity, zip code, and bank balance should never determine your health.

In January of 2015, I was honored to become Chair of the Congressional Black Caucus Health Braintrust, a venerable institution founded on the fundamental principle of healthcare as a civil and human right. I believe public health is a public trust, and I am committed to protecting that trust by advocating for better health outcomes for the most vulnerable, under-served segments of our society.

The *Kelly Report on Health Disparities* was compiled in this vein, examining the root causes and impact of health disparities in America and providing a comprehensive set of legislative and policy recommendations to reverse them. The *Kelly Report* features commentary and analysis from key Members of Congress and thought leaders in the public health space on a wide range of adverse health conditions plaguing communities of color.

The whole can only ever be as healthy as its parts. For America to achieve true health equity, lawmakers, community leaders, and industry stakeholders must come together to reduce disparities and improve health outcomes nationwide. We all have a part to play in creating a healthier America. This report is my contribution to this critical effort.

Sincerely,

A handwritten signature in black ink that reads "Robin L. Kelly". The signature is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

Dr. Robin L. Kelly
 Chair, Congressional Black Caucus Health Braintrust

*Of all the forms of inequality,
 injustice in healthcare is the
 most shocking and inhumane.*

DR. MARTIN LUTHER KING JR

EXECUTIVE SUMMARY

History has shown us that the lack of access to healthcare, health insurance, and health providers has contributed to the gaps we observe in national health outcomes.

There is no doubt that we have come a long way in improving our collective national health. Exactly one century ago in 1915, the average lifespan for an American was 54 years. Today, that lifespan has increased an additional 25 to 78.8 years of age. In many respects, we can attribute this longevity to the gains we have made on the healthcare front. We have vaccinated millions to prevent diseases like polio, improved the science of organ transplantation, produced more than half of the world's new medicines in the past decade, and developed pioneering research and rehabilitation hospitals like the Cleveland Clinic and the Rehabilitation Institute of Chicago. Still, America wrestles with persistent health disparities.

Thirty years ago, then Health and Human Services Secretary Margaret Heckler's task force on Black and minority health reported vast differences in health outcomes between racial and ethnic minorities and White populations in the United States. Nearly 20 years later, Congress commissioned a report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," studying the extent of racial disparities in healthcare. Their report found continued unequal treatment of minority populations in our health system.

WE MUST CURE OUR NATION OF HEALTH DISPARITIES

America cannot truly be a healthy nation until we cure our nation of health disparities and address the underlying social determinants that cause them. Many of the gaps that exist in public health are shaped by generations of cultural bias, injustice, and inequality. Today in America, minorities experience higher rates of infant mortality, HIV/AIDS, and cardiovascular disease than Whites, and substantial differences in disease incidence, severity, progression, and response to treatment.¹

African Americans have higher rates of mortality than any other racial or ethnic group for eight of the top ten causes of death. Cancer rates for African Americans are ten percent higher than those for Americans of European descent. African Americans make up more than one third of all U.S. patients receiving dialysis for kidney failure despite representing only 13 percent of the overall U.S. population, and African American are nearly two times more likely to have diabetes as non-Hispanic Whites.

Similarly, Latinos have higher rates of preventable diseases than non-Hispanic Whites. As it stands, more than 77 percent

of Latino adults are overweight or obese, compared with 67.2 percent of Whites. Latinos are 15 percent more likely to have liver disease than non-Hispanic Whites, and particularly concerning is the fact that one-in-four Latino households are food insecure, compared to just one-in-ten White households.

These statistics are just a snapshot of the health crisis facing minority populations. It is not in our national interest to allow this to continue.

BRIDGING THE GAP

In securing a healthier future, we must strengthen our public health infrastructure and employ community-oriented, multi-disciplinary approaches to American health that draw attention to critical issues and inspire legislative action to bridge the national health gap.

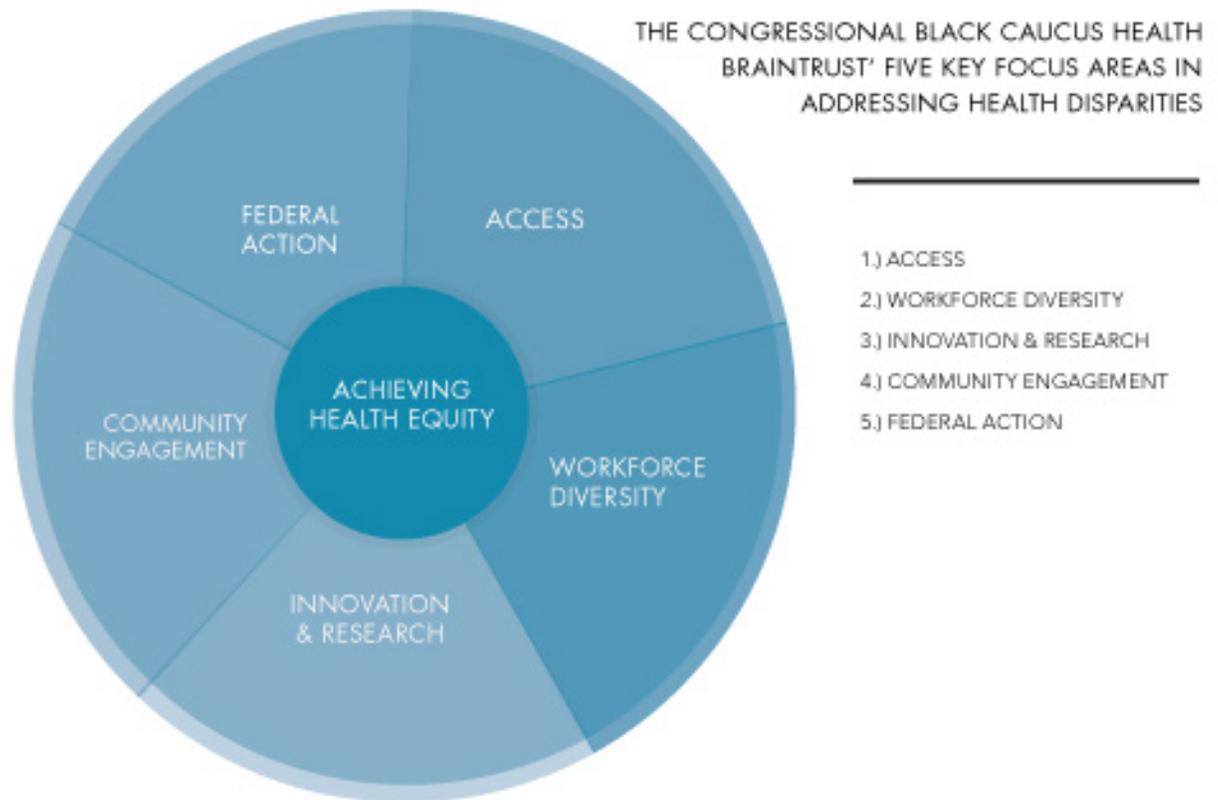
According to a 2014 study by the Commonwealth Fund—a private, nonpartisan, health policy, health reform foundation—the U.S. ranks last among 11 wealthy industrial nations (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom) in terms of "efficiency, equity and outcomes," in the health space.² These statistics are in spite of the fact that we have the world's most expensive health care system. That same study found that American physicians face particular difficulties receiving timely information, coordinating care, and dealing with administrative hassles. Additionally, many U.S. hospitals are still catching up with the adoption of certain modern health information systems.

Provisions in the Affordable Care Act (ACA) have helped rouse reforms in the delivery of healthcare. It has also helped spur critical investments in important preventative and population health measures. But the ACA alone cannot bridge the health divide.

It is important that the public health, legislative, and scientific communities coordinate to address health inequality in a targeted and aggressive manner.

AMERICA'S HEALTH STRATEGY NEEDS RETOOLING

A 2013 Centers for Disease Control and Prevention (CDC) examination of persistent causes for the racial gap in life expectancy found higher death rates for African Americans due to heart disease, cancer, homicide, diabetes, and perinatal conditions. The life expectancy gap (which was 5.4 years for African



American males vs. White males, and 3.8 years for African American females vs. White females) would have been even larger if not for the lower rates of death in the Black population from suicide, unintentional injuries, and chronic lower respiratory diseases.³

As referenced frequently throughout this report, African Americans experience striking disparities in virtually all of the major health indicators. The *2015 Kelly Report* in particular examines breast cancer, cardiovascular disease, obesity, nutrition, asthma, colorectal cancer, diabetes, hepatitis, HIV/AIDS, lupus, mental health, oral health, and sleep-related disparities in minority populations with a particular focus on the African American community (as this is a Congressional Black Caucus-Health Braintrust–led report).

America's health strategy needs retooling to achieve health parity. People of color make up the fastest growing segment of our population, and an increasingly large number of our

healthcare recipients. Therefore they should also make up a larger percentage of our health workforce.

The Congressional Black Caucus Health Braintrust has chosen to focus on five key areas in addressing health disparities: 1.) Access, 2.) Workforce Diversity, 3.) Innovation & Research, 4.) Community Engagement, and 5.) Federal Action. Comprehensive examination, advocacy, and action from individuals, communities, and legislators will be essential to achieving health equity.

There is no time like the present to enact policies with the focused goal of providing health security to all Americans. Right now, the practice of eliminating health disparities must be perfected. We must have a broader and more inclusive dialogue to transform healthcare and improve efficiency, equity, and outcomes for patients and communities.

The 2015 Kelly Report on Health Disparities in America is not intended to be the end-all solution to America's minority health

crisis. What this report is intended to do is appropriately frame the discourse on public health and advance the work and development of effective strategies to improve health outcomes in minority communities.

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30 YEARS AFTER THE HECKLER REPORT: MARCHING TOWARD A HEALTHIER FUTURE

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MARCHING TOWARD A HEALTHIER FUTURE

I once heard a historian say that history is not a steady stream of events, but rather a series of punctuation points, like ripples from stones tossed into water. I believe that we are at the cusp of just such a punctuation point as we commemorate two landmark anniversaries for our nation this year—the 30th anniversary of the *Report of the Secretary’s Task Force on Black and Minority Health* (also known as the *Heckler Report*) and the 5th anniversary of the Affordable Care Act.

The *Heckler Report*, released in 1985 by the U.S. Department of Health and Human Services, marked the first time the U.S. government convened a group of health experts to conduct a comprehensive study of the health status of minorities. This legacy report documented persistent health disparities that accounted for 60,000 excess deaths each year and identified six causes of death that accounted for more than 80 percent of mortality among racial and ethnic minorities when compared to Whites: cancer; cardiovascular disease and stroke; chemical dependency, measured by deaths due to cirrhosis; diabetes; homicide and accidents (unintentional injuries); and infant mortality.¹

The publication of the *Heckler Report* elevated minority health onto a national stage and continues to serve as a driving force for the monumental changes in research, policies, programs, and legislation to end health disparities in America. As minorities grow closer to comprising the majority of the U.S. population by 2050, it is important now more than ever to propel energy toward closing the gap in health disparities. Due to advances in technology and improvements in access to care, we have an unprecedented opportunity to make major strides in achieving health equity for all Americans. Health disparities affect us all and are far too costly to ignore—studies have shown the expense of health inequity and premature death cost the U.S. economy \$1.24 trillion between 2003 and 2006.² This, coupled with the number of lives lost too soon to preventable causes, makes health disparities an issue relevant to all Americans.

Over the past 30 years, the *Heckler Report* has influenced advances in our nation’s progress toward health equity through new techniques in data collection; dedicated institutes, centers, offices, and commissions of minority health across the country; innovative community-level interventions; and transformative policies and legislation. These advances reflect the vision of former HHS Secretary Margaret M. Heckler who, in 1985, determined that we must act swiftly to address the excess deaths among racial and ethnic minorities and the health inequity that plagued our country. In her words, health disparities were “an affront both to our ideals and to the ongoing genius of American medicine.”

Secretary Heckler, members of the Task Force convened to develop the report, and other visionaries had an unwavering commitment and a heart of service to enact change. With that commitment came a tremendous opportunity. The *Heckler Report* created an opportunity to engage the nation in thoughtful discussions about the health needs of minority communities. Individuals from across the nation—public health professionals and health care providers to advocacy groups; researchers and academic institutions to policymakers—further contemplated solutions to a dilemma that required immediate scrutiny.

As a result, milestones lined the path toward health equity: the Jackson Heart Study explored reasons for certain cardiovascular health disparities; the Healthy Start program brought infant mortality prevention efforts to underserved communities; the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care gave guidance on how healthcare organizations can provide respectful and responsive services to diverse communities; and a HHS mandate reaffirmed the commitment to the appropriate inclusion of data on minority groups in HHS research, services, and related activities.

More than a generation after the *Heckler Report*, the Affordable Care Act and its key tenet of quality, affordable, and accessible health care is touching the lives of Americans every

day. When President Obama signed this legislation into law, it opened up a remarkable window of opportunity in the movement to reduce health disparities and achieve health equity. As of March 2015, approximately 16.4 million uninsured people had gained health coverage since the law was passed five years ago. Today, more racial and ethnic minorities with private insurance are guaranteed access to preventive services without cost sharing. As of May 2015, 15 million Blacks/African Americans, 17 million Hispanics/Latinos, eight million Asian Americans, and one million American Indians with private insurance had access to recommended preventive services, such as blood pressure screenings, flu vaccinations and other immunizations, well-woman visits, and HIV screenings without cost sharing.

The Affordable Care Act has led to unprecedented progress in addressing health disparities in America and helped advance recommendations of the *Heckler Report* forward by:

- Increasing coverage options for racial and ethnic minorities and reducing the number of uninsured in populations most affected by health disparities** – As of March 2015, 2.3 million Blacks/African Americans (ages 18 to 64 years) and 4.2 million Hispanics/Latinos (ages 18–64) had gained health insurance coverage since October 2013. This represents a respective decrease of 9.2 and 12.3 percentage points in the rate of uninsured.
- Expanding access to primary health care by investing in community health** – The \$11 billion in the Affordable Care Act for the nearly 1,300 federally supported community health centers has increased the number of patients served by nearly 5 million. Approximately, one out of every four patients served at a community health center is African American; and one of every three patients at a health center is Latino.
- Increasing the diversity of our nation’s health workforce** – Currently, African American physicians make up about 18 percent and Latino physicians make up about 16 percent of National Health Service Corps (NHSC) physicians, compared to 6 percent and 5 percent of the national physician workforce, respectively. The Affordable Care Act has more than doubled the size of the NHSC and thereby will contribute to the diversity and cultural competency of the workforce available to serve our nation’s most underserved communities.
- Increasing access to maternal and child health services through the Maternal, Infant, and Early Childhood Visitation Program and by requiring health insurers to cover 10 essential benefit categories, including maternity and newborn care** – Over 390,000 Black/African American women, over 208,800 Asian American women, and over 278,000 Latinas, in the individual market alone, will gain maternity coverage under the Affordable Care Act.
- Strengthening federal minority health infrastructure to reduce health disparities** – by strengthening the authorities of the HHS Office of Minority Health, establishing Offices of Minority Health within six HHS agencies (Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Food and Drug Administration, Health Resources and Services Administration, and Substance Abuse and Mental Health Services Administration), and re-designating the National Center on Minority Health and Health Disparities to a NIH Institute.
- Ensuring individuals are protected from discrimination in health care** – The Affordable Care Act prohibits discrimination on the basis of race, color, national origin, sex, disability, or age in any health program or activity receiving federal financial assistance; any program or activity administered by an executive agency; or any entity established under Title I of the Affordable Care Act or its amendments. These entities and programs must provide information in a culturally and linguistically appropriate manner, which promotes better access to care and better care for racial and ethnic minorities, including individuals with limited English proficiency.
- Improving data collection and research** – The Affordable Care Act strengthens federal data collection efforts to standardize data collection on race, ethnicity, sex, primary language, and disability status and increases investments in research focused on disparities. HHS adopted new data collection standards in October 2011 that include greater granularity by race and ethnicity in population health surveys. These changes will help us better understand the causes of health disparities and develop effective interventions to address disparities.

The data collection standard for primary language provides new opportunities for tracking disparities by language proficiency and is an important enhancement as the nation implements key provisions related to increasing access and preventive services of the Affordable Care Act.² The new standard related to disability will allow HHS to identify disparities in disability status across data systems in a more consistent way and provide new opportunities for monitoring health among population subgroups by disability status.³

The Obama Administration has taken unparalleled steps to reduce health disparities and advance equity and opportunity. The Affordable Care Act, which has built upon the important

work of the *Heckler Report*, is saving lives and ensuring that millions who previously did not have access to health care now have the certainty and peace of mind that comes with coverage. From coverage to preventive care to innovative research and a more diverse health workforce, the Affordable Care Act is a crucial bridge toward the health equity envisioned by the authors of the *Heckler Report*.

The Affordable Care Act and the health disparity gaps that have been reduced since the *Heckler Report* are signs of progress: cancer deaths among Blacks/African Americans have decreased; HIV mortality rates in Black/African American communities have declined; obesity rates among low-income preschoolers have declined for the first time in three decades; childhood vaccination disparities between racial and ethnic minorities and Whites are nearly nonexistent; and teen pregnancy has shown recent declines among all racial and ethnic groups.

Despite our progress, our work is not done. We are still a nation where minorities are less likely to get the preventive care needed to stay healthy, less likely to receive quality care, and more likely to face poorer health outcomes.

- The rates of premature death (death before age 75 years) from stroke and coronary heart disease are higher among non-Hispanic Blacks/African Americans, than among Whites.⁵
- The disparities improved slightly for death rates from diabetes, but Blacks/African Americans, Hispanics/Latinos, and American Indians/Alaska Natives still die from diabetes complications at a higher rate than Whites.⁶
- Asian Americans have the highest incidence rates of liver cancer for both sexes compared with Hispanics/Latinos, non-Hispanic Whites, or non-Hispanic Blacks/African Americans.⁷
- The infant mortality rate was highest for infants of non-Hispanic Black/African American mothers—a rate 2.3 times that of non-Hispanic Whites—and was also higher among infants born to American Indian/Alaska Native and Puerto Rican mothers.⁸
- Suicide is the second leading cause of death among American Indians/Alaska Natives ages 15 to 34 years.⁹
- Native Hawaiians/Pacific Islanders are 30 percent more likely to be diagnosed with cancer, as compared to Whites.¹⁰

We recognize that health and health care are only one piece of the puzzle. We must also look to the conditions in which people live, learn, work, and play—the social determinants of health—to help solve the health disparities that afflict so many communities of color. Poverty, lack of access to high-quality education, unemployment, unhealthy housing and unsafe neighborhoods significantly influence the health of individuals and communities.

Disparities persist, but there is hope. We have witnessed groundbreaking developments in science, powerful advances in public health and health care, and new, multi-sector collaborations at our disposal—opportunities that create an environment ripe for action.

To this end, we rely on the roadmap outlined in the *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* and the *National Partnership for Action to End Health Disparities* to both guide our path and mobilize our communities toward health equity. The *HHS Action Plan to Reduce Racial and Ethnic Health Disparities*, our most comprehensive federal commitment to reducing health disparities, charges HHS agencies and offices to heighten the impact of HHS policies and programs to reduce health disparities. The *National Partnership for Action to End Health Disparities* is mobilizing a nationwide, comprehensive, and community-driven movement to combat health disparities, using a social determinants of health approach by bringing together multiple sectors, such as transportation, agriculture, veterans affairs, housing, environmental protection, and the justice sectors, to advance equity in all policies.

Today, we are embarking upon a remarkable moment to fulfill the American promise of equality and opportunity. And whether we rise to meet it—whether we can look back another 30 years from now and consider this period in history as the moment when we faced an unprecedented opportunity for change and made the most of it—depends on all of us to do our part in our communities. For some, this means getting connected to care for the first time; for others, it means educating the next generation through awareness-raising activities. Health disparities impact us all and through our collective efforts, we can accelerate momentum toward achieving a nation free of disparities in health and health care and a nation in which everyone has the opportunity to reach their full potential for health.

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HEALTH DISPARITIES: THEN & NOW

As Chair of the Congressional Black Caucus Health Braintrust, African American health is of particular interest to Dr. Kelly. The following data shows health disparities that existed between African Americans and White Americans at the time of the Heckler Report's release in 1985 and their status 30 years later.

FIGURE 1. AGE-ADJUSTED DEATH RATES BY SELECT CAUSE & RACE IN 1985 & 2013^{1*}

SELECTED CANCERS:	1985		2013	
	BLACK	WHITE	BLACK	WHITE
Cancer	357.8	277.9	254.1	219.7
Diabetes mellitus	44.4	21.4	51.7	26.1
Diseases of heart	578.2	499.6	282.8	226.3
Stroke	141.4	99.2	65.7	46.9
Chronic liver disease & cirrhosis	25.9	15.4	9.8	14.5
Accidents (unintentional injuries)	56.1	44.5	40.3	53.9
Assault (homicide)	35.3	6.5	22	3.7

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

FIGURE 2. AGE-ADJUSTED MORTALITY RATE BY SELECT CAUSES, RACE & GENDER IN 1985 & 2013^{1*}

SELECTED CAUSES:	1985				2013			
	WHITE		BLACK		WHITE		BLACK	
	MALE	FEMALE	MALE	FEMALE	MALE	FEMALE	MALE	FEMALE
Cancer	358.3	227.8	502.5	262.2	262.6	188.1	320.8	212.8
Diabetes mellitus	22.4	20.5	39.1	47.5	32.1	21.2	59.2	46.2
Diseases of heart	655.6	388.8	717.6	479.8	286.8	177.6	353.2	231.3
Stroke	103.7	95.1	151.3	133.2	47	46	72.6	60.1
Chronic liver disease & Cirrhosis	21.9	9.9	37.9	16.4	19.7	9.6	14	6.5
Accidents (unintentional injuries)	66.4	25.3	92.2	27.7	72.1	36.5	60	24
Assault (homicide)	9.7	3.4	61.8	12.7	5.3	2	39.6	5.6

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

FIGURE 3. AVERAGE ANNUAL AGE-ADJUSTED CANCER INCIDENCE RATES BY PRIMARY SITE & RACIAL/ETHNIC GROUP IN 1981 & 2012⁺

SELECTED CANCERS:	1981		2012	
	BLACK	WHITE	BLACK	WHITE
All Sites	489.0908	453.4384	474.3407	450.3461
Esophagus	12.7533	3.7401	3.6333	4.7493
Colorectal	64.0612	67.187	47.7031	37.6054
Pancreas	18.8004	11.703	16.8705	12.7869
Larynx	8.4331	5.4135	4.691	3.0294
Lung (Male)	149.6803	96.8576	87.3961	62.1689
Lung (Female)	46.0439	40.8749	54.8562	49.5777
Breast (Female)	111.5419	127.8104	132.1668	131.8896
Cervix	19.107	9.1364	7.5475	6.2944
Prostate Gland	170.1277	114.6607	184.1565	107.6243

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

FIGURE 4. AVERAGE ANNUAL AGE-ADJUSTED DEATH RATES FOR CANCER BY RACE IN 1985 & 2012²⁺

SELECTED CANCERS:	1985		2012	
	BLACK	WHITE	BLACK	WHITE
All Sites	268.0573	207.2522	194.4051	166.4442
Esophagus	9.9275	3.26	3.7344	4.283
Colorectal	30.4886	26.7525	19.9229	14.289
Pancreas	14.4315	10.3261	13.414	10.9268
Larynx	2.9673	1.4205	1.7134	0.9735
Lung (Male)	117.504	86.6912	69.007	56.1204
Lung (Female)	29.6421	30.8104	34.7788	37.6605
Breast (Female)	34.8506	33.1129	29.4253	20.7144
Cervix	8.9837	3.2659	3.6938	2.1485
Prostate Gland	67.2593	31.2808	41.7911	18.1297

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

FIGURE 5. AGE-ADJUSTED FIVE YEAR RELATIVE SURVIVAL RATES FOR CANCER BY RACE IN 1981 & 2007²⁺

SELECTED CANCERS:	1981		2007	
	BLACK	WHITE	BLACK	WHITE
All Sites	40.7	53.7	62.8	70
Esophagus	9.4	8.9	8.9	23.5
Stomach	16.9	17.1	25.4	27.5
Colorectal	49.7	58.7	60.7	67.1
Pancreas	4.8	2.8	4.7	7.9
Larynx	52.8	69.3	46	63.9
Lung (Male)	9.3	11.3	11.6	16.1
Lung (Female)	15	16.7	18	21.2
Breast (Female)	65.8	79.4	82.2	92.1
Cervix	55	68.7	61.5	72.3
Prostate Gland	66.8	75.9	97	99.8
Urinary Bladder	69.9	77.5	64	80.1

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

FIGURE 6. INFANT MORTALITY BY ETHNICITY IN 1985 & 2012^{3^}

RACE/ETHNICITY OF MOTHER:	1985	2012
All Mothers	10.4	6.0
White	8.9	5.1
Black	18.6	10.9

* Rate based on underlying cause of death. Age Adjusted to 2000 Standard Population at age 18+. All Sex. Per 100,000 population.

+ Age Adjusted to 2000 Standard Population. All ages. Per 100,000 population.

^ Per 1,000 live births. Infant Mortality includes infant, neonatal, and postnatal.

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A HEALTHIER VILLAGE: 1
COMMENTARIES FOR OUR COMMUNITY

MESSAGE FROM THE CONGRESSIONAL BLACK CAUCUS CHAIR

CONGRESSMAN G.K. BUTTERFIELD (NC-01)
CHAIR, CONGRESSIONAL BLACK CAUCUS



The Congressional Black Caucus has long been a voice for issues affecting the African American community, and has been particularly engaged on the issues of access to affordable healthcare and disparities among minorities. By all measurable statistics—from health outcomes to participation in health professions—African Americans lag behind. We face many challenges when it comes to health and overcoming these disparities. The landmark legislation known as the Affordable Care Act (ACA), which I helped to draft in the House Energy and Commerce Committee and was signed into law in 2010, was a step in the right direction to address health disparities.

Opposition has slowed progress. In 2012, the Supreme Court ruled that state expansion of Medicaid under the ACA is optional. Based on that decision, twenty-two states, including my home state of North Carolina, effectively eliminated access to healthcare for many low-income African Americans and denied billions of federal dollars in aid, which could have stimulated each state's economy. The House of Representatives has held more than 60 votes to repeal parts or all of the ACA. And approximately 6.4 million Americans, including many in North Carolina, would have lost health subsidies had the Supreme Court ruled against those provisions of the ACA. Adding to these challenges are the efforts to reduce funding for the U.S. Department of Health and Human Services and its agencies, which would widen health disparities between African Americans and other groups.

Our primary mission to reduce health disparities must be to uphold and improve the ACA and encourage states to expand Medicaid under the ACA. Minority groups that have systematically experienced social and economic disadvantages continue to face great obstacles to optimal health and continue to lag behind Whites in quality of care, access to care, and health outcomes. By encouraging those twenty-two states to act, we can exponentially improve access to care for the most vulnerable populations and infuse billions into state economies. We must also be vigilant in upholding all aspects of the ACA to ensure that millions of people do not lose health insurance they deserve. Additionally, the CBC will continue to push for further investments in meaningful health programs that will lead to the elimination of health disparities.

We also seek to reduce disparities within the healthcare industry. It is important that physicians, researchers, manufacturers, and insurers are representative of the communities they serve and create STEM education pipelines to increase the number of African Americans in these professions.

Finally, I would like to call your attention the passage of the 21st Century Cures Act by Congress in July. This bipartisan bill helps reduce health disparities by developing new treatments to serve African American communities. The bill included nine provisions, which I sponsored, and shows that members of both parties can come together to help improve health care for all. I am encouraged that this bill can be signed into law and create momentum to further address health disparities.

In closing, it is my hope that as you read through this report you will continue the dialogue on healthcare access and identify additional solutions to reduce health disparities. We all have a part to play. I look forward to continuing our work to establish and maintain healthy communities.

Sincerely,

Representative G. K. Butterfield
Chairman, The Congressional Black Caucus

THE NEXUS OF QUALITY IMPROVEMENT & HEALTH EQUITY

DANIEL E. DAWES, ESQ.
ATTORNEY & EXECUTIVE DIRECTOR OF GOVERNMENT AFFAIRS,
POLICY & EXTERNAL AFFAIRS, MOREHOUSE SCHOOL OF MEDICINE



This year marks several significant anniversaries in our nation's long and ongoing struggle for health equity. 150 years have passed since the end of the Civil War and the creation of the Freedmen's Bureau, an organization established to provide health care, education, and assistance to freed slaves. It also marks the 50th anniversary of the March to Selma and 30 years since the release of the Heckler Report, a landmark publication documenting racial and ethnic health disparities throughout the United States. The report labeled such disparities "an affront both to our ideals and to the ongoing genius of American medicine," and it resulted in the creation of the Office of Minority Health at the U.S. Department of Health and Human Services.

While changes in health policy relative to minority health and racial and ethnic disparities were slow between the mid-1800s to the mid-1900s, there was a tremendous effort to elevate the health status of all minorities and improve the provision and quality of care they received across the United States once the federal government established the Office of Minority Health in 1986.

Since 1990, the federal government has also prioritized the reduction or elimination of health disparities in its public health agenda for the nation, *Healthy People*, and has passed three major pieces of legislation every decade thereafter intended to directly address health equity-related issues in a comprehensive and meaningful way, including the *Disadvantaged Minority Health Improvement Act of 1990*, the *Minority Health and Health Disparities Research & Education Act of 2000*, and the *Patient Protection and Affordable Care Act of 2010*.

Since the Affordable Care Act's enactment, major strides have been made to improve the overall access and quality of health care. Health insurance coverage for low-income and minority communities with 16 million Americans receiving coverage through the newly created Health Insurance Marketplaces or through the Medicaid Expansion within 29 states and the District of Columbia.¹ African Americans and Latinos have expe-

rienced the greatest decline among all racial groups. According to the White House, "[s]ince the Marketplaces opened and Medicaid expansion began, the uninsured rate among African Americans has dropped 41 percent and Latinos declined 29 percent, with an estimated 2.3 million African American adults gaining coverage, and about 4.2 million Latino adults gaining coverage."

In addition to increasing access, the Affordable Care Act has helped to improve quality by increasing adolescent vaccination rates and reducing hospital acquired conditions by 17 percent.² Despite these major increases in health coverage and quality improvement, however, few health care disparities have been eliminated. The Agency for Healthcare Research and Quality's (AHRQ) *2014 National Healthcare Quality and Disparities Report* stated that, "parallel gains in access and quality across groups led to the persistence of most disparities."³

Altogether, approximately 83,000 racial and ethnic minorities die each year as a result of health disparities, and we spend an estimated \$300 billion as a nation because of these disparities.⁴ In fact, \$82.2 billion of that can be attributed to direct health care expenditures and losses in productivity.⁵ These statistics provide only an overview of a problem that is multifaceted and arcane. Health disparities are driven in large part by social and physical determinants of health, and often result from policies adopted without meaningful assessment of their impact on racial and ethnic minorities and other vulnerable populations. For example, in states that have not expanded Medicaid, there is a "coverage gap" affecting low-income adults who are ineligible for Medicaid but do not earn enough to qualify for marketplace subsidies.

This gap disproportionately impacts poor Black adults since they disproportionately reside in the South where most states have not expanded Medicaid.⁶ This disparity in coverage will likely contribute to further health disparities over time.

As we continue on this journey of health care transformation, one major area that has been neglected involves the nexus between quality improvement and health equity. For the first time since it began releasing separate annual reports on healthcare quality and healthcare disparities in 2003, AHRQ¹ in 2015 combined both reports into one, giving readers a better snapshot of how these two issues intersect across the country. In general, the report showed an interesting trend—states with higher healthcare quality scores tended to show higher disparities in care among racial and ethnic groups. States with lower health care quality scores tended to show lower disparities in care among racial and ethnic groups, meaning that in these states all racial and ethnic groups receive lower quality care.¹

With the *American Recovery and Reinvestment Act*, the *Affordable Care Act*, and the *Medicare Access and CHIP Reauthorization Act of 2015*¹ steering us away from a fee for service system to a system focused on quality, value, and accountability, there is concern that this could lead to a separate and unequal healthcare system. A system resulting in striking differences in the provision of health care services based on one's racial and ethnic background or geographic location. Therefore, more attention in this area is needed to ensure that consumers, as well as providers and payers serving these communities, are not unfairly penalized. This must entail bringing all communities to the table and working collaboratively to design models that are focused on achieving equity in health care.

These findings indicate that if we are to achieve real health equity, we cannot simply improve access and quality. We must also proactively consider the impacts of policies on racial and ethnic minorities, and work to address the social and physical determinants of health. With growing diversity in our country and the current failure to reduce or eliminate associated risk factors that can influence health and health outcomes, it is imperative that policymakers, researchers, and the larger health care and public health community more fully examine the intersection of quality improvement initiatives and health disparities. We must then work to identify, develop, and implement appropriate strategies to advance health equity among vulnerable populations.

Examples of such health care disparities include the fact that compared to other races, fewer American Indians and Alaska Natives receive complete written discharge instructions following hospitalization for heart failure.⁷ Avoidable hospitalizations for all conditions are higher for Blacks than Whites,⁸ and Black and Hispanic parents are more likely than their White counterparts to experience poor communication with their child's health care providers.⁹ Indeed, the health disparities confronting other vulnerable populations are many and varied as well. People in these populations may experience symptoms that go undiagnosed, under-diagnosed, or misdiagnosed for cultural,

linguistic, or other reasons.

Quality improvement initiatives, including payment and delivery system reforms may similarly exacerbate racial and ethnic health disparities if they are guided by a one-size-fits-all approach and fail to consider unique issues impacting under-resourced and underserved communities. Few people would argue that health plans and providers should be held to the highest standards and deliver the best quality care to all, regardless of their patients' racial and ethnic, socioeconomic or health status. However, failure to take into account the unique circumstances and issues confronting these providers as they strive to deliver optimal patient-centered care or provide these payers and providers with the flexibility and resources they need to enhance care in their communities will only lead to suboptimal care.

Safety net providers and payers who serve a largely lower-socioeconomic or culturally diverse patient population often times treat patients with higher rates of chronic disease, disability, and mental illness. Their patients often have limited English proficiency and health literacy, and face significant challenges with the social and physical determinants of health in their communities. These providers are the main source of health services to underserved communities and should not be discouraged or unfairly penalized for caring for low-income, racial, or ethnic minorities by rigid quality measures that, in many cases, were not developed with input by these communities. To do so, would have devastating impacts on vulnerable communities and could deepen existing health disparities. There is a middle-ground approach that could ensure that safety net providers are not let off the hook for sub-quality care, while also recognizing the additional factors impacting health outcomes.

Some recommendations for policymakers would include developing strategies with organizations representing communities of color to identify a standard set of socio-demographic variables (patient and community-level) to be collected and made available for performance measurement and tracking disparities; developing an approach that would compare health plans with similar mixes of racial and socioeconomic beneficiaries to assess improvements under the Star Ratings system; as well as delay penalizing plans until the National Quality Forum has completed its trial period examining the impact of adjusting quality measures for socio-economic status and the Office of The Assistant Secretary for Planning and Evaluation (ASPE) has completed its study of the effect of individuals' socio-economic status on quality measures and resource use. Finally, policymakers need to seriously dedicate more funding and provide meaningful resources to address health equity and quality issues impacting communities of color and other at-risk populations. By taking these steps, we will be able to realize the Healthy People 2020 goal of achieving health equity, eliminating disparities,

and improving the health of all groups.

- **Author's note:** Unfortunately, since the passage of the *Affordable Care Act*, the AHRQ has been the target of repeated attempts to dismantle it or significantly decrease its appropriations. This is concerning because AHRQ's research has tremendously helped to advance evidence-based policymaking especially related to health disparities. Without this critical agency, it would be difficult to track the disparities in health care on an annual basis and determine where policymakers should focus their efforts.
 - **Author's note:** Southern states in general show lower quality care and fewer disparities in care, interestingly the South has higher and costlier disparities in health status, which is overwhelmingly borne by African Americans.
 - **Author's note:** Also referred to as the "Doc Fix," the legislation addressed the Sustainable Growth Rate (SGR), which threatened physician Medicare reimbursement for nearly 18 years. In essence, it reauthorized many of the programs that had expired in the *Affordable Care Act* and demonstrated support for many of the delivery and payment system reforms espoused in the ACA. One could argue that the *American Recovery and Reinvestment Act* laid the foundation for the *Affordable Care Act*, and the *Medicare Access and CHIP Reauthorization Act of 2015* paved the way for these reforms to more easily get implemented.
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AFFORDABLE & QUALITY HEALTHCARE: A RIGHT FOR ALL AMERICANS

THE HONORABLE MARC H. MORIAL
PRESIDENT & CEO, NATIONAL URBAN LEAGUE



Thirty years ago, then Secretary of the Department of Health and Human Services, Margaret Heckler issued a report that has since helped to save, prolong, and better the lives of millions of Americans.

The Report of the Secretary's Task Force on Black and Minority Health—better known as *The Heckler Report*—brought the issue of health equity to the forefront of national conversations about healthcare. As a direct result of this report, Congress created an Office of Minority Health within the Department of Health and Human Services in 1986. This office has led many important efforts including the release of National Standards for Culturally and Linguistically Appropriate Service in Health and Healthcare and other critical movements that reduce health disparities.

The Heckler Report helped drive the national dialogue around health reform toward a focus on equity and access for all, particularly the poor and underserved. This has been a core mission of the National Urban League since its inception.

In the 20th century, our nation marched forward in addressing racial disparities through a combination of research, advocacy, civil litigation, and political action in partnership with leaders including W.E.B. DuBois, W. Montague Cobb, Historically Black colleges, and other civil rights organizations, including the National Urban League. In the 21st Century, many of the same challenges remain, and the role of civil rights organizations in addressing them is more important than ever.

In that spirit, The National Urban League is proud to work with Congresswoman Robin Kelly and the Congressional Black Caucus Health Braintrust as they reintroduce the Health Equity and Accountability Act (HEAA) this Congress. HEAA is a comprehensive, broadly supported legislative proposal to reduce disparities in healthcare access and outcomes for communities of color. As a linchpin to preserving the equity framework in the

national health reform dialogue, it was the foundation of many key provisions that were included in the Affordable Care Act (ACA). As co-chair of the HEAA Community Working Group—a coalition over 300 national, state and local stakeholders—the National Urban League looks forward to working closely with the Congresswoman to pass this critical legislation.

As a leader on health disparity elimination, the National Urban League has coordinated community health programs in cities across the country that focus on chronic disease prevention and management, HIV awareness and testing, food security and hunger prevention, maternal child health, senior citizen health, and health literacy education, among other issues. We also continue to educate communities about their options and benefits under the Affordable Care Act and provide consumers with assistance enrolling in health insurance plans. During the first ACA enrollment period in November 2014, the National Urban League, the Greater Phoenix Urban League, and the Urban League of Hudson County (NJ), in partnership with other affiliates, provided direct community enrollment assistance as ACA Navigators. Building on our Community Health Worker approach and related expertise, approximately 25 Urban League affiliates have provided their communities with assistance as Navigators, Certified Application Counselors, In-Person Counselors or Champions for Coverage—resulting in over 8 million outreach touches and over 600,000 directly educated over the last two enrollment periods. These gains demonstrate the effectiveness of providing targeted, culturally relevant outreach and engagement services. Through the National Urban League's *Project Wellness* programmatic initiatives and culturally appropriate and resonant curriculum, we address the different perceptions that African Americans and other underserved communities have of health, wellness, illness, disease, and healthcare by empowering these communities to improve their health and serve as effective health advocates in their local community.

We have seen the incredible power of the Affordable Care Act

on the nation's health and wellbeing. Since its passage, an estimated 31.8 million Americans have gained access to healthcare. As of April 2015, the overall uninsured rate has dropped to 11.9 percent—translating to nearly 9 out of 10 Americans having health insurance. For African Americans, the percentage of uninsured individuals has fallen from 20.9 percent to 13.6 percent from the fourth quarter of 2013 to the first quarter of 2015. This represents a net change of 7.3 percentage points. During this same period, Hispanics also made large gains, with their uninsured rate dropping from 38.7 to 30.4 percent—a difference of 8.3 percentage points.¹

Today, no individual can be denied coverage for healthcare because of pre-existing conditions and healthcare companies cannot cap the amount of coverage they provide individuals. Consumers have saved an estimated \$9 billion dollars because the law requires health insurance companies to spend at least 80 cents of every dollar on consumers' healthcare and empowers states to review and negotiate premium increases. At the same time, fewer Americans are losing their lives or falling ill due to hospital-acquired conditions, like pressure ulcers, central line associated infections, and falls and traumas—which are down 17 percent since 2010.²

Preliminary data show that between 2010 and 2013, there was a decrease in these conditions by more than 1.3 million events. As a result, 50,000 fewer people lost their lives, and there were \$12 billion in cost savings.

Despite this measurable progress, the National Urban League's *2015 State of Black America Equality Index*³ reveals persistent disparities in health among Black and Latino communities, signaling a call to action to move the nation closer toward health equity.

The evidence is clear: access to quality healthcare saves and prolongs lives, and helps millions become more economically stable and productive. And yet, many of our elected officials continue to play politics instead of expanding affordable healthcare to more Americans. In addition to attempts to thwart expanded access in Congress, many state leaders continue to block efforts to expand healthcare access to their constituents. These actions are a choice. And they are choices that will cost lives and livelihoods.

People's lives matter more than politics. We have to build on the nation's progress and ensure that access to quality and affordable healthcare is not reserved for the privileged and wealthy.

The Affordable Care Act (ACA) set us on an accelerated path to close health disparities. The HEAA builds on gains of the ACA by providing a comprehensive framework for additional

federal resources, policies, and infrastructure needed to close the remaining gaps. Let's continue on the path to health equity.

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GUN VIOLENCE: THE NEED FOR A PUBLIC HEALTH STRATEGY

DAVID SATCHER, MD, PHD
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SATCHER HEALTH LEADERSHIP INSTITUTE, MOREHOUSE SCHOOL OF MEDICINE



Gun violence, particularly in African American communities, has remained one of the more persistent public health issues we face as a nation that I've observed throughout my career. Taking a public health approach to addressing gun violence would allow for a systematic examination of the causes and potential solutions to this problem, but barriers limit our ability to fully deploy this strategy.

Public health is the collective effort of a society to create the conditions in which people can be healthy; relative to violence, the public health approach has never been fully applied. The four-step public health approach begins with identifying the problem, which we have done well in studying gun violence, but it is not enough. We must determine the causes of the problem, then determine what works to prevent it. Finally, we must implement and evaluate solutions, including policies.

Gun violence is a leading cause of death and disability worldwide. In our own country, firearm homicides take over 11,000 lives per year.¹ While we recall tragic mass shootings, attacks such as these have accounted for less than 200 deaths over the last 16 years. But we ignore the thousands of firearm homicides that are not part of mass shootings, and the communities disproportionately affected by the problem. Gun violence accounts for a major disparity in excess death, especially in black males;² it is the leading cause of death in African American men between the ages of 10 and 24 years,³ and takes the lives of African Americans at over four times the rate of the general population.⁴ We as a nation must come together, put our differences aside and take on all the causes of violence in a very deliberate way.

Causes of gun violence include things like poverty, lack of education, mental illness, and even policies that make it too easy to perpetrate violence. For instance, these disparities converge in the easy availability of crack cocaine and access to guns, which coincided with a significant upturn in violence among black

males in the 1980s. The action taken was mass incarceration that continues today.

In order to fully understand the causes we need to adequately fund research into the problem. As with many public health problems, the cause is most likely a complex set of factors interacting in the social milieu. The resources to thoroughly examine the causes of gun violence and develop interventions that pinpoint those causes are simply not there.

One of my most memorable yet disparaging experiences that occurred while serving as Director of the Centers for Disease Control in the mid-1990s was the Congressional attempt to eliminate the National Center for Injury Prevention and Control. A 1993 study published in the *New England Journal of Medicine* found that guns in households posed a three-fold risk of homicide by a family member or intimate partner⁵ despite the fact that the research passed scientific rigor, guns-rights groups strongly and successfully lobbied Congress to prohibit any further CDC funding for the study of gun violence as a public health problem. The CDC continues to do a good job of cataloguing gun violence and deaths, but much of the violence is not reported, and when it is, reports are through confidential surveys that do not show a significant difference by race or ethnicity. Despite thousands of gun-related deaths still occurring every year, Congress has yet to restore funding for the CDC to apply the public health approach to gun violence.

In 1998, the *Surgeon General's Call to Action to Prevent Suicide* noted that firearms are major factors in the rising rate of suicide. Moreover, although women attempted suicide twice as often as men, men succeeded four times as often, due in great part to the fact that men were more likely to use firearms than women, who tended to use drugs or pills. The report recommends treating suicide as a public health issue and providing access to care for mental health problems.

The following year, in 1999, the Columbine massacre was so shocking to our nation that the White House and Congress appropriated three-quarters of a million dollars to develop *Youth Violence: A Report of the Surgeon General*.⁶ The report clearly documented gun violence as a public health problem, but by the time the report was released in 2001, the attention and shock of Columbine had waned and the nation had moved on.

To adequately intervene, we need to better understand the cause so we can better target the solutions. In order to accomplish this, we need to direct resources to applying the public health approach to understanding and preventing gun violence. When it is clear what interventions are effective because they have been funded and implemented in selected communities, we can then replicate them more widely.

MD: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; Substance Abuse and Mental Health Services Administration, Center for Mental Health Services; and National Institutes of Health, National Institute of Mental Health.

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IMPROVING ACCESS **2**
TO CARE & DIVERSITY IN CARE

ACCESS TO HEALTHCARE AS A SOCIAL DETERMINANT

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INTRODUCTION

In health care, there exists an “eternal triangle” of the three system considerations that create the backdrop for patient experiences. These three elements are the access to care, the cost of services, and quality of care that patients experience within the system.¹ While each of these elements is intimately related and critically important, it can be argued that access to care may be the most fundamental. Without the ability to enter the system and effectively engage with providers, the cost and

quality of those inaccessible services become moot.

Bearing that in mind, the Affordable Care Act (ACA) functioned primarily as a measure to increase access to care. Based on the importance of health insurance in navigating our healthcare system, the ACA aimed to expand access through a combination of making health insurance more affordable and expanding the accessibility of public insurance options like Medicaid and Medicare. The measure became law with a guiding principle that all Americans should have—at minimum—the opportunity

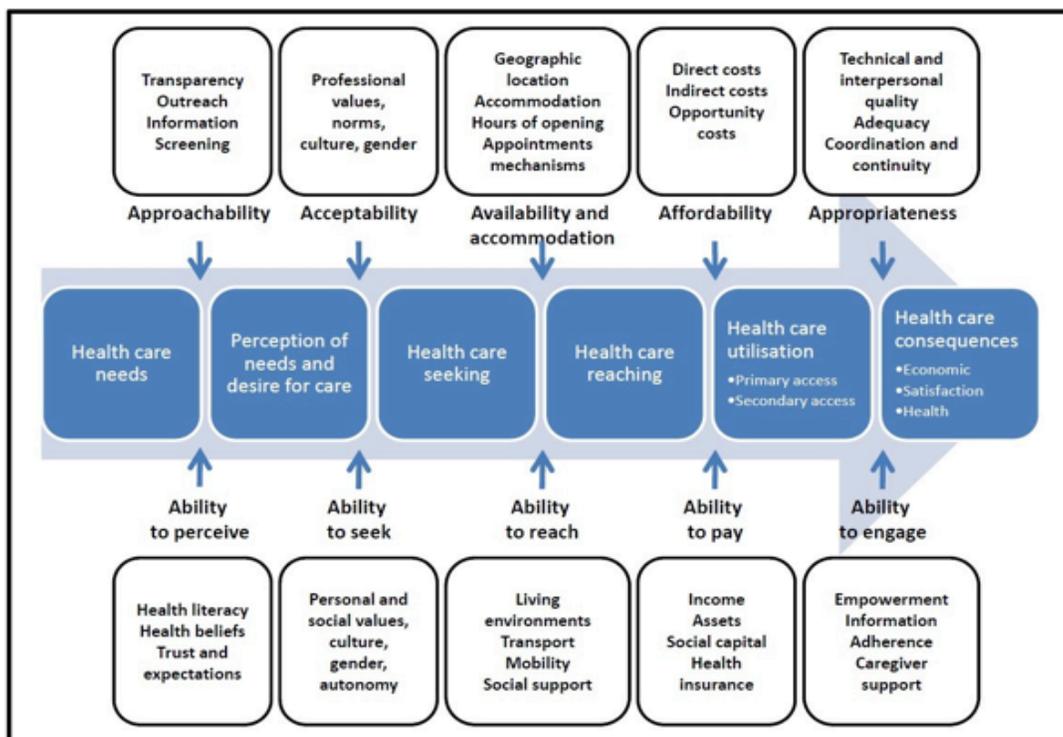


FIGURE 1. A CONCEPTUAL FRAMEWORK OF ACCESS TO HEALTH CARE. (FROM LEVESQUE ET AL)

to achieve good health.

While access to care is frequently described in terms of health insurance status, this is not the only metric of access. In fact, health insurance is but one facet of a much larger concept of true access to healthcare. In aggregate, the many dimensions of healthcare access create a series of factors that can impede the path to health. For some groups—racial and ethnic minorities among them—the confluence of these factors is a fundamental cause of the disparities in health outcomes.

This brief will elaborate on the many dimensions of healthcare access, describe the groups most susceptible to inequities in access, and describe the interventions that have been both recommended and implemented to address these disparities in access to health care.

DEFINING HEALTHCARE ACCESS

Healthcare access has historically been measured and defined in a number of ways. As previously noted, it is most often described in terms of insurance status. Still, other measures such as a patient's identification with a usual source of care, the number of provider contacts a patient has, and the extent of patients' unmet medical needs have also been described. To fully understand how health care contributes to health inequities, it is best to think broadly about access to health care.

One of the more comprehensive frameworks, proposed by Levesque et al., helps facilitate this broad view of health care access by describing access as a function of both provider-facing and patient-facing factors.² Mounting research continues to demonstrate that disparities in what Levesque described as "supply-side" and "demand-side" factors have resulted in disparities in health outcomes.

SUPPLY-SIDE

In the provision of services, there are a number of dimensions that affect a patient's actual healthcare access. These include issues such as provider approachability, the availability of a healthcare facility with regard to its location and hours, the affordability of services, and also the acceptability of the system in aligning with patient values and norms.

The role of these dimensions in creating and sustaining racial and ethnic disparities has been well described. In fact, most of these dimensions were identified in *Unequal Treatment*, the Institute of Medicine's landmark report on health disparities published in 2002.³ Since that time, further studies continue to elucidate their effect. For instance, perceptions of the accept-

ability of a provider or system can often be correlated to provider-patient concordance—that is, the racial, gender, and geographic similarities between patients and providers.⁴ With the persistent underrepresentation of minorities in medicine, this is certainly a bigger issue for minority patients than for their white counterparts. Additionally, issues of availability and accommodation have also been described as barriers, with studies among physician trainees consistently demonstrating waning interest in practicing in underserved areas.⁵ Finally, studies like the biannual National Healthcare Disparities Reports have demonstrated that the appropriateness of care—that is, whether the care provided is of high quality and delivered in a timely manner—is more often an issue in minority communities.⁶

DEMAND-SIDE

Similar to the provision of care, there are a number of access dimensions facing patients. Most are predicated on certain capacities and abilities that patients have to engage the healthcare system. These include the ability to perceive a health need, how empowered patients feel to seek care, patient ability to physically reach a facility, and patient ability to engage their providers. Each of these dimensions has also been strongly implicated in the persistence of health inequalities.

The abilities to seek and engage are both strongly correlated to patient trust and perceptions of discrimination.⁷ From the legacy of medical experimentation on African Americans left by studies like the Tuskegee syphilis experiment to the experience of segregation in hospitals around the nation just one generation ago, many African American patients have inherited not only their elders' genes, but also their negative experiences with American healthcare. Additionally, the ability to perceive a health need is impacted by health literacy, cultural beliefs, and education—all of which disproportionately impact the interaction of minority patients with the healthcare system.⁸ Finally, the ability to reach a facility is impacted by circumstances such as transportation limitations, work hours, and home supports, which are also noted in the literature to be barriers to care disproportionately faced by minority patients. The cumulative effect of the barriers to access in terms of these dimensions creates a picture of an inaccessible system for far too many minority patients.

VULNERABLE POPULATIONS FOR DISPARITIES IN HEALTHCARE ACCESS

Against the backdrop of this more expansive definition of healthcare access, the list of vulnerable populations at risk for these inequalities only grows. While the breadth and depth of disparities are better documented in some groups than others,

inequalities, themselves, have been found based on age, education, gender, geography, immigration status, income, English-proficiency, sexual orientation, racial & ethnic group, and rural-urban residency among many other factors. Each of these factors has been found to somehow impact a patient's access to health care, whether it is insurance status, patient-provider communication, or quality of care.

Though they are discussed as discrete groups that experience disparities in health care, it is important to remember that each of these factors are inherently compounded. For example, while racial and ethnic disparities in access to health care are well documented, these disparities can vary depending on where in the country one lives. Geographic variation in distribution of health care can increase or decrease racial and ethnic disparities in access. Furthermore, demographic characteristics such as income status, education level, and employment are often correlated.

IMPACT OF DISPARITIES IN HEALTH CARE ACCESS ON HEALTH OUTCOMES

These disparities in access to health care have been connected with numerous health outcomes. This includes overall health measures such as quality of life, functional status, and mortality.^{21,22} It has also been shown to impact the outcomes of specific illnesses including multiple types of cancer,^{23,24,25} cardiovascular and cerebrovascular disease,^{26,27,28} diabetes,²⁹ maternal and infant health,^{30,31} as well as pulmonary diseases,^{32,33,34} among many others. Access inequities have also been shown to impact process outcomes including cancer screening and vaccination rates.

INTERVENTIONS TO ADDRESS DISPARITIES IN HEALTH CARE ACCESS

The increasing attention given to health inequities and their continued presence has triggered a growing body of research on how we can explicitly address health disparities. It has long been thought that a rising tide would raise all boats—improved health care would improve outcomes for all populations—but recent studies have shown that in some cases they have actually exacerbated health disparities. New interventions often do not disseminate to vulnerable populations as quickly creating increased disparities.

Strategies to address disparities in access can be implemented at all levels of the socioecological model: policy, community, organization, interpersonal, provider, or patient. In the end—just

as with the “eternal triangle”—it all begins with access to care. At present, a range of interventions have been proposed and implemented with a goal of expanding true healthcare access. These include innovations such as school-based health centers, including health equity as a measure of health care quality,³⁵ utilizing community health workers and patient navigators,^{36,37} increasing the cultural competence of the provider workforce,³⁸ and improving health care coverage.³⁹ It will take these strategies—and the concerted efforts of policymakers and health system leaders—to make access to care a reality for African American patients nationwide.

Editor's Note: The above submission is a condensed version of an article: Access to Healthcare as a Social Determinant authored by Dr. Bryant Webb and Dr. Elaine Khoong. The research was funded by a grant through the National Library of Medicine at the National Institutes of Health.

TABLE 1. PATIENT FACTORS CORRELATED WITH DECREASED HEALTHCARE ACCESS.

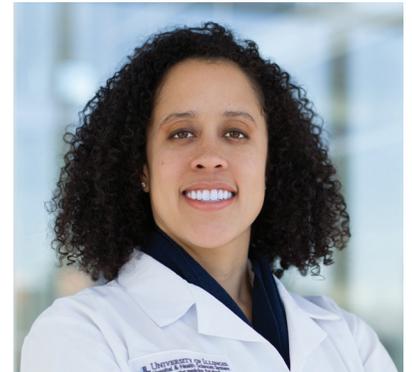
FACTOR	BRIEF DESCRIPTION
AGE	Elderly patients may not receive evidence-based care in acute stroke. ⁹ Age concordance may also impact the quality of the patient-physician communication. ¹⁰ Age also influences the likelihood of having discontinuous health insurance and thus access to health care. ¹¹
EDUCATION	Individuals with lower levels of education are less likely to receive advice on self-management or lifestyle change recommendations. These individuals are also more likely to delay seeking care and avoid using allied health professionals (e.g., physical therapists). ¹² Individuals with lower health literacy are also less likely to receive preventive services or demonstrate understanding necessary to adhere to medication regimens.
EMPLOYMENT	Families that are not working or have self-employed or part-time employed individuals often do not have continuous insurance. ¹³
GENDER	Females are less likely to receive aggressive recommendations and treatment for cardiovascular disease. Gender concordance may also impact the quality of the patient-physician communication.
GEOGRAPHY	There is large geographic variation in utilization of effective healthcare services. In some areas of the country < 40% of Medicare enrollees receive effective care while in other parts of the country > 55% receive appropriate care.
IMMIGRANTS	Immigrant populations are less likely to have continuous insurance, a usual source of care, or receive quality evidence-based care or patient-provider communication. Immigrant populations have worse access than non-immigrant populations of the same race, ethnicity, and socioeconomic status.
INCOME	Income level impacts the likelihood that a patient will have discontinuous insurance coverage and thus whether they will have a usual source of care and be able to access timely health care. Patients of lower income levels are also more likely to delay seeking care, have barriers to receiving care from specialists or allied health professionals. Low-income patients are also less likely to receive advice on lifestyle changes.
LANGUAGE STATUS	Patients with lower English proficiency are less likely to have a usual source of care and delay acquiring care. ¹⁴ These patients have even worse access than their English proficient counterparts who are of the same race, ethnicity, and socioeconomic status. ¹⁵
LGBTQ PATIENTS	Lesbian and gay patients are more likely to avoid care than their heterosexual counterparts and report greater dissatisfaction and difficulties communicating with their healthcare provider. ¹⁶
MENTAL ILLNESS	Individuals with mental illness are less likely to receive age appropriate preventive and screening services. ¹⁷
PRISONERS & FORMERLY INCARCERATED	Patients who have been formerly incarcerated have greater difficulties accessing medical and dental services. ¹⁸ These individuals report having unmet medical need and being unable to identify a usual source of care. ¹⁹
RACIAL & ETHNIC MINORITY	Higher incidence and mortality as well as lower rates of proven interventions for a number of diseases have been suspected to result from a multitude of causes including lower screening rates, worse follow-up, different health beliefs, lower adherence, as well as worse patient-provider communication. These disparities exist across the age spectrum and include children and older patients. Minority populations are also more likely to be uninsured or lack continuous insurance coverage.
RURAL	Patients in rural areas have to travel two to three times further to seek specialty care in comparison to their urban colleagues. ²⁰ These patients are also more likely to have discontinuous insurance and as a result lack a usual source of care and delay seeking of medical care.

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IMPROVING THE DIVERSITY PIPELINE IN MEDICINE: DIVERSITY WILL SAVE & IMPACT LIVES

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There is no longer a need to define the obvious: health disparities exist. If you are Black, Latino, Asian, Native American, female, gay, incarcerated, or disabled, you are systematically more likely to have increased obstacles in accessing health care and are therefore more likely to have worse health outcomes. In 2003, the landmark report by the Institute of Medicine (IOM), *Unequal Treatment*, defined this conversation, spelling out the extent to which race, ethnicity, sexual orientation, and other disadvantaged characteristics have been shown to impact a person's health. Health disparities are thusly recognized as a national concern that continues to permeate the academic literature.¹

Our governmental leadership has similarly taken steps to address the issue. Drafted by experts in multiple federal agencies, *Healthy People 2020* outlined goals for our nation's health that include interventions to eliminate health disparities. However, the solutions otherwise remain difficult. How do we affect change in a system that is otherwise ingrained with historical inequities? How do we promote the health of one segment of society without also neglecting all persons who deserve high quality care?

One solution that the IOM highlighted deserves the attention of political, academic, and corporate stakeholders alike: supported by evidence, the diversification of the workforce of health care professionals does improve patient outcomes impacted by health care disparities. With the broad inclusion of persons from diverse backgrounds, patients report:

- improved communication with their physician
- improved trust in the relationship and recommendation given
- increased adherence to treatment plans

The Sullivan Commission, convened under a grant from the

W.K. Kellogg Foundation, issued its ground-breaking 2004 report, *Missing Persons: Minorities in the Health Professions*, that expands the concept of diversification as a solution in great detail.² Acknowledging that the inequities in health care delivery are caused by multifactorial and historical dynamics that require similarly complex solutions, the Commission reviews the statistics concerning minorities within the health professions, which continue to plague our workforce even now, a decade later. The Association of American Medical Colleges provides regular updates on the matriculation and graduation rates of students into MD-granting schools; in 2014, an alarming 8.9 percent of all physicians in the U.S. were Black or African American, American Indian or Alaska Native, and Hispanic or Latino.³ The other health professions including dentistry, nursing, pharmacy, social work, and psychology also show similar dearth of these underrepresented minorities. While the business community has deemed workforce diversity as an important factor in maintaining competitiveness in the marketplace for some time and has provided sound argument for the same parallels within healthcare, it has resulted in little change.

Now is the time for a concerted call to action. Diversity makes a positive impact. The evidence is clear. And yet for more than a decade, we as a nation continue to face alarming rates of health-care disparities that cause illness and death. The call to action for diversity is more than an argument for the sake of numbers or quotas. The call to action is not about promoting the righteousness. This call to action for equity within the healthcare workforce will impact and save lives.

Efforts have and are being made within academia and the philanthropic realm. Universities and foundations support recruitment efforts of ranging caliber: the promotion of science/technology/engineering/math (STEM) within primary and high schools, the establishment of shadowing and mentoring programs, scholarships, and research and summer enrichment programs. There is increased recognition of the concept of a pipeline from early

school-age, to high school, to college that must be enriched with information and advice throughout the years of study. The question of how we achieve diversity remains a quandary as our efforts to recruit additional minorities have shown little success. While there is no denying that individual students benefit from enrollment in such opportunities, our outcomes across the population are not impressive.

The typical recruitment efforts focus on young persons from highly ranked high schools and universities or within close proximity of academic medical centers that host programs and offer resources. The reliance on the ability of these students to have achieved positions in these institutions is heavy and is counterproductive to the end goal of increasing overall diversity. Weak points early in age along the pipeline into the health professions often lie in the inadequate preparation, advising, and mentoring resources for students of diverse backgrounds. Underrepresented minority students are often first generation college attendees, come from lower socio-economic backgrounds, are ill-prepared in their primary and secondary education, and often have little exposure to health care professional mentoring. In addition, once they do succeed through their primary education, there often exist limitations of academic and advising resources at the minority-serving institutions and community colleges that house large numbers of underrepresented minority students.

Programs like the Tour for Diversity in Medicine seek to address these very issues and increase the audience of students that consider careers in health care. The Tour for Diversity in Medicine (T4D), the flagship program of Motivating Pathways Inc., is a grassroots effort to educate, cultivate, and inspire minority high school and college students through local programming hosted by current underrepresented minority professionals. Having hosted more than 2700 students across twenty-three states and the District of Columbia, T4D has gained several insights from its efforts that can be implemented through legislative and policy action items.

1. In line with the Sullivan Commission recommendation for a public awareness campaign surrounding diversity, funding should be provided to support programming and easily accessible and distributable information that exposes students to career options within the healthcare professions. Early advising in all public and private education should include career development introduction that highlights the pipeline into college and professional schools. Typically those communities that have access to or partnership with an academic medical center have these opportunities, but more widespread dissemination of both STEM focused

programming and career development coursework should be deployed.

2. Programs should include recognition and promotion of support for specific psychological needs including self-determination and motivation as significant factors in the success of students along the pipeline into health care professions. As students gain exposure to career options, students from any variety of disadvantaged backgrounds require additional support to assure that they can be successful. Students have interests and may possess the internal drive to succeed but are stymied by their self-doubts as well as surrounding negativity from family, teachers, or advisors. Early educational efforts to assure that students from all backgrounds are aware of their options should also acknowledge a student's internal beliefs of limitations and the external influences that may deter their ability to achieve.
3. Programming should develop hands-on and interactive approaches to exposure that include mentoring as a priority. Information alone is not sufficient to allow the students to form educated connections to a future career. Mentors who are available to provide first-hand insight and advice are a necessary component to the student's exposure. Mentors can assist with recruitment into the field, can guide students in their preparation efforts, and can provide the motivating experiences that are fundamental.

The issue of diversity of the health care workforce is complex, though not debatable. We as a nation must commit to changing the landscape within which healthcare services are delivered to patients, regardless of race or creed, or geographic boundary. While we cannot escape our history of racism and discrimination, we are at the point of recognizing that there are proactive opportunities that must be developed and implemented in order to improve health outcomes for all citizens, not only those who can afford it or who have ease of access.

By increasing exposure of our youth to fields in health care and motivating them along the pipeline of education into a career, we not only invest in our future but we also invest in the lives that each future physician/dentist/nurse will one day assist. This simple and yet impactful solution is not a panacea but is supported by evidence as well as acceptance. The time is now that we step beyond mere discussion and commit to larger scale implementation.

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TESTIMONIAL: IMPROVING THE DIVERSITY PIPELINE

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ENRICHING MEDICINE THROUGH DIVERSITY: AN ANESTHESIOLOGIST SPEAKS ON STRENGTHENING THE MEDICAL SPECIALTY RANKS

Disparities in healthcare have been well documented. Not only is there a difference in the quality of healthcare treatment patients receive based on socioeconomic and ethnic backgrounds, but there is an even greater disparity in the number of African American physicians caring for them. The most significant gap exists among certain specialty fields. I have seen this firsthand in my work as an anesthesiologist. In 2009, the Anesthesia Quality Institute reported that there were approximately 41,693 anesthesiologists practicing in the United States. Fifty-four percent were White, 15 percent were Asian, and 3 percent were African American.¹ A Rand Report completed an extensive evaluation of anesthesiology, including demographics in both 2007 and 2013. In those 6 years, the percentages of African American anesthesiologists reported were even lower at 2.4 percent and 1.95 percent respectively.² A lack of representation in a critical medical field is a crisis reverberating through all aspects of patient care. In this specialty field, the physician providing the care matters as much if not more as other specialties.

Anesthesiologists contribute uniquely to patients' medical care. They are the patient's only physician-advocates through pre-operative, intra-operative and post-operative periods. We know patients care is enhanced when they believe their providers have similar identities, relate to their experiences, and hear their concerns. Physicians having that shared identity when treating patients help improve their medical outcomes. Empathy and effective communication with patients not only improve their care, but also encourages patients to become active participants in their healthcare decision-making process. The study, *"Race, Gender, and Partnership in the Patient-Physician*

Relationship," published in *Journal of the American Medical Association (JAMA)* 1999 suggested that "ethnic differences between physicians and patients are often barriers to partnership and effective communication."³

"Increasing Racial and Ethnic Diversity Among Physicians: An Intervention to Address Health Disparities," supports "the continuation of efforts to increase the number of minority physicians, because patients had more satisfaction with providers of identical race."⁴ Patients' perceptions are critical, and do influence their confidence in the medical treatment they receive. At the core, when patients receive medical care from a physician who resembles them, it reassures the patient that racial bias will not play a part in their treatment decision-making process. A 2011 Johns Hopkins University study presented 215 clinicians stories about fictional patients. They were asked how they would medically treat them. The qualitative stories were designed to uncover and identify clinicians' unconscious biases. The study results found that most clinicians' biases were based on race and socioeconomic status.⁵

Patient pain management is one of anesthesiologist's primary tasks. Racial and ethnic disparities exist in quality of pain care treatment provided to patients. A 2009 literature review of pain management by race consistently documented greater prevalence, impairment, and less treatment for the severity of pain for non-Whites. Overall, minorities received poorer pain assessment and treatment in all types of pain including acute, cancer, post-operative, chronic, and end of life.⁶

The challenges African American youth must overcome when seeking to enter the field of medicine can be daunting. Whether for lack of exposure to medical careers, too few role models, inaccessibility to educational resources, and/or financial constraints, African American youth are not entering into healthcare in adequate numbers. The small percentage that do become physicians (3.5 percent of all United States physicians are African American), are usually not choosing anesthesiology.

Currently, exposure to the anesthesiology specialty and its crucial contributions to healthcare are almost non-existent. Numerous opportunities are missed that would attract curious young minds to this field. For instance, African American anesthesiologists are seldom represented or discussed in any forms of media. Even opportunities to foster medical students' interest in anesthesiology are relegated to a one-month optional rotation. I submit that without early and continued exposure in medical college, even fewer African American physicians will enter this specialty.

Entering through the exclusionary door to highly specialized medicine will not simply open and allow the underserved access. There are three key components needed to push through those gates. First, any plan of action must include long-term mentoring. I first learned about anesthesiology from my mentor, who constantly encouraged me to pursue my goal of becoming a physician and more importantly, consider anesthesia. His mentoring did not stop there; we still speak weekly. He continues guiding and encouraging me throughout my journey. This responsibility falls on both current physicians and parent(s) of our youth to establish this connection and provide the necessary ongoing support.

Perseverance and resiliency are required for aspiring Black physicians. It does not come easy or without sacrifice. In the process of reaching that goal, there are disappointments, failures, and at some times discrimination. I remember being told I "did not value myself," and to "give up this dream of being a doctor." These criticisms can sow seeds of doubt. My parents constantly reminded me that becoming a physician was bigger than any obstacles, and that barriers exist because I had much to contribute. With their support and belief in me, I was encouraged not to quit or give up.

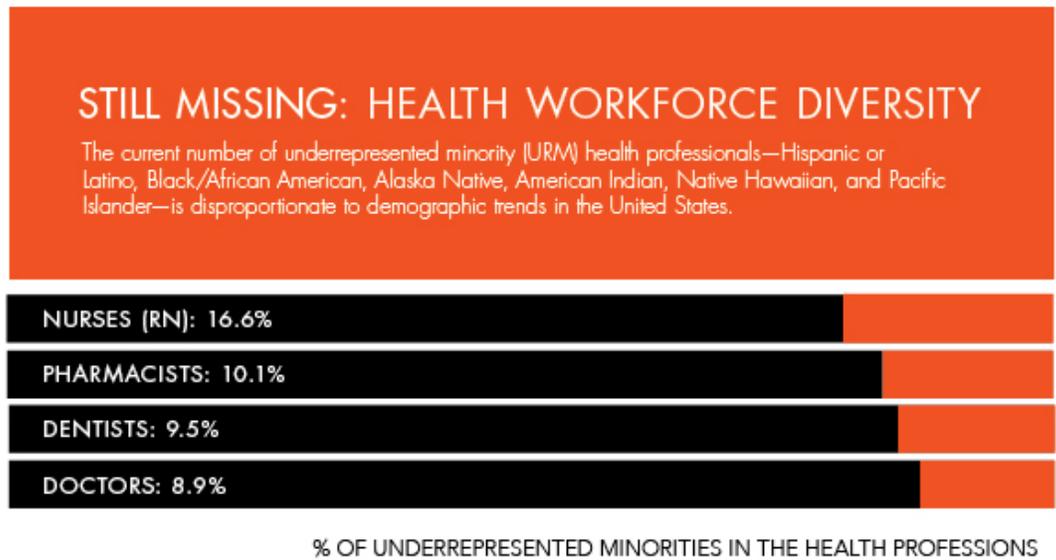
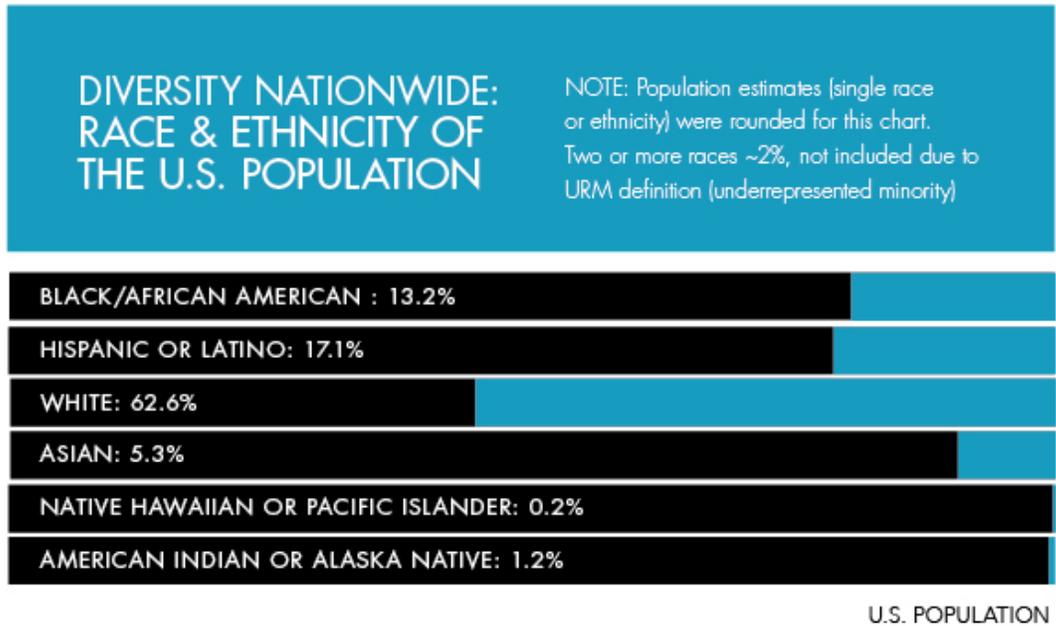
Often overlooked is that a physician must have a clean background. Too often African American inner city youth and others that face an additional variety of social and gender barriers are denied the dream or the opportunity of pursuing a fulfilling career in anesthesiology because of prior infractions. Any problems with the law from shoplifting to DUIs can derail a medical career, and contributes to, rather than ending the disparity. Therefore, my challenge to the youth is to develop critical thinking and decision-making skills that are invaluable tools for success.

Recruitment disparities for African Americans in anesthesiology are alarming. It cannot be overlooked any longer and requires effective remedies to increase our representation in this specialty. Denying underserved communities healthcare providers, particularly anesthesiologists, with shared experiences is a travesty. We must take effective steps to recruit, expose, and

mentor African Americans into this specialty. Otherwise how can we expect African American patients to find their voices in an institution that has long turned a deaf ear to the underserved healthcare needs? Without a greater influx of African American anesthesiologists, we continue the risk of leaving our community in the hands of those who will treat them unjustly because of their inadequate empathy and, more importantly, their biases.

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DIVERSITY IN THE HEALTH PROFESSIONS



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A NEW HEALTH FUTURE:
HEALTHCARE CURES AND
INNOVATION FOR THE 21ST CENTURY

3

21ST CENTURY CURES: THE FUTURE OF MEDICAL INNOVATION IS NOW

HONORABLE FRANK PALLONE (NJ-06)
RANKING MEMBER, HOUSE ENERGY & COMMERCE COMMITTEE



Through the 21st Century Cures Initiative, the Committee on Energy and Commerce endeavored to create bipartisan legislation that would bolster medical research, advance cutting edge science, and improve the process by which treatments are discovered and approved. That Initiative included meeting with various stakeholders to identify strategies to increase the pace that treatment and cures get to patients. I am proud to report that in July 2015 Congress passed the landmark "21st Century Cures Act." I believe the Act has the potential to achieve these tremendously important goals as well as have a profound effect on health outcomes and achieving health equity in America.

The provision of the Act that I am most proud we included is the \$10 billion in mandatory funding for the National Institutes of Health (NIH). From fiscal year 2016 through fiscal year 2020, the NIH Innovation Fund would provide \$2 billion each year to fund innovative research opportunities. This is a real victory for America's patients and researchers.

Federal funding is the foundation of our biomedical ecosystem and one of the best investments we can make to spur economic prosperity, drug and device development, and cures for the 21st Century. Between 1998 and 2005, federally-funded, biomedical research contributed to the development of 48 percent of all drugs approved by the FDA and 65 percent of drugs that received priority review in that period. Results like this is why increased funding for the NIH, the largest source of funding for biomedical research in the world, has been a top priority of mine.

Despite the proven importance of NIH research, we have seen a decline in funding for NIH in recent years. When adjusted for inflation, NIH received more than \$8.2 billion less in funding in 2015 than in 2003. Consequently, the application success rate for research project grants has significantly declined. The total application success rate for research project grants in 2003 was 32 percent compared to 18 percent in 2014.

The 21st Century Cures Act would reverse this harmful trajectory by injecting new resources into NIH. I am confident that with this new mandatory funding, the NIH's many institutes and centers, including the National Institute of Minority Health and Health Disparities, will be equipped to conduct groundbreaking research on the many diseases we face today. The mandatory funding would also support critical research priorities such as the precision medicine efforts that have been championed by President Obama. By improving our ability to get the right treatment to the right patient, precision medicine holds great promise in improving health outcomes and reducing harmful and costly health disparities that continue to plague minority communities.

In addition to increased NIH funding, the Initiative made clear that more must be done to recruit and retain the next generation of biomedical researchers. That means that we must create an environment where students from all backgrounds see careers in biomedical research as viable. We heard from stakeholders that difficulty obtaining grant funding and student loan debt, specifically for clinician scientists, prevents some early career scientists from pursuing biomedical research careers and makes others abandon them. We also heard about problems with the recruitment and retention of women and minorities into the biomedical workforce.

To combat those problems, the 21st Century Cures Act would improve the NIH's loan repayment programs for clinician researchers, increase funding for research projects led by early career scientists, and require the NIH to address building and maintaining a diverse biomedical workforce as part of the new NIH strategic plan requirement. Currently, NIH loan repayment programs for clinician scientists, including a program for scientists who do research into health disparities as well as a program for individuals from disadvantaged backgrounds, are capped at \$35,000 per year and are limited to certain types of research projects or researchers. This legislation would increase that cap

to \$50,000 per year plus a yearly inflation adjustment and expand the types of research projects that clinician scientists in the NIH loan repayment programs can pursue.

The Act would supplement NIH's current programs for young scientists by requiring that a portion of the NIH Innovation Fund be used to support research efforts of early career scientists. That means that more young scientists will have the funding necessary to build research projects that can successfully compete for R01 and other large research grants. The Act would also increase NIH's focus on ensuring participation by scientists from minority communities as part of its efforts to maintain the leading biomedical workforce in the world.

Finally, the 21st Century Cures Act makes clear that improving treatment outcomes requires that all populations be adequately represented in clinical trials. It includes a Sense of Congress that the National Institute on Minority Health and Health Disparities should include strategies for increasing representation of minority communities in its strategic plan. The Act would also achieve this goal by requiring NIH to issue guidance identifying when it is appropriate to consider age as an inclusion or exclusion criteria for participation in clinical trials. The NIH would also be required to publically report the number of children broken out by race and gender who participate in clinical trials funded by NIH. This would help ensure that children, including those from minority communities, are adequately represented in clinical trials and that we can determine the safety and effectiveness of drugs on children at the subgroup level.

As the Ranking Member of the Energy and Commerce Committee, I am committed to working to improve health outcomes for all Americans and achieving health equity. While more must be done, I believe that passage of the 21st Century Cures Act is an important step towards achieving those goals.

THE DIGITAL HEALTH REVOLUTION: WILL IT REDUCE OR INCREASE HEALTH DISPARITIES FOR MINORITIES?

ABNER MASON
FOUNDER & CEO, CONSEJOSANO



Healthcare professionals, policymakers, political leaders, and politicians have talked a lot about how to reduce healthcare disparities in minority communities across the U.S. This dialogue must be continued because many of the solutions we've identified thus far have yet to close the disparities gap. In a country with a healthcare system as sophisticated and costly as ours, it is inexcusable that disparities continue to exist, and—in some cases—are becoming more pronounced.

I want to focus my contribution to this important report on the Digital Health Revolution. It is important to assess whether or not the massive transformation that our health system is in the process of undergoing will reduce healthcare disparities for minorities or direct its benefits elsewhere, while overlooking the very communities that could benefit most from high-quality, low-cost, convenient, and personalized healthcare products and services.

So let's start with some good news. We have bridged the Digital Divide. This is an achievement we should celebrate. For example, as noted in Nielson's March 2014 report on Multicultural Consumers and Smartphones, smartphone ownership in the U.S. reached 68 percent by January 2014. However, smartphone ownership rates were 73 percent for African Americans, 77 percent for Hispanics, and 78 percent for Asian Americans.¹ Minorities are leading the growth of smartphone ownership, and they are adopting smartphones at a higher rate than the U.S. average.

This is important because smartphones have become the primary way these users access the Internet. So not only has the Digital Divide been bridged, but soon, most Americans will carry the Internet with them wherever they go.

So having bridged the Digital Divide, when it comes to Digital Health, have we created a "bridge to nowhere"?

The Digital Health Revolution is well underway. Leading digital health accelerator Rock Health reports there was \$2.1 billion in digital health investment funding in the first 6 months of 2015, meaning that 2015 is keeping pace with 2014 and may well exceed it.² In addition to venture capital dollars flowing to the digital health sector, existing players including insurance companies, health systems, pharmacy retailers, and drug companies are placing bets on digital health companies. These investors are funding companies in a wide range of areas, including wearable and bio-sensing analytics and big data, healthcare consumer engagement, telemedicine, enterprise wellness, and electronic health records.

I am Founder and CEO of ConsejoSano, a company that is part of the Digital Health Revolution. ConsejoSano is a mobile app that connects Spanish speakers in the U.S. with native Spanish-speaking healthcare professionals for 24/7-access to general health advice; nutritional counseling, including diabetes management; and mental health services.

This use of technology is an innovative—even radical—solution because it uses licensed practicing physicians in Mexico to provide health advice and services to Spanish speakers in the U.S. While we do not write prescriptions, we are able to resolve about 50 percent of our callers' health related issues. By providing this health advice, we are able to expand access to high-quality, affordable, convenient, and confidential health advice to Hispanics whom would be unable to connect with Spanish-speaking healthcare professionals otherwise.

This is an example of using Digital Health—in this instance, a smartphone application—to reduce a major disparity in access to linguistically and culturally appropriate healthcare services for Spanish speakers. In this case, the lack of access, which results in major disparities in care and health outcomes, is large and growing. For example, California is now 40 percent Hispanic, yet only five percent of doctors in California speak Spanish.

It is important to note that two-thirds of Hispanics in the U.S. either only speak Spanish, or are more comfortable speaking Spanish when discussing complicated issues like healthcare.

While my company is using Digital Health to reduce disparities for Hispanics, we are an exception to what appears so far to be the rule. There are very few African American or Hispanic venture capitalists making the decisions on which digital health companies will get investment funding, and there are also very few start-up teams with African Americans, Hispanics, or women in senior leadership positions. This lack of minority voices and perspectives during the decision-making process results in issues that disproportionately affect minorities not getting the attention they need or deserve.

This problem will not be solved quickly, but there are some steps we can take at the policy level that can make a big difference.

Here are two specific recommendations:

1. Support policies that use the increasingly "smart-er phone" to deliver healthcare services. This will be a very effective strategy to increase access to high-quality affordable healthcare services that can meet the unique needs of minority populations.
 2. Use federal funding from the various health related agencies to support research programs, pilots, and demonstration projects that specifically target minorities. This will play a key role in determining the issues of focus for Digital Health companies. Given the importance Digital Health can play in reducing disparities, federal health agencies should be directed to prioritize, and when appropriate, direct funding to research programs, pilots, and demonstration projects that focus on solutions that address health disparities.
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 2. Gandhi, M. (2015). *With \$2.1B in digital health funding, first half of 2015 is keeping pace with 2014*. Rock Health

Digital Health is transforming the U.S. health system and in the process, creating previously unimaginable opportunities to reduce healthcare disparities. The two policy changes above will help to make the promise of Digital Health real for all Americans.

THE WAY WE ARE:
REPORTS ON EQUITY, OUTCOMES
& HEALTH DISPARITIES IN AMERICA

4

WHERE YOU LIVE SHOULD NOT DETERMINE WHETHER YOU LIVE

JUDITH SALERNO, MD, MS
PRESIDENT & CEO, SUSAN G. KOMEN



CLOSING THE GAP IN BREAST CANCER DISPARITIES THROUGH COLLABORATION: THE CHICAGO MODEL

African American women in the U.S. are 41 percent more likely to die of breast cancer than white women, even though they are less likely to be diagnosed with the disease. They also have the highest rates of the most aggressive and most difficult to treat breast cancer subtypes—such as triple negative breast cancer. African American women are more likely to be diagnosed at younger ages than white women and are often diagnosed with late-stage diseases when treatment options are limited and costly, and the prognosis is poor.¹

These inequities are often attributed to a variety of biological, socioeconomic, and cultural factors, but no single factor or combination adequately explains them. One thing is clear:

Breast cancer mortality rates in the African American community constitute a health crisis that cannot be ignored.

We must get beyond the mantras of “bad genes,” “bad luck,” and “bad lifestyle,” to change these appalling statistics and prevent untimely deaths by ensuring equal access to high-quality care and life-saving treatment.

Since 1982, the Susan G. Komen breast cancer organization has invested more than \$37 million in over 1,800 community health programs, specifically addressing breast cancer disparities through root cause solutions encompassing community collaboration, health systems improvement, and patient navigation.

Komen has also provided about \$90 million in groundbreaking medical research grants to aid our understanding of the biological, environmental, and social factors that contribute to disparities.

One of the most promising community approaches supported by Komen is the Metropolitan Chicago Breast Cancer Task Force (the “Task Force”). Physicians, community leaders, and public health advocates across Chicago convened to form the Task Force in 2007. Komen provided \$2.6 million to support the work of the Task Force, which is a collaboration of the Sinai Urban Health Institute, Avon Foundation for Women, Blue Cross Blue Shield of Illinois, National Institutes for Health, Illinois Department of Public Health, Telligen and a host of other public and private entities.

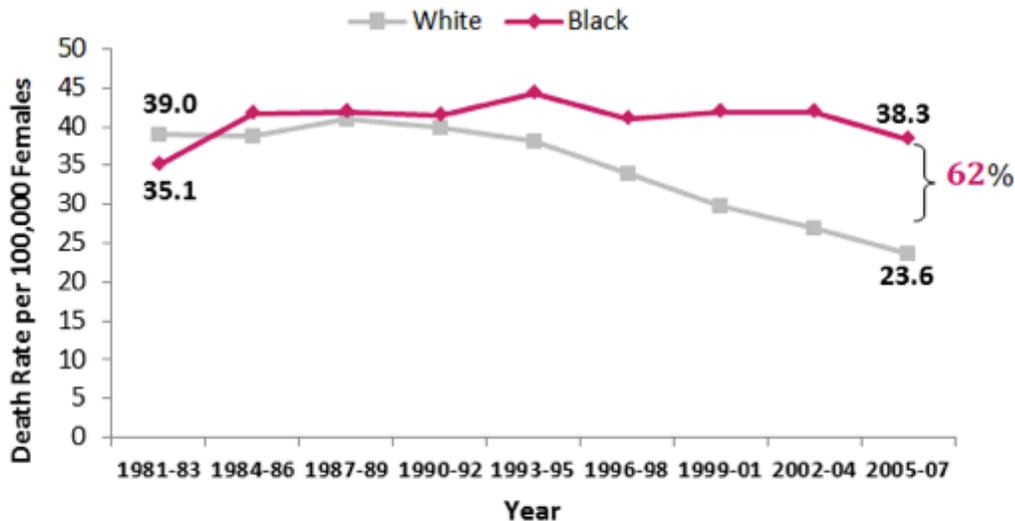
Upon its creation, the Task Force set out to reduce breast cancer mortality rates, which were an alarming 62 percent higher for women in Chicago’s most economically disadvantaged neighborhoods versus more affluent areas of the region. In five years, the work of the Task Force has reported stunning progress: a 35 percent reduction in the death rate gap between African American women and White women in the region.

The Task Force Model informs the strategy and lights the path toward closing the gap in breast cancer disparities in communities across the U.S.—a fight that Komen believes is winnable.

The following is a summary of the *2014 Metropolitan Chicago Breast Cancer Task Force Report: “How Far Have We Come? Improving Access to and Quality of Breast Health Services in Chicago”*

Citations have been omitted. The full version of the Report can be found here: <http://www.chicagobreastcancer.org>

Figure 1. Black: White 3 Year Age-Adjusted Aggregate Breast Cancer Mortality Rates in Chicago, 1981-2007



By 2007, Black Women in Chicago were dying at a rate 62% greater than White women.

Data Source: Illinois Department of Public Health Vital Statistics

Data Prepared By: Sinai Urban Health Institute

INTRODUCTION

Across the United States, healthcare disparities affecting African American women in certain locations, such as Chicago, have resulted in significantly worse outcomes for many different major diseases, including breast cancer. As a result, African American women in Chicago are far more likely to die of breast cancer compared to white women, at rates above the national average and averages of other cities. These realities most recently came to light in 2006 when researchers published a disturbing study documenting a large and growing inequality in survival from breast cancer in Chicago.

In the 1980s, Black women and white women died of breast cancer at relatively comparable rates. By 2006, improvements in screening and treatments caused breast cancer death rates to fall by half for white women. Those improvements, however, did not seem to reach African American women, who were dying of breast cancer at a 62 percent higher rate than white women in the region. Additionally, death rates for African American women in Chicago remained higher in comparison to other

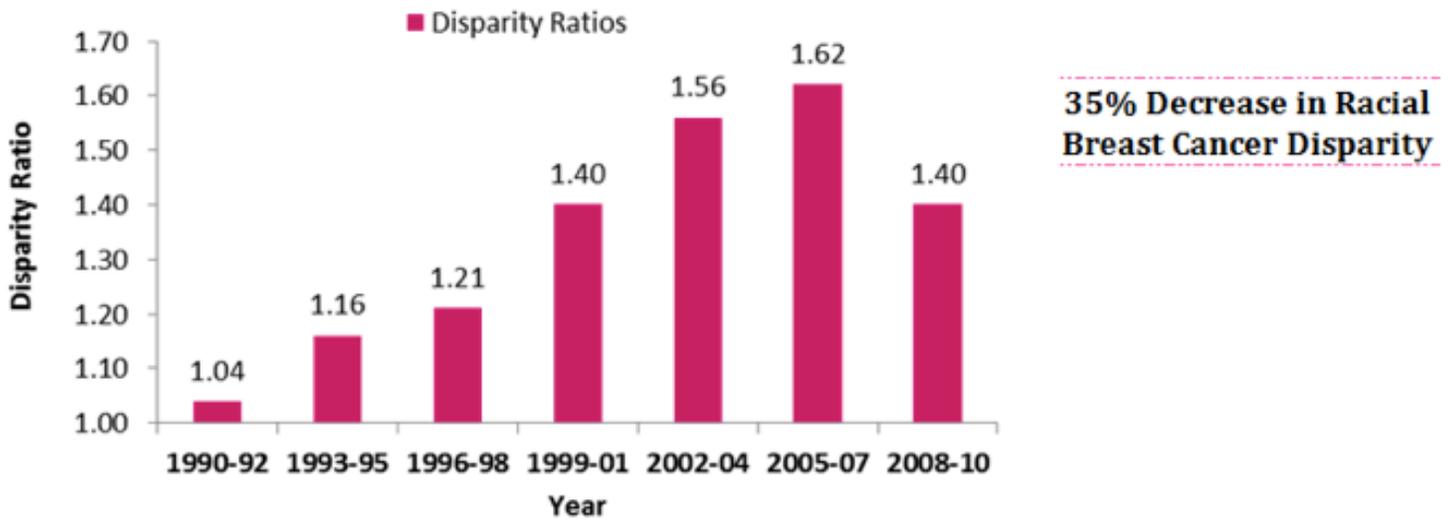
cities such as New York, Baltimore, and San Francisco. These facts suggested that the health system in Chicago, rather than biology, was at play.

CALL TO ACTION

Community concern surrounding the published disparities data led to a Call to Action that mobilized the Chicago metropolitan area to demand change and resulted in the creation of the Task Force.

The Task Force published an initial report in October 2007 that highlighted three possible issues causing the increased breast cancer death rate for Black women in Chicago:

- Less access to mammography
- Lower quality of mammography services
- Less access to and lower quality of treatment

Figure 2. Breast Cancer Mortality Disparity Trend, 1990 - 2010

COMPREHENSIVE ASSESSMENT

The Task Force created a specialized healthcare collaborative program called the Chicago Breast Cancer Quality Consortium. The Consortium collects mammography screening and treatment data from area institutions to determine if they are meeting national standards of care for finding and treating breast cancer. Through the Consortium, the Task Force demonstrated that quality of care varies in Chicago, especially for mammography services. This variation and fragmentation of care, particularly on Chicago's south side, is likely to affect the stage of diagnosis, the adequacy of treatment, and survival.

The Consortium has also shown that Chicago has systemic barriers that inhibit access, including: (1) a lack of financial resources, including insurance; (2) public health programs that provide free services but are unreliable because of chronic underfunding, suboptimal equipment, and inadequate staff training and expertise; (3) variation in the quality of care with potentially more lower-quality care provided to poor, uninsured, and publicly insured women; and (4) inequitable distribution of high quality breast care resources and low participation in screening by public providers. It has also been found that the breast imaging centers of excellence are generally absent from areas where the breast cancer mortality is highest and are absent from where

women of color live. Many other quality resources are inequitably distributed.

The Task Force addresses these challenges by collaborating with health care partners to improve the quality of care and by providing free trainings to health care professionals, especially in safety net venues where resources to pay for trainings are scarce.

COMMUNITY ACTION THROUGH ADVOCACY, OUTREACH, EDUCATION, & PATIENT NAVIGATION

The Task Force's community organizing and public policy programs are working to address breast cancer mortality disparities in Chicago. Importantly, the Task Force engages grassroots organizations that serve African American and Latina women, helping to increase success while empowering the community.

Through **Screen to Live**, a free community-based outreach, education, navigation, and quality improvement program, over 1,000 women in Englewood and West Englewood receive services. This area has one of the highest breast cancer mortality rates in Chicago with less than 25 percent of women aged 40 and over receiving regular screenings.

In 2012, the Task Force launched **Beyond October** to address the chronic shortfall in mammography services for both uninsured and underserved women, offering free mammograms to women across Metropolitan Chicago. Through **Beyond October**, the Task Force worked with health institutions to donate free mammograms, with a goal of providing 1,000 free mammograms by 2013. Both highly resourced hospitals and safety net hospitals generously donated mammography services to **Beyond October**. The Task Force then worked with community organizations to organize outreach events and initiatives in the community. In addition to education and mammogram services, the Task Force also provided navigation services to free diagnostic and treatment services, and collaborated with organizations, such as the Sinai Urban Health Institute to reach, educate, and navigate women to breast care.

HOW FAR HAVE WE COME?

This report documents the first sign of a decrease in the mortality disparity in Chicago since 2005 (Figure 2) after a persistent increasing trend over 20 years. Since 2007, the Task Force and others, such as the Sinai Urban Health Institute's *Beating Breast Cancer* program at the University of Illinois, have partnered to improve women's access to high quality breast care and to navigate women to care. The Task Force has become a leader in comprehensive assessment of the breast health system, measuring quality for breast cancer screening and treatment.

WHERE WE GO FROM HERE

Our goal is to eliminate this disparity completely. We are proud of the work Chicago has done to close this gap and are committed to forging ahead by:

- **Increasing access to quality breast health care for all women** – We will navigate more than 2,000 women in partnership with 18 institutions, which is a 25 percent increase from 2013. Through the Extra Help, Extra Care, **Beyond October**, and **Beyond Enrollment** programs, women in need of diagnostics and treatment will receive more cohesive and comprehensive navigation.
- **Improving the quality of mammography services for all women** – Through our Mammography Quality Initiative, we expect a 5-to-10 percent participation increase in mammography facilities and radiologists providing feedback on the quality of mammograms. This would be the first effort

nationwide to build such an informative mammography surveillance system, with an estimated 650,000 mammograms expected statewide. Armed with this data, we will continue to engage stakeholders in custom process improvement initiatives to collectively increase the quality of mammography at the provider, technician, and facility level. This information-intervention approach represents one more step towards eliminating the disparity.

- **Improving access to high quality treatment and understanding of breast cancer treatment disparities** – We will build upon our treatment quality data project to comprehensively measure the full complement of breast cancer treatment and variation in breast cancer types in Chicago.
- **Advocating to enact policy changes to strengthen our health-care system and prevent cuts to the Illinois Breast and Cervical Cancer program**
- **Partnering to expand the Chicago Model as a replicable and scalable model to address breast cancer disparities across the country**

It is our hope that this report inspires action. Together we can work to ensure that every woman has an equal chance at survival from breast cancer.

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AFRICAN AMERICANS & CARDIOVASCULAR DISEASE

ELLIOT ANTMAN, MD
PAST PRESIDENT, AMERICAN HEART ASSOCIATION



We know the statistics: approximately 85.6 million Americans are living with cardiovascular disease (CVD) or the after-effects of stroke. CVD is our nation's leading cause of death and most costly chronic disease.¹

We also know that a person's race or ethnicity should not increase his or her risk of suffering from or surviving a heart attack or stroke. But unfortunately, CVD has a disproportionate impact on many racial and ethnic groups. Today, nearly half of all African American adults have some form of CVD.²

As a country, we need to improve cardiovascular health and care for all of our citizens. Better primary and secondary preventive measures for underserved populations will translate into cost savings early in the life cycle by reducing the number of heart attacks and strokes and the cost of caring for patients who experience them.

At the American Heart Association/American Stroke Association, we have a number of efforts underway to improve the cardiovascular health of African Americans specifically. These include raising awareness of stroke among the African American population through our *Power to End Stroke* campaign, partnering with community leaders and other key stakeholders to improve the health of diverse communities through our *Empowered to Serve* initiative, and advocating for public policies that will bridge the disparity gap in care and health outcomes. Addressing the health disparities that African Americans and other race and ethnic groups face will be essential to achieving our organization's goal of improving the cardiovascular health of *all* Americans by 20 percent and reducing deaths from cardiovascular diseases and stroke by 20 percent by the year 2020.

CARDIOVASCULAR HEALTH INDICATORS FOR AFRICAN AMERICANS

A number of factors influence cardiovascular health, and racial

disparities exist in many of the key risk factors for cardiovascular disease. First, high blood pressure increases the risk for heart attack and stroke and can cause heart damage even before patients experience symptoms. African Americans have the highest rate of high blood pressure in the world and typically develop high blood pressure earlier in life than other race/ethnic groups. Research suggests African Americans may carry a gene that makes them more sensitive to salt, increasing the risk of high blood pressure.³ Lifestyle factors—such as diet, physical activity, and smoking—influence blood pressure too.⁴

Obesity also increases the risk of heart disease, stroke, and other health problems. Blacks have significantly higher obesity rates than Whites.⁵ Black children also have higher rates of physical inactivity than White children.⁶

Tobacco use is another important risk factor for CVD. In 2013, 15 percent of Black female adults and 21.1 percent of Black male adults reported smoking cigarettes. Black students were less likely than White students to report any current tobacco use, which includes cigarettes, cigars, and smokeless tobacco.⁷ However, exposure to secondhand smoke is higher for minorities.

Having health insurance is a critical factor in determining whether a patient has access to the treatment that he or she needs for a heart attack or stroke. In October 2013, 22.4 percent of African Americans were uninsured, as compared to 14.3 percent of Whites. The implementation of the Affordable Care Act (ACA) has led to a dramatic decline in uninsured rates. For African Americans, the uninsured rate has dropped 9.2 percentage points since 2013, corresponding to 2.3 million African American adults gaining coverage.⁸ While progress is being made to reduce the rate of uninsured African Americans, more still needs to be done.

We see other racial disparities in the treatment of heart disease and stroke. For example, Blacks suffer from higher hospitalization rates for heart failure than Whites.⁹ Studies have also shown

that of patients undergoing percutaneous coronary intervention, Blacks and those of other races may be less likely than White patients to receive referrals for cardiac rehabilitation, a medically supervised program that includes exercise training, education on heart healthy living, and counseling.¹⁰ Research shows that cardiac rehabilitation can lower mortality rates and prevent second cardiac events, among other health benefits.¹¹

These disparities all contribute to poorer cardiovascular health outcomes for African Americans. One year after a heart attack, African Americans have higher mortality and readmission rates than White patients.¹² Blacks are also more likely to die after a stroke than their White counterparts.¹³ Cardiovascular disease now contributes to nearly 40 percent of the difference in life expectancy between Blacks and Whites.¹⁴

BRIDGING THE GAP: CARDIOVASCULAR DISEASE & HEALTH EQUITY

Addressing racial disparities in the risk factors for heart attack or stroke, in access to and the quality of treatment for these conditions, and in cardiovascular health outcomes is at the foundation of much of the work that the American Heart Association does to increase research funding, prevent disease, improve access to care, and improve the quality of care. There are a number of policies that researchers, the medical community, and lawmakers can adopt that can be particularly impactful in bridging the disparity gap.

First of all, increased participation of minorities in clinical trials and additional analysis of research results by race, age, sex, and the intersection between them is needed to improve our understanding of the cardiovascular health of African Americans and the disparities that different minority groups face. According to a recent FDA report, only half of major cardiovascular clinical trials published between 1997 and 2010 reported racial data.¹⁵ As FDA implements its Action Plan regarding demographic subgroup data, it will be important to ensure that this data is complete, accurate, and readily available to clinicians, researchers, and patients.

Given the prevalence of certain risk factors for CVD in the African American community, regular preventive screenings are important to identify individuals at greater risk of a CV event as early as possible. However, Blacks are more likely than Whites to lack access to preventive screening services.¹⁶ Funding at the national and state levels for the Centers for Disease Control and Prevention's WISEWOMAN initiative or other similar programs that provide free screening and lifestyle intervention services to low-income, uninsured, or underinsured women is therefore needed

to ensure that people from all backgrounds receive these critical services. Between July 2008 and June 2013, the WISEWOMAN program served nearly 150,000 low-income women and provided over 217,000 screenings for cardiovascular disease.¹⁷

Our nation's schools can promote healthy habits that children can carry with them throughout their lives. The National School Lunch Program provided almost 5 billion lunches in 2014, over two-thirds of which were free and reduced-priced meals available to certain children based on their household incomes.¹⁸ School meal participants who are food insecure or marginally food secure are more likely to be Black.¹⁹ Congress asked the U.S. Department of Agriculture to update national nutrition requirements for school lunches in the Healthy Hunger-Free Kids Act of 2010, and as of December 2014, 95 percent of schools had been certified as meeting the updated standards.²⁰ Congress should not roll back these standards and instead build on the progress made by continuing technical assistance and other support to schools to ensure effective implementation. Additionally, schools can also promote healthy lifestyles by providing daily physical education to all students in grades K-12, and Congress could consider the Fitness Integrated with Teaching Kids Act (H.R. 2013/S.1075) to help schools implement evidence-based PE programs.

Access to affordable, high-quality health insurance helps patients get the treatment that they need for a heart attack or stroke. To continue to build on the progress that the ACA has made in reducing the uninsured rate for African Americans, all states should expand their Medicaid programs as authorized under the law. Approximately 2.9 million African American adults qualify for coverage if all states expand their Medicaid programs under the ACA, but one million of these individuals cannot apply because their states have chosen not to expand the program.²¹ Additionally, the federal government needs to continue to invest in enrollment education and outreach to racial and ethnic minority groups to help them learn about their new insurance options.

Developing and expanding hospital quality improvement programs is important for improving health outcomes for all patients with CVD and particularly for racial minorities. The American Heart Association's *Get with the Guidelines* initiatives help hospitals improve patient care by consistently following the latest evidence-based treatment standards.²² At hospitals participating in these programs, care for patients with heart failure and coronary artery disease has improved for all racial groups, reducing or eliminating racial disparities in care.^{23,24}

Finally, addressing the barriers to participation in cardiac rehabilitation programs could help to improve the racial disparities in utilization rates. Barriers to participation include lack of referral

or follow-up by a physician, cost, work or home responsibilities, and scarcity of programs in rural or low-income communities. Medicare covers cardiac rehabilitation for patients with heart attack, coronary artery bypass surgery, heart failure, and other cardiac conditions, but a requirement that only physicians—not physician assistants, nurse practitioners, or clinical nurse specialists—can supervise these programs reduces access to and increases the cost of cardiac rehabilitation. Legislation has been introduced in Congress (S.488) that would address this issue.

We know that 80 percent of heart disease and stroke is preventable, and better medical treatments and follow-up care make cardiovascular disease more treatable than ever before. With these actions and others, we can reduce cardiovascular health disparities in the African American community and build healthier lives free from cardiovascular diseases and stroke for all who live in the United States.

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CHILDHOOD OBESITY: AN EPIDEMIC THAT'S NOT JUST FOR KIDS

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First Lady Michelle Obama's "Let's Move," Campaign exists because Childhood Obesity is a real problem in this country and cannot be ignored. The Centers for Disease Control and Prevention (CDC) states that approximately 17 percent (or 12.7 million) of children and adolescents aged 2–19 years are obese¹.

The unfortunate truth is that like many medical issues, childhood obesity is disproportionately more prevalent in minority populations. According to the CDC, the prevalence among children and adolescents between 2011 and 2012 was significantly higher among Hispanics (22.4 percent) and non-Hispanic Blacks (20.2 percent) than among non-Hispanic Whites (14.1 percent).²

One of the very reasons I became a physician was to help end this epidemic. Hailing from the most obese state in the union, Mississippi, I grew weary of my community making the headlines because of our expanding waistlines.

Even more worrisome was witnessing my family members develop the medical complications associated with becoming obese as a child. My youngest brother became a pre-diabetic at the age of twelve, and at that moment, it became more than an epidemic to help eliminate. Obesity became a personal threat.

Yet, like many families, I found it more difficult to manage my brother's weight than I expected. The will to eat better, make healthier choices, and exercise more all help but do not fix the problem. There are other factors that come into play when attempting to change behavior and alter mindset.

As physicians, we learn about the social determinants of health and how external social factors can affect populations' health outcomes, such as environmental safety issues affecting a child's ability to play outside or the difficulty a family faces accessing fresh produce in certain zip codes.

For young African Americans, cultural body image misconcep-

tions like the acceptance of being overweight as "big boned," but considering it healthy. For others, the opposite can happen, leading to the development of low self-esteem or self-image because of being overweight, secondary bullying, or misguided parents.

Despite all of this knowledge, we have now been fighting childhood obesity for more than two decades. Why have we not overcome this, you ask? My answer is that stakeholders are not taking responsibility.

Who are the stakeholders, you might ask? You! Everyone has a personal responsibility to help end this epidemic, from parents to providers to politicians.

And if you do not fall into one of those categories, you are not off the hook. Be a role model and a concerned citizen. Our current generation of children and young adults is the first generation to have a shorter life expectancy than their parents, according to a report published by The National Institutes of Health and the Department of Health and Human Services in 2005.³

What do we do? In the home, we must become educated about nutrition. Eat foods that are fresh and not processed, despite the deceptive labeling. Make real lifestyle changes that show results. For physicians and other providers, stop telling patients to diet and exercise without providing true guidance.

For our leadership, hold the industries contributing to an unhealthy future accountable. There must be transparency and responsibility in marketing to our children. Deceptive labeling is unfair and has devastating consequences that diminish our children's health outcomes.

Every time we decide not to support legislation that gets real nutritious foods and physical activity to our youth, we miss an opportunity to lengthen the lives of future generations.

The time has come for our leadership to take action. You, our legislators and representatives, must hold the food industry accountable for their role in this childhood obesity epidemic. In the same way that the government called the tobacco industry to task, it's now time to do the same to these industries. The USDA must also step up to the plate to ensure that labeling and marketing is held to an ethical standard that protects the rights of our children. If the United States government does not make this epidemic a true priority, the health future of this country will remain bleak.

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PROVIDING A REAL SOLUTION TO CURBING CHILDHOOD OBESITY

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PROGRAM COORDINATOR, STEPS FOR KIDS INSPIRA
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From headlines to statements from public leaders, childhood obesity has been named one of our nation's most critical and imperative policy issues. They are right. Conquering childhood obesity is essential to creating a more stable, healthy, and productive future and to deterring the financial impact of chronic disease in the US. There has been a mad rash of "answers" to ending childhood obesity, which are mainly nutrition and exercise based. If it was that simple, we would give a child a granola bar and tell them to run around the track after school.

If it really were that simple, we wouldn't be writing this article. There would be no need.

Let's face it, America—it is not that simple and we can't turn our focus away now. Not when the going gets tough. As Americans, we need to examine childhood obesity, its impact on underrepresented populations and once and for all, find the real solution. We need smart, wise investments. We owe it to our future generations. When the going gets tough, Americans get going.

DISPARITIES IN CHILDHOOD OBESITY

Children with obesity are more likely to experience high blood pressure, hyperlipidemia, insulin resistance and type-2 diabetes, sleep apnea, asthma, steatohepatitis, GERD, joint problems, discrimination and poor self-esteem. They are more likely to become obese adults, where they run the increased risk of arthritis, heart disease, diabetes and cancer. And they are most likely to be African American, Hispanic, and Native American.

Poverty predisposes children to becoming overweight or obese. If a parent has completed college, studies show their children eat more vegetables and consume less sugary drinks than those of parents who have completed high school or less. A child's environment exacerbates their risk for weight gain and disordered

eating if the parents are given to societal pressures of oversized portions of processed food in front of the TV and sedentary entertainment. Based on national data we know that lower income areas have fewer parks and bike trails, less availability of organized sports, fewer full service grocery stores where produce and lower fat foods are available, and more fast food restaurants. More than 60 percent of African American, Hispanic and Native American families live in these neighborhoods compared to 31 percent of White and Asian families.¹

These children are not developing healthy behaviors because they have no examples of healthy eating and lifestyle choices. This difference will maintain higher obesity rates. Behavioral health is a critical component of childhood obesity.

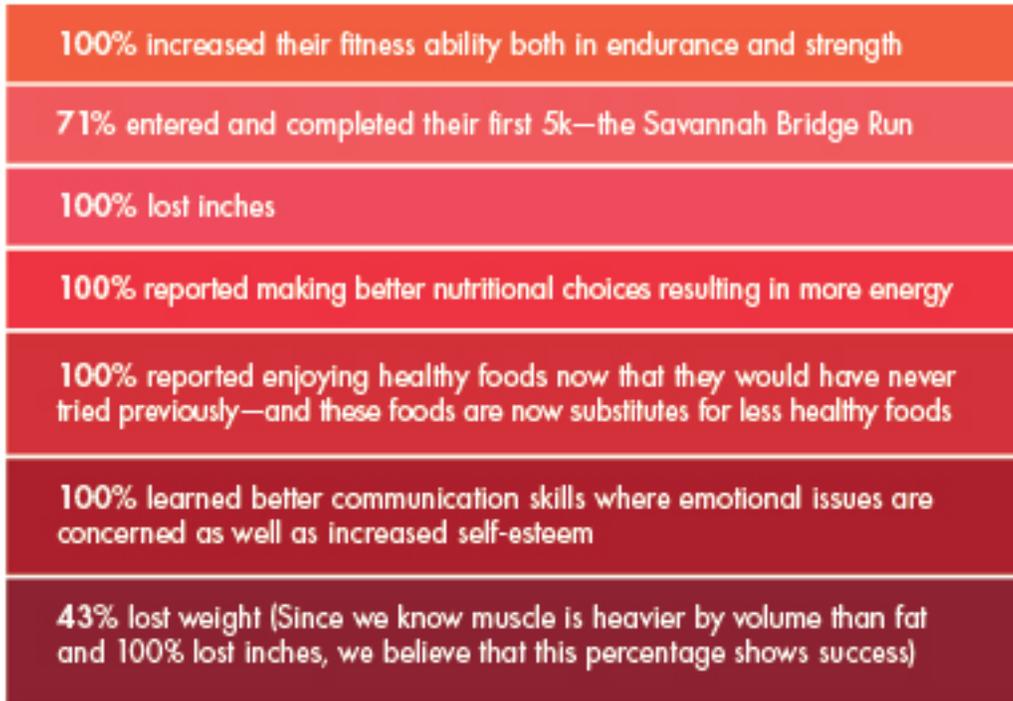
THE NEED

Ineffective parental role modeling of unhealthy eating patterns and lack of physical activity give children a false 'normal' of family life. Add sedentary behavior, eating from the window (fast food), and consumption of sugary, simple carbohydrate laden foods and drinks is a recipe for obesity and disease. While these factors increase the obesity risk, they also promote disordered patterns of weight-control.

There is a correlation between this behavior and depression leading to interpersonal difficulties. As these behaviors continue, they can spiral out of control, becoming more difficult to reverse and even address. Early intervention is crucial to change these—often, generational—patterns.

Children and teens with obesity may face psychological in addition to medical concerns. Low self-esteem, feelings of worthlessness, or feeling overwhelmed by a situation seemingly out of their control may give way to suicidal thoughts, increased

OUR PILOT STUDY RESULTS USING THIS MODEL SPEAK FOR THEMSELVES.



school absences, and early drop out as the downward spiral continues. This process is much more common than people realize, and it happens much easier than one would think.

TREATMENT & PREVENTION OF CHILDHOOD OBESITY

Addressing this crisis is a national imperative; how to address it is the question. Obesity prevention or treatment programs tend to focus on 'energy-balance,' i.e., the balance between what we eat and what we do to conduct normal physical activity and growth. It seems a simple equation, but what we ignore is how complex that balance is—it includes environmental, cultural, social, and psychological factors that affect what we eat and what we do.

To really stop childhood obesity, we have to deal with the fundamental issues. We have to give children the motivation to change behavior, support them by providing them with coping skills to deal with their barriers, and help them address the cultural or ethnic practices that influence their ability to change. Behavioral health programs that help children identify and deal

with their emotions add the missing piece to childhood obesity prevention. *COPE* (Childhood Obesity Prevention and Education) in Georgia and *STEPS for Kids* in New Jersey are two interventions that do this by implementing a behavioral approach.

OUR PROGRAMS

COPE is a community based nonprofit which combats childhood obesity through a combination of nutrition education, fitness, and behavioral health in predominantly after school settings; complete with a parent engagement component. COPE's mission is to prevent, reduce, and identify indicators of childhood obesity through our threefold approach. The inclusion of behavioral health is the element that truly sets COPE apart. COPE was founded with the belief that we must teach kids healthy coping skills in order for them to learn balance in life and health.

Cognitive Behavioral Therapy (CBT) is a proven successful psychotherapy process that helps a person take steps towards behavior change. The concept of CBT is that one's thoughts and feelings determine one's behavior. Even though we cannot con-

control every aspect of our surroundings, we can control how we process what happens to us. Children must develop a healthy relationship with food so they don't fall prey to poor eating habits and unhealthy behaviors.

The Substance Abuse and Mental Health Services Administration (SAMHSA) is the agency within the U.S. Department of Health and Human Services that leads public health efforts to advance the behavioral health of the nation. They recommend CBT as the most effective therapy for drug and alcohol addictions. Knowing this, we believe that it is also the most effective method to accurately and effectively reduce childhood obesity.

COPE utilizes this model to deliver its weight-management program. Our counselors have backgrounds in addictions, and experience working with children and serving the at risk community. The same licensed counselors serve the entire 36-session, 12-week program to allow time for trust to grow. Each participant has the opportunity to address toxic emotions triggering compulsive eating behaviors, and our holistic family approach gives the entire family time to identify unhealthy behaviors contributing to the child's need to mood alter/escape their reality through the misuse of food or sugar.

This compares to an intensive outpatient program but without the cost to the families, since we offer our programs free of charge. Obviously all children suffering from obesity do not have psychological or emotional issues requiring therapy, and it is important to note that having obesity does not equate to having an eating disorder or an addiction. However, since many do, we offer a safe place to identify those who need more intervention.

STEPS for Kids uses the Empowerment Model—based on the belief that people are able to control and direct their own lives. Empowered people are able to transform their situations by identifying their problems, creating goals and objectives, developing strategies to meet those goals, finding and using the resources they need, acting to change their lives, and reflecting on what they achieve. Through interactive group-based sessions, families receive the tools they need to change their own lives. They learn how to navigate the barriers to stopping the cycle of obesity that they find in themselves, their families, their communities, their environment, and in society.

As every situation is unique, STEPS for Kids challenges children and their families to develop their own solutions to the problems they identify. Families come to the program by referral from a pediatrician. The free 14-week program provides caregivers and children access to masters-level social workers, registered dietitians, and exercise specialists, who lead them through an evidence-based curriculum developed at Yale University in New

Haven. Families explore emotional eating, issues with self-esteem, and bullying with others who, like them, are dealing with overweight or obese. Participants are safe to share their feelings and be supported, knowing that they are not alone.

Through the Empowerment Model, STEPS for Kids encourages co-operation, the development of life skills, and critical thinking and analysis. Children feel encouraged, happy, and empowered. STEPS for Kids helps families to believe in their ability to live their best lives. This sets them up for a lifetime of good health and good choices.

NEXT STEPS IN ADDRESSING CHILDHOOD OBESITY

Legislative action is needed now to ensure proper funding opportunities exist to support conquering childhood obesity through behavioral interventions. Funding will support research to test and develop behavioral programs that are streamlined, effective, and generalizable. The time is now to deal with childhood obesity using the missing piece—behavioral health. If we are to change the trajectory of this nation, if we are to create a future with a healthy, productive, and successful population, we need to get on the move.

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TESTIMONIAL: CHILD NUTRITION & FOOD SCARCITY

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1ST VICE CHAIR OF THE CONGRESSIONAL HISPANIC CAUCUS (CHC)
CHC HEALTH TASKFORCE CO-CHAIR



Teachers and schools in my home state of New Mexico have been recognized on national TV for their efforts to make sure their students have access to food when they leave the classroom.

These selfless teachers, like many others, deserve the praise and recognition. But I worry that society is missing the bigger picture, which is the fact that these local heroes are stepping up across the country because their elected leaders are not investing in child nutrition. That is especially true in our poorest communities where malnutrition impacts every facet of family life.

In fact, I would argue that hunger affects more children, more often, and in a more profound way than most other consequences of poverty. Nearly 16 million American children face hunger, and most of the food they receive is not considered healthy; rather, their parents are more inclined to buy the most affordable food available.¹ The lack of access to healthy food hurts a child's development, including physical and mental health, academic achievement, and future economic prosperity, according to Feeding America, a national advocacy organization.²

The Southern Education Foundation reported earlier this year that, for the first time, low-income students are now a majority (51 percent) of the children attending public schools in the U.S.³ The Foundation based its conclusion on an analysis of federal statistics that show the number of students who are eligible to receive free or reduced-price lunches. In New Mexico, more than two-thirds, or 68 percent, of children come from low-income families.

However, while the vast majority of those students take advantage of the national school lunch program, fewer than half participate in school breakfast programs. And even though many families receive food assistance in the form of SNAP benefits, that assistance doesn't stretch far.

I learned through my own experience—a very limited, one-week experience—how difficult it is to survive on \$4.50 a day in SNAP benefits. I took the SNAP Challenge and had to purchase food for the week with a \$31.50 budget. I lived mostly on rice, beans, pasta, peanut butter sandwiches, Top Ramen, six eggs, a few pieces of fruit, and a small package of ground beef. Notably missing were vegetables, which I couldn't afford to buy. I clearly went without a balanced diet for that week.

What struck me most was how children live on that diet, without proper amount of proteins and nutrients, and how it affects their health. Ultimately, malnourished children are not ready for school and they won't perform well when they are worried about where they will get their next meal.

More than half of SNAP recipients in New Mexico, about 220,000, are children. In 2011, more than one-third of all Hispanic households were more than twice as likely than White/non-Hispanic households to be food insecure.⁴

Despite the grim statistics about poverty and hunger, many policy-makers want to cut investments in proven programs that make a difference in the daily lives of children. Congress cut SNAP benefits by \$8.6 billion as part of the Farm Bill in 2013. We had to fight to limit those cuts.

And in New Mexico, which ranked first in the nation for child hunger for the past two years, one state bureaucrat in charge of implementing the federal SNAP program denied that we even have a hunger problem.⁵ State officials are now trying to tie work requirements to SNAP benefits, which will further limit access to the program.

We shouldn't be cutting these programs; we should fully fund them, and invest in additional initiatives that are showing success in ensuring children have access to nutritious meals—every day. Government agencies should be partnering with the

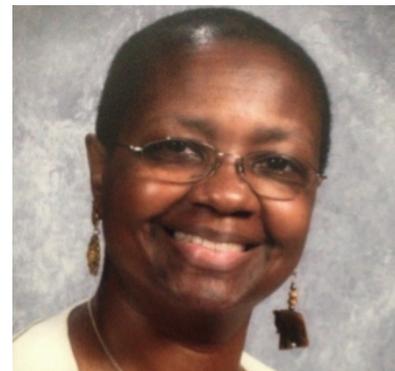
private sector and non-profits to ensure we are tackling child nutrition from every angle.

We can, and we probably should identify the myriad of programs and individual efforts around the country that are successfully helping schools and families meet the nutritional needs of children. But we must do more than that. I have called for a new War on Poverty, and child nutrition should be the centerpiece of that effort.

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CHAMPIONING SCHOOL MEAL PROGRAMS TO ADDRESS DISPARITIES IN CHILDREN'S FOOD SECURITY

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FOOD INSECURITY DISPROPORTIONATELY BURDENS FAMILIES AND CHILDREN OF COLOR.

Public school personnel are among those best poised to identify children's needs. With 3 in 4 reporting that they work with significant numbers of children of color, the American Federation of Teachers (AFT) members recognize disparities that impact kids' ability to thrive. On a recent survey, AFT members ranked hunger and nutrition as top priorities in children's health.

Research confirms what AFT members observe: food insecurity, or the "lack of consistent access to adequate food," disproportionately impacts children of color. While about 1 in 10 children live in a food insecure household, that proportion inflates to over 15 percent among Black children. Additionally, of households with very low food security among children, Hispanic households represent a larger share than any other racial or ethnic group.¹ While nearly all children's diets lack a sufficient amount of vegetables, Black children stand alone as a racial group eating less than half the recommended amount. Furthermore, both Black and Latino children's vegetable consumption is on a significant downward trend, while White children's consumption has slightly ticked upward.²

FOOD INSECURITY WEAVES A TANGLED WEB AROUND CHILDREN, INTERRUPTING IMPORTANT RELATIONSHIPS, DISRUPTING TRAJECTORIES TOWARDS SUCCESS, AND DULLING EFFORTS TO THRIVE.

Food insecurity impacts health and education. For example, food insecurity has been linked to poorer physical health, such as higher hospitalization rates and higher numbers of chronic health conditions. Often, these conditions contribute to chronic absenteeism, taking from instructional time.

Food insecurity is connected to impaired social skills, such as behavioral problems and impaired self-control. Young children frequently exhibit high levels of impulsiveness and hyperactivity, or low social ability. As adolescents, they are more likely to be suspended and not get along with other children.³

Mental illness is associated with food insecurity, as well. Food insecure children exhibit higher rates of depressive disorders and internalized anxiety. Elementary school-aged children see psychologists at more than twice the rate of peers. Further, by elementary school, "children who are hungry are four times more likely than non-hungry children to have a history of needing mental health counseling; seven times more likely to be classified as clinically dysfunctional; seven times more likely to get into fights frequently; and twelve times more likely to steal."⁴

Food insecurity is also correlated with poorer academics. By interrupting cognitive development, food insecurity manifests in school as lower gains in reading and math, as well as higher likelihood of repeating a grade. Additionally, children labeled as not just food insecure but "hungry" are twice as likely to require special education services as children in families that are not hungry.⁵

FEDERAL SCHOOL MEAL PROGRAMS ARE IDEAL FOR ADDRESSING DISPARITIES IN FOOD INSECURITY AMONG CHILDREN.

School meal programs reach an incredible amount of children in families struggling with food insecurity. An estimated 70 percent of food insecure families receive support in the form of a reduced-price or free school lunch.⁶

For years, the federally supported National School Lunch Program and School Breakfast Program have sought to address disparities in access to healthful foods and food security. A

2008 study found that just over two in five schools with high proportions of children of color (>45 percent) offered fresh fruit or raw vegetables daily. However, the same schools were significantly more likely to participate in USDA's fruit and vegetable program. Compared to schools with lower percentages of students of color, these schools were also significantly less likely to offer dessert and significantly more likely to provide entrées with an average of fewer than 30 percent calories from fat.⁷

Expanding on these successes, Congress made an historic commitment to children's wellness with the Healthy, Hunger-Free Kids Act of 2010 (HHFKA). HHFKA required the U.S. Department of Agriculture (USDA) to incorporate leading scientific recommendations for dietary intake into school meal nutrition guidelines. In keeping with the Institute of Medicine recommendations, school lunches and breakfasts were required to phase in healthful changes:

- Offer fruits and vegetables separately
- Offer fruit daily at breakfast and lunch
- Offer vegetables daily at lunch and diversify the types of vegetables served each week
- Require students to select a fruit or a vegetable
- Offer more whole grain-rich options
- Offer a meat or alternate protein source at breakfast daily
- Offer fat-free and low-fat fluid milk, along with water as a drink option
- Offer meals that meet age-specific calorie ranges
- Reduce the sodium content of meals
- Prepare meals using ingredients that contain zero grams of trans fat per serving

Overwhelmingly, schools are successfully implementing these ambitious goals. And despite some initial complaints, about 70 percent of both students and families are satisfied with the higher quality foods offered as a result of the new standards.^{9,10} At lunch, students are selecting significantly more fruits; they are also consuming significantly more vegetables and healthy entrée options. Increased consumption is in turn related to reduced plate waste.^{11,12} Participation in school breakfast programs has increased since the standards were implemented, too.¹³ Uptake for healthier meals is especially up among low-income children.^{14,15}

Schools implementing HHFKA have done an amazing job to improve food security among children. To best serve students, the current nutrition standards should be maintained, and their impact celebrated. Yet these are hard-won victories. More than 9 in 10 school meal programs face at least one challenge to implementing the standards; workarounds are inadequate, expensive, inefficient, and/or unsustainable.¹⁶ To sustain progress, we must assure a foundation for lasting success. That will mean turning from a narrow focus on the nutritional content of meals to the kaleidoscope of elements that create them.

FIRST, INGREDIENTS MATTER.

Fresh, local and sustainably-produced foods are better tasting, better for the environment, and better for our bodies. More than three in four school meal programs report that cost and availability of healthful foods is a barrier to implementing the new requirements.¹⁷ Farm to school programs are a promising approach to ensure access to these foods. 'Farm to school' is an umbrella term for a menu of best practices in nutrition education and food production. For instance, schools can choose to

- Invest in the local economy with procurement models that connect more directly to producers;
- Engage students in the farm-to-table process through school gardening; or
- Promote adventuresome and healthful eating through student taste tests.

Under HHFKA, for the first time, schools across the country had a chance to compete for a piece of \$5 million per year in grant funding and technical assistance to support farm to school programs. While the National Farm to School Network called this a "groundbreaking" commitment, it fell dramatically short of demand, which was more than five times higher than available support. The Farm to School Act of 2015 would help meet demand by increasing annual funding to \$15 million. The bill would also address access among people of color by expanding approved sites to include preschools, summer food service providers, and after school programs; more purposefully engaging tribal schools and producers; and improving participation of farmers and ranchers of color.

SCHOOLS NEED 21ST CENTURY KITCHENS TO PREPARE WHOLESOME, HEALTHFUL FOOD FROM SCRATCH.

About 9 in 10 school meal programs need at least one new piece of equipment, and 3 in 10 report that this is a barrier in their work to continue to meet federal nutrition standards.^{18,19} To eliminate trans fats, schools are moving from frying to baking foods; this requires ovens. To store fresh fruits, raw vegetables and low-fat dairy options, schools need refrigerators. To offer students more than reheated frozen foods, schools need space with appropriate plumbing and electrical infrastructure to prepare and store large amounts.

After a thirty-odd-year hiatus in support, USDA used funds from the American Recovery and Reinvestment Act to provide \$100 million in equipment grants to purchase, renovate, or replace food service equipment. In 2010, an additional one-time appropriation of \$25 million was made available for the same purpose. Applications for these grants exceeded \$630 million, suggesting a substantial unmet need for equipment upgrades.²⁰

SCHOOL PERSONNEL WITH GOOD JOBS ARE BEST POISED TO PROMOTE CHILDREN'S WELLNESS.

To meet the new nutrition standards, school meal programs seek to standardize recipes and work methods, and cook more from scratch. Both transitions need skilled staff with full-time work. Nearly two in three school meal programs report that gaps in staff training are a barrier to implementing the new nutrition standards and nearly half name shortage of labor hours as a barrier.²¹

The HHFKA required the development of professional standards for staff of school food authorities. The rule, published in March 2015, became effective on July 1. It established hiring standards; set training requirements based on the number of students served; and provided guidance for tracking compliance with both standards. The USDA announced up to \$150,000 in support for each state to implement the standards.

The Smarter Lunchrooms Movement has developed a promising set of strategies that should be explicitly integrated into training requirements for staff at every level. With \$5.5 million from USDA, the Cornell Center for Behavioral Economics in Child Nutrition Program helps school meal programs apply evidence-based, low and no-cost strategies to promote healthful eating behaviors.

- For example, by moving diverse fruit options next to cash registers, a Minnesota school directed students' impulsively purchasing habits towards healthful items.
- A New York middle school moved its portable salad bar to the center of the lunchroom, forcing students to walk around it; increased visibility consistently increased sales.
- By requiring cash payments for desserts and soft drinks, rather than accepting PIN account numbers or debit cards, high school meal programs see higher sales of nutritious foods.²²

Despite investment Smarter Lunchrooms strategies through HHFKA, some sites struggle to adhere to the program.²³ Congress can direct USDA to explicitly link training and technical assistance related to the new professional standards to their Smarter Lunchrooms work. Linking the move towards professional mastery to data-driven recommendations can help school meal programs learn, implement, evaluate and adhere to best practices.

SCHOOL MEAL PROGRAMS SHOULD BE DESIGNED TO SERVE ALL CHILDREN.

School meal programs' policies and practices frequently reflect decisions about adults' budget concerns and convenience rather than what is best for children. For instance, "alternate meal" and "unpaid balance" policies apply when a student has surpassed some threshold—such as five unpaid meals or a negative balance of \$12. The child is offered an alternate meal, often less substantive, less nutritious and cold, such as a cheese or peanut butter sandwich and milk. The child may be given a sticker to wear, or a letter for the backpack, as a reminder to parents to pay the account. The cashier may ask a child to return a complete meal that's already been set on the tray. Parents may be called, texted or emailed about adding to the account balance.

Too often these policies are often insufficient, ineffective, discriminatory and burdensome to implement. In a survey on this topic, nearly one in three AFT members in schools with these policies report seeing a child go hungry. More than 1 in 4 witnessed a child stigmatized, such as kept from a school function or field trip. More than 1 in 10 saw a policy negatively impact a child's cognitive, academic or athletic performance.

USDA recently opened a comment period on this issue. However, it is not clear how the comments will be used. Congress can

direct USDA to conduct a public briefing on their investigation, with a specific eye toward providing technical assistance on strategies that help schools prioritize children's health and move away from segregating children by income level.

As another example, for every 100 low-income children eating lunch, just 53.2 participate in school breakfast programs.²⁴

Though this is a record high, given the importance of breakfast to cognition and academic success, there is work to do. Alternate service models boost access to healthful foods and participation in school meal programs.

- **Breakfast in the classroom** brings bagged or hot options directly to young students in the first few minutes of class.
- **Grab-n-go kiosks and carts** among middle school students can increase the numbers eating breakfast.
- **Food trucks** outside of high schools have the potential to introduce more varied cuisines and compete with fast food options.

New models are most successful when they are designed and implemented with input from the diverse staff whose workload will be impacted, including food service workers, custodial staff and classroom educators.

USDA's new Community Eligibility Provision program (CEP) is also promising. The program provides free breakfast and lunch to *all* students, reduces administrative burden on families and schools, and eliminates the need for "alternate meal" or "unpaid balance" policies. However, the threshold for eligibility may be a barrier—schools must already offer both breakfast and lunch. Further, some districts are worried about identifying low-income children and the potential impact on eligibility for Title I funding through the Elementary and Secondary Education Act. Where CEP has been implemented, it's widely celebrated. Congressional leaders can amplify the voices of the districts that have tried, and like, CEP, to better raise awareness of its potential and successes to date.

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CHILDHOOD ASTHMA

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Close to 10 million children (10 percent) in the U.S. currently have asthma—the most common childhood disease.¹ Asthma is characterized by airway inflammation and narrowing of the airways. Symptoms include wheezing, shortness of breath, chest tightness and coughing. Although there is no cure for asthma, symptoms can be managed with medication and lifestyle modifications. Yet, asthma still accounts for up to two million emergency department visits each year and over \$50 billion medical expenses annually.²

PREVALENCE OF ASTHMA

Non-Hispanic Black children suffer the greatest burden of this disease with more than 16 percent of children likely to have asthma compared to Hispanic (9 percent) or non-Hispanic White (8 percent) children.³ Over the last ten years the prevalence of asthma is increasing, particularly among low-income minority children.⁴ Black children are now two times more likely to develop asthma compared to White children. The causes of asthma are not well known and most research does not focus on preventing asthma from developing. This may lead to worsening disparities in the prevalence of asthma for Black children.

DISPARITIES IN ASTHMA OUTCOMES

Although serious adverse health outcomes are largely preventable, Black children are twice as likely to be hospitalized or have an emergency department visit and four times more likely to die from asthma compared to White children.⁵ This significant disease burden affects a child's physical and academic development. Children with more severe asthma are more likely to have worse school attendance, lower grades, lower quality of life, and more likely to be overweight/obese, contributing to overall worse health. Despite a significant focus and attention on these dispar-

ities over the past ten years these disparities in outcomes have only improved slightly when accounting for the increasing disparity in the prevalence of asthma described above.⁶

RISK FACTORS FOR POOR ASTHMA OUTCOMES

According to the National Asthma Education Prevention Program (NAEPP) guidelines,⁷ most children with asthma can improve asthma control and prevent morbidity through appropriate self-management skills. These guidelines state that asthma management needs to focus on the following four areas: 1) appropriate medication use, 2) environmental control to reduce exposure to known allergens, 3) symptom monitoring, and 4) regular medical care.

APPROPRIATE MEDICATION USE

Multiple medications have been FDA approved for managing asthma symptoms. There are two types of medications most commonly used: 1) controller medications which are daily use medications designed to reduce inflammation over time and 2) rescue or quick relief medications which are used as needed when asthma symptoms develop. Underuse of controller medication is associated with worse asthma control and morbidity as well as over use of rescue medication to relieve acute symptoms. Black and Hispanic children are less likely to use controller medications. This underuse may be a result of 1) failure of physicians to prescribe long-term controller medications to patients who should receive them according to NAEPP guidelines or 2) logistical barriers making it difficult controller medications from pharmacies due to insurance coverage, cost, or transportation barriers, and 3) poor adherence to medications due to patient factors such as beliefs that the medications are not working, concerns about side effects, lack of motivation/confidence to

adhere, or issues remembering to take the medication or establish good routines. Black families are much more likely to report lower perceived benefits of medications and are more likely to have medication concerns such as worries about side effects. Low-income families are more likely to report logistical barriers acquiring medications. These barriers and health beliefs have shown to be directly associated with lower rates of adherence for many medications for chronic illnesses including asthma. Poor controller medication adherence has been directly associated with greater risk of Emergency Department (ED) visits, hospitalizations and cause of oral corticosteroids.⁸

ENVIRONMENTAL CONTROL

Reducing exposure to environmental triggers of asthma is a critical component of asthma control. Residential allergen and irritants such as dust mites, cockroaches, pets, cigarette smoke, nitrogen dioxide (from gas stoves), and mold/mildew can trigger asthma exacerbations. Low-income families are at the greatest risk for toxic exposures within their home, neighborhoods, and communities, thus contributing to disparities.

It is well documented that low-income families are at the greatest risk for inadequate housing and live in urban areas with higher levels of outdoor air pollution, which increases the likelihood of environmental exposures. National Cooperative Inner City Asthma study was a large national study of seven inner-city areas in the U.S. with predominantly Black or Hispanic children with asthma. Over 60 percent had annual family income under \$15,000 and had a family history of asthma.⁹ Most of the homes were in poor repair with leaky roofs, broken windows, peeling paint. Evidence of mice allergens in inner city homes is as high as 90 percent and has been directly linked to increased asthma symptoms. Outside of the family home, urban families are more likely to be exposed to violence and higher levels of chronic stress that has also been linked to worsening asthma prevalence and morbidity. Urban areas also have worse outdoor air pollution as well due to increased vehicle traffic and other sources. Combined together low-income urban families are at particular risk for exposure due to poor housing conditions, outdoor air pollution, and community violence, which may contribute to known disparities.

HEALTH SERVICE UTILIZATION

National asthma guidelines recommend that children with asthma receive routine medical care focused on managing their asthma, at least every 1-to-6 months depending on the severity

of asthma. These visits provide the clinician the opportunity to assess asthma management and control, evaluate and modify, as needed, the current treatment plan, provide education on asthma self-management, and develop a collaborative relationship between health care provider and family. These routine care visits are seen as opportunities to potentially address increasing risk of asthma exacerbation prior to it occurring and thus improving overall well-being and reducing unnecessary ED visits and associated healthcare costs.

Black and Hispanic families are more likely to have ED visits for asthma and less likely to have routine medical care visits even if they have an established primary care provider.¹⁰ This pattern of episodic emergency care can lead to fractured care across multiple providers, lack of preventive care that may include prescriptions for long term controller medications, and gaps in asthma management knowledge to prevent future exacerbations. Reasons for this disparity may include lack of insurance coverage, greater number of logistics barriers, and low motivation/understanding about the need for preventive services. With regards to insurance coverage, this pattern of health care visits is seen even in Medicaid populations who would have access to preventive services. Although minority families face more logistical barriers such as transportation, limited time off from work, lack of available evening/weekend appointments, and difficulty navigating the clinic phone system to set up an appointment, there are still remaining factors that explain this gap in healthcare services. Research has shown that due to the cyclical nature of asthma symptoms, many families are not motivated or aware of the need for preventive care, particularly during periods of low symptoms. Many refer to this belief as “no symptoms, no asthma” to describe families who do not address asthma during symptom free periods.¹¹ This health belief has been associated with lower medication adherence, lower rates of preventive care, and less attention to environmental control measures.

INTERVENTIONS

Low-income families have multiple competing priorities for their time. They face additional ongoing stressors such as obtaining access to food and housing that are burdensome and time consuming. They have higher rates of unemployment, job turnover, legal involvement, and disability/illness that place an undue burden on families. These additional stressors take away from the families’ ability to manage their child’s asthma. Given the competing demands, families are more likely to skip day-to-day self-management activities to prevent symptoms, which can lead to greater occurrence of acute symptoms and increasing stress for the families. Thus interventions need to

be considerate of how much time is being asked of families and focus on engaging them in preventive care in order to avoid acute symptoms and additional stress over time. Since many children with asthma are not developmentally ready to manage asthma independently it is important to engage multiple caregivers in asthma management. Previously most of the research has focused on the primary caregiver, specifically mothers. However, interventions that engage alternative caregivers such as teachers, babysitters, and other family members have shown improvement in asthma control by ensuring that the child has multiple people aware of asthma and able to provide support as needed.

EVIDENCE BASED INTERVENTIONS

Although effective treatments to manage and control asthma are well identified, there has been little change in health care use and asthma control over this time.¹² This suggests that it is critical to identify and implement interventions that engage a range of stakeholders including individuals, families, communities, health care providers, and schools/workplaces for more effective interventions. Multi-level interventions that work across different settings have been identified as the most effective interventions for asthma, particularly to address racial and ethnic disparities.¹³ Furthermore, given the multiple targets for intervention, such as asthma knowledge, environmental exposures, medication adherence, and symptom monitoring, it has been found that interventions tailored to individuals based on their needs and gaps in asthma management are the most efficacious.¹⁴ Asthma management interventions have been developed and implemented in many settings including: 1) health care provider offices; 2) family homes; 3) online/web support, 4) school/work settings, 5) community coalitions. Each of these settings has identified interventions that have been shown to be effective in improving an individual's asthma control and well-being.⁸¹ By implementing evidence-based interventions into settings that can reach large numbers of children, learning can be optimized with less demand on resources.

LEGISLATIVE POLICIES

In 2012, multiple federal agencies convened an intra-agency Asthma Disparities Working group co-chaired by the U.S. Department of Health and Human Services, Environmental Protection Agency, and Department of Housing and Urban Development that formulated a federal action plan to directly address child asthma disparities that align with Healthy People 2020. This plan outlines three strategies to promote collaboration to reduce asthma health disparities by 1) promoting

guidelines based asthma management, 2) providing integrated asthma care in communities with asthma disparities, and 3) improving capacity to identify children most impacted by disparities, and 4) facilitating efforts to prevent onset of asthma. Legislative efforts are needed to continue to implement this important strategic plan designed to directly target racial and ethnic disparities in childhood asthma.

An area that is directly represented in the Federal Action Plan is the role of Centers of Medicare Services (CMS) in asthma care. CMS, particularly Medicaid, is a key stakeholder in directly addressing asthma disparities. As highlighted above, racial and ethnic minority families demonstrate significant gaps in asthma management knowledge that can benefit from evidence-based education interventions. However, many families do not have appropriate insurance coverage or access to certified asthma educators to provide this much needed education.

RESEARCH INVESTMENTS

Recently the NHLBI released their draft of strategic visions for their research funding programs. They specifically targeted funding projects that evaluate methods to best implement evidence-based interventions into community settings that serve at-risk populations. Our previous research efforts have identified a number of efficacious interventions to improve asthma control in children but these interventions are rarely routinely implemented within community programs. Research efforts are needed to understand which methods will best promote implementation and sustainability of evidence-based programs in diverse settings. By partnering with community agencies, researchers can directly implement and evaluate their programs in real world settings while directly improving the lives of families who need the most help.

SUMMARY

Black children are at the greatest risk for developing asthma, and those with asthma are at the highest risk for poor outcomes, including higher rates of healthcare utilization, poorer quality of life, and even higher rates of death due to asthma. Despite targeted focus on this area, there have been only slight improvements in these disparities that are often not seen due to the ever-increasing prevalence of asthma in minority populations. Research investments on this topic have shown that evidence-based interventions that can be tailored to individual needs can be effectively implemented in different community settings to reach our most at-risk populations. Greater focus is needed to understand the best methods for implementing and

sustaining these programs to reduce known health disparities in pediatric asthma and improve the lives of over 10 million children with asthma.

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TESTIMONIAL: COLORECTAL CANCER: A PREVENTABLE SCOURGE

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REFORM IMPLEMENTATION WORKING GROUP



The issue of colorectal cancer is personal to me...

Like far too many Americans, my father, the late Congressman Donald M. Payne (NJ-10), did not realize the importance of screening for the disease until it was too late. By the time he was screened, the disease had advanced beyond the possibility of recovery. Just a few weeks later, at the age of 77, my father passed away.

My father's passing was a wake-up call for me—and a call to action. I received my first screening at age 54—nine years after the recommended age for African American men to get screened. My gastroenterologist found and removed 13 polyps at my initial examination. Just a year later, I had three more polyps removed. Fortunately, they all turned out to be benign. However, had I put off the screening or avoided it altogether, the polyps could have developed into cancer, and I could have experienced the same fate as my father.

When it comes to colorectal cancer, there is some good news at the national level: In the last decade, there has been a 30 percent decrease in the incidence of colorectal cancer, due mostly to an increase in screening rates. And, according to the American Cancer Society, colorectal cancer death rates have been decreasing for men since 1980 and for women since 1947, thanks in large part to screening and improvements in treatment.

However, many of the statistics on colorectal cancer remain frightening.

Although the disease is highly preventable and treatable when detected early, colorectal cancer is the second leading cause of cancer death in the United States. About one in twenty Americans will be diagnosed with the disease at some point in their lives.

The American Cancer Society reports that about one in four people will have polyps by age 50 and one in two people will have polyps by age 75.¹ These polyps have the potential to turn cancerous if left unchecked. Because symptoms are often not present in the early stages of the disease, many individuals forgo screening.

Too many people, especially men, also forgo checkups and screening because of misperceptions about testing and barriers to care. These barriers are financial, social, and cultural, including stigmas associated with screening.

The statistics are even worse for African American communities.

THE DISPROPORTIONATE IMPACT OF COLORECTAL CANCER ON AFRICAN-AMERICAN COMMUNITIES

Despite decreasing colorectal cancer incidence rates, there is a significant disparity between African Americans and other racial groups in terms of screening, incidence, and survival rates.

African Americans have the highest incidence and mortality rates for colorectal cancer, and the five-year survival rate for White Americans suffering from colorectal cancer is almost double the rate for African Americans.

Even worse, African Americans also disproportionately suffer from cancer more generally. They have the highest death rate and shortest survival rate of any racial and ethnic group in the United States for most cancers.

Although the overall racial disparity in cancer death rates is decreasing, in 2007, the death rate for all cancers combined continued to be 32 percent higher in African American men and 16 percent higher in African American women than in White men and women, respectively.²

There are many reasons these disparities exist.

African American and other minority communities are disproportionately affected by poor provider-patient communication and health literacy issues. They also lag behind in access to and quality of care, as well as timeliness of care.

A big part of the problem is financial. African American communities tend to have lower incomes and wealth than White communities, and there is an undeniable link between socioeconomic status and health outcomes. According to an April 2015 report by the Urban Institute and the VCU Center on Society and Health, there are “strong ties between income and health,” in part because those with less income and wealth are “less likely to afford an education, healthy lifestyles, or safe and healthy neighborhoods.”

The report also recognized that “Economic hardship makes people more vulnerable to diseases and to harmful biological effects of stress.”

In Congress, I have been working alongside advocates, survivors, and my colleagues to break down cost barriers to life-saving cancer screenings and to expand access to innovative treatments. This year, along with Congressmen Charlie Dent (PA-15), Joe Courtney (CT-2), and Michael Fitzpatrick (PA-8), I introduced *The Removing Barriers to Colorectal Cancer Screening Act*, bipartisan legislation that would remove financial barriers to life-saving colorectal cancer screenings and treatment for Medicare beneficiaries.

Medicare-aged individuals account for two-thirds of colorectal cancer diagnoses. But under the current Medicare cost-sharing structure, many seniors are faced with unreasonably high costs that deter them from receiving cancer screenings.

The Removing Barriers to Colorectal Cancer Screening Act would correct a loophole by waiving cost sharing under Medicare for preventive colonoscopies, even if a polyp or tissue is removed.

Leading public health and advocacy organizations, like the American Medical Association, AARP, and the American Cancer Society Cancer Action Network, have come out in support of this legislation because they recognize that no senior on a fixed income should have to choose between their health and paying the bills.

Removing barriers to colorectal cancer screening will save lives and a significant amount of money in direct and indirect costs linked to the disease.

Among the problems behind colorectal cancer disparities in African American communities are social and cultural factors. Research suggests that African Americans are often reluctant to get screened for the disease because of a lack of trust in health providers and because of stigmas that surround screening.

Nearly half of African Americans do not get screened at the recommended time. Many tell me that they feel the process is too invasive. Others are simply afraid of getting screened because they have never been through the process before. The reasons these individuals avoid getting screened are important because we can use them to inform our approach to increasing screening rates and eliminating the scourge of colorectal cancer.

A NEW APPROACH TO FIGHTING COLORECTAL CANCER

We need a new approach to eliminating colorectal cancer that focuses on direct engagement with those most at risk of the disease.

On June 14, 2015, in Newark, New Jersey, the Colon Cancer Alliance and the National Black Church Initiative launched “Now is the Time,” a nationwide, church-based initiative that aims to prevent colorectal cancer by increasing the screening rate among African Americans.

“Now is the Time” aims to achieve this goal by engaging directly with African Americans in churches through sermons and health navigators who are available to provide information on colorectal cancer, including the various screening methods available.

The message of the initiative is simple: Adults, both men and women, should not put off getting screened, because it can save their lives.

I’m proud to serve as the Honorary Chair of this awareness campaign, and I’m just as proud that the initiative launched in Newark, my hometown. These kinds of efforts give us opportunities to ensure that African American communities have all the necessary facts about colorectal cancer and screening methods.

For those who are reluctant to get a colonoscopy, we can inform them about the multiple effective screening methods available, not just colonoscopies, including various stool based, at-home screening methods.

We can let them know that simple, affordable tests are available, and we can stress just how important it is to get screened—especially if they are over the age of 45 or have a family history of colorectal cancer, both of which put them at a higher risk.

There is no doubt that health is personal, and by personalizing the issue of colorectal cancer, we can motivate people to take a proactive approach to their health.

PUTTING AN END TO COLORECTAL CANCER: NEXT STEPS

After witnessing my father lose his battle with colorectal cancer, it became my mission to raise awareness about the importance of preventive care and to help reduce health disparities.

In my capacity as a Member of Congress and as Co-Chair of the Congressional Men's Health Caucus, I will continue to work with anyone who shares this commitment. I will go anywhere and speak with anyone so that no one has to suffer the loss of a loved one to colorectal cancer, like my family did.

I encourage all Americans to talk out loud about colorectal cancer to help eliminate the harmful stigmas that too frequently stand in the way of timely care.

Consult with your doctor about getting screened and about available screening methods. Know that colorectal cancer impacts both men and women—a fact that is too often not discussed.

Finally, have a conversation with your family and friends about the importance of screening for colorectal cancer, especially if there are factors that put you at higher risk, like personal or family history, or if you have Type 2 diabetes or pre-cancerous polyps.

Eliminating colorectal cancer certainly will not be easy, but it is a goal we should aspire to meet. Raising awareness and spurring people to get screened will save lives—and that is something we can all get behind.

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THE RATIONALE FOR COLORECTAL CANCER SCREENING: A CALL TO ACTION

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INTRODUCTION

Cancer that develops in the large intestine or rectum is known as colorectal cancer (CRC). It is one of the most preventable malignancies because early detection allows for appropriate treatment that impacts long term outcomes. The combination of well-defined precancerous lesions, such as polyps, combined with a long asymptomatic period, provides a window of opportunity for effective screening. Yet in spite of this, CRC remains a major cause of morbidity and mortality. The current options for CRC screening are strongly anchored in evidence demonstrating utility in reducing poor outcomes and achieving health equity.

THE EPIDEMIOLOGY OF COLORECTAL CANCER

Around the world, CRC is the third most commonly diagnosed cancer among men and the second most common among women.¹ For an average risk individual, the chance for CRC is 5 percent over a lifetime, and it is most likely to occur after the age of 50.² While there has been a decline in the incidence and mortality rates in the United States, every year there are still over 132,000 new cases diagnosed and at least 49,000 Americans die of the disease.³

HOW COLORECTAL CANCER DIFFERS ACCORDING TO RACE & ETHNICITY

In the United States, African Americans have been found to have a 20 percent higher incidence rate and a 45 percent higher mortality rate from colorectal cancer compared to Whites.^{4,5} There are also significant differences in life expectancy among Blacks compared to Whites. While there was a 39 percent reduction in mortality rate for White men between 1960–2005, during the same period there was a dramatic 28 percent increase in mortality for Black men.⁶ Of note, incidence rates among other

racial groups including Hispanics, Asian Americans, and Native Americans, are lower than those among Whites. The factors that underlie these differences have not been fully elucidated but most likely encompass both modifiable factors (e.g. diet, smoking, socioeconomic status, body mass index, and cultural beliefs) as well as non-modifiable factors (e.g. race/ethnicity, gender, and genetic predisposition). These findings do suggest there is a need for appropriate risk stratification for CRC and for more aggressive screening in high-risk populations, particularly among Blacks in the United States. Such an approach has been recommended by both the American College of Gastroenterology (ACG) as well as the American Society for Gastrointestinal Endoscopy (ASGE) with the suggestion to start screening Blacks at the age of 45 since they tend to develop the disease at an earlier age.^{7,8}

FACTORS THAT IMPACT THE TRENDS IN COLORECTAL CANCER EPIDEMIOLOGY

Despite some overall gains, several factors continue to impact the epidemiology of CRC. These elements include any personal or family history of CRC or adenomatous polyps, inflammatory bowel disease (IBD), and inherited genetic syndromes such as familial adenomatous polyposis (FAP), and hereditary non-polyposis colorectal cancer (HNPCC). Guidelines recommend earlier and more aggressive screening for these high-risk populations. As evidenced by the presence of both modifiable and non-modifiable risk factors, the pathogenesis of CRC seems to be influenced by a combination of genetics as well as the environment. Indeed, the disease results from the progressive accumulation of both genetic as well as epigenetic changes in the colonic epithelium. Currently, genetic tests are available that identify patients with inherited mutations associated with FAP and HNPCC. While this technology is promising, only two-to-six percent of CRC cases are attributable to common inherited

mutations, suggesting other variables are playing a role in the development of this disease.⁷

WHY SCREENING FOR COLORECTAL CANCER REALLY MATTERS

Numerous studies have demonstrated favorable CRC outcomes if the cancer is identified and treated at an early stage. In fact the 5-year survival rate is greater than 90 percent when CRC is identified at an early stage. However, if the cancer spreads beyond the colon, 5-year survival is less than 10 percent.¹⁰ Compared to other cancers where the primary goal is early detection of neoplasia, CRC can actually be prevented with detection and removal of polyps, which are precursors to cancer.¹¹

Removal of polyps is associated with not only considerable reductions in the development of CRC,¹² but it has now been demonstrated to have significant mortality benefits.¹³

AVAILABLE COLORECTAL CANCER SCREENING TESTS & WHICH SHOULD BE DONE

The CRC screening tests available can be grouped into two broad categories: prevention and detection. Prevention screening tests detect cancer as well as precancerous polyps, and are generally structural exams such as colonoscopy, flexible sigmoidoscopy, CT colonography, and double-contrast barium enema. By comparison detection tests are only able to identify CRC lesions and consist of fecal tests, including the fecal immunochemical test (FIT), fecal occult blood testing (FOBT), and Fecal DNA testing.¹⁴ As a gold standard, colonoscopy is a test that uses a flexible camera to carefully examine the surface of the entire colon and to potentially remove any polyps that are identified. In patients with no lesions detected during a screening colonoscopy, the interval for the next surveillance examination can be extended to 10 years. While strengths and limitations exist for each available screening option, in general, the best test is the one that is done since the biggest threat to the development of CRC in populations is a low screening rate. Despite mounting evidence that CRC screening is life saving, screening rates remain surprisingly low for this preventable cancer with only 59 percent of the U.S. population age 50 and older reporting being current with screening recommendations.¹⁵ Between 2000 and 2010, the use of colonoscopy in the US almost jumped from 19 percent to 55 percent.¹⁶ It is striking to note that differences in CRC screening rates exists across states from a high of 76 percent in Massachusetts to a low of 57 percent in Wyoming. These rates reflect barriers that exist to effective screening, which originate from physicians, patients, as well as society, and include not only cost, but also access to care, communication, knowledge, attitudes, and general acceptance.

Barriers to screening have contributed to racial and ethnic differences in CRC screening rates. Compared to Whites, Blacks and Hispanics are less likely to be screened. Minority populations and low socioeconomic status are considered to be factors resulting in low CRC screening rates.¹⁷

BARRIERS TO EFFECTIVE COLORECTAL CANCER SCREENING

Colonoscopy is an accurate and effective screening technique that is endorsed by many societies, including the American Cancer Society, U.S. Multi-society Task Force, American College of Radiology, and ACG.^{18,19} Not only does knowledge about these guidelines impact practice, consideration must also be given to the modality for CRC screening. Studies have demonstrated that most physicians overwhelmingly prefer colonoscopy as the test of choice,²⁰ and their recommendations play a crucial role in the decision to get screened for CRC.²¹ A mere discussion of CRC screening at the time of an office visit may be sufficient to motivate patients to complete CRC screening. However, since all screening tests have some benefit, techniques other than colonoscopy may be more suitable for specific patients, depending on their individual circumstances. For example, wealthy patients frequently opt for colonoscopy, while those from lower socioeconomic groups tend to choose at home stool testing over endoscopy.²² Patient preference vary by ethnicity as well, with African Americans less likely to choose endoscopy compared with Caucasians.²³ Considering the evidence above, physicians should recommend one best option to their patients using evidence-based medicine and taking into account patient specific factors. CRC screening guidelines are complicated, and offering multiple options still requires shared decision making in practice.²⁴ Many physicians have reported that health insurance remains very influential for screening recommendations.²⁵

At the center of the discussion related to screening is the patient's participation in completing the process. Low compliance for CRC screening by patients can be attributed to several factors, including lack of insurance, cost, lack of knowledge of cancer and screening, not seeing a need for testing, embarrassment, lack of symptoms or health problems, fear of perceived pain, and anxiety of testing. This is in addition to failure by recommendation from a physician.²⁶ Lack of knowledge is a major barrier to screening, particularly for immigrants, ethnic minorities, and underserved populations because of challenges in effective communication. Studies looking into lack of knowledge about colon cancer screening identified many other knowledge gaps, including low health literacy. Some individuals did not have a basic understanding of human anatomy and were not able to identify the location of the colon, nor its purpose. A subset of these individuals did not believe colon cancer existed. Furthermore, a

surprising amount of educated individuals could not accurately describe the colon's function, confusing it with the rectum and anus.²⁷ Those that had some fundamental knowledge of colon anatomy lacked an adequate understanding about the causes and risk factors of colon cancer. Many individuals without symptoms or family history do not feel concerned about this disease. Some are under the impression that causes of colon cancer center around food and thought that bowel cleansing was a good way to maintain or re-establish health. Others cited that they did not get screened because they did not smoke, drink, eat unhealthy foods, or participate in anal sex, all of which they perceived to be high-risk behaviors associated with CRC.²⁸ Research studies also suggest that immigrants may experience unique barriers, such as language and cultural differences with their healthcare providers, which can lead to poorer communication about the importance of screening.

Patient-physician language discordance presents an important barrier as patients who do not speak English are less likely to be screened.²⁹ Language has been documented as a barrier for individuals who speak Spanish, Vietnamese, as well as Creole, just to name a few.³⁰ Cultural beliefs can also result in lower screening rates; for example, Italian-Australians, Macedonian-Australians and Greek-Australians were found to believe that nothing can be done to treat 'malignant' cancers and that in fact, treatment of cancers may hasten death.³¹ They also believe that consumption of 'unnaturally' grown foods, eating foods sprayed with pesticides or experiencing strong emotions may cause cancer. Studies with African Americans have indicated that the lack of CRC knowledge, lack of physician recommendation, and a distrust of the health care system and providers impede screening; as well as a fatalistic views (beliefs that screening and treatments are 'futile' since it is in "God's hands"), which has also been reported as a barrier for CRC screening.³²

OPTIONS TO OVERCOME BARRIERS

Advocates who help coordinate care (navigators) provide an option for tackling screening disparities by helping patients navigate the intricacies of the health care system.³³ They can better address the unique needs of a patient and are responsible for almost anything, such as helping patients get insurance, finding transportation to doctors' appointments, healthcare education, and emotional support. Endorsements by various professional organizations have helped to improve awareness of the benefits of CRC screening in the medical community. Furthermore, the decision by the Centers for Medicare & Medicaid Services to support screening colonoscopy had a significant impact on the popularity of this modality as other players followed suit. Public perception and support has greatly impacted the implementa-

tion of screening, especially colonoscopy. Public interest in colonoscopy reached a turning point in March of 2000 with as the first colon cancer awareness month. This initiative was spearheaded by news icon Katie Couric, who advocated for CRC screening on the national stage by televising her own colonoscopy after her husband's death from the disease at an early age.³⁴

CONCLUSION

Colorectal cancer is a prevalent disease that is preventable through screening. Although screening rates have improved, barriers persist for minorities in particular, and this has allowed for disparities in the prevalence and mortality of the disease. It is no longer a debate—screening for colorectal cancer saves lives.

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DIABETES IN THE AFRICAN AMERICAN COMMUNITY

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HEALING OUR VILLAGE



Diabetes is one of the most devastating and prevalent chronic diseases in our country. The number of Americans diagnosed with diabetes has more than tripled in the past three decades, from 5.6 million in 1980 to 20.9 million in 2011.¹ Currently, it is estimated that 29.1 million Americans, or nearly 10% of the population has diabetes.² Unfortunately, an estimated seven million Americans remain undiagnosed. Knowing one's risk for type 2 diabetes is the first step towards staying healthy. Research has shown that being more active and eating healthier can significantly reduce one's risk. Nevertheless, diabetes continues to grow at an alarming rate and it is the seventh leading cause of death in the U.S.³

If left untreated, diabetes can lead to severe, costly and long-term complications such as: heart disease, kidney failure, stroke, peripheral vascular disease (PVD), lower extremity amputations (LEAs) and visual impairments. Adults with diabetes have heart disease death rates about two to four times higher than adults without diabetes. Similarly, it is estimated that approximately 28% of deaths from cerebrovascular disease and approximately 55% of deaths due to renal failure can be attributed to diabetes. The death rate in the elderly due to diabetes is even higher with approximately 71% of deaths occurring among people aged ≥ 70 years and 8% of deaths occurring among people aged 65–69 years.⁴

There have been a number of medical advances in the treatment of diabetes, as well as increased access to medical care, in recent years. Yet, disparities in diabetes still persist. The toll diabetes takes, on racial and ethnic minorities, is alarming. Minorities have a higher prevalence of diabetes compared to other racial and ethnic groups. Compared to the general population, African Americans are disproportionately affected by diabetes; in fact, they are twice more likely to suffer from diabetes than are whites.⁵ Approximately 13.2% of all African Americans aged 20 years or older have diagnosed diabetes.⁶ Not only are African Americans disproportionately living with diabetes they

are also more likely to suffer from diabetes complications and comorbidities. A study in 2012 found that they were 3.5 times more likely to be hospitalized for lower limb amputations as compared to non-Hispanic whites.⁵ In 2013, African Americans were twice as likely as non-Hispanic Whites to die from diabetes.⁵ If these numbers continue to increase, African Americans will be facing a diabetic epidemic by 2050. Furthermore, racial and ethnic minorities are more likely to suffer from diabetes complications such as, end-stage renal disease and lower extremity amputations. In fact, unmanaged diabetes can increase the risk of chronic kidney disease progressing to kidney failure or end-stage renal disease (ESRD). This results in a preventable disease accounting for the third leading cause of death among African Americans.

ECONOMIC IMPACT OF DIABETES

The impact of diabetes is not limited to the quality of life of the individuals afflicted with the disease, but also has a tremendous economic impact on our healthcare system. Diabetes is a very costly disease primarily as a result of the demands it places on the healthcare industry, especially due to diabetes complications and comorbidities. More than 40% of all health care expenditures attributed to diabetes come from higher rates of hospital admissions and longer average lengths of stay per admission, constituting the single largest contributor to the attributed medical cost of diabetes. Of the projected \$475 billion in national expenditures for hospital inpatient care (including both facility and professional services costs), approximately \$124 billion (or 26%) is incurred by people who have diabetes, of which \$76 billion is directly attributed to their diabetes.⁷

While the rising health care expenditures impact all Americans with diabetes, the burden of this increased cost is not evenly spread through the diabetic population. A 2013 American Diabetes Association study found that African Americans face

greater cost disparities and higher per-capita health care costs for diabetes treatment. In fact, African Americans face the highest per-capita health care costs—\$9,540 compared to \$8,101 for whites and \$5,390 for Hispanics. The study also found that African Americans with diabetes visit the emergency department 75% more than the general population with diabetes and end up paying 41.3% higher per-capita for hospital in-patient costs than whites.

The annual attributed health care cost per person with diabetes increases with age, primarily as a result of increased use of hospital inpatient and nursing facility resources, physician office visits, and prescription medications. Approximately 59% of all health care expenditures attributed to diabetes are for health resources used by the Medicare population (aged 65 years and older).⁸

MEDICATION NON-ADHERENCE

People with diabetes who control their blood glucose have a documented improvement in both their quality of life as well as an increase in their job productivity by remaining employed longer with a lower absenteeism rate. Additionally, patients with diabetes who are able to control their long-term blood sugars (hemoglobin A1C) may increase their life span and lower their medical costs. However, the evidence is abundant that medication non-adherence in chronic disease management, especially among diabetic patients, continues to be a significant problem whose impact is affecting the quality and cost of care. As such, one of the major issues driving hospital readmissions and excessive use of emergency and urgent care services is poor medication adherence.

A 2013 University of Minnesota survey showed that: 40% of patients filled their prescriptions on the day of discharge; 20% filled them one or two days later; 18% waited three to nine days; and 22% of patients had not filled their prescriptions by the time of the follow-up telephone call (median, 12 days; interquartile range, 8-18 days). Thus, non-adherence has been associated with poor health outcomes, increased hospitalizations, and a significant economic burden. In some states, more than 40% of patients sustain significant risks by misunderstanding, forgetting, or ignoring health care advice (including, but not limited to, medication adherence).^{9,10}

LEGISLATIVE EFFORTS

Every 17 seconds, another person in the United States is diagnosed with diabetes. This alarming statistic underscores the

seriousness of diabetes and the challenges we face in addressing our nation's growing diabetes epidemic. The primary goals of the Patient Protection and Affordable Care Act (ACA) is to increase access to healthcare and provide preventative care, in an effort to achieve health equality. Within the law there are provisions providing new initiatives to end the diabetic epidemic in disparately affected populations, whom bear a disproportionate burden of not only the disease but also the uninsured or underinsured populations in this country. The ACA requires free preventive care, which includes diabetes screenings for adults with high blood pressure and for pregnant women. A recent study found prior to implementation of the ACA nearly 2 million working-age adults with diabetes lacked health insurance.¹¹ Now with implementation, insurance companies are prevented from denying coverage to those with diabetes or other pre-existing conditions and prevented from charging those with diabetes higher premiums simply due to their condition. Furthermore, the ACA prevents insurance companies from having an annual or lifetime limit on coverage or the ability to drop coverage when a person needs health care the most.

The Congressional Black Caucus along with the Congressional Hispanic Caucus and Congressional Asian Pacific American Caucus have sought to address the diabetes disparity and other health disparities in minority communities by introducing the Health Equity and Accountability Act (HEAA). HEAA builds on the advancements of the Affordable Care Act (ACA) by providing federal resources, policies, and infrastructure to eliminate health disparities in all populations, regardless of race, ethnicity, immigration status, age, ability, sex, sexual orientation, gender identity, or English proficiency. Furthermore, the bill improves and guides federal efforts in the following vital areas: data collection and reporting; culturally and linguistically appropriate health care; health workforce diversity; health care services; health outcomes for women, children and families; mental health; high impact minority diseases, such as diabetes; health information technology; accountability and evaluation; and addressing the social causes of health disparities. HEAA would provide grants to public and non-profit health care providers to treat diabetes in minority communities.

In summary, the management of diabetes is very complicated requiring routine physical activity, meal planning, medication administration (oral or injection) and treatment regimen adherence. Access to innovative, novel therapies and delivery systems in diabetes management must be incorporated into any diabetes education and training program. This will require more coordinated interaction with the patients, the healthcare provider, and the health plan case management and quality teams. In addition we suggest a Congressional mandate requiring consistency in the reimbursement for coordination of care services, diabetes education and nutrition counseling between Federal

and State agencies especially for medically underserved populations as well as the mandatory inclusion of diverse minority populations living in the United States to be included in clinical research trials before the FDA approves the drug for release. If we don't take action it is estimated that as many as one in three American adults will have diabetes in 2050 which will only expound this crisis in minority populations.

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TESTIMONIAL: A CURED CONGRESSMAN CONTINUES THE BATTLE AGAINST HEP C IN WASHINGTON

HONORABLE HANK JOHNSON (GA-04)
VIRAL HEPATITIS SURVIVOR, ADVOCATE



With expanded access to health coverage through the Affordable Care Act, bold leadership from Congress and the Administration and innovative solutions to ensure that everyone has access to a cure, we can win this battle in our communities as well.

INTRODUCTION

My story is a microcosm of hepatitis C in the African American community. Diagnosed in 1998 after experiencing chronic fatigue, I was devastated when doctors told me I had hepatitis C and likely only 20 more years to live. At the time, treatment was incredibly difficult to bear, and while I can say joyously today that I am cured, it wasn't until my fourth attempt that the medication worked for me. Today's therapies for hepatitis C are far more effective at curing everyone who wants and needs it. This is especially true for African Americans; we were cured at much lower rates—which I experienced during my first three rounds of failed treatment—and I am grateful others will not have to endure the severe side effects that I did.

So much has changed since I was first diagnosed, both for me and for my community. I won my personal battle with hepatitis C. With expanded access to health coverage through the Affordable Care Act, bold leadership from Congress and the Administration, and innovative solutions to ensure that everyone has access to a cure, we can win this battle in our communities as well. This experience inspired me to advocate for the other millions of Americans living with this debilitating condition. In service to those living not only with hepatitis C itself, but also with the stigma that accompanies it, I now share my story and plan to do so for far longer than 20 years. I encourage everyone—from community to Congress—to join me in ending hepatitis C in the African American community and beyond.

A SILENT INEQUITY: HEPATITIS C IN THE AFRICAN AMERICAN COMMUNITY

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Hepatitis C is an insidious virus. The majority of those living with hepatitis C (HCV) are asymptomatic, allowing the virus to slowly damage the liver over decades without a person ever feeling ill.¹ Once symptoms present, the damage done is often severe. Communities of color and other marginalized populations are silently bearing a disproportionate burden of this communicable, chronic, and potentially life-threatening disease.² While there are many challenges, we have the opportunity to eliminate hepatitis C and, with its elimination, realize an enormous public health victory.

HEPATITIS C – THE BASICS

Nationwide, over three million Americans are thought to be living with hepatitis C, but due to under-resourced surveillance, this and other data likely represent underestimates. Shockingly, up to 75 percent of the estimated 3.2 million people living with HCV also do not know.³ Many communities experience significant disparities in incidence and prevalence of hepatitis C, including veterans, particularly Vietnam-era service members;⁴ communities of color;⁵ people living in jail or prison;⁶ people who inject drugs; and “baby boomers,” those born from 1945-1965, who make up a massive 75 percent of the total prevalence of HCV in the US.⁷ African Americans are particularly disproportionately affected, as with many other health conditions. While African Americans comprise about 13 percent of the population, they represent 25 percent of all hepatitis C cases.⁸ For African Americans ages 45 to 65 years, hepatitis C-related chronic liver disease is the leading cause of death.⁹

Dr. Howard Koh, former Assistant Secretary of Health for the U.S. Department of Health and Human Services, described the viral hepatitis epidemic (referring to hepatitis B and C) as “the silent epidemic.”¹⁰ Hepatitis C is an infectious blood-borne virus that can be cleared from the body spontaneously in about 15 to 30 percent of cases. For the large majority of people who

become infected but unable to clear HCV, the condition will become chronic.¹¹ HCV affects multiple systems in the body, but is primarily considered a liver disease. Over time, the virus causes liver scarring which can lead to fibrosis, cirrhosis, severe liver damage, end-stage liver disease, and liver cancer.¹² Hepatitis C is currently the primary cause of liver cancer in the U.S.¹³—a highly aggressive cancer with a devastatingly low survival rate¹⁴—and one of the main reasons for liver transplantation.¹⁵ The virus’ effects can also be exacerbated by other conditions disproportionately affecting African Americans and other communities of color including obesity, diabetes, and HIV/AIDS.¹⁶

The silver lining? In just the 26 years since hepatitis C’s discovery, science has advanced such that, not only is hepatitis C preventable, it is *curable*. Just in the past few years, new direct-acting antivirals revolutionized the treatment landscape, and African Americans living with hepatitis C stand to gain the most. Cure rates are now 90 percent or above, treatment regimens were shortened dramatically, and side effects are now minimal.¹⁷ Whereas past treatments were particularly ineffective for African American patients, these new drugs offer parity in cure rates.¹⁸ There are many challenges, but given appropriate resources and commitment, it is possible to turn the tide on this epidemic, realize health equity for African Americans and other affected communities, and eliminate the largest blood-borne infectious disease epidemic in the United States.

HEPATITIS C IN THE AFRICAN AMERICAN COMMUNITY: OUR CHALLENGES

Like too many other health and social conditions, there are a variety of grim inequities regarding the hepatitis C epidemic among African American communities requiring intervention from the individual to the sociopolitical level.

INADEQUATE TESTING

There is a dangerous lack of awareness about hepatitis C, its prevention, transmission, and treatment. With 75 percent of those living with hepatitis C unaware of their infection¹⁹ an enormous amount of education is needed—both for community and for providers—to increase screening rates, especially given that African Americans are less likely to be offered an HCV test even in the presence of known risk factors.²⁰ Knowing one's health status is the critical first step toward appropriate care and prevention.

HISTORIC & CURRENT TREATMENT BARRIERS

Standard treatment for the most common hepatitis C genotype in the United States—genotype 1—used to be pegylated interferon-alfa and ribavirin. This combination offered low treatment rates at its best, curing approximately 40 to 50 percent of Caucasians, with African Americans faring much worse—seeing only about a 20 percent cure rate. Six years ago scientists discovered this is likely due to particular genes (IL28B polymorphisms) allowing pegylated interferon-alfa to work as hepatitis C treatment, genes that African Americans are much less likely to inherit.^{21,22} An 80 percent chance of treatment failure, combined with debilitating side effects, created a large disincentive to even begin treatment.

Last year, highly effective new treatments were approved offering 95 percent cure rates for African Americans,²³ finally offering real hope despite the sticker shock their price tags evoked. Now, with market competition, public and private health care payers are receiving deep discounts, but budgetary concerns remain and access to the drugs is highly restricted.²⁴ It is absolutely vital to expand access to these groundbreaking treatment regimens as broadly and as quickly as possible. Particularly given the stark disparity in past cure rates and remarkable disincentive to endure difficult treatment, African Americans who have lived with hepatitis C for so many years now deserve and require immediate access to this life-changing curative therapy.

BARRIERS TO HEALTHCARE

Treatment, of course, is only one aspect of the spectrum of care for hepatitis C. African Americans who are at risk of acquiring or are living with hepatitis C encounter the same healthcare barriers as those with many other health conditions. Despite the opportunities created by the Affordable Care Act for increased health insurance coverage, too much of the African American community still falls through the cracks. Disturbingly, nearly 60 percent of uninsured African Americans who would qualify for

Medicaid if expanded live in states without plans to implement Medicaid expansion.²⁵ Not only is access to healthcare broadly important, but unfettered access to drug addiction treatment—particularly medication assisted therapy, such as buprenorphine, for opioid dependency—is also essential, as injection drug use currently drives hepatitis C transmission in the United States.²⁶

RESISTING HARM REDUCTION, IGNORING THE INCARCERATED

Much has been written on the contribution of drug war policies to the mass and highly disproportionate incarceration of African Americans in the United States.²⁷ One of the many troubling effects of the war on drugs as it relates to public health is many policymakers' resistance to and rejection of harm reduction programs and policy for our communities,²⁸ as well as in jails and prisons. At a basic level, harm reduction-based interventions, which complement rather than replace other methods of addressing addiction, offer strategies to minimize drug-related harm for users and the communities they live in without coercion or judgment.

Unfortunately, despite overwhelming evidence of their effectiveness, harm reduction is often vilified for encouraging drug use and its many benefits denied.²⁹ The past decades' emphasis on criminalizing drug use rather than addressing it as a complex biopsychosocial health issue has created a dearth of syringe access programs and medication assisted therapy options for drug treatment both within and outside correctional facilities.³⁰ This combination of long-proven interventions is critical to preventing hepatitis C transmission³¹ among people who inject drugs and people who live in jail or prison, who are at high risk simply by virtue of being incarcerated not only due to drug use, but also to tattooing and the often violent nature of life during incarceration.³²

Incarceration, in and of itself, is a risk factor for acquiring hepatitis C.³³ African American and Latino communities face a high degree of exposure to this risk given their disproportionate incarceration.³⁴ It is imperative that correctional health systems be included and supported in implementing screening and prevention initiatives, as well as in offering care and cure to their populations (including staff). As the vast majority of those living in jail or prison will return to their communities,³⁵ prison health is an essential component of public health.

A WAY FORWARD

As we continue “the march toward health equity” as Representative Robin Kelly so aptly put it, for African Americans, other communities of color at risk for and living with hepatitis C, and beyond, we must consider strategies inclusive of, but not limited to, the following:

- Significantly increasing hepatitis C awareness, testing (especially among the baby boomer birth cohort), diagnosis, and linkage to care and treatment in African American communities. Many of these activities are supported by the critical work of the Division of Viral Hepatitis at the Centers for Disease Control and Prevention, which is currently severely under-resourced
 - As the cost for curative hepatitis C therapy drops, current policies—many without scientific basis—restrictions on access to treatment must be regularly reviewed and amended to ensure the broadest access possible, especially for African Americans
 - Increasing resources for and inclusion of the spectrum of hepatitis C services within correctional health systems, from prevention to non-coercive drug treatment to curative therapy, including mechanisms for increasing treatment access
 - Providing additional support for hepatitis C-related research and ensuring adequate participation of African Americans and other underrepresented populations
 - Immediately lifting the ban on the use of federal funds for syringe access programs. Congress annually attaches a policy rider to the Labor, Health and Human Services, and Education appropriations bill that prohibits local jurisdictions from using existing funding (such as HIV prevention funds) for syringe access programs, which provide crucial public health and linkage to care services to a historically very hard to reach population. Reversing this ban is imperative.
 - Expanding access to medication assisted therapy, such as buprenorphine, for opioid dependency
- Hepatitis C has taken its toll for long enough. It can be prevented and it can be cured. To continue to blatantly ignore this epidemic will cost us—it will cost us lives, it will cost us billions of dollars in care and lost productivity; and later, when we reflect, it may very well cost us our collective conscience.

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HIV/AIDS

HONORABLE BARBARA LEE (CA-13)
CO-CHAIR CONGRESSIONAL HIV/AIDS CAUCUS
HEALTH CARE TASK FORCE CHAIR OF CONGRESSIONAL
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INTRODUCTION

As a lifelong activist, co-chair of the bipartisan Congressional HIV/AIDS Congressional Caucus, and the author or coauthor of every piece of HIV/AIDS legislation since I came to Congress, I have a special sense of mission and commitment to stopping the epidemic of HIV/AIDS in our communities and around the world. Since this epidemic began more than thirty years ago, advances in medical treatment and care have made it so that those living with HIV are living longer, healthier lives. Additionally, the annual number of HIV infections has been reduced by more than two-thirds. Yet the Centers for Disease Control (CDC) estimates that 1.2 million people in the U.S. are living with HIV and that nearly one in seven people infected with HIV are unaware of their status.

As we mark the 25th anniversary of the Ryan White Program and of Ryan White's death, we are reminded of the importance of continuing to make investments in lifesaving health programs and the work ahead to turn the tide on the HIV/AIDS epidemic in the United States.

On World AIDS Day last year, President Obama said that we can achieve an AIDS-free generation "if we stay focused, and if we keep fighting" and challenged the world to "come together to set new goals" in the war against AIDS.

During my tenure in Congress, I have been proud to work with leaders such as Congresswoman Maxine Waters, who spearheaded the establishment of the Minority AIDS Initiative, and longtime Chair of the Congressional Black Caucus Health Braintrust, former Congresswoman Donna Christensen.

Most recently, I joined forces with Congresswoman Waters and current Health Braintrust Chair, Congresswoman Robin Kelly—supported by 32 of our colleagues—to work toward updating the National HIV/AIDS Strategy. This strategy is crucial to ensuring that the most vulnerable communities have the resources and

support they need to address this crisis. This includes addressing outdated and harmful HIV criminalization laws; scaling-up education on sexually transmitted infections, sexual orientation and gender identity; battling stigma that prevents people from accessing lifesaving care and treatment; and increasing access to affordable treatment and prevention.

Marginalized communities, such as low-income communities and communities of color in the U.S., continue to be disproportionately affected by this epidemic. We know that 2.1% of those living in urban poverty are affected by HIV and that African Americans make up 44% of the HIV-positive population—despite constituting only 14% of the U.S. population. Furthermore, Latinos face three times the HIV infection rate as their White counterparts. These and other marginalized communities, such as women and men who have sex with men (MSM), face ongoing stigma as a result of a lack of adequate HIV/AIDS education. For example, 15 percent of health education classes did not even mention HIV in 2013. This stigma discourages people from seeking treatment and accessing other preventative measures that could lessen the risk of infection.

That is why support for programs, such as the Ryan White Program and the Minority AIDS Initiative, is so important. These programs provide critical resources to improve access to life-saving treatment and help reduce disparities in health outcomes in low-income and African American communities. As a member of the House Appropriations Committee, I will continue to work with my colleagues to fight to ensure robust federal funding for these vital programs.

GLOBAL HIV/AIDS EPIDEMIC

I am proud to have played a role in the creation of President's Emergency Plan for AIDS Relief (PEPFAR) and am proud of the

leadership of the CBC Chair, Congresswoman Eddie Bernice Johnson for working in bipartisan manner to push for the creation of PEPFAR. In 2002, the CBC wrote to President Bush calling for an “expanded U.S. initiative” to “respond to the greatest plague in recorded history.”

To date, PEPFAR has supported over 7.7 million people with lifesaving treatment and prevented millions from becoming infected with HIV. Last year, we reached the incredible milestone of one million babies born HIV-free due to PEPFAR services. Between FY2010 and FY2017, PEPFAR supported country governments in adding 141,677 new health care workers to the health system in sub-Saharan Africa and worldwide.

Yet, a December 2014 UNAIDS report estimates that we have five years to break the epidemic for good or risk it rebounding out of control.¹ If we want to realize the dream of achieving an AIDS-Free Generation by 2030, we need to continue—and scale-up—our investments in these lifesaving programs. Congress can do its part by providing robust funding for PEPFAR and the Global Fund and rejecting budget cuts that threaten to paralyze proven lifesaving HIV interventions. Evidence continues to show that scaling-up treatment for people living with HIV not only saves lives, but also greatly reduces the chances of an HIV-positive person transmitting the virus to others.

In the fight to end HIV/AIDS, investments in treatment and education save lives. They bring us closer to the ultimate goal: achieving an AIDS-free generation. Congress has the opportunity to make this a reality. There’s no excuse for inaction.

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STATE HEALTH DEPARTMENTS' IMPACT ON AFRICAN AMERICANS AND HIV

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State public health agencies serve an essential and unique role in the delivery of HIV prevention, care, and treatment programs. Public health agencies are the central authorities of the nation's public health system; as such, they are essential to the monitoring, prevention, and management of HIV. State public health responsibilities include: disease surveillance; epidemiology and prevention; provisions of primary health care services for the uninsured and underinsured; and overall planning, coordination, administration, and fiscal management of public health services.

State public health agencies provide leadership, resources, and technical assistance to local and community-based agencies and work in partnership with the federal government, other state and local agencies, and community-based entities to meet the health needs of people living with HIV. State and local health departments have a primary responsibility to address the disproportionate impact of HIV on communities and to improve health outcomes for these populations.

An estimated 1.2 million people are living with HIV in the United States, with approximately 50,000 new infections each year. Of the 50,000 new infections each year, 63 percent were among men who have sex with men (MSM). Young people ages 13 to 24 years are also deeply impacted by HIV, especially young Black or Latino MSM.

AFRICAN AMERICANS & HIV

African Americans are the population most disproportionately impacted by HIV. While Black/African Americans account for approximately 12.6 percent of the total U.S. population, they account for 46 percent of all new HIV infections. African American men have new HIV infection rates that are seven times higher than those of White men, and African American women have new infection rates that are twenty times those of

White women. While African American women account for 29 percent of new infections, this is a significant decrease over the past ten years. Unfortunately, the same is not true for African American men, especially African American MSM. CDC data show that since 2006, HIV incidence has increased among Black and Latino gay men/MSM, notably those aged 13 to 24 years. Even more concerning is that there are more new HIV infections among young African American gay men/MSM than any other subgroup of gay men/MSM.

HIGH IMPACT PREVENTION

CDC's flagship HIV prevention program, the "HIV Prevention by Health Departments" program, funds state and local health departments to provide the foundation for HIV prevention and control nationwide. Health department efforts are essential to meeting goals of high-impact prevention and as part of the National HIV/AIDS Strategy in reducing the annual number of new HIV infections and reducing HIV-related health disparities, particularly among racial and ethnic minority communities and gay men/MSM of all races and ethnicities. High Impact Prevention allows state health departments to maximize their resources and focus efforts where the epidemic is having the largest impact, particularly among African Americans.

In 2012, the FDA recommended the use of antiretroviral medication by the most vulnerable HIV-negative individuals as a pre-exposure prophylaxis (PrEP). The use of non-occupational post-exposure prophylaxis (nPEP) in a safe and timely manner has also been used as an intervention for individuals recently exposed to HIV. These biomedical interventions are just examples of the growing toolbox of HIV prevention. Unfortunately, there is no categorical public funding to pay these effective biomedical tools and the costs associated with the assessment and care engagement (e.g., counseling and adherence support) of current and potential patients. The lack of public funding for

this prevention modality is a barrier for African Americans at risk for HIV infection.

RYAN WHITE PROGRAM

The Ryan White Program serves more than 500,000 people, or over half of the people living with HIV (PLWH) in the United States who have been diagnosed. The Ryan White Program is crucial for meeting the health care needs of PLWH while improving health outcomes. These resources are critical throughout, and after, the ACA is implemented. Part B of the Ryan White Program funds state health departments to provide care, treatment, and support services, and the AIDS Drug Assistance Program (ADAP) is available for low-income uninsured and underinsured individuals living with HIV.

The ACA provides opportunities to increase access for many PLWH to the care and prevention services needed to help end the epidemic. ADAPs will continue to provide medications directly and access to insurance through premium and co-pay assistance. Ryan White Part B will continue to provide essential services, such as medical case management, treatment adherence services, and outpatient health services.

Building on the success of Ryan White Part B coordination services and ADAPs is paramount to ending the HIV epidemic. For example, data from HRSA's 2012 Ryan White HIV/AIDS Program Services Report of a subset of jurisdictions in the South (Atlanta, GA; Memphis TN; Miami, FL; North Carolina; South Carolina) indicate that approximately 68 percent of African Americans/Black MSM is virally suppressed. This figure far exceeds national viral suppression rate of 30 percent. This demonstrates the unique success of Ryan White in accelerating health outcomes for disproportionately impacted populations. Among the services necessary to improve health outcomes are linkage to and retention in care, and improving access to medications that suppress viral loads, reducing transmission leading to fewer new HIV infections.

HEALTH DEPARTMENTS PROGRAMMING FOR AFRICAN AMERICANS

Health department HIV programs are focused on reducing new infections amongst Black/African Americans, particularly MSM. Below are just three examples of programming taking place across the nation.

The Tennessee Health Department engaged Black/African American MSM through focus groups and leveraged their

relationship with community-based organizations in urban and rural areas. The health department was able to gain a better understanding of condom usage, drug and alcohol use, HIV testing patterns and ways in which safe sex messages are received by the community.

The Louisiana Department of Health has launched Wellness Centers that target Black/African American MSM to ensure that they are engaged in care services. When people are engaged and retained in care, there are better health outcomes.

The Florida Department of Health established a Gay Men's Advisory Group, which regularly reviews documents and materials created by the health department and provides feedback on the effectiveness and the messages that speak best to diverse populations of gay men in Florida.

RECOMMENDATIONS TO CONGRESS & THE PRESIDENT

- Protect the Affordable Care Act (ACA) and continue to push for full expansion of Medicaid to ensure access to insurance and treatment to millions of African Americans who are currently or were previously uninsured.
- The National Alliance of State and Territorial Directors recommends lifting the congressional funding ban that prevents states from using federal funds for syringe access programs.
- Allocate funding to target HIV and HCV awareness, education, outreach and testing programs for African Americans, utilizing a health equity approach.
- Allow health departments to pay for PrEP and related costs to expand access to this prevention modality for African Americans.
- Maintain the Ryan White Program to ensure that African Americans have access to medications and the supportive services necessary to end the HIV epidemic.

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LUPUS: A SIGNIFICANT PUBLIC HEALTH ISSUE FOR THE AFRICAN AMERICAN COMMUNITY

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Lupus strikes without warning, affects each person differently, and has no known causes or cure. It is a chronic autoimmune disease in which the immune system becomes imbalanced and fails to distinguish between viruses, bacteria, and healthy tissues and organs. An estimated 1.5 million people in the United States suffer from the disease.

Lupus among racial and ethnic minority groups is a dramatic and significant public health problem that cries out for national attention and resources. Ninety percent of all people affected by lupus are women—although men and young children also develop the disease—and African Americans are three to four times more likely to develop lupus. The lupus spectrum encompasses various forms of the disease, such as drug-induced lupus, neonatal lupus, and systemic lupus erythematosus (SLE), which can impact any organ or tissue in the body, including the kidneys, joints, heart, brain, and blood system and skin. People with lupus can experience significant symptoms, such as pain, extreme fatigue, hair loss, cognitive issues, and physical impairments that affect every facet of their lives. Many suffer from cardiovascular disease, strokes, disfiguring rashes, and painful joints. For others, there may be no visible symptoms. The root causes of lupus are not known and there is no cure. However, scientists believe there are three factors that can lead to the development of lupus, including genetics, environmental triggers, and hormonal influences.

There is no question that lupus disproportionately affects women of color and that morbidity and mortality are observed to be at much higher rates in those populations. Recent studies indicate that lupus affects 1 in 537 young African American women.^{1,2} The LUMINA (Lupus in Minority Populations: Nature vs. Nurture) study/report states that “African American lupus patients are more likely to have organ system involvement, more active disease, higher frequency of auto-antibodies, lower levels of social support, and more abnormal illness related behaviors compared with White lupus patients.” Other studies have demonstrated that minority women tend to develop lupus at a younger age, ex-

perience more serious complications, and have higher mortality rates—up to three times the incidence of mortality than that of Caucasians. Outcomes for lupus nephritis—lupus that affects the kidneys—are worse for minority populations compared to Caucasian lupus patients. Additionally, non-White patients are more likely to suffer from lupus-related depression, cardiovascular disease, and diabetes, and have worse health-related quality of life than White patients.³ While the root causes of these disparities are not well understood, studies looking at this problem have found that people of lower socioeconomic status have higher rates of incidence, severity, and mortality from lupus than people with higher socioeconomic status.

WHAT IS CURRENTLY BEING DONE

In recent years, there has been an erosion of funding at the National Institutes of Health and other vital agencies—such as the US Food and Drug Administration’s (FDA) approval of safe and effective treatments for patients. Without adequate and robust funding for biomedical research, progress into discovering, developing, and delivering new medications to people with lupus will continue to be delayed. The result will have a devastating impact on all people with lupus, especially members of the African American community who are at greatest risk for the disease.

RESEARCH

Findings from the Hopkins Lupus Cohort, a longitudinal study that has followed patients with lupus through quarterly (or more frequent) visits since 1987, highlighted the factors that contribute to a lack of health equity in lupus. They include education level, adherence to medical advice and medications, social support, medical insurance, access to care, and geographic area of residence. This research suggests that there is an urgent need

to focus on healthcare access, education about lupus, and increased awareness and adherence to therapies prescribed by physicians.

In recent years, the United States Centers for Disease Control and Prevention (CDC), has been conducting an epidemiological study to determine the prevalence and incidence of lupus at five sites across the United States, including:

1. Atlanta, Georgia
2. New York City, New York
3. Detroit, Michigan
4. San Francisco, California
5. Indian Health Service based in Alaska

Preliminary findings indicate that the prevalence of lupus is higher than previously thought, but data from all sites have not yet been analyzed. Generally, the study found that Black women living with lupus were diagnosed at a younger age compared to White women, and had a higher proportion of renal disease and end-stage renal disease. In particular, the Michigan and Georgia investigators found substantial evidence that African Americans are affected by lupus at a greater rate and more severely than other populations.

The investigators plan to use their lupus patient registries to conduct ongoing studies to document the progression of the disease and the economic burden of lupus over time, which, according to data analysis already available, is substantial. (Of note: Other research has shown that the costs associated with lupus nephritis can top \$65,000 per patient per year). Through improved management of the disease, people with lupus now have increased survival rates, but many will face a lifetime of serious health problems that will require expensive medical care, citing the need for increased investment in lupus research and development of new and more targeted therapies to bring the disease under control and improve quality of life.

NEEDS ASSESSMENT

There is evidence-based research that can inform the development of proactive initiatives to address this significant public health problem.

The Lupus Foundation of America is committed to identifying ways to streamline and strengthen the link between research and prac-

tice by focusing on the determinants of lupus disparities among African Americans, testing and evaluating community-based interventions to increase health equity, and working with a broad base of collaborators to help achieve positive results.

Past studies have helped us understand that disparities exist with regard to the incidence and prevalence of lupus, but they have not given us the kind of baseline information we need to know about medical care, access to care, and other important health needs for those living with the disease. The Lupus Foundation of America is currently conducting a study to determine why it takes an average of six years for someone with lupus to receive an accurate diagnosis. Additionally, the study will look at the services individuals need once diagnosed, including an understanding of the issues related to access to quality and affordable health care.

AWARENESS CAMPAIGNS

The "Could I have Lupus" campaign, designed by the Ad Council, launched in March 2009 with a goal to increase awareness of lupus among young minority women of childbearing age (18 to 44 years) and to educate them on how to identify early warning signs of lupus in hopes of increasing the likelihood of early diagnosis. The Lupus Foundation of America was the founding partner on the campaign. The campaign was a \$2,393,103 investment. With over \$70 million received in donated media support, the total return on investment was over 2,800 percent, meaning that for every dollar invested, the campaign received \$28 in donated media support. Campaign results include:

- The percentage of women reporting that they had recently seen or heard about lupus increased significantly, from eight percent in 2009 to 15 percent in 2010.
- More women reported visiting a website to get information about lupus, increasing from nine percent in 2009 to 14 percent in 2010.
- Among women reporting multiple symptoms of lupus identified from a list of common symptoms, five percent said they had already spoken with a doctor about a lupus evaluation, a small but significant increase from 2009 (two percent).

Recently, the Lupus Foundation of America launched the KNOW LUPUS awareness campaign to combat the fact that nearly two-thirds of the general public knows little or nothing about lupus.

The campaign features a series of television public service announcements, which includes testimonials and statements from people with lupus and celebrity advocates. The centerpiece of the campaign is an online, animated, and interactive game to test people's knowledge of lupus and drive support for lupus research. While the campaign is still in its beginning phase, long-term goals include increased awareness and knowledge of lupus in order to improve health equity for all who suffer from lupus.

PATIENT & PROVIDER EDUCATION

Greater physician and patient education could increase health equity in lupus patients. Those most likely to be sick are also more likely to be uninsured and less likely to have access to the care they need, according to The Lupus Initiative, a multi-faceted education program championed by the Lupus Foundation of America and centered on increasing medical professionals' understanding and awareness of lupus. The Lupus Initiative, funded by the U.S. Department of Health and Human Services, Office of Minority Health, provides comprehensive educational resources to physicians, educators, students and other medical professionals to help them diagnose, treat and manage lupus in patient populations disproportionately affected based on race, ethnicity, and gender. The more a medical professional knows about lupus, the more likely he or she is to identify its signs and symptoms early and accurately to diagnose the disease or refer a patient to a specialist.

THERE IS SO MUCH TO BE DONE

March 9, 2011, marked an important landmark for the lupus community. The FDA announced approval of the first drug ever designed specifically for the treatment of lupus and the first drug approved for lupus in over 50 years. But one drug will never be enough to treat lupus, which impacts every person differently. The fact remains that we need a robust and expanded biomedical research effort on lupus, and we need an arsenal of safe and effective lupus treatments. Additionally, we must conduct research to truly understand specific physical, social, emotional, and other challenges that can be overwhelming for medically underserved, minority populations. Past efforts have not yet succeeded in creating greater health equity, in part, because they may be based on generalities and not actual social, emotional, and medical needs. But some studies suggest that it would be important to develop teams of experienced physicians, educators, and caregivers working with patients and their loved ones to strengthen social support, enhance self-efficacy,

and decrease co-morbidities such as smoking, hypertension, and obesity.

CLINICAL TRIALS

Treating the vast and varying symptoms of lupus is challenging. Developing therapies directed at the disease itself has proven even more difficult. The drug development landscape for lupus has changed for the better over the years with more than 30 compounds in development for lupus, and the demand for patient participation in clinical trials is extremely high. Lupus is a model disease for heterogeneity and disproportionate burden on minority communities, where traditionally participation in clinical trials has been lacking.

There must be a focused effort on developing and implementing a clinical trial education action plan for lupus to increase participation in minority populations that are disparately affected by lupus and who are historically underrepresented in clinical trials.

Recommendations on how to achieve positive results include:

- Creating culturally appropriate and sensitive educational materials about the benefits of participation in a clinical trial
- Developing strong local and community leaders to create trust and promote participation in clinical trials and research
- Promoting the need and understanding to engage in clinical trials; use effective culturally appropriate recruitment mechanisms to improve the connection of people with lupus with clinical trials and academic sponsors
- Supporting new and innovative clinical trial designs across clinical and sociodemographic subpopulations to facilitate drug discovery in lupus and identify new targets for drug development

NATIONAL PUBLIC HEALTH AGENDA FOR LUPUS

Recently, the CDC, the National Association of Chronic Disease Directors (NACDD), and the Lupus Foundation of America collaborated to develop the first-ever National Public Health Agenda for Lupus. The first-ever Public Health Agenda for Lupus will provide a broad public health approach to lupus diagnosis, disease management, treatment and research, and serves

as an overall blueprint for action in lupus to help guide future policy, planning, advocacy, and action initiatives. Organized and framed under the CDC Four Domains of Chronic Disease Prevention that include epidemiology and surveillance, environmental approaches, health care system interventions, and community programs linked to clinical services, the Agenda also specifically addresses health disparities.

While the final report will be available in Fall 2015, a number of recommendations focused on improving health equity include: expanding the studies of incidence and prevalence of lupus among racial and ethnic minorities and examining disparities in quality of life and care through additional cohort studies; leveraging collaborations among community and faith-based organizations to promote community-based self-management services; and, developing comprehensive awareness campaigns with targeted messages to ensure timely diagnosis and proper treatments.

CONCLUSION

The significance of lupus in the African American community can no longer be ignored, and it is clear there is much work to do in improving health equity among those who suffer from this disease. The anchor for improving health equity begins with a robust medical research effort that will uncover the causes of lupus leading to new, effective, and tolerable treatments that can improve the quality of life for all people with lupus. In addition to funding a robust biomedical, clinical, and public health research effort in lupus, together we must work to ensure patients and physicians are educated about lupus to help reduce the time to disease diagnosis, ensure patients are starting the correct treatments faster in order to limit organ damage, and ensure patients are connected with valuable and culturally appropriate supports and services to help manage living with this cruel and mysterious disease.

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MENTAL HEALTH DISPARITIES

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By definition, diagnosable mental health conditions are accompanied by a decrease in functioning. The implication, then, is that any role one might typically fill in society, be that as student, co-worker, productive citizen, or parent to name just a few possibilities, is subject to impairment. This ripple effect is one of many reasons that disparities in mental illness and access to mental health care should be of great concern to policy and lawmakers. It seems however, that mental health disparities are an afterthought until a headline grabbing tragedy pushes the issue, albeit temporarily, to the forefront of national discussion.

Consider Elizabeth, a 42-year-old woman with Major Depressive Disorder. Her school age child is falling behind academically because he is preoccupied with worry about his mother. Additionally, because of her depression Elizabeth lacks the patience or concentration to assist him with his homework. When she sees her Primary Care Provider (PCP), her high blood pressure has worsened because hopelessness about her future and low energy make exercising or eating mindfully prohibitively difficult tasks. Her PCP suspects that Elizabeth is depressed, and she tells him that she will consider therapy. She does not follow through by calling the local community health center, however, due to concerns that her family would think she was “crazy.”

Meet Daniel, a 27-year-old man with Schizophrenia in a state that opted out of Medicaid expansion. No longer covered by his parents’ insurance, he does not have employer-sponsored coverage as an option because his symptoms have made working impossible. Without his medication, he has been in the medical emergency room five times in the past year after drinking alcohol to quiet the auditory hallucinations that plague him nightly. Though family is willing to take him in, he is delusional about them really being who they say they are and lives on the street instead. While camped out near a local grocery store, his bizarre appearance leads the employees to call law

enforcement. The result—not only an arrest for misdemeanor trespassing, but also a felony charge for terroristic threats after he yelled at the police officer whose uniform frightened him. Too paranoid to work with his lawyer, Daniel’s incompetence to stand trial delays the resolutions of his legal case.

Then there’s Cody, a 12-year-old boy in a family of five in a rural town. He has average intelligence, but also struggles with untreated Attention Deficit Hyperactivity Disorder (ADHD). Compared to his siblings, he requires more frequent redirection from his parents in order to finish his homework, which is misinterpreted as laziness, undermining his relationship with his caregivers. At school, he falls behind, not because he is incapable of understanding the work, but because the ADHD symptoms make it difficult for him to keep up with the larger assignments that come with middle school or for him to pay attention throughout his testing periods. There are no child psychiatrists in his rural county, or any of the surrounding rural counties for that matter, and rather than being diagnosed and treated for ADHD, Cody internalizes the negative feedback he receives from the adults around him, becomes demoralized regarding school, and drops out in the 10th grade.

The preceding fictional vignettes illustrate the ways in which stigma, insurance coverage gaps and geographical health disparities limit access to mental health care. Additionally, they highlight a sample of the myriad of negative outcomes that can result from unaddressed symptoms of mental illness. People like Elizabeth, Daniel, and Cody will not make their way into the news cycle, but their needs are real and worth society’s sustained attention. As a mental health care provider who treats children and adults in a variety of settings, I have met many real people with similarities to the fictional Elizabeth, Daniel, and Cody. Odds are, regardless of your profession, so have you: approximately one out of every five Americans has a diagnosable mental illness. According to the World Health Organization,

mental illness is the leading cause of disability in developed countries such as the United States.¹

The good news: we have treatments that we know can help the vast majority of people with mental illness. The bad news: these treatments only reach approximately half of the children and adults in this country who could benefit from them.

Ethnic minorities, those with limited financial means, rural populations and children are at higher risk of not receiving the appropriate treatment. In a discussion of disparity, at the most basic level there is a mismatch between supply and demand. While there is often more emphasis placed on the “supply” side of delivering services once an illness has developed, there are also great opportunities for lawmakers to impact the “demand” side of the equation by governing with the social determinants of mental health, environmental issues which increase risk of mental illness and its symptoms, in mind. Some of these social determinants of mental health include childhood trauma, adverse features of housing and neighborhoods, unemployment, food insecurity, and poverty. Indeed, addressing these areas are critical in mental health prevention and by their nature require the attention and intervention of policy makers outside of the realm of medicine.

Racial minority populations, particularly Blacks, Hispanics, and Native Americans experience greater levels of exposure to those social determinants of mental health than the broader U.S. population. Blacks and Hispanics are also less likely to have health insurance coverage. In addition to concrete financial and access barriers, the role of stigma must be acknowledged. Members of racial minority groups may fear “double stigma,” which is experiencing both discrimination because of mental illness and racism. This can be a powerful deterrent to seeking mental health care services, and, in fact, population based studies provide evidence that even when factors such as income and insurance status are controlled for, Blacks are less likely to use mental health services than Whites. Perceived racism in and of itself has also been shown to be associated with symptoms of mental illness. Finally, if members of racial minority populations desire a provider who shares their background, the underrepresentation of minorities within the mental health field makes this improbable at times, impossible at others.

The following healthcare system intervention points are just a sample of the available options that could improve access or decrease demand for specialty mental health care, serving to close the gaps between need and access that perpetuate mental health disparities.

- **Increasing Insurance Coverage** – Populations affected by mental health care disparities are also more likely to be uninsured. They are also more likely to experience paying for mental health services out of pocket as prohibitively expensive.
- **Incentivizing collaborations between PCPs and mental health professionals** – By marshaling patients’ pre-existing relationships and frequent contact with their PCPs, screening and initial intervention for mental illness in primary care settings is a promising intervention. This approach decreases the stigma that some may feel with having to attend a specialty mental health clinic in order to receive services, and leverages an existing therapeutic relationship. Reimbursement for outpatient collaborations between primary care doctors and mental health professionals, such as phone consultation and chart reviews by psychiatrists who collaborate with PCPs, would increase the sustainability of mental health care delivery in primary care settings.
- **Mental healthcare workforce diversification through pipeline programs** – Members of underserved populations, which are under-represented in the ranks of mental health care professionals, are more likely to treat underserved populations. They may also be less likely to have exposure to mentors and resources that can guide them through the training process. The SAMSHA Minority Fellows’ program, which supports the professional development of minority psychiatrist and psychologists, is one example of a highly successful mental health professional development program.
- **Support for the Expansion of Visiting Nurse Programs** – Programs such as the Nurse Family Partnership in which nurses provide support to vulnerable, low-income mothers during pregnancy and the child’s infancy have been demonstrated not only to affect mortality outcomes, but also to impact the mother and child’s mental health. Long-term studies revealed that mothers had fewer behavioral impairments due to substance use and fewer parenting attitudes that predispose them to abuse their children. The children were less likely to have behavioral problems at school entry and were less likely to reveal depression, anxiety and substance use at age 12.
- **Telehealth Mental Health Interventions** – Rural communities, many of which lack mental health providers, can benefit from the expansion of telehealth services. Though it does not increase the mental health workforce, it can expand the reach of it. Support for funding telehealth equipment and systems as well as Medicaid programs that reimburse fully for telehealth services are ways to support this promising model.

- **School-Based Health** – In many ways, schools are the de facto mental health care system for children. Additionally, observations by teachers are a major driver for mental health evaluation referrals. Increasing behavioral health services within schools brings care to the communities where children work, play and live. Additionally, with easier access to teachers and administrators, school-based mental health providers have the potential to more readily tailor interventions to the classroom so that critical learning opportunities are not missed.
- **National Health Service Corps** – The National Health Service Corps is a highly successful loan repayment program offering full and half-time service opportunities to primary care practitioners who see patients in underserved areas. Physicians in the discipline of Child and Adolescent Psychiatry, one of the greatest pediatric medical care shortage areas in the country, are not currently eligible to participate. Given the National Health Service Corps' success with other fields and the fact that the average U.S. medical school graduate has \$180,000 of student loan debt, it is highly likely that allowing the participation of child and adolescent psychiatrists would increase their mental healthcare delivery in underserved areas.
- **Mental Health Courts and Diversion Programs** – With deinstitutionalization of the mental health care system and the release of the chronically persistently mentally ill into communities that often have inadequate safety net mental health resources, this vulnerable population's involvement with the criminal justice system has shown a stark increase. The mentally ill are more likely to deteriorate under the harsh conditions of jail and to be disciplined for inability to follow correctional rules. They may experience trauma and disruptions in community care if they were receiving it, which can worsen mental health outcomes. Additionally, with felony or drug charges, they may be unable to access social service programs upon release that would be critical to a successful transition back to the community. Mental health courts and diversion programs have the potential to halt this spiral.

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MINORITY ORAL HEALTH IN AMERICA: DESPITE PROGRESS, DISPARITIES PERSIST

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When you talk about racial barriers, you can't avoid talking about economic barriers, I think increasingly today as historical racial barriers are being broken down on some levels, the economic barriers continue to persist.

DR. ADA COOPER

Although oral health in the United States has by many measures improved dramatically over the past 50 years, it still represents a significant public health issue that affects low-income and minority populations disproportionately. Recently released data from the Centers for Disease Control and Prevention (CDC) underscore these disparities, showing significantly greater rates of *untreated* dental caries (cavities) among African Americans and Hispanics than among their White, non-Hispanic counterparts. Black and Hispanic populations also suffer disproportionate rates of tooth loss. Although the exact relationships between dental disease and other chronic diseases are not fully known, it is safe to say that maintaining good oral health is critical to achieving good overall health. Put simply, the prevalence of preventable, untreated dental disease among racial and ethnic minority populations is unacceptable. We as a nation must do better.

BARRIERS TO CARE TIED TO SOCIOECONOMIC FACTORS

"When you talk about racial barriers, you can't avoid talking about economic barriers," says Dr. Ada Cooper, an African

American dentist practicing in New York City. "I think increasingly today as historical racial barriers are being broken down on some levels, the economic barriers continue to persist."

According to the U.S. Census Bureau, in 2013, African Americans made up 13.2 percent of the American population, while Hispanics comprised 17 percent.¹ Yet racial minorities constitute a disproportionate share of the nation's Medicaid beneficiaries compared to representation in the overall population: 21 percent of Medicaid beneficiaries are African American and 30 percent are Hispanic.² (It is important to note that the ethnicities and races categorically measured by the U.S. Census Bureau do not account for the broad diversity of cultures and numerous other factors affecting people's health and access to health care.)

Medicaid-enrolled children in some states are currently receiving dental care at a rate equivalent to those covered by private insurance. But most state Medicaid dental programs fail to provide adequate care, especially to adults. The average state Medicaid program allocates less than two percent of its budget for dental services.

This is reflected in the fees state Medicaid programs set for various dental procedures. According to the American Dental Association Health Policy Institute (HPI), Medicaid fees ranged from a low of 30 percent of market rates for the same procedures (California) to a high of 69 percent of market rates (Arkansas) in 2012.³ Overhead for dental offices in many cases is significantly greater than Medicaid reimbursement rates, meaning that in many states, dentists actually lose money caring for Medicaid enrolled patients. Initial credentialing to qualify as a Medicaid provider can take months, and excessive administrative burdens are additional disincentives for dentists who might otherwise participate in the program.

Supported by vigorous advocacy by state dental societies, a handful of state legislatures have significantly improved their adult dental Medicaid benefits in recent years. Colorado now provides a number of adult dental services, including restorations (fillings), root canals, crowns, surgical procedures, and partial or full dentures. Adult Medicaid enrollees are allowed up to \$1,000 annually in dental services. But Colorado is an outlier. At this writing, 12 states provide comprehensive coverage, 20 provide limited coverage, 15 provide emergency-only coverage and four provide no coverage for adult Medicaid enrollees. States in which African Americans comprise a high percentage of all residents also tend to be those with some of the poorest Medicaid dental benefits. There is also an increasing, recurring pattern of African Americans migrating to southern states, many of which have the most limited Medicaid dental benefits.

For instance, nearly one-third of Mississippi and Louisiana's populations are African American, yet the states have emergency-only and limited dental coverage, respectively.

Children fare better than adults under Medicaid, owing to the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provision, which specifies a comprehensive set of benefits for enrollees under age 21. But coverage is one thing; actually receiving care is another. Although Medicaid utilization among children increased from 2011 to 2012 in all but 13 states and Washington, D.C., underfunding inhibits provider participation, making it difficult for many eligible children to find a dentist who accepts Medicaid.⁴ Even when dentists who will accept Medicaid patients are available, many families don't know how to connect with these dentists.

UNTREATED CARIES AND TOOTH DECAY

Dental caries is an infectious disease in which bacteria that cause cavities can be transmitted from one person to another. Cavities can be prevented very early in the disease process, so that less treatment is ultimately needed, reducing the risk of catastrophic damage and serious infection.

A May 2015 CDC data brief casts the dental divide in America in sharp relief: More than one in four adults ages 20-to-64 has untreated dental caries.⁵ A breakdown by ethnicity is particularly troubling. Forty-two percent of African American adults and 36 percent of Hispanic adults have untreated disease, as compared to the 22 percent of Caucasians. An earlier CDC data brief found that untreated tooth decay in primary teeth among children ages two to eight is twice as high for Hispanic and African American children, compared with Caucasian children.⁶

Disparities also affect critical preventive treatments. Dental sealants, used to prevent cavities, are more prevalent in Caucasian children (44 percent) compared with African American and Asian children (31 percent, each) and Hispanic children (40 percent).

Native American communities face some of the greatest challenges in accessing dental care and, as a result, have punishingly high levels of dental disease. Access issues include:

- Geographic isolation;
- Low population densities;
- Jurisdictional and regulatory complexity;
- Lack of economic development;
- High unemployment and poverty;
- Low educational attainment;
- Lack of social, economic and transportation infrastructure; and
- Severe political, cultural, social and economic disenfranchisement.

A 2014 IHS survey found that 37 percent of American Indian children ages one to five had untreated dental decay. One major obstacle to addressing the astonishing decay rates among Native Americans is the fragmented way federal agencies compile data.⁷

THE ROLE OF MINORITY PROVIDERS

In a recent New York Times guest column, psychiatrist Damon Tweedy wrote, "As a general rule, black patients are more likely to feel comfortable with black doctors. Studies have shown that they are more likely to seek them out for treatment, and to report higher satisfaction with their care. In addition, more black doctors practice in high-poverty communities of color..."⁸

National Dental Association President Dr. Carrie E. Brown points out that African American and Hispanic dental providers disproportionately serve African American and Hispanic patients.

"It is important to note that the increasing costs of care delivery, coupled with low Medicaid reimbursement rates, continues to challenge our members' efforts to deliver quality dental care to those most in need," she said.

The Robert Wood Johnson Foundation in 2001 created Pipeline, Profession and Practice: Community-Based Dental Education, also known as the Dental Pipeline Program, a 10-year initiative to help dental schools increase access to dental care for underserved populations.⁹ Twenty-three schools participated in the program, which included an increased focus on community-based clinical education programs, revising dental school curricula to support these programs, and increasing recruitment and retention of underrepresented minority and low-income students. A similar program, granted by the Robert Wood Johnson Foundation in 1971, more than doubled the number of Hispanic students attending the University of California, San Francisco School of Dentistry.

“We were very pleased with the increase in number of minority applicants and those matriculating to medical and dental schools,” said Dr. Donna Grant-Mills, Associate Dean for Student Affairs and Admissions at the Howard University College of Dentistry.

Because minority dentists comprise a disproportionately small percent of the overall number of practicing dentists, it is important that all dentists be aware of the needs of underserved communities and are willing to meet those needs.

The American Dental Association in 2003 developed the ADA Institute for Diversity in Leadership, which is designed to enhance the leadership skills of dentists from racial, ethnic or other groups that have historically been underrepresented in those roles.

BRINGING BETTER ORAL HEALTH INTO UNDERSERVED COMMUNITIES

Even when dental care is available to residents of underserved communities, connecting patients with dentists can be challenging.

Dentists in Washington, D.C. organized that city’s first Give Kids A Smile (GKAS) event in 2003, which is when the American Dental Association launched the program.

Working in the Howard University dental clinic, volunteer dentists—including a substantial cadre of Howard faculty—screened more than 200 children from Abram Simon Elementary School, located in one of the city’s poorest wards and with a largely African American student body. About half of the children required follow-up care—many of them suffered from severe tooth decay. DC Dental Society member dentists agreed to provide the follow-up care at no cost.

“We had only three parents who called,” said Dr. Sally Cram, an organizer of the event and ADA spokesperson. “Two of the parents took the referral list but never made an appointment to see a dentist. The third parent scheduled an appointment, but the child never showed up.”

Clearly, simply having dental care available to underserved populations is not enough.

“Effective follow up and outreach to incorporate strategies that will improve community participation has been a long-time puzzle to dentistry,” said Dr. Michael James Lopez, a Hispanic Dental Association trustee. “Success in education and treatment comes from building relationships, trust and respect.”

Providing culturally competent oral health education, and helping patients navigate an often daunting and confusing public health system, are critical to helping families in underserved communities. The ADA in 2006 launched the Community Dental Health Coordinator (CDHC) pilot program to train community health workers who help people overcome barriers to optimal oral health and connect with dentists who can provide needed care. Now, community colleges in New Mexico, Illinois, Arizona, Florida and Virginia are either already offering the CDHC curriculum or are expected to do so as soon as Fall 2015.

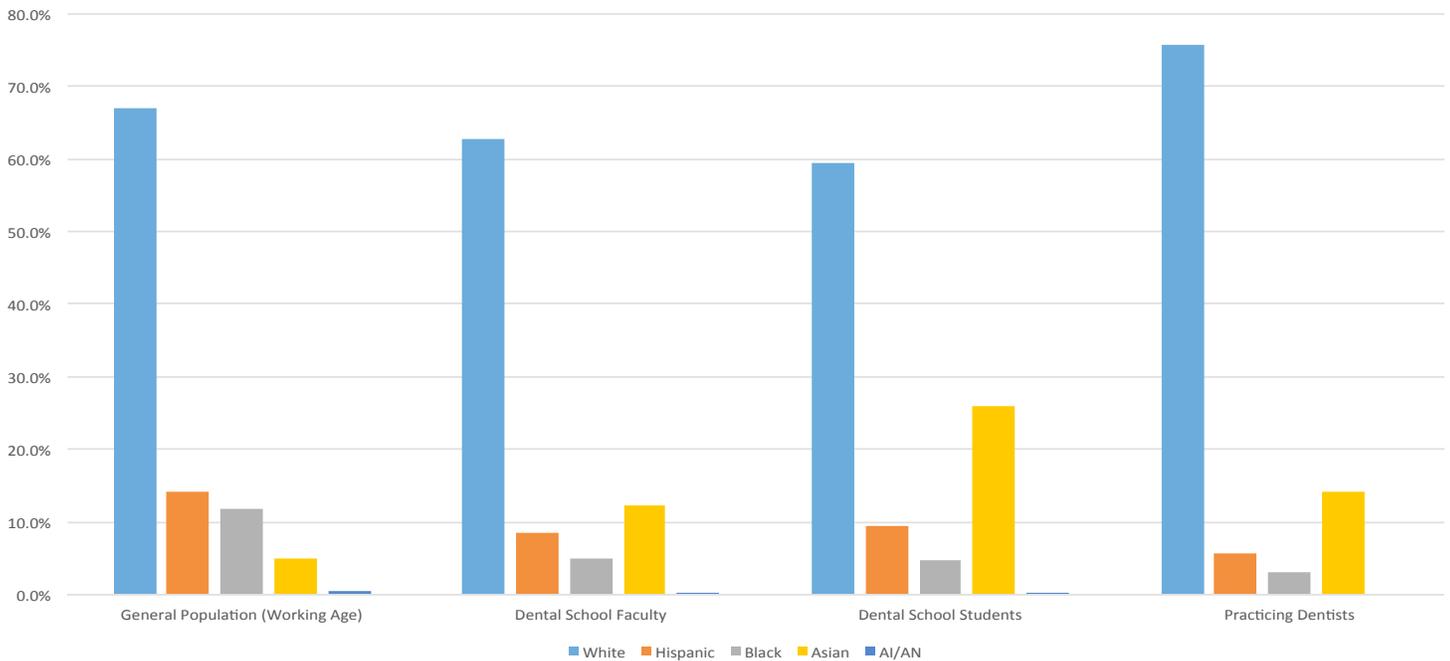
While treating existing disease is imperative, oral health education and disease prevention are the ultimate answers. Long-term oral health improvements will occur when more parents understand—and convey to their children—the benefits of good nutrition, and the dangers of tobacco, poor nutrition, excessive alcohol intake, drug use and other unhealthy behaviors. Simple measures, such as regular brushing and flossing, can dramatically improve the oral health of millions who do not understand how to take care of their families’ teeth and gums.

Community water fluoridation is the most economical tool in disease prevention, and also has the advantage of not requiring any action from those who benefit from it. Fluoride in community water systems prevents at least 25 percent of tooth decay in children and adults, even in an era with widespread availability of fluoride from other sources, such as toothpaste. The ADA is collaborating with other public health advocates and federal agencies with the goal of increasing the availability of optimally fluoridated drinking water to 80 percent of the U.S. population on public water systems by 2020, up from the current level of 74.6 percent.¹⁰

BRIDGING THE DENTAL DIVIDE

Economic, geographic, cultural and language barriers continue to impede too many people—especially racial and ethnic mi-

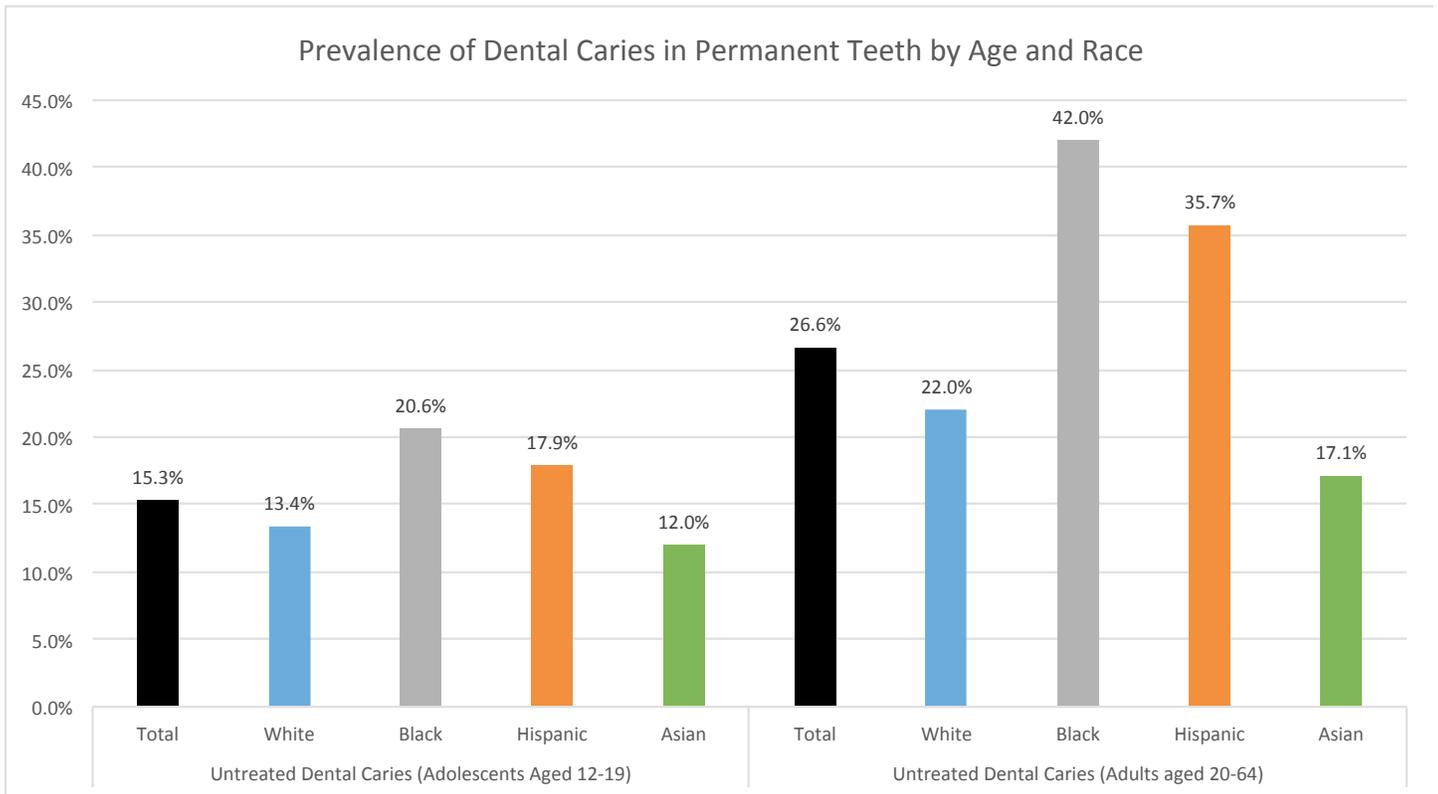
General population, dental school faculty, students and practicing dentists by ethnicity



norities—from attaining good oral health. Change is possible, but not until we as a nation commit to it.

THE ROLE OF GOVERNMENT

- **The Action for Dental Health Act (H.R. 539)**, introduced by Congresswoman Robin Kelly of Illinois, would allow organizations to qualify for CDC oral health grants to support activities that improve oral health education and disease prevention. The grants would also be used to develop and expand outreach programs establishing dental homes for children and adults, including the elderly, blind and disabled.
- Many of the federal programs designed to alleviate the stresses associated with poverty, especially for children, constantly face the threat of crippling budget cuts. When adequately funded, programs like **Women, Infants, and Children** and the **Supplemental Nutrition Assistance Program** can help educate families about the importance of healthy behaviors.
- **Medicaid** is the single largest source of health care for the poor. Yet many states fail to provide statutory minimum benefits to a majority of enrolled children, and adult benefits are almost universally inadequate. Congress should consider adding a dental benefit for adults under Medicaid.
- **Federal Dental Services** – The CDC Division of Oral Health supports community prevention programs, and conducts population-based research to better understand the nation’s oral health. One of the division’s primary goals is to “reduce inequalities in oral health.”
- Dentists in the Commissioned Corps of the U.S. Public Health Service, the Indian Health Service and the National Health Service Corps all have roles in bringing badly needed preventive and restorative oral health care and education to underserved and disadvantaged populations throughout the country. These federal services have long used student



loan repayment incentives to successfully recruit dentists to work in underserved areas. Many of these dentists choose to locate permanently in those areas after fulfilling their contractual obligations to these agencies.

States also must act to improve the oral health of their neediest residents by:

- Improving Medicaid funding and administration;
- Implementing strategies to redirect people seeking dental treatment in emergency rooms to dental offices in order to establish dental homes;
- Supporting programs that target at-risk children and adults in schools, community centers and other locations; and
- Working with private organizations and dentists to coordinate dental care for the vulnerable elderly and other special needs populations.

Dentists have fought for decades to improve the oral health of the underserved, and we will continue to do so. The American Dental Association in 2013 created Action for Dental Health, a nationwide, community-based movement to provide care *now* to people already suffering with dental disease, strengthen and expand the public/private safety net, and bring oral health education and disease prevention into the communities in greatest need.

We know that the nation's dentists can make a difference. But dentists alone cannot win the war on untreated disease. For that to occur, every relevant sector of society must take part—government, the private and charitable sectors, educators, the other health professions—everyone with a stake in a healthier, more productive nation.

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SLEEP DISPARITIES IN THE AMERICAN POPULATION: PREVALENCE, POTENTIAL CAUSES, RELATIONSHIPS TO CARDIOMETABOLIC HEALTH DISPARITIES & FUTURE DIRECTIONS FOR RESEARCH & POLICY

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It was recently estimated that 28 to 40 percent of the U.S. population sleeps for 6 hours or less on a nightly basis. This is alarming, since insufficient sleep and poor sleep quality have been associated with many adverse health outcomes, including weight gain and obesity,¹ hypertension,²⁻⁴ hyperlipidemia,^{2,3} inflammation,⁵ diabetes,^{2,6-8} stroke,^{3,9} heart attack,^{3,10} and a shorter lifespan.¹¹⁻¹⁵ Additionally, inadequate sleep has a relationship with neurocognitive impairment.¹⁶⁻¹⁸ Sleep is an important domain of health and well-being, and it is possible that sleep represents not only a modifiable risk factor for cardiometabolic disease, but an important factor in health disparities.

DO SLEEP DISPARITIES EXIST?

Many studies show that racial/ethnic minorities, especially African Americans, and those of lower socioeconomic position are more likely to experience insufficient sleep and are more likely to be impacted by sleep apnea. However, they are also less likely to be effectively treated. The following paragraphs detail some of these findings.

Data pooled from many studies of sleep across populations showed that Blacks/African Americans obtained less sleep than Whites, including less Slow Wave Sleep—or “deep sleep”—which is critical for the healing and restorative properties of sleep, and important in memory and emotion regulation. Further studies have also found that Blacks/African Americans had poorer sleep efficiency^{25,27} than Non-Hispanic Whites. Taken together, these studies show that, on average, Blacks/African Americans have shallower, less restful sleep when that sleep is evaluated in the laboratory. Another approach to understanding whether sleep disparities exist is to evaluate whether people of various racial/ethnic groups are more or less likely to report short or long sleep durations, relative to 7-8 hours. One

study²⁸ found that, relative to Non-Hispanic Whites, Blacks/African Americans were 41 percent more likely to be short sleepers (6 or fewer hours); similarly, Non-Mexican Hispanic Adults were 26 percent more likely to be short sleepers.

Sleep may represent a modifiable risk factor for poor health, or it may simply be a marker of some other risk factors.³¹ Although several studies that followed individuals over time suggest that sleep might actually cause metabolic and/or cardiovascular disease,^{20,32-34} the role of sleep in health disparities has only begun to be studied. Not only is sleep related to cardiovascular and metabolic disease, but these conditions are more prevalent among racial/ethnic minorities. Since racial/ethnic minorities, especially Blacks/African Americans, also experience less sleep, it is plausible to suggest that insufficient sleep may be one of the reasons underlying health disparities. If this were the case, the relationship between sleep and cardiometabolic disease would depend on race/ethnicity. It turns out that several studies have documented this.

For example, data from the Chicago area³⁵ found that over 5 years, blood pressure in Blacks/African Americans increased at a rate that was faster than their White counterparts. However, when their sleep was examined, it was found that this increase in blood pressure was completely explained by differences in sleep duration. Thus, differences in sleep explained differences in blood pressure change. Other studies found that in a nationally-representative sample, the relationship between sleep duration and C-reactive protein (a cardiovascular risk marker for inflammation) differed by race, and that the relationship between sleep duration and obesity, diabetes, hypertension, and hyperlipidemia depended on self-identified race/ethnicity.² This further suggests that in the population, the relationship between sleep and cardiometabolic disease depends on race/ethnicity and that sleep may be one of the driving forces behind racial disparities in health.

Insufficient sleep is not the only important public health factor related to sleep. Sleep disorders, such as insomnia and sleep apnea, also have implications for public health. Insomnia is associated with significant functional deficits and increased risk for cardiovascular disease and psychiatric illness. Nationally-representative data from the CDC³⁸ showed that Blacks/African Americans were more likely to report taking >30 minutes to fall asleep. Sleep apnea is associated with functional deficits, such as crashes and accidents, and is also associated with psychiatric problems. But the most serious consequences of sleep apnea seem to be related to cardiovascular mortality. Untreated sleep apnea, especially severe sleep apnea, is associated with death due to cardiovascular events, such as heart attack and stroke. Further, those who receive treatment for their sleep disorder are able to eliminate their risk for earlier death. Studies have found that African Americans were more likely to have sleep apnea—and more likely of greater severity—compared to Whites. In addition, Non-Mexican Hispanics/Latinos were more likely to report choking/gasping during sleep and snoring, consistent with sleep apnea.

Identifying and treating sleep disorders is an important public health goal. But as with insufficient sleep, racial/ethnic minorities are more likely to experience sleep disorders, especially sleep apnea, and they are less likely to be effectively treated.

UNPACKING RACE/ETHNICITY FINDINGS

What could be the potential underlying determinants of these and other sleep health disparities? While there are many potential causes, such as genetic and epigenetic factors, socioeconomic factors—including poverty, work and occupational demands, and neighborhoods—may play a significant role.^{30,42-44} Previous studies that have examined associations between sleep quality and socioeconomic factors have tended to report that lower socioeconomic position is associated with higher rates of sleep disturbance^{27,42,44,48-52} and less sleep.^{53,54} Poverty limits a person's ability to exert control over many aspects of their life, and this may contribute to sleep problems as well. For example, working shifts or multiple jobs, having long commute times, and having to work long hours interferes with sleep. People in poor neighborhoods may feel unsafe or may otherwise make it difficult to sleep. Excess light in the bedroom can inhibit melatonin production at night,⁴⁵⁻⁴⁷ which may interfere with sleep continuity and architecture. In addition, low socioeconomic status may be inhibiting successful treatment of sleep apnea^{55,56} and children of lower socioeconomic status are less likely to even be referred for sleep apnea treatment.⁵⁷

In addition to socioeconomics, differences in sleep may partially

be due to differences in knowledge, beliefs, attitudes, and priorities about sleep. If sleep is seen as less important, especially compared to critical concerns like putting food on the table, it may not be a high priority. Also, a lack of knowledge about the importance of sleep and sleep disorders may lead to individuals getting less sleep or not seeking treatment for sleep disorders.

Perceived racial discrimination may be a unique stressor that takes a toll on sleep in a unique way.⁵⁸⁻⁶⁰ Racial discrimination can be experienced on an individual level, but it is often the result of systematic biases that exert profound effects on physical and mental health. For example, those who reported racial discrimination in healthcare settings were approximately twice as likely to report sleep disturbance.⁶⁰ Other studies have also shown that experiences of discrimination were associated with shorter sleep duration and more sleep difficulties.⁶¹

Another important but often overlooked factor relevant to racial/ethnic minorities is household size, crowding, and bed sharing.⁶²⁻⁶⁵ Bed sharing likely negatively impacts sleep quality.^{62-64,66} The bedroom may also serve as a unique emotional stressor, with intimate partner violence in the past year associated with a 3-7-fold increase in sleep disturbances.⁶⁷

Environmental noise is another factor that may link sleep and health disparities. Exposure to noise at night can disrupt sleep in profound ways.⁶⁸⁻⁷⁰ For example, noise can also cause reliable and profound changes to sleep, even if it does not cause frank awakenings.⁶⁸⁻⁷¹ It is possible that those living in noisier neighborhoods or households are getting less restful sleep, which impairs the ability of sleep to perform important biological processes that promote health.

SLEEP AS A SOCIOCULTURAL PHENOMENON

In addition to being a physiological phenomenon, sleep is a social and cultural phenomenon.⁷²⁻⁷⁴ Simon Williams observes, "When we sleep, where we sleep, and with whom we sleep are all important markers or indicators of social status, privilege, and prevailing power relations."⁷² This is depicted in the Social-Ecological Model of Sleep and Health (Figure 1), which shows sleep at the interface of upstream social-environmental influences and downstream physiologic consequences.

MOVING FORWARD

Sleep may be as important as diet and exercise for the maintenance of health. It is a biological need that is driven by engaging in behaviors. And these behaviors are culturally determined and

Figure 1. The Social-Ecological Model of Sleep and Health (adapted from¹⁴)

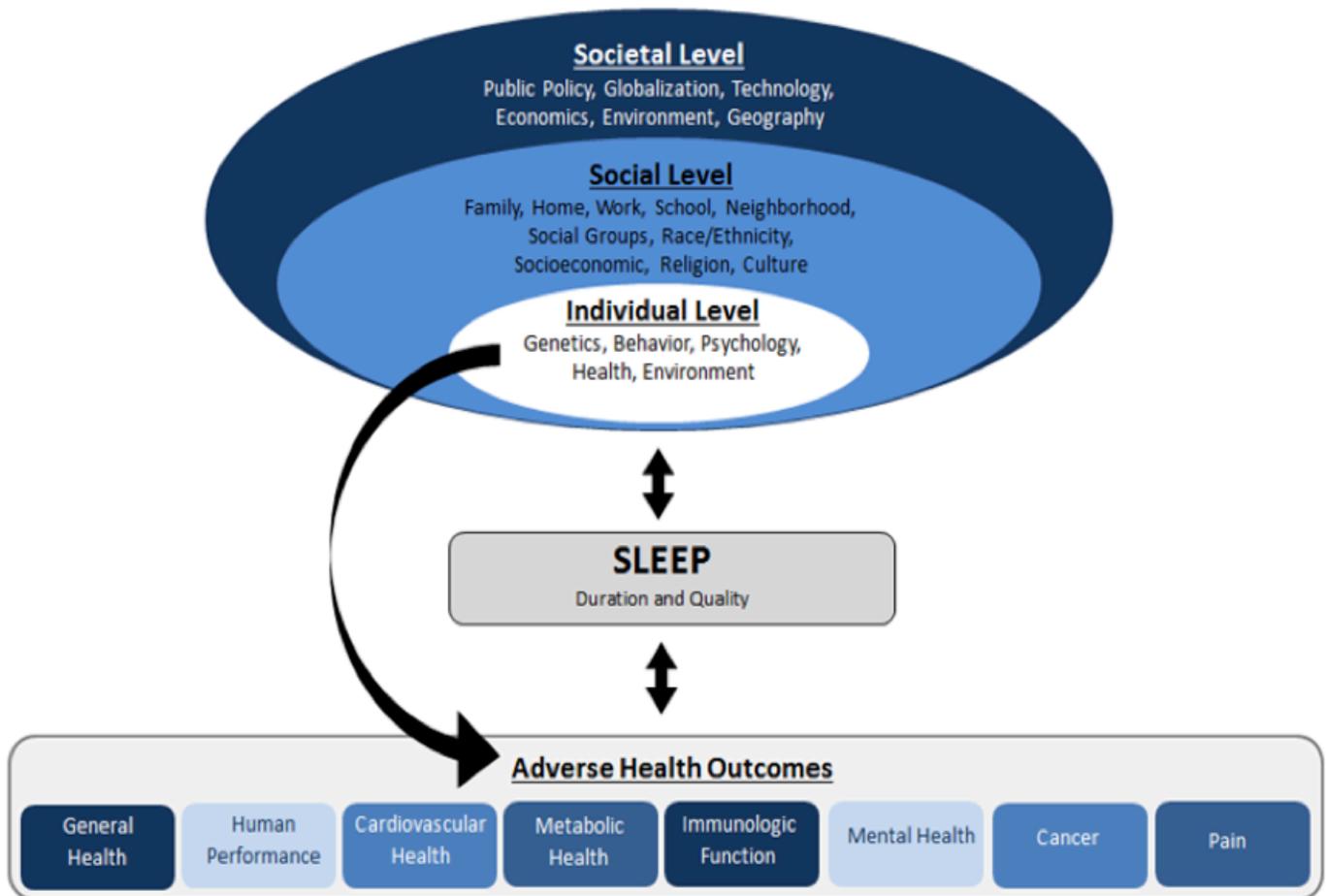


Figure 1 depicts the role of sleep at the intersection of health and the social environment. It shows that downstream of sleep are potential adverse health outcomes. The upstream sleep determinants include individual-level factors, which are the most direct causes of a person's sleep patterns. The model also recognizes the social and societal systems that exist outside of the individual that play important roles. Taken together, sleep is an end result of this complex, multi-layered system, and sleep itself exerts influence over health. The model also recognizes that the individual level factors affect more than just sleep.

likely, at least as much a product of the environment, as they are a product of biology. Understanding the social, behavioral, and environmental influences on sleep will be key to understanding the role of sleep in health

All of these factors are relevant to studying sleep and health disparities. Important health disparities exist, especially in terms of cardiometabolic disease and quality of life. Further, sleep is related to many of these same outcomes. And there is emerging data that show that sleep may be one of the factors driving some of these health disparities.

There is still more work that needs to be done to understand exactly how sleep plays various roles in health and more, including its effect on health disparities. More data is needed to sufficiently document sleep health disparities using better approaches to study sleep that go beyond the use of survey questions. Scientists will need to more thoroughly determine the physiologic, behavioral, social, and environmental determinants of sleep health disparities and appropriately intervene to improve the sleep, diagnosis, and treatment of sleep disorders in minorities who are most vulnerable. Studies are needed to examine the role of sleep as a modifiable risk factor for cardiometabolic disease in general and cardiometabolic health disparities. There is opportunity to address the poor follow-through for sleep disorders treatment (especially sleep apnea) in the context of implementation research. Finally, studies are needed to bridge laboratory and population approaches to studying sleep and health. More rigorous studies on real-world, diverse samples are needed.

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REACHING OUR TRUE POTENTIAL:
RECOMMENDATIONS TO ACHIEVE

HEALTH EQUITY 5

REACHING OUR TRUE HEALTH POTENTIAL: RECOMMENDATIONS TO ACHIEVE HEALTH EQUITY

Inequities in health and health care in communities of color remain deep and persistent. These inequities span from the cradle to the grave, evidenced by higher rates of chronic disease and premature death. Though there are a number of challenges in addressing these disparities, there are equally as many opportunities for us to advance and achieve health equity.

As mentioned throughout this report, new approaches and partnerships are needed to help close the health gap in the United States. The Congressional Black Caucus Health Braintrust, under the direction of Congresswoman Kelly, has prioritized 1.) **Access to Care**, 2.) **Workforce Diversity**, 3.) **Innovation and Research** in the health space, 4.) Proactive **Community Engagement** on public health matters, and 5.) **Federal Action** to pass impactful healthcare legislation and appropriate sufficient resource funding to expand health research activities and grants to combat racial and ethnic health disparities and chronic and infectious diseases.

To that end, this concluding chapter will focus on key findings that have been summarized and discussed in this *Kelly Report*. Recommendations are made in the areas of access, workforce diversity, innovation and research, federal action, and community engagement. It is Congresswoman Kelly's hope that these recommendations will help close the health disparities gap and be acceptable to both the public at-large and public health stakeholders.

ACCESS

Access to comprehensive, quality health care services is important for the achievement of health equity and for increasing the quality of a healthy life for everyone. Accordingly, the following recommendations are offered to improve access:

- Ensure full implementation of Medicaid expansion.
- Enhance the availability of national health data to better address the needs of vulnerable populations, including having data broken down by race, ethnicity and gender.



- Support health center service delivery sites in medically underserved areas (urban and rural) and place support programs that encourage primary care providers to practice in communities with shortages.
- Prioritize prevention and disease management that will serve to improve quality of health care in all populations.
- Support efforts to make healthcare more affordable.
- Support the utilization of trusted community members, such as Community Health Workers in health care delivery.

WORKFORCE DIVERSITY

Research confirms that minority patients are more likely to adhere to the health care recommendations provided by someone who looks like them. Underserved populations typically suffer higher rates of health disparities, particularly chronic and preventable diseases. Accordingly, the following recommendations are offered to improve workforce diversity:

- Expand training programs that bring new and diverse workers into the healthcare and public health workforce
- Develop programming that exposes students to career options within the healthcare professions
- Promote programming that develops hands-on and interactive approaches to exposure that include mentoring as a priority
- Support Science, Technology, Engineering, and Math within primary and high schools
- Create medical and research based “shadowing” and “mentoring” programs, scholarships, and research and summer enrichment programs
- Support efforts to expand minority health care professionals in leadership positions
- Expand healthcare occupations that qualify under the National Health Service Corps Service Loan Repayment Program
- Support funding for historically black colleges and universities and other institutions serving minority populations

INNOVATION & RESEARCH

We are beginning to fully recognize how innovations in digital technology affect the ways health care is delivered and how individuals manage their own health. We must increase investment in digital and biotechnology and increase funding for the basic sciences if we are to revolutionize healthcare policy to the benefit of vulnerable populations. Accordingly, the following recommendations are offered to enhance medical innovation and research:

- Increase participation of minorities in clinical trials
- Streamline grant administration for funding health disparities
- Increase the availability, quality, and use of data to improve the health of minority populations
- Support the advancement of culturally and linguistically appropriate services.
- Promote data sharing between health systems stakeholders such as health department surveillance data and hospital assessment data
- Promote the healthcare interpreting profession as an essential component of the healthcare workforce to improve

access and quality of care for people with limited English proficiency

- Support investment in innovative digital technologies, cloud computing and medicalized smartphones to enhance health care
- Increase and commit funding that explore additional cures into rare diseases, in particular diseases that disproportionately impact minorities and communities of color
- Continue to support the testing of payment and service delivery models aimed at improving the quality of care and population health outcomes

FEDERAL ACTION

Strong federal action is crucial to appropriating the funding resources and advancing the political will to end health inequity. Accordingly, the following recommendations are offered: to spark federal action on health disparities:

- Protect and improve Medicare and Medicaid
- Uphold and improve the Affordable Care Act
- Continue or increase funding for pivotal programs and partnerships that strive to close health gaps (Ryan White, Healthy Start, NIH)
- Add dental and vision benefits for adults under Medicaid and Medicare
- Pass mental health and substance abuse legislation in Congress
- Support federal long-term care policy
- Bring together multiple sectors (transportation, agriculture, housing, environment, education, and justice) to advance health equity
- Address Gun Violence as a public health epidemic
- *Pass critical health disparities legislation such as* (but not limited to):

1.) The Health Equity and Accountability Act (HEAA)

This is the Congressional Black Caucus, Congressional Hispanic Caucus, and Congressional Asian and Pacific American Caucus’s signature health disparities bill.

Sponsor: Rep. Robin Kelly (IL)

2.) H.R. 224 – The Recognizing Gun Violence as a Public Health Emergency Act

This legislation would require the Surgeon General to submit to Congress an annual report on the effects of gun violence on the public's health.

Sponsor: Rep. Robin Kelly (IL)

3.) H.R. 539 – Action for Dental Health Act

This legislation amends the Public Health Service Act to reauthorize oral health promotion and disease prevention programs through FY-2020. This aims to improve essential oral health care for lower income individuals by breaking down barriers to care.

Sponsor: Rep. Robin Kelly (IL), Rep. Mike Simpson (ID)

4.) H.R. 768 – Stop AIDS in Prison Act of 2015

This bill requires the Federal Bureau of Prisons to develop a comprehensive policy to provide HIV testing, treatment, and prevention for inmates in Federal prisons.

Sponsor: Rep. Maxine Waters (CA)

5.) S. 613, H.R. 1728 – The Summer Meals Act of 2015

This bill aims to reduce hunger and combat child obesity by strengthening and expanding access to Summer Nutrition Programs so children can continue to access nutritious meals and snacks during the summer when they are unable to access free and reduced price school meals.

Sponsor: Rep. Don Young (AK), Rep. Rick Larsen (WA), Sen. Kirsten Gillibrand (NY), Sen. Lisa Murkowski (AK)

6.) H.R. 2651 – Eliminating Disparities in Diabetes Prevention, Access and Care Act

This bill will enhance research at the National Institutes of Health on the causes and effects of diabetes in minority communities. Additionally, under the bill, the Centers for Disease Control and Prevention will provide more effective diabetes treatment, prevention and public education to highly impacted populations.

Sponsor: Rep. Diana DeGette (CO)

7.) H.R. 2715 – The Stop Child Summer Hunger Act of 2015

This bill amends the Richard B. Russell National School Lunch Act to require the Department of Agriculture to establish a program providing eligible households with summer Electronic Benefits Transfer (EBT) cards in order to give children access to food during the summer months to: (1) reduce or eliminate children's food insecurity and hunger, and (2) improve their nutritional status.

Sponsor: Rep. Susan Davis (CA)

8.) H.R. 2866 – Healthy MOM Act

The Healthy MOM Act provides for a special enrollment period for pregnant women (that essentially says women who get pregnant in non-open enrollment months should get a special open enrollment period for the Marketplace).

Sponsor: Rep. Bonnie Watson Coleman (NJ)

9.) H.R. 1220 – Removing Barriers to Colorectal Cancer Screening Act of 2015

The Removing Barriers to Colorectal Cancer Screening Act of 2015 works to correct an oversight in current law that requires Medicare beneficiaries to cover the cost of their copayment for a "free" screening colonoscopy if a polyp is discovered and removed during the procedure.

Sponsors: Rep. Charlie Dent (PA), Rep. Donald Payne Jr. (NJ)

10.) H.R. 1586 – REPEAL HIV Discrimination Act of 2015

The REPEAL Act ("Repeal Existing Policies that Encourage and Allow Legal" HIV Discrimination) calls for review of all federal and state laws, policies, and regulations regarding the criminal prosecution of individuals for HIV-related offenses.

Sponsor: Rep. Barbara Lee (CA)

11.) H.R. 1706 – Real Education for Healthy Youth Act of 2015

This bill would give America's youth the information they need to make educated decisions about their health. The bill would expand comprehensive sex education programs in schools and ensure that federal funds are spent on effective, age-appropriate, medically accurate programs.

Sponsor: Rep. Barbara Lee (CA)

12.) H.R. 2730 – National Prostate Cancer Plan Act

Establishes in the Department of Health and Human Services (HHS) the National Prostate Cancer Council on Screening, Early Detection, Assessment, and Monitoring of Prostate Cancer to: (1) develop and implement a strategic plan for the accelerated development of diagnostic tools for prostate cancer, (2) review the effectiveness of diagnostic tools for prostate cancer, (3) coordinate prostate cancer research and services across federal agencies, (4) evaluate all active federal prostate cancer programs, and (5) ensure the inclusion of men at high risk for prostate cancer in clinical, research, and service efforts.

Sponsor: Rep. G.K. Butterfield (NC)

13.) H.Res. 296 – Calling for Sickle Cell Trait Research

Recognizes the challenges in addressing health outcomes among people with Sickle Cell Trait and Sickle Cell Disease. Encourages the medical community to make individuals aware of their Sickle Cell Trait status. Urges the Department of Health and Human Services to develop a public awareness campaign regarding the importance of individuals knowing their Sickle Cell Trait status and to expand access for screening and counseling. Commits to supporting research on Sickle Cell Trait and Sickle Cell Disease.

Sponsor: Rep. Barbara Lee (CA)

- Promote behavioral health integration into primary care—including addictions
- Improve cultural competency of healthcare providers
- Support coordinated care models that include integration of community health workers and other trusted allied health professionals to promote healthy behaviors locally
- Consider social determinants of health, including housing, food security, violence, and economic stability, when developing models of care in order to effectively address health disparities.
- Support free screening and lifestyle intervention services to low-income, uninsured, or underinsured populations.
- Facilitate opportunities for providers to refer patients to community services and resources.
- Educate communities about options and benefits under the Affordable Care Act
- Support community participatory research that legitimizes community actions to address the fundamental environmental, social, and economic causes of health inequities
- Develop or support educational efforts and public awareness campaigns to engage targeted communities.
- Promote healthy behaviors within the places and spaces that live, work, play and pray

CONCLUSION

W.E.B. DuBois' seminal sociological study, *The Philadelphia Negro* (1899) observed that the most difficult problem in improving (Black) health in America was the attitude of the nation. DuBois remarked: "There have...been few other cases in the history of civilized peoples where human suffering has been viewed with such peculiar indifference."

There is no place for this "peculiar indifference" in modern health policy. Like the right to vote, health care is a fundamental civil right that must be promoted, protected and supported for minority populations. Health is a basic need whose value is undeniably recognized in our universal desire to experience good personal health for ourselves, and our families.

We cannot sit by idly when it comes to the health of minorities in America. Addressing health disparities is not just a moral issue; it's an issue about the future of our national physical, economic,

COMMUNITY ENGAGEMENT

More can be done to equip individuals and communities with the information and resources they need to act collectively to improve their health. We must engage with the community to identify and eliminate health inequities. Accordingly, the following recommendations are offered:

- Support coordination of community health programs

and security well-being. It is our responsibility to come together as a nation—at all levels of government and from all walks of life—to effectively achieve health equity in our nation.

The health checklist recommendations pictured on the next two pages were taken from the following sources:

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1. Office on Women's Health (2013). *Screening Tests and Vaccines*. Retrieved from <http://www.womenshealth.gov/screening-tests-and-vaccines/screening-tests-for-women/>
 2. Agency for Healthcare Research and Quality (2014). *Women: Stay Healthy at Any Age*. Retrieved from <http://www.ahrq.gov/patients-consumers/prevention/lifestyle/healthy-women.html>
 3. Healthy Women (2015). *Preventative Health Screenings for Women*. Retrieved from <http://www.healthywomen.org/content/article/preventive-health-screenings-women>
 4. Agency for Healthcare Research and Quality (2014). *Men: Stay Healthy at Any Age*. <http://www.ahrq.gov/patients-consumers/patient-involvement/healthy-men/healthy-men.html>
 5. Men's Health Network (n.d.). *Get It Checked*. Retrieved from <http://www.menshealthnetwork.org/library/getit-checkedpostermen.pdf>
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RECOMMENDED CHECKUPS AND SCREENINGS				
WOMEN ♀	Ages:	20-39	40-49	50+
	Physical Exam (Including evaluation of overall health, BMI, etc.)			
Every 3 years		●		
Every 2 years			●	
Every year				●
Blood Pressure				
Every year		●	●	●
Cholesterol				
Every 5 years		●	●	●
Diabetes (Type II) HGBA1c or fasting plasma glucose screening				
Every 3 years			Starting at 45	●
Eye Examination				
Annually		●	●	●
Dental Cleaning and Checkup				
Twice a year		●	●	●
Hearing Assessment				
Every year		●	●	●
Tuberculosis (TB Skin Test)				
Every 5 years		●	●	●
Blood Tests & Urinalysis				
Every 3 years		●		
Every 2 years			●	
Every year				●
EKG				
Establish Baseline		Age 30		
Every 2 years			●	
Every year				●
Tetanus Booster				
Every 10 years		●	●	●
Rectal Exam				
Every year		●	●	●
Hemoccult				
Every Year			●	●
Breast Health				
Clinical Breast Exam Every Year		●		
Clinical Breast Exam Every 1-2 Years			●	
Mammography				●
Reproductive Health (Pap smear and pelvic exam)				
Every 2 years		●		
Every 3 years			●	●
Colorectal Health				
Every 3-4 Years				●
Self Exams				
Breast – To look for abnormal changes/lumps		●	●	●
Skin – Look for moles, freckles, cancer		●	●	●
Oral – Sign of lesions in mouth or on tongue		●	●	●
Bone Health – bone mineral density test				
Discuss with physician				Age 60
Estrogen				
Discuss with physician				●
Sexually Transmitted Diseases (STDs)				
Every year. *If at risk		●	●*	●*
HIV				
Periodic Testing if at risk. All pregnant women should get tested.		●	●	●
Hepatitis B & C				
Periodic Testing if at risk.		●	●	●

RECOMMENDED CHECKUPS AND SCREENINGS				
MEN 	Ages:	20-39	40-49	50+
	Physical Exam (Including evaluation of overall health, BMI, etc.)			
Every 3 years		●		
Every 2 years			●	
Every year				●
Blood Pressure				
Every year		●	●	●
Cholesterol				
Every 5 years		●	●	●
Diabetes (Type II) HGBA1c or fasting plasma glucose screening				
Every 3 years			Starting at 45	●
Eye Examination				
Annually		●	●	●
Dental Cleaning and Checkup				
Twice a year		●	●	●
Hearing Assessment				
Every year		●	●	●
Tuberculosis (TB Skin Test)				
Every 5 years		●	●	●
Blood Tests & Urinalysis				
Every 3 years		●		
Every 2 years			●	
Every year				●
EKG				
Establish Baseline		Age 30		
Every 2 years			●	
Every year				●
Tetanus Booster				
Every 10 years		●	●	●
Rectal Exam				
Every year		●	●	●
Testicular exam				
Every year		●	●	●
Prostate & PSA Blood Test				
Every year			*	●
* African-American men and men with a family history of prostate cancer may wish to begin prostate screen at age 40 or earlier				
Hemoccult				
Every Year			●	●
Colorectal Health				
Every 3-4 Years				●
Self Exams				
Testicle – to look for abnormal changes/lumps. Monthly		●	●	●
Oral – signs of lesions in mouth or on tongue. Monthly		●	●	●
Bone Health – bone mineral density test				
Discuss with physician				Age 60
Testosterone Screening				
Discuss with physician			●	●
Sexually Transmitted Diseases (STDs)				
Every year. *If at risk		●	●*	●*
HIV				
Periodic Testing if at risk		●	●	●
Hepatitis B & C				
Periodic Testing if at risk		●	●	●

SOURCES

WOMEN

<http://www.womenshealth.gov/screening-tests-and-vaccines/screening-tests-for-women/>

<http://www.ahrq.gov/patients-consumers/prevention/lifestyle/healthy-women.html>

<http://www.healthywomen.org/content/article/preventive-health-screenings-women>

MEN

<http://www.ahrq.gov/patients-consumers/patient-involvement/healthy-men/healthy-men.html>

<http://www.menshealthnetwork.org/library/getitcheckedpostermen.pdf>

ACKNOWLEDGMENTS

Nathaniel Horn, MD
Late Honorable Louis Stokes
Honorable Donna Christensen, MD
Honorable Maxine Waters
Keenan Austin
Jeff Carroll
Cynthia Barginere, DNP (C), RN, FACHE
Kendra Brown, JD
Nicole Cheek Cranston, DDS
Delia Davis
Michelle Gaskill, BSN, MHSA
Andrew Goodwin
Waverly Gordon JD, MHA
Miki L. Grace
Vanessa Griggley-Owens
Tiffany Guarascio
Abdul Henderson
Rachel Jacob
Stephanie Brown James
Ashley Jones
Mahelet Kebede, MPH
Courtney Kerster
Dion Lawson
Janine Lewis, MPH
Nina Luvin-Johnson, MD
Jerrica Mathis, MS Ed
Moriel McClerklin, MD
David Miller, DDS
Virgil Miller
Deanne Millison, JD
Edith P. Mitchell, MD
Marcus Montaña
Anne Marie Murphy, PhD
Todd Occomy, MD

Monica Pham, JD
Gary Puckrein, PhD
Sharon Rachel
Timothy Robinson, JD
Susie Saavedra
Nadera Sweiss, MD
Sabrina Terry-Webb
Donna Thompson, RN, MS
Edwin Ukpaby
Gretchen Wartman
Cheryl Watson-Lowry, DDS
Britt Weinstock, PhD
Cheryl Whitaker, MD, MPH
Robert Winn, MD
American Dental Association
National Dental Association
American Medical Association
National Medical Association
National Minority Quality Forum
The Sullivan Alliance
