

Asthma and Allergy Foundation of America

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2020 ASTHMA DISPARITIES INAMERICA

A Roadmap to Reducing Burden on Racial and Ethnic Minorities

EXECUTIVE SUMMARY

Asthma Disparities in America A Roadmap to Reducing Burden on Racial and Ethnic Minorities

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About the Asthma and Allergy Foundation of America (AAFA)

Founded in 1953, AAFA is the oldest and largest non-profit patient organization dedicated to saving lives and reducing the burden of disease for people with asthma, allergies and related conditions through research, education, advocacy and support. AAFA offers extensive support for individuals and families affected asthma and allergic diseases, such as food allergies and atopic dermatitis (eczema). Through its online patient support communities, network of local chapters and affiliated support groups, AAFA empowers patients and their families by providing practical, evidence-based information and community programs and services. AAFA is the only asthma and allergy patient advocacy group that is certified to meet the standards of excellence set by the National Health Council. For more information, visit **aafa.org**.

About This Report

AAFA synthesized current data and knowledge related to health disparities—and where available, asthma in particular—and offers recommendations for action. These actions do not constitute AAFA policy or commit AAFA to the activities. This report originated with AAFA's strategic initiative to improve care for underserved populations. During the next phase of this initiative, a workgroup of likeminded organizations and stakeholders will meet to prioritize activities to drastically reduce asthma's burden on at-risk populations.

EXECUTIVE SUMMARY

In the United States, the burden of asthma falls disproportionately on Black, Hispanic and American Indian and Alaska Native populations. Decades of extensive research and public health data identified disparities in asthma prevalence, mortality and health care utilization along racial and ethnic lines.

Health care quality generally improved for many people within the last decade. While disparities in health outcomes between various racial populations have begun to narrow, stark inequities in asthma outcomes persist.

The purpose of this report is to describe the current landscape, highlight promising innovations and offer solutions for various stakeholders to evaluate and implement.

This report is cautiously optimistic. Although progress has been slow, recent advances in policy, program development, and research point to the possibility of more significant improvement in the near future.

More importantly, we are encouraged by the widespread and renewed dedication of our many partners to bridge the racial and ethnic gaps in asthma care and outcomes. For many stakeholders—including the Asthma and Allergy Foundation of America (AAFA)—continuing to chip away at the unequal burden of asthma remains a mission-critical priority.

This report represents AAFA's ongoing commitment to drastically reducing the burden of asthma in underserved populations that bear the biggest burden of this disease.



OVERVIEW OF DISPARITIES IN ASTHMA

This report describes asthma disparities in Black and Hispanic populations in detail. Key examples of such disparities at the national level are highlighted below:

Puerto Ricans have the highest rate of asthma prevalence compared to any other racial or ethnic group in the U.S.

Nearly 25 million people in the United States are living with asthma,¹ but prevalence rates differ significantly by race and ethnicity. Puerto Ricans have the highest rate of asthma prevalence. Black Americans are also disproportionally diagnosed with asthma compared to white Americans.



Current Asthma Prevalence by Race and Ethnicity

Asthma-related data for American Indian (AI) and Alaska Native (AN) populations are limited.

Data on asthma conditions for AI/AN communities are limited. National datasets do not consistently contain reliable asthma data for AI/AN groups. Some regional data shows AI/AN individuals are twice as likely to experience asthma symptoms every day.

Although this report looks specifically at disparities related to Black race and Hispanic ethnicity, it's important to also acknowledge the disproportionate burden of asthma on Indigenous Americans. Tribal nations have among the highest rates of asthma prevalence, morbidity and mortality. Immediate investment in better data collection and research in this population is necessary to inform disparities reduction efforts, programs and interventions.

Black individuals are nearly three times as likely to die from asthma than white individuals.

Differences in mortality rates present startling evidence of racial disparities in asthma. Deaths due to asthma—although decreasing overall—occur at a much higher rate in the Black and Puerto Rican populations than in the white population.



Asthma-Related Deaths by Race, Ethnicity and Residents of the Commonwealth of Puerto Rico

Source (U.S): CDC, National Center for Health Statistics, National Vital Statistics System: Mortality (2010-2018) Source (PR): Puerto Rico Department of Health, Technical report, Puerto Rico Asthma Project (2010-2015)

Asthma-related deaths were identified as those coded as J45-J46 as the underlying cause of death using the International Code of Diseases 10th revision (ICD-10).

Mortality estimates show age-adjusted rates.

Mortality estimates for Black and white race do not include people of Hispanic ethnicity.

Data for Puerto Rico includes data only from the approximately 3.5 million residents of the Commonwealth of Puerto Rico and does not include the approximately 5 million Puerto Rican Americans living on the U.S. mainland.

Asthma-related emergency department (ED) visits are nearly five times as high for Black patients compared to white patients.

Asthma disparities are perhaps greatest between Black and white populations in terms of ED visits. Increased ED visits are indicative of poor asthma control.



Asthma-Related ED Visits by Race

Source: CDC, National Center for Health Statistics, National Ambulatory Medical Care Survey (2010-2017)

ED estimates for Black and white race include people of Hispanic ethnicity. Crude rate per 10,000 population



ROOT CAUSES OF DISPARITIES IN ASTHMA

Racial and ethnic disparities in asthma are the result of complex interactions between varying levels of **social, structural, biological and behavioral** determinants.

AAFA developed the following conceptual framework for root causes of asthma disparities, adapted from several existing models, including the World Health Organization's Conceptual Framework for Action on the Social Determinants of Health and Healthy People 2020's "place-based" organizing framework. AAFA's model specifically highlights the overwhelming role of race and ethnicity in amplifying social, structural, and individual stressors.



AAFA's Framework for Root Causes of Asthma Disparities

SOCIAL AND STRUCTURAL DETERMINANTS

Social determinants of health are defined as "the conditions in which people are born, grow, live, work and age."² The social determinants identified in AAFA's framework are categorized into the following five key domains:

- Economic stability (e.g., poverty, employment)
- Education (e.g., early childhood education, higher education)
- Physical environment (e.g., environmental conditions, quality of housing)
- Social environment (e.g., social class, social cohesion)
- Health care (e.g., access to care, quality of care, health literacy)

Structural determinants of health are defined as "the wider set of forces and systems shaping the conditions of daily life."² These forces are deeply ingrained in U.S. policies, governance and culture, and have led to systematic disadvantages of Black and Hispanic Americans. Examples of structural factors that have helped exacerbate racial and ethnic disparities in asthma include:

- Systemic racism and discrimination
- Residential segregation and discriminatory housing policies
- Discriminatory hiring and promotion practices
- Stereotyping and stigmatization
- Explicit and implicit bias
- Environmental injustice

The causal relationship between social advantage and better health is especially well-documented in asthma. Research shows that asthma disparities are highly driven by socioenvironmental and economic conditions, and that structural injustices over time have led to accumulated disadvantage for specific racial and ethnic populations in the U.S.

The concepts of social and structural determinants are intrinsically entangled, complex, and reciprocal in nature. In addition, structural racism—which alone is a significant driver of asthma disparities—is intertwined with and amplifies socioeconomic disadvantages such as poverty, poor housing, and lack of access to health care.

Disparities in asthma are intensified by the cumulative risk from these overlapping determinants.



BIOLOGICAL DETERMINANTS

Although a large and compelling body of evidence points to social and structural determinants as the dominant causes of asthma disparities, at least some of the differences in asthma outcomes can be attributed to biological factors.

African ancestry shared by Black and Puerto Rican populations has been identified as a potential genetic predictor of asthma.³ Further understanding of the association between ancestry and asthma continues to be an area of active investigation.

Researchers also seek to explain genetic variations related to asthma. Though the extent to which genes contribute to asthma disparities is not entirely clear, various genes have been found to influence an individual's:

- Susceptibility to asthma (heritability)⁴
- Progression of asthma (severity)⁵
- Response to treatment⁶

Interactions between genetic factors and environmental triggers may also impact asthma susceptibility. Racial and ethnic minority populations in the U.S. are disproportionately burdened by exposure to environmental triggers—such as tobacco smoke and other air pollutants—which have been linked to reduced lung function in people with certain genetic variants.



BEHAVIORAL DETERMINANTS

An individual's behaviors play a substantial role in determining asthma outcomes. These behaviors are often modifiable through interventions to improve asthma self-management. Individual factors that may contribute to disparities in asthma include:

- Non-adherence to treatment
- Negative beliefs about medication and health care system
- Distrust of the medical establishment
- Misperceptions about illness and asthma severity
- Tobacco use

Such behaviors are often associated with poor asthma control, worse outcomes, and lower quality of life. Adherence to medication, in particular, is a critical self-management strategy for effective asthma control and is highly impacted by personal and cultural attitudes toward medication use. Studies have identified some trends in negative beliefs related to medication among racial and ethnic lines,⁷ potentially contributing to disparities in asthma outcomes.

Additionally, historical exploitation of Black bodies in unethical medical experiments—such as the Tuskegee Study—has led to lasting, intergenerational distrust of the medical establishment among Black families.⁸



The existence and causes of asthma disparities related to race and ethnicity have been studied and documented in great detail. Focus in recent years has shifted from describing the problem to *addressing* it. Although efforts in reducing disparities have been slow, the picture isn't entirely bleak. A growing number of strategies and opportunities to address upstream determinants of health have produced notable results in recent years.

The "Asthma Disparities in America" report highlights emerging approaches toward effective, sustainable, and scalable solutions through:

- Public policy reform
- Direct interventions to improve asthma self-management
- Community-based programs
- Advancement in research and science

Although there is no exact prescription for reducing asthma disparities, it is within these areas that some progress has been made and from which new avenues could emerge to drastically decrease the burden on populations disproportionately affected by asthma.

A ROADMAP TO DRASTICALLY REDUCING ASTHMA DISPARITIES

The mission of the Asthma and Allergy Foundation of America (AAFA) is to save lives and reduce burdens of asthma and allergies through support, research, education and advocacy. The Foundation's current strategic plan calls for improving care for the most vulnerable populations impacted by these diseases.

This report provides an overview of asthma disparities and strategies to improve asthma health in underserved populations. AAFA looks forward to partnering with like-minded individuals and organizations to work together to build sustainable, patient-centered solutions.

CATEGORY		STRATEGIES
PUBLIC POLICY	Health Care	 Expand health insurance coverage for socioeconomically disadvantaged adults and children Improve coverage of asthma guidelines-based care and treatments by expanding specialist care coverage, lowering copays, expanding eligibility criteria, and removing prior authorization and step therapy barriers Increase diversity in the primary and specialty health care workforce Increase the percentage of minority patients with a "usual source of care" by addressing provider shortage areas, removing financial barriers to office-based primary care services, and expanding the primary care infrastructure to integrate better care coordination Develop sustainable models for care coordination and case management that do not place financial burdens on patients Encourage and incentivize state and local health departments to adopt
	Economic Stability	 comprehensive community asthma programs Increase minimum wage for jobs often held by minority workers Reduce the racial wage gap in the U.S. labor market Implement tax policies that help low-income families accumulate more wealth
	Education	 Increase access to quality early childhood education and care Create more equitable school finance systems Reduce exposure to environmental triggers by improving school building conditions and improving air quality in and around schools Enact federal and state legislation to put important protections in place for schoolchildren with asthma.
	Physical Environment	 Improve housing quality for rental units, including assisted rental units like public housing, through "healthy home" policies and green building practices. Directly finance or support reimbursement models for programs that align asthma clinical interventions with home assessments, indoor environment improvements and remediations to reduce asthma triggers Increase access to affordable, quality housing through expanded rental assistance programs, tax credits and inclusionary zoning programs Desegregate residential neighborhoods through mobility programs and neighborhood revitalization efforts Encourage smoke-free environments Combat environmental injustice and reduce exposure to pollution by strengthening clean air policies, reducing transportation-related emissions, restricting zoning of polluting sources and transitioning to a clean energy economy

CATEGORY		STRATEGIES
		Integrate principles of shared-decision making into practice
INTERVENTIONS	Clinical	 Bridge communication gaps between health care providers and patients by training "patient advocates/navigators" to identify and remedy specific problem areas in patient-provider communication
		 Develop and implement training programs for health care professionals to identify asthma patients with social determinants of health-related issues and build community partnerships to match patients with local resources
		 Educate nurses, health educators, community health workers, and promotoras to provide guidelines-based asthma care and patient education on new treatments
		 Reduce financial barriers to filling prescriptions, expand patient assistance programs, and integrate pharmacy care into medical practice by filling prescriptions during physician/ED visits
		• Expand pharmacy access by providing a three-month supply of asthma medicines
		 Offer personalized, culturally-appropriate asthma action plans using the patient's and caregivers' language and wording
		 Expand access to specialist care by increasing referrals from primary to specialty care and recruiting more specialists for areas with provider shortages
		 Support patients with comorbidities by providing care coordination and case management
		 Expand case management to school settings by including school nurses as partners in a child's care team
		 Develop multidisciplinary teams of case managers
		 Expand adoption of comprehensive asthma AS-ME education programs for high-risk populations
	Educational	 Increase CDC and NHLBI funding to sustain and scale successful Asthma Self-Management Education (AS-ME) programs
		 Review inhaler technique at every care touchpoint, including home visits, ED and urgent care visits, and at schools when school nurses administer medicines
		 Reduce exposure to triggers in the home by providing trigger-abatement products and offering referrals to resources such as cleaning services, mold removal, pest management, and legal/housing assistance
	Home-Based,	 Support and expand programs for community health workers, promotoras, nurses, social workers and certified asthma educators to conduct home-based assessments and interventions
	School-Based,	Increase number of school nurses nationwide
	Community- Based	 Remove barriers for implementing comprehensive school-based asthma management programs through increased funding, awareness, and training
	Buseu	 Continue efforts to stock undesignated quick-relief asthma medicine in schools, ensure schools are equipped to obtain asthma medicines, and train appropriate staff to administer medicines
		 Build broad-based community partnerships with local stakeholders to tailor solutions and increase buy-in and sustainability

CATEGORY		STRATEGIES
	Basic Science	 Identify effective biomarkers of asthma and develop tests to measure biomarkers in an easy, rapid, and noninvasive way at the point of care
		 Increase representation of African-ancestry, Indigenous American-ancestry, and admixed populations in genomics datasets to support genome-wide research in underrepresented populations
		 Promote and incentivize epigenomic and pharmacogenomic studies of asthma in Black individuals, Indigenous Americans, and Hispanic subgroups
		 Invest in the development of precision medicine for asthma
	Clinical and Epidemiological Research	 Significantly increase participation of Black, Hispanic, and Indigenous Americans in clinical trials
		 Address cultural stigmas and myths about research among minority populations and build trust in medical establishment and particularly in minority research
		 Expand research of patterns of asthma risk factors, morbidity, and mortality in underrepresented populations—particularly Black, Hispanic and Indigenous Americans— to inform public health interventions
		 Improve data collection standards to ensure uniformity in racial and ethnic data collection across agencies
_		 Transform national, state and local surveillance systems to utilize uniform data collocation standards
RESEARCH		 Improve data collection to monitor disparities experienced by AI/AN populations and Hispanic subgroups
RESE		 Provide public access to disaggregated data to identify disparities within subgroups of each population
	Translation, Implementation, and Health Services Research	 Support research to inform interventions to reduce asthma disparities and collaborate to ensure the translation of research findings to policy and practice
		 Conduct further research studies and tests among racially and ethnically diverse populations to discover successful strategies that show increased patient adherence to proven asthma management strategies and medicines
		 Test and scale models for payment systems and program structures that integrate all components of comprehensive, evidence-based asthma care
	Diversity and Engagement in Research	Support patient-centered outcomes research and community-based participatory research in asthma
		 Align research needs with the needs of patients from underrepresented racial and ethnic groups
		 Establish policies and practices to support research that engages diverse, multi-sector stakeholders throughout the research process
		Increase racial and ethnic diversity among researchers studying asthma
		 Fund and develop programs to support early-stage investigators devoted to research on minority health
		 Include physicians and researchers from diverse backgrounds on editorial and review boards

CATEGORY		STRATEGIES
PARTNERSHIPS	Multi- Stakeholder Collaboration	 Strengthen sustainable partnerships between patients/families, health care professionals, researchers, biotech and pharmaceutical companies, educators, schools, community leaders, government agencies, health care systems, health care payers, employers, national and local organizations, advocates, policymakers/legislators and the media to reduce disparities in asthma Facilitate collaboration between federal, state and local agencies and non-governmental organizations to aid in promoting effective policies/ programs to reduce asthma disparities
	Patient/Family Engagement	 Improve trust in health care by engaging diverse patients and families at the onset of program, policy, and research development Include patient/family advisors in development of educational materials and research protocols, creation of patient portals, and advising on health facility design Appoint diverse patients to advisory councils, task forces and project committees Ensure successful patient and family member engagement by establishing transparent processes, identifying mechanisms to act on patient and family input, and properly training health care and research staff on implementing patient and family engagement strategies Fairly compensate patient and family advisors for their expertise and participation in advisory roles
	Community Engagement	 Include and advance community voice, support, and participation Include community partners as early as possible when developing asthma care or research programs Develop provider-community relationships to support people and families with asthma

AAFA supports the notion of "health in all policies"—a holistic approach to improving health by acknowledging the health implications in all sectors.⁹ While policies and interventions that directly relate to health care are essential in reducing asthma disparities, they are not enough. Many social and structural determinants of health fall outside the realm o<u>f traditional health care</u>.

Promising solutions will require partnerships across many sectors, including health, education, labor, housing, social services and city planning. Adopting this approach allows for solutions that address the complex and interconnected factors perpetuating health inequity.

LOOKING FORWARD

Over the past fifteen years, there have been moderate advances in U.S. public policy, health care and research, but gaps in asthma outcomes between Black, Hispanic, Indigenous American populations and white populations have not changed. Minority groups continue to bear disproportionate hardship in managing asthma.

This review of the current state of Asthma Disparities in America serves as a national call-to-action to fix the structural and social inequities that continue to plague vulnerable, at-risk patients and families with asthma.

The Asthma and Allergy Foundation of America remains committed to taking bold actions to facilitate significant improvement and building collaboration with federal, state, and non-governmental entities and individuals who share the similar goal to save lives and reduce the harm and unequal burden of asthma on underserved groups.

READ THE FULL REPORT AT aafa.org/asthmadisparities





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