
UNEQUAL AIR AND CARE:

Federal Impact on
Pediatric Asthma
Disparities in 4 U.S. Cities



A collaborative project of WE ACT For Environmental Justice with Jesus People Against Pollution (JPAP), Deep South Center for Environmental Justice (DSCEJ), and Green Door Initiative (GDI).

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To download an electronic version of this report please visit weact.org/asthmadisparities

About WE ACT

WE ACT for Environmental Justice builds healthy communities by ensuring that people of color and/or low income residents participate meaningfully in the creation of sound and fair environmental health and protection policies and practices. WE ACT has offices located in New York City, NY, and Washington, D.C. Visit us at weact.org.

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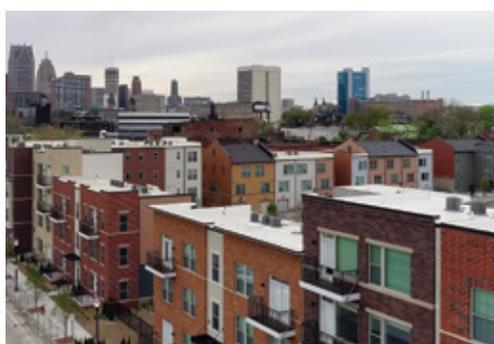
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ASTHMA DISPARITIES

Table of Contents



Preface /2
Executive Summary/3

Section 1:

Project Description/6
Goals/6
Methodology/7
Key Findings/8
Summary of Recommendations/9

Section 2:

Asthma in the U.S/11
Asthma Disparities and Children of Color/11
History of Federal Asthma Mandate/12
The President's Task Force/12
The Federal Asthma Action Plan/13

Section 3:

Hearing from the Experts: Asthma Stakeholders/14
Jackson/14
New Orleans/18
Detroit/19
New York/21

Section 4:

Mapping the System: Identifying Key Players/24

Section 5:

Recommendations/26
References/31
Appendix/32

PREFACE

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane"

The Rev. Dr. Martin Luther King, Jr. at the Second National Convention of the Medical Committee for Human Rights, Chicago, Illinois, March 25, 1966.

Imagine a mother with an asthmatic child who cannot replace their lost inhaler because Medicaid will only cover a certain number of inhalers. Or the mother whose public housing apartment is so riddled with mold, mice, and roaches that her child often wakes up in the middle of the night with an uncontrollable, unrelenting cough that causes him to miss school a few days a week.

Imagine the pediatrician who, despite all efforts can only provide seven minutes of care to an asthmatic patient; leaving them no time for education or engagement with the patient or their caretakers. This is the stark reality for millions of children of color in America but not for others.

It is well-documented that some of the most polluted environments in America are where people of color live, work, play, pray and learn. It is also well understood that the negative health outcomes that people who are of color or low income experience because they live, work or play around such polluted environments. The historical redlining that occurred many decades ago that has pushed poor people into polluted corridors is still negatively affecting marginalized people everywhere. The disparities in asthma treatment, service, education, and care for children of color is unequal and unfair.

Executive Summary



In the United States, asthmatic children of color experience higher rates of emergency department visits, hospitalizations, missed school days, and deaths due to asthma complications. Across the country, 20.4% of Puerto Rican and 18.7% of black children 0-17 are living with asthma, compared to 11.7% of white children. These disparities need concerted and deliberate attention by

the federal government in order to reduce the social and economic burdens of asthma borne by many families of color nationwide.

The federal government employs a variety of actions across agencies and departments to decrease asthma disparities impacting U.S. children. On December 16-17th, 2010, a federal

ASTHMA DISPARITIES

asthma strategy, titled the Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma Disparities, was created at a workshop in Washington D.C. The workshop was sponsored by the Asthma Disparities Working Group of the Task Force on Environmental Health Risks and Safety Risks to Children - established in 1997 by Executive Order 13045. This report sought to highlight the work accomplished by the federal government over the last seven years to reduce asthma disparities among children of color and low income.

Project Description

This report – *Unequal Air and Care: Federal Action On Pediatric Asthma Disparities Across 4 U.S. Cities* - highlights work done to assess and discuss the strategies outlined in the Federal Action Plan, and to assess their effectiveness at reducing the disparate burden of asthma in disadvantaged children aged 0-8 in four U.S. cities:

- Jackson, Mississippi
- New Orleans, Louisiana
- Detroit, Michigan
- New York City, New York

This report offers a set of community-derived recommendations specific to the strategies outlined in the Federal Action Plan that we believe can strengthen systemic action for addressing pediatric asthma disparities.

We conducted 12 stakeholder engagement meetings with asthma advocates within federal, state and local government, community-based organizations, and among clinicians and other public health professionals within each locality and Washington D.C., in order to assess the

impact of the federal strategies at the local level. Participants shared their experiences with specific strategies implemented when working in their localities, and shared their knowledge, attitudes, and beliefs on how federal strategies can assist with local problem solving to prevent and reduce asthma incidence.

Key Findings

- Federal approaches to asthma disparities are too broadly focused and thus are not written for the population they are intended to serve – those suffering a disproportionate risk and health burden due to asthma.
- Federal approaches to asthma disparities must direct more focus on the social and political factors that children of color and low income face.
- Coordination at the federal level has been limited and insufficient for effective reductions in asthma disparities.
- Federal agencies must view climate change through a public health lens when addressing indoor as well as outdoor environmental health issues like air pollution and storm surges at toxic waste sites.
- Federal agencies must fully adopt a systems approach to tackling asthma disparities by concentrating more effort at supporting community-based capacity to address asthma disparities.

Summary of Recommendations

Through facilitated systems-mapping exercises in Jackson, Detroit, and New Orleans; participants identified and discussed potential opportunities for better coordination amongst various actors including national, state, and local government agencies, philanthropic funders, community-based organizations, universities, business, and health care institutions.

ASTHMA DISPARITIES



Key recommendations include:

- Addressing the social and environmental determinants of health that contribute to pediatric asthma disparities in America.
- Establishing a Health-in-all-Policies agenda across federal sectors by adopting an inter-sectoral approach to building a culture of health for disadvantaged children.
- Expanding the capacity to deliver integrated comprehensive asthma care to children in communities with racial and ethnic asthma disparities.
- Building the capacity of state and local governments, as well as clinical and non-clinical community-based organizations / institutions, to provide community-level care for asthmatic and at-risk children.

Section 1

Project Description



In 2015, the W. K. Kellogg Foundation funded a collaborative initiative among WE ACT for Environmental Justice, Green Door Initiative (GDI), Deep South Center for Environmental Justice (DSCEJ), and Jesus Peoples against Pollution (JPAP) that sought to forge a multidisciplinary work group of professionals serving communities of color and low income to assess and characterize a 2010 federal asthma agenda – the Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma Disparities (hereafter referred to as The Federal Action Plan).

Goals and Objectives

This initiative had two clear objectives:

- (1) To assess and help strengthen the efficacy of strategies outlined in the Federal Action Plan in the treatment and management of asthma among children of color and low-income aged 0-8 in four U.S. jurisdictions: New Orleans, Louisiana; Jackson, Mississippi; Detroit, Michigan; and Northern Manhattan in New York City.
- (2) To work with key stakeholders across the four states to develop and disseminate evi-

ASTHMA DISPARITIES

dence-based recommendations which communities, state and federal partners could adopt for systematic approaches to tackling asthma disparities for the improvement of asthmatic children in those locales.

Methodology

The early years of child health and development are critical.¹ Therefore, engaging multiple sectors of partners who either directly or indirectly affect the lives of children is crucial. It was important for the project partners to bring together a cadre of experts, including: federal, state, and local government officials, state and city health departments, asthma program officers, doctors, pediatric specialists, clinicians, researchers and other public health professionals, and environmental justice advocates who all shared a common goal to reduce the disparate burden of childhood asthma on children of color and low-income.

The approaches taken in this initiative included developing a group of advisors, bringing together federal, state, and local asthma stakeholders from various parts of the asthma system and reviewing and discussing the body of both independent and joint federal efforts conducted to date. This included:

- Five roundtable discussions across the four cities and Washington DC;
- Three systems-mapping activities;
- Four 1-on-1 in-depth interviews;
- Eleven key informant interviews and advisory meetings.

Over the past two years, WE ACT and partners held two meetings in each city. The only exception is in New York City, where we performed

key informant qualitative interviews with representatives from the New York City Department of Health and Mental Hygiene (NYC DOHMH), the Icahn School of Medicine Pediatric Specialty Unit at Mount Sinai, and other leaders and representatives from community-based organizations serving children of color and low income in Northern Manhattan and the South Bronx. We took this approach in New York initially due to scheduling conflicts with a larger number of clinical specialists and government personnel, however, we saw that as an opportunity for a one-on-one approach to engaging stakeholders.

Two meetings were conducted in Washington DC, one each year of the project, to engage steering committee advisors and other meeting attendees with representatives from the federal agencies who serve on the President's Task Force who were also co-leads for the development of the Federal Action Plan.

For evaluative purposes, we partnered with researchers from the New York Academy of Medicine to perform additional key-informant interviews with stakeholders in all cities as a means of further assessing local strategies for dealing with asthmatic children, while also identifying opportunities for enhancement of the strategies outlined in the Federal Action Plan.

The purpose of these meetings was to engage federal, state, and local experts and thought leaders on asthma care and management in each of the participating states in order to identify best practices for closing the gaps between federal, state, and local strategies for the reduction of asthma disparities in children aged 0-8. While several years have passed since the release of The Federal Action Plan, there is still a great need for a continued and even a renewed federal focus on asthma health disparities.

ASTHMA DISPARITIES

The leadership and guidance from our partner organizations, steering committee members, and advisors was instrumental in identifying meeting invitees, and organizing and hosting sessions in their locales. Upwards of 50 stakeholders from the four cities and Washington DC were engaged and participated in this project.

Key Findings

WE ACT and its partners recognize the significant effort by various federal agencies on targeted aspects of asthma - including the EPA's Asthma Team and their Asthma Empowerment Program, the Centers for Disease Control and Prevention's (CDC) Merck Childhood Asthma Network (MCAN), and Housing and Urban Development's (HUD) Healthy Homes program, along with their regional asthma summits. However, our findings have uncovered a number of compelling observations regarding federal strategies for asthma disparities:

1. Federal approaches to asthma disparities are too broadly focused, and thereby are not written for the population they are intended to serve - those suffering a disproportionate risk and health burden due to asthma.

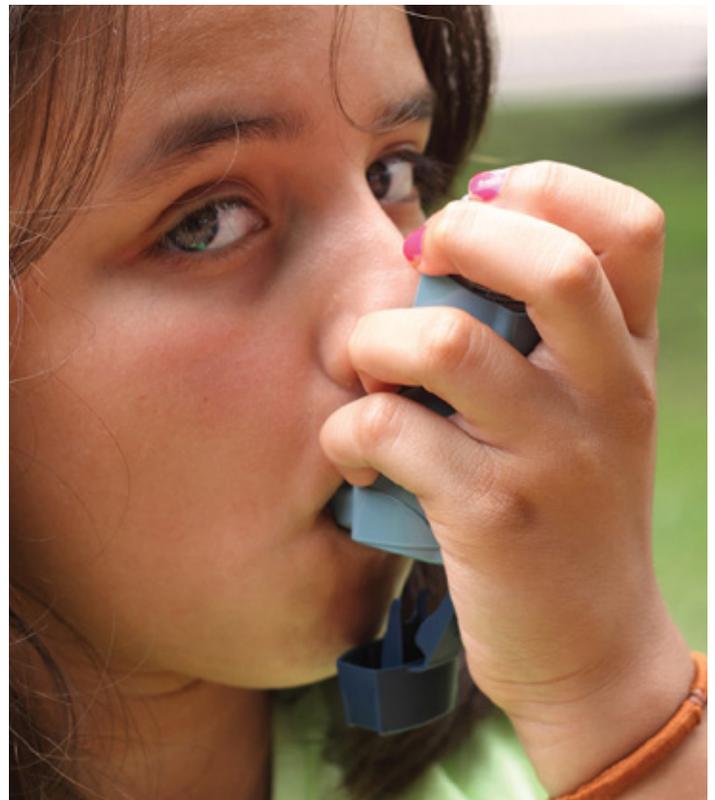
Rationale

- While federal strategies must be written broadly to encompass the needs of all people living with or at risk of developing asthma, such approaches are not the most efficient when dealing with specialized and vulnerable children of color and low income. Specific and concerted effort must be made to address those factors that are sometimes specific and unique to vulnerable children who are most at risk.

According to one New York City stakeholder:

"A lot of the strategies are too broad and don't really translate to meeting the needs of New Yorkers, especially those [who are] most vulnerable. It is like putting us all in one basket and that approach will not mean success for those most in need. Minority populations are a lot more layered than that."- Teodora Evtimova, NYCDOHMH Asthma Network Coordinator

2. Federal approaches to asthma disparities must take into consideration the social and political factors that children of color and low income face -- like stress, poverty, poor housing, and access to quality health care.



Rationale

- Social determinants of health -- including individual behaviors and systematic bias -- have a greater impact on health outcomes than medical treatment or care.²

ASTHMA DISPARITIES

- Social factors and other -adverse childhood experiences--including mental, emotional and physical abuse, household violence, and mental illness--all have a huge impact on chronic diseases from obesity to lung cancer, and studies have shown that the likelihood of developing asthma increases with the number of cumulative adverse childhood experiences reported.³

"One major thing that makes the federal strategies impractical is that [they don't] take into consideration some of the social issues that affect childhood asthma."

- Dr. Sandra Hayes, Mississippi

3. Improved coordination amongst federal agencies, including others of the President's Task Force, must take place in order to effectively address asthma and asthma disparities.

Rationale

- Effective coordination across federal agencies around asthma still contains many gaps and missed opportunities. Agencies like the U.S. Environmental Protection Agency (EPA), Centers for Disease Control and Prevention (CDC), National Heart Lung and Blood Institute (NHLBI), and the Department of Housing and Urban Development (HUD), all work to reduce the burden of asthma. However, effective coordination and implementation amongst federal programs is still lacking -- leaving missed opportunities and scattered resources.

- Opportunities to coordinate and engage agencies like the Department of Transportation (DOT), the Department of Education (DOE), the Centers for Medicaid and Medicare Services (CMS), the Administration for Child care Services (ACS) and the Department of Energy must occur. This will help with the adoption of a "Health

in All Policies" initiative, taking a preventative precautionary approach to policies impacting land use, school siting, and the health effects of climate change.

4. A true systematic approach to asthma disparities must be adopted and federal agencies must establish policies to increase engagement with -- and establish sustainable funding for -- community-based organizations in the delivery of non-clinical community-based health care and education for families and children with at risk of developing asthma.

Rationale

- A large majority of participants reported that prior to attending our meetings, they were not familiar at all with the Coordinated Federal Asthma Disparities Plan. This indicates that dissemination and engagement at state, local and community levels has been inadequate. Federal strategies should be more widely communicated to state, local and community groups through broader dissemination, direct engagement, and technical support.

- Strategic partnerships with state health and community-based health and environmental organizations are also greatly needed in order to address those social determinants of health that affect asthma outcomes in children ages 0-8.

- Adequate federal responses to asthma should include funding for specific asthma services that fall outside typical insurance systems, such as those from businesses, banks, and other private entities; and leveraging impacts among common activities by combining funding across categories.

ASTHMA DISPARITIES

Summary of Recommendations

Our community/government stakeholder meetings have led to a number of recommendations. The following summarizes the overarching themes that encompass the whole of our recommendations. Please see Section 5 for a detailed set of recommendations that are specific to federal asthma strategies.

1. Federal agencies must do more to address social determinants of health that affect asthma disparities among children of color and low income.

Issues of poverty, poor housing, adverse childhood experiences, or limited access to quality asthma care due to Medicaid are important drivers to children's risk and complications with asthma. If agencies are serious about addressing the disparity, they must seriously address the social and environmental determinants of asthma.

2. Federal agencies must leverage their power to influence access to asthma specialists at the community level through Federally Qualified Health Centers.

Our investigations have found that poor children on Medicaid do not have adequate access to the asthma specialists they may need at the community level. Most often, we find asthma specialists associated with hospitals or academic medical centers choosing to opt out of serving patients at community centers or at the community level - oftentimes due to issues with Medicaid. Federal agencies are missing the opportunity to leverage federally qualified health centers in order to reduce barriers to accessing quality asthma care.

3. Federal agencies must put forth a renewed and concerted effort to address asthma in schools and daycare settings -- *"it's the low hanging fruit"*.

Through better coordination with the Department of Education and the Department of Social Services, federal agencies working towards reducing asthma disparities can use opportunities to increase asthma education for children and families, improve the use of asthma action plans in schools, work on increasing access to school nurses, address indoor air quality and integrated pest management, and also tackle school citing and bus idling practices for a "health in all policies" approach.

4. Federal agencies must view climate change through a public health lens when addressing environmental health and air pollution issues.

The disproportionate number of toxic and polluting industrial facilities located in disadvantaged communities is a true environmental justice issue. The risk faced by frontline communities due to storm surges at toxic waste sites and tackling increasing extreme weather events, produces dire health consequences for disadvantaged communities. By mapping air quality hazards such as highways, bus depots and industrial polluting sources in relation to communities and schools, prevention, intervention and research efforts can be directed towards communities with the highest need.

5. Federal agencies must adopt a systems approach to tackling asthma disparities.

The higher prevalence and morbidity of asthma among disadvantaged children reflects a systemic issue and therefore requires systematic action in order to genuinely reduce disparities. Incorporating community-based organizations, early childhood networks, churches, schools, et.al. constitutes a strategically important method of disseminating information, education and care to families with children who suffer from asthma. Direct and proactive engagement must occur from leadership and decision-makers.

ASTHMA DISPARITIES

Section 2

Asthma Disparities in the U.S.



As mentioned earlier, in 2015, the CDC estimated that 6.2 million children - roughly 8.4% of all children under age 18 in the U.S.² - have asthma; a potentially life-threatening disease that requires ongoing management at an annual cost of roughly \$50 billion nationally. Significant racial and socio-economic disparity exists where children of color and low income are disproportionately affected by the burden of the disease. In addition to the disparities in the prevalence

of the disease, there are also significant racial, ethnic and socioeconomic disparities in asthma outcomes. Among children with asthma, black children are twice as likely to be hospitalized, more than twice as likely to have an emergency department visit, and four times more likely to die due to asthma than white children. Addressing these disparities in asthma has been a long-term priority for federal agendas and a shared goal for government and non-govern-

ASTHMA DISPARITIES

ment groups alike. Higher prevalence and morbidity of asthma in communities of color and low income communities reflects a systemic issue and therefore requires systematic action in order to reduce disparities. (See figure1).

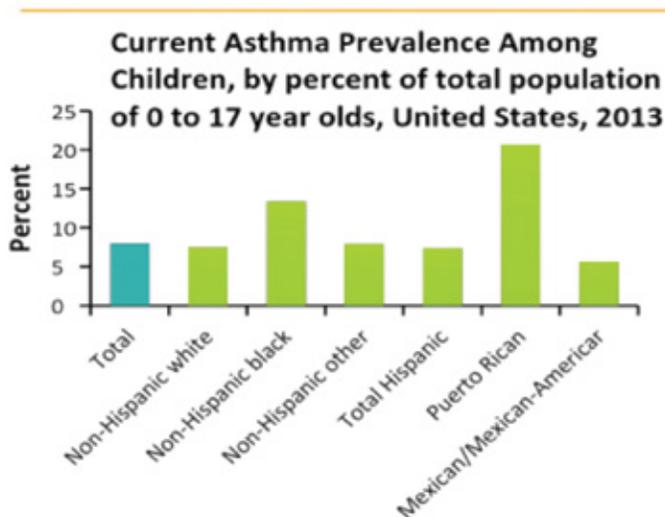


Figure 1: Asthma Prevalence Percentages for Children by race and ethnicity in the United States from 2008 until 2015.²

Federal Asthma Mandate

The Children’s Health Act of 2000 required the Director of the National Heart, Lung, and Blood Institute (NHLBI), through the National Asthma Education and Prevention Program (NAEPP) Coordinating Committee (CC), to identify all federal programs that carry out asthma-related activities, develop a federal plan for responding to asthma, and submit recommendations to the Congress on ways to strengthen and improve coordination of asthma-related activities of the federal government.

NHLBI’s recommendations for strengthening federal coordination of asthma activities focused on five goals:

- Discover ways to prevent asthma attacks and minimize uncontrolled asthma by improving understanding of the causes of asthma and its exacerbations;
- Gather, analyze, and disseminate data at the national, state, and local levels on a variety of asthma parameters, including morbidity, mortality, health-service utilization, federal expenditures, and quality of life;
- Identify and overcome barriers to full implementation of the NAEPP Guidelines;
- Enable optimal functioning of children with asthma in school and child-care settings;
- Develop and evaluate community-based interventions to address the asthma problem, particularly in high-risk communities.

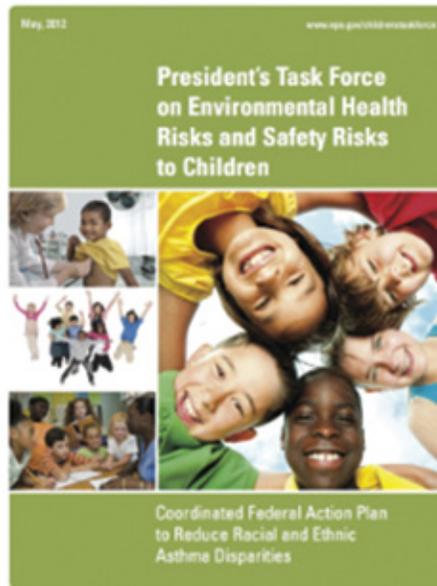
While the Children’s Health Act of 2000 was a major step and extremely vital as an instrument of legislation ensuring the enactment of best practices for protecting children’s health and safety, the mandate alone is insufficient at maximizing full coordination of federal activities and resources for the betterment of marginalized asthmatic children.

The President’s Task Force

Executive Order 13045, issued in 1997, established the President’s Task Force on Environmental Health Risks and Safety Risks to Children.⁵ The Secretary of the U.S. Department of Health and Human Services (HHS) and the Administrator of the U.S. Environmental Protection Agency (EPA) co-chair the Task Force, which comprises representation of 17 federal departments and agencies and White House offices. The Task Force is charged with the following:

ASTHMA DISPARITIES

- Identifying priority issues of environmental health and safety risks to children that are best addressed through interagency efforts;
- Developing strategies to protect children's environmental health and safety;
- Recommending and implementing interagency actions; and
- Communicating information to federal, state and local decision-makers for use in protecting children from environmental health and safety risks.



The Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma Disparities

In May 2010, the Task Force published the *Coordinated Federal Action Plan to Reduce Racial and Ethnic Asthma Disparities* (Federal Action Plan).² The Federal Plan sets forth a number of recommendations aimed at addressing preventable factors related to effective asthma management in order to reduce disparities in the treatment and management of asthma.

This plan was birthed on the premise that the magnitude of the problem of asthma disparities and the breadth of stakeholder involvement needed to address it would require a level of interagency coordination of federal resources, as well as those already existing federal partnerships with state, local health departments, community-based organizations and asthma coalitions,

and health foundations.

The Federal plan reflects a broad-based consensus of federal agencies and is an outcome of the collaborative interagency Asthma Disparities Working Group, co-chaired by HHS, EPA, and HUD. These agencies believe that effective and feasible federal efforts to address asthma disparities are contingent upon:

- Coordination across federal agencies, other levels of government, and community partners;
- Utilizing existing federal resources and optimizing their impact through synergies; and
- Emphasizing activities that address the preventable factors that impact asthma disparities.

There are four strategies outlined in the plan:

Strategy 1:

Reduce barriers to the implementation of guidelines-based asthma management;

Strategy 2:

Enhance capacity to deliver integrated, comprehensive asthma care to children in communities with racial and ethnic asthma disparities;

Strategy 3:

Improve capacity to identify the children most impacted by asthma disparities;

Strategy 4:

Accelerate efforts to identify and test interventions that may prevent the onset of asthma among "ethnic and racial minority" children.

Section 3

Hearing from the Experts: Community, Government, Medical Stakeholders

Public health research shows that your zip code may matter more than your genetic code- where you live impacts your health and contributes to health disparities. WEACTION engaged community partners and a range of stakeholders on the ground in four cities - including representatives from local departments of health, asthma programs managers, clinicians, asthma educators, researchers, pediatricians and asthma specialists, advocates, academia and community organizations which work with or for disadvantaged children.

Our investigations on the ground highlight committed, informed, thoughtful and often frustrated but always optimistic advocates. They know that, place matters.

Cities at a Glance - Place Matters

There is a clear and well established link between poverty, race/ethnicity, community conditions, substandard housing, and disparate health outcomes.⁶

Jackson, Mississippi: Sorry Kids. No Medicaid Expansion Here

"Sometimes the resources are there but our communities don't know how to access them" - Dr. Sandra Hayes



ASTHMA DISPARITIES

“Even when solutions exist there are disparities in the access of such solutions” - Ms. Lena Jones

Mississippi ranks last, or close to last in almost every leading health outcome.⁷

Many of Mississippi’s poor health outcomes are due to the social determinants of health, including food insecurity, lack of public transportation, affordable housing and education.⁸

In Mississippi, those without a high school diploma and earn less than \$15,000 a year have the least favorable health outcomes, with people of color having worse health outcomes.

Asthma in Mississippi

About 76,700; or greater than 1 in 10 children in Mississippi have a chronic respiratory illness. Asthma hospitalization rates are highest among children 4- years old and younger, and about 30 percent of Mississippi families that have a child with asthma, say the disease has a significant impact on the entire family.

The Mississippi State Department of Health’s Asthma Program and its partners say they focus on communities with the greatest needs. They increase asthma awareness, educate people on how to avoid environmental asthma triggers, partner with community stakeholders, and help residents manage their own health.

However we learned that due to cuts in funding, the asthma program within the state’s health department was not up and running for quite some time prior to our visits to Jackson in 2016 despite the need to discuss the local issues that exacerbate the problem of asthma and respiratory illness in the children there. The program has been re-instated

An Environmental Injustice

Located in the Gulf, residents of some Mississippi residents face a myriad of health problems due to legacy pollution from chemical and timber industries, as well as an inundation of power plant and toxic facility siting in communities of Mississippi. Air quality issues, and exposure to toxic chemicals makes asthma a serious challenge for children in cities like Columbia and Jackson.

One Mississippi attendee noted, “part of the void that existed was knowing where to go for what you needed. It was not well publicized back then [that] Mississippi even had an air pollution problem, and it certainly hadn’t been mapped where the asthma hotbeds were. That is happening now, but back then, I would search every journal page, this, that, and other and say, wow, there are only one or two meaningfully published accounts of pollution in Mississippi.”

“But I can tell you that there are community groups across the region and across the state that are recognizing that the particulate matter that comes from our refineries and the other things that are in the area, and the recycling and recirculation of the particulate matter associated with the absorbents in the Gulf oil spill have a lot of folks taking a very, very keen look at the asthma incidence along the coast of Louisiana through the middle of the state, but also in Mississippi, Alabama, and Florida as well.”

When it comes to caring for asthmatic children in Mississippi, stakeholders cited a number of barriers:

- **Severe shortage of asthma specialists and health care providers throughout the region.**

ASTHMA DISPARITIES

“We have lack of specialists and pediatric pulmonologists, limited or no access to specialty care, few acceptance of Medicaid mechanisms for reimbursement, and doctors lacking the knowledge or the guidance, or the ability to follow National Asthma Allergy Education and Prevention guidelines.”

The shortage of asthma specialists was not the only barrier mentioned. Meeting participants also discussed:

- Ongoing physician education to ensure proper identification of asthma severity;
- Lack of physician awareness or training on asthma management guidelines (leading to mistreatment or inappropriate prescriptions), and
- Lack of staff capacity at providers' offices to help with the creation of asthma management plans and to educate parents.

It was noted that having a health educator, or community health worker in the provider's office to offer counseling and education to patients after they see the doctor is helpful and effective in providing additional education to parents and successfully developing an asthma action plan with the family.

• Limitations in coverage from Medicaid

“I think one of the major issues in terms of medical care service delivery and access and the lack thereof is impacted by the fact that our state did not accept the Affordable Care Act Medicaid expansion. There are people in this state who work on a daily basis but were unable to qualify through the marketplace. So, that impacts their ability to get care under the Affordable Care Act.”

With Mississippi being the poorest state in the nation, the decision by the State of Mississippi to not accept federal funds or get involved

with Medicaid expansion is both unfortunate and calamitous. This leaves 138,000 low-income residents, the majority of whom are black, with no insurance options at all. As a result, poor asthmatic children cannot receive the preventive health services available through Medicaid.⁹

• Lack of transportation and the burden of distance between residents and care

In rural states like Mississippi, where there is a limited transportation system; some children are often forced to travel on average 40+ miles to see a specialist. This is a huge impediment for children and families who have limited resources to travel and may not own a car.

“When you go back to the table, when you talk to those persons who have compiled this fabulous document [the Action Plan], and they ask why it's not working, you will be able to say that I have seen it for myself in a community where the closest clinic is 50 miles”.

Experts touted the success and the need for more mobile health outreach clinics like that of Tugaloo College, but stated the need for leadership and guidance of a health director, increased support from federal and state government agencies, and increased coordination at the community level to overcome duplicity, distrust, and disengagement of community organizations.

• Limited access to care in schools due to shortage of school nurses and limited use of asthma action plans in school

Established in 1888, the public school system in Jackson, Mississippi is the second largest school district in the state and is the **only urban school district in the state**.¹⁰ When it comes to implementing asthma care services and reducing

ASTHMA DISPARITIES



environmental exposures within schools, meeting participants discussed the lack of resources and **disparities within the educational system** of Mississippi.

On-the-ground experts find that this disparity leads to lack of school nurses, minimal use of asthma action plans, and lack of knowledge amongst everyone including school administrators, teachers, students, and parents.

“We need to understand how asthma is being handled in schools and especially since children can’t have their inhalers with them in school - since it’s considered a drug. They’d have to go to the principal’s office and IF there is a school nurse. However there aren’t school nurses in ev-

ery school. One nurse will cover multiple schools and a child at one particular school, experiencing an episode will have to wait until a nurse gets there, if a nurse gets there.”

- **Racial Disparities in access to resources and information**

Experts expressed that black and brown residents in Mississippi are often burdened due to disparities in resources as well as in access to information to acquire such resources. For instance, the damage to homes and the proliferation of mold and mildew caused by **Hurricane Katrina** left residents of Mississippi along with New Orleans, with a poor built environment and toxic indoor air quality issues.

During our discussions, attendees shared their experiences with Hurricane Katrina and the Federal Emergency Management Agency (FEMA). They noted differences in the distribution of FEMA funds for making housing repairs to roofs and other infrastructure. White families were receiving funds from FEMA while some blacks were not. It was expressed that black families – affected by **disparities in access to information** - were not made aware of the process to collect funds from FEMA and were surprised to hear that their white neighbors were able to repair their homes quicker because of the FEMA funds they had received. The resulting effects of an unsafe, unhealthy housing stock on asthmatic children are disheartening.

As two attendees observed:

“FEMA has a problem with understanding mold.”

“It’s more and more institutionalized poverty and institutionalized missed education.”

ASTHMA DISPARITIES

Asthma in New Orleans (NOLA): The Moldy City



Not unlike Jackson, Mississippi, New Orleans is a city facing significant health challenges. In a city already plagued with high rates of asthma, Hurricane Katrina changed the landscape of the disease in New Orleans. The flooding that ensued caused tremendous increases of mold in the air.

In Louisiana, people living with asthma face a higher risk of dying from the disease than any

other state in the United States. About 200,000 adults have asthma and about 12% of families in Louisiana had asthmatic children.¹¹

According to Dr. Floyd Malveaux, 12 to 15 % of New Orleans' children suffer from asthma, a rate higher than the national average of 10%.¹²

Children under the age of five have the highest asthma-related hospitalization rates, and 5% of children with asthma reported missing school in the year of 2011 because of asthma.¹³

During our meetings with constituents in New Orleans, we learned that the landscape of asthma management and treatment for New Orleans' asthmatic children looked very similar to that of Jackson Mississippi - bleak.

Asthmatic children in NOLA face serious barriers with accessing asthma care in their two most inhabited places: homes and schools.

Poverty - The Undercurrent

"There have been real issues with the quality of transportation, but also, **the whole poverty thing**. But I think **policy is a key issue**".

The many dimensions of poverty; evident by deprivations of food, shelter, sanitation, safe drinking water, social exclusion, lack of education, unemployment and low income¹⁴ – are all working in concert to create negative health effects on children with asthma in New Orleans.

As one stakeholder noted, "in New Orleans, there's a pretty significant rate of poverty for children, about 39% in 2013. When you have that level of poverty in terms of working families and children that are impacted in these families, it's very challenging, in terms of helping moms and dads, to help manage the child's disease."

ASTHMA DISPARITIES

What we witnessed in New Orleans was similar to conditions in Jackson Mississippi.

- **Limitations in coverage from Medicaid;**
- **Disparities in access to resources and information from FEMA;**
- **Hazardous air pollutants and legacy environmental contamination and injustice;**
- **Limited access to care in schools due to shortage of school nurses and limited use of asthma action plans in schools.**

Schools: The Low Hanging Fruit

Access to quality asthma care in schools was a common refrain in our meetings with New Orleans stakeholders.

It's been expressed that schools in New Orleans Parish are considered the worst performing in one of the worst performing states.

In the aftermath of Hurricane Katrina, the Louisiana Recovery School District seized most of the city's public schools and gradually began assigning them to charter organizations.¹⁵

Over 90% of New Orleans schools have become charter schools with plans in place for any remaining public schools. Charters are publicly funded, but run by independent boards making centralized efforts to address asthma care in schools an impossible feat.

"Since they moved to the charter schools, they have one nurse for a whole system. If you have a child with an asthma episode, it can be very difficult if the nurse isn't there".

"And one of the challenging components about the charter school process, I called it, is because there are really no centralized ways of getting in-

formation out and holding folks accountable for measuring and reporting back measurements, because each one (charter) intends to be its own corporation".

Detroit, Michigan: Disparities in Pay to Physicians

"You can't do asthma in seven minutes" - Dr. Elliott Attisha MD

Imagine a city that's moderately resourced in terms of federal funding for asthma services, state level asthma programs, and a historically active, yet resurging community-academic asthma consortium which is working on an extensive



ASTHMA DISPARITIES

strategic agenda for coordinated, comprehensive community-level asthma care. Yet the city sharply mirrors lower resourced cities like New Orleans and Jackson with regards to lack of specialists within city limits, poverty, housing, transportation and distance, and legacy environmental justice issues of toxic air pollution from the industrial sector. As a result, the cities all have similar health outcomes for children with asthma.

Like New Orleans and Jackson, Detroit is a city where poverty and housing also resonated as two significant problems.

One meeting attendee expressed, “with poverty being such a huge issue, housing is definitely going to be – quality housing is definitely going to be an issue...” Despite the stark similarities between such geographically and economically diverse cities, an interesting perspective was articulated when we engaged community, medical, academic and foundation experts in Detroit.

Disparities in Reimbursements

Engagement with physicians, health educators and other actors in the system of asthma care in Detroit led to a discussion on the challenges with Medicaid reimbursements for providing supplemental asthma education, in-home interventions, and the utilization of community health workers as a sustainable part of the clinical team.

Attendees spoke of:

- Unequal distribution of funds between different counties of Michigan where communities with greater need received sub average proportion of funding distributions;
- Differences in neighborhoods where Medicaid covers reimbursement for community health workers;



- Medicaid billing codes for billable asthma education services being “turned off” and inaccessible for practitioners to use for billing Medicaid.

A Medical Perspective

In a city like Detroit, a private practitioner can see on average 40 patients a day; leaving him or her all of five to seven minutes per patient visit. This creates huge impediments for medical professionals aiming to implement National Asthma Education and Prevention Program guidelines (NAEPP) for the diagnosis and management of asthma.

Practitioners spoke of the dire need to incorporate and sustain community health workers to help provide education and follow up in the clinic, home, and school. Clinicians we’ve engaged recognize, “In an ideal scenario, you’d have a provider, who does the history intake, does the physical exam, but then you’d have a team member who would be able to do some of the education and everything else that’s involved, right? So then that provider can get through more visits and hand off certain components of that visit to that staff. It’s expensive, it requires additional staffing, and most offices can’t do that.”

Meeting the medical needs of inner city, urban or rural children of color presents many challenges outside of their physical or biological conditions.

ASTHMA DISPARITIES

Medical professionals must begin to look more closely at adverse childhood experiences (ACE) and factors such as:

- chronic stress
- household violence
- physical, sexual or emotional abuse
- emotional neglect
- household mental illness

Also, the large range of health outcomes including obesity, lung cancer, and asthma are significantly higher for those reporting ACEs.¹⁶

Northern Manhattan, New York

There's no surprise that of the four cities examined for the project, a more resourced city like New York City has a more intricate system of asthma stakeholders and is better equipped to obtain federal funding for state asthma programs. Northern Manhattan sits within a geographical location of the city where communities of color have been overwhelmed with poor air quality due to pollution from toxic facilities and mobile sources, and other health hazards that compromise the ability of community residents to live long and healthy lives.¹⁷

As we've seen with all the other low-income communities of color in our project; regardless if urban or rural, Northern Manhattan children are similarly plagued by severe health threats due to complications with asthma. Northern Manhattan shares legacy environmental justice issues similar to Jackson, New Orleans, and Detroit. Children with asthma in Northern Manhattan are also faced with issues like insufficient coverage



for asthma care and services under Medicaid, and many of the social determinants of health; however, the lack of pulmonary specialists, or of transportation were not key issues shared in New York City.

ASTHMA DISPARITIES

Cultural competency and physician training

Key challenges in regards to quality of asthma care that stood out in a diverse city like New York included language and cultural barriers between physicians and patients - similar to what we've heard in Detroit. Participants expressed a need for improved relations between physicians and patients, and a level of understanding on the part of medical providers that will improve their ability to reach and serve their populations.

"The language barriers between the providers and the participants because English is not the primary language of many of the physicians and the cultural competency of those physicians who are providing care in our community... there are a lot of doctors who don't speak English very well. So, it's very difficult to get the information right - translate it properly," said one observer.

Healthy Housing

In addition to physician training and cultural competency, the most profound issue that resonated with many of the experts and informants in New York City was the need for safe, affordable, and healthy housing.

As one key informant reflected, housing agencies and landlords are viewed as stakeholders who do not necessarily see themselves as needing to provide a healthy environment despite their major role in maintaining safe and healthy housing. This view poses a major challenge. The need for a policy action or mandate around safe and healthy housing was heavily discussed.

"Also, this other issue of housing and health. Like



I said, housing agencies don't see themselves as somebody that needs to provide a healthy environment. Being able to mandate some - ideally, we should be able to mandate all agencies, housing agencies, any housing program that receives federal money should provide a smoke-free, pest-free, mold-free environment for all of their residents, not just the ones with asthma. So that's still a valid thing, and I think that's the role of - that's how I see the role of the federal government, you know." -NY Key informant

Government Response

We convened a meeting with various stakeholders, steering committee members, and advisors from each state to engage with officials from government agencies in Washington DC to report our discussions and findings. Officials responded with the following questions:

- How can such broad Federal strategies get translated and implemented at the state level?

ASTHMA DISPARITIES

Are there suggestions on how the national strategies can be tweaked?

- How can we work on the ground to get busy providers interested in such trainings or accessing the resources available as well as the ability to implement, especially clinic-wide trainings for doctors at Federally Qualified Health Centers (FQHC)?
- How can we actually put the guidelines into action in the communities, especially low income communities?
- Not every kid needs comprehensive care or a specialist but for those who do, how do we identify them?

Federal agencies also responded with the following comments:

- It is important for Certified Health Workers (CHW) to establish certifications to help foster Medicaid reimbursement for their “case management” services.
- Need communities to come up with best practices for instance, “how was it for them to close the communication gap and get communication out through coordinated care”?
- Need to push for more landlords to initiate healthy homes practices voluntarily.
- Need a sustainable funding mechanism, HUD no longer has healthy homes grants.

There were a number of activities that the agencies were eager to highlight which gives a snapshot of the many efforts underway at the federal level to reduce disparities including:

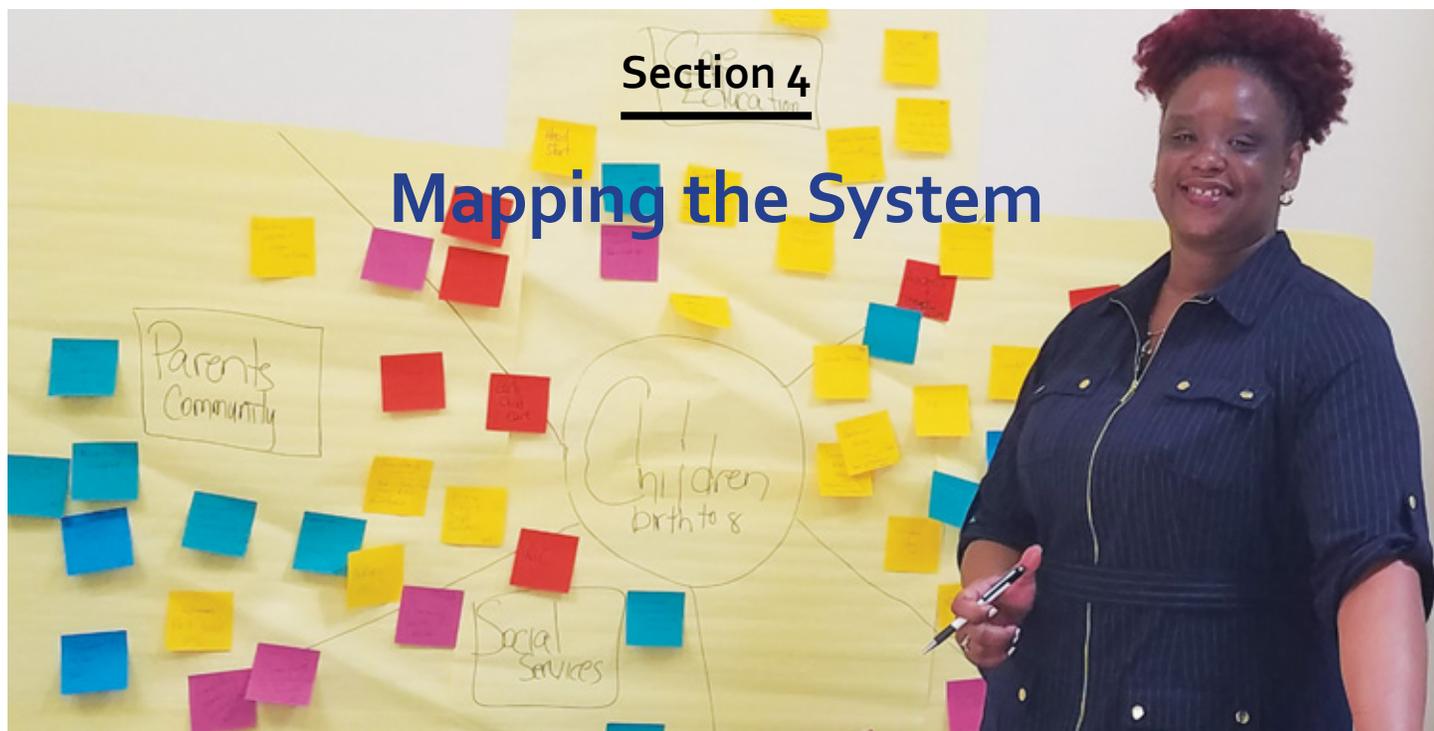
- HUD’s push for more CHW training as HUD sees as critical;

- HUD’s focus on smoke-free housing and smoking cessation;
- NHLBI talks of their new focus on “implementation” research;
- NHLBI offering funding to support community-driven needs assessments (4 in the U.S.)
- CMS having done some cost-benefit analyses and innovation awards (some specific to asthma) helping people engage with payers;
- HUD’s Green and Healthy Homes initiatives;
- EPA- sponsored summits that promote home interventions (9 so far),
- Hosting Asthma Summits, “Summits bring ‘payers and state Medicaid to the table;”
- EPA’s unsuccessful push to work with Healthy Head Start programs.

Conclusion

As we see by taking a deeper look into the nuances associated with providing quality care to poor and marginalized children with asthma, the same recurring overall themes emerge - all of which speaks specifically to the social, environmental, and political determinants of health more so than medical determinants such as poverty, housing with unhealthy indoor environments, medical providers who don’t understand patients’ social and emotional needs, payment systems that limits access to funds. Although government agencies have successfully implemented individual actions to address asthma, these social determinants of health must become a broader national focus within all agencies and levels of government, as well as other actors who work in the system of care for children in their early developmental stages.

ASTHMA DISPARITIES



The care and education of children with asthma or at risk of asthma takes place in many different settings with different practitioner traditions, practices and cultures. It is funded through multiple government and nongovernment sources, and operates under the management or regulatory oversight of diverse agencies with varying policies, incentives, and constraints.

"So it takes innovation, it takes creative thinking, it takes multiple partners coming to the table, and if you do all of that, I think great things can happen."

- Dr. Elliott Attisha MD

During year two, project steering committee members organized and convened a second meeting in each city to engage attendees in a facilitated systems-mapping workshop. We chose 'actor-mapping' as the particular type of systems map since our goal was to offer a visual depiction of the key organizations and/or in-

dividuals that make up and/or influence various pieces of siloed asthma systems, and to discuss the opportunities to foster relationships amongst key players.

Actor maps help to:

- Better understand current actors and their roles in the system;
- Diagnose the level of engagement and strength of connections among actors;
- Identify opportunities to **build new relationships** and explore other parts of the system;
- Identify potential points of **intervention and levers of change**;
- **Identify and discuss ideas** and questions that the map raises for both strategy and evaluation purposes (e.g., developing a strategy, focusing an evaluation's questions and design).

ASTHMA DISPARITIES

Why Systems Maps?

System mapping is a process often cited in social change literature as an effective way to infuse systems thinking into strategy development and evaluation efforts.¹⁸ We realize that a large-scale problem such as asthma disparities among children aged 0-8 cannot be solved by any individual or single entity, no matter how powerful.

We believe that the keys to successful reduction in asthma disparities lies in optimizing the activities, relationships, and interactions among the various components of the system,¹⁹ because how well we do at addressing this need, depends on how well each of the components are working.

Collaborative Opportunities

When developing the framework for identifying actors, we focused on five sectors¹⁸:

- Care and Education
- Health
- Social Services
- Parents & Community
- Other

The results of each of our mapping sessions yielded examples of a number of collaborative opportunities between somewhat related and non-related entities.

Workshop participants brainstormed, discussed, and mapped entities under each sector whose goods and services potentially impact asthma disparities among children.

For instance, under *Care and Education* in addition to typical institutions

like schools and daycare centers, we identified academia, early childhood networks and even building-level committees, planners and developers as potential partners for building programs and strategies to address asthma.

We were able to see how some professionals like community health workers sit on the cusps of health, education, and social services and therefore provide a golden opportunity to leverage relationships, and coordinate services, while also providing the important components of care that children and families need.

Lastly, we saw how actors in the Other category, like policy advocates, banks, foundations, industrial facilities, and energy efficiency companies also impact childhood asthma.

Ultimately, if communities are to reduce the disproportionate burden of health outcomes from asthma faced by children of color and low income, stakeholders must build intersectoral connections between actors who are often decentralized, and uncoordinated.



ASTHMA DISPARITIES

Section 5

Recommendations

The following recommendations were drawn from the many stakeholder meetings, mapping sessions and key informant interviews held under this initiative. Using the Federal Action plan as a framework, each recommendation is organized in response to the strategies and action steps outlined in the Federal Action plan. Our hope is to provide another lens by which federal agencies can approach asthma and other health care disparities within poor-resourced communities for the benefit of children of color and low income aged 0-8 years old.

Federal Strategy One - Reduce barriers to the implementation of guidelines-based asthma management.

Federal priority 1.1 - Explore strategies to expand access to asthma care services.

Community / Local Stakeholder Recommendations

- Identify and establish sustainable funding mechanisms to support programs and collaborations that meet the need of areas with high asthma disparities. For instance, community health workers can be used to take a preventative rather than reactionary role in asthma care, management, and education.
- Use Medicaid to finance the provision of transportation access for residents seeking care for their asthma – especially in rural locations where distance is a challenge.
- Prioritize Medicaid funding for asthma out-

reach programs in communities and schools, such as mobile clinic asthma programs to visit schools and communities.

- Expanding access to care could occur simply with the activation of already-existing Medicaid codes for asthma services and education that clinicians are not allowed to use.

Federal priority 1.2 - In health care settings, coordinate existing federal programs in underserved communities to improve the quality of asthma care.

Community / Local Stakeholder Recommendations

- HHS should mandate physicians, particularly those funded through Medicaid, and those serving Federally Qualified Health Centers (FQHCs), to know and follow NAEPP guidelines.
- CMS should provide sustainable funding through Medicaid for health educators in clinics to take parents and children through asthma action plans and provide general asthma education and support for self-management.
- Mandatory cultural competency and language trainings for clinicians and staff at FQHCs who receive federal funds. This is especially important for physicians who do not speak the language or understand the culture of the community they serve. This can be done through clinic-specific grand rounds, refreshers, and engagement opportunities using community

ASTHMA DISPARITIES

groups and organizations familiar with the population.

Federal priority 1.3 - Reduce environmental exposures in homes.

Community / Stakeholder Recommendations

- Poverty and poor housing conditions are social determinants of health that need to be addressed as a major priority in all federal asthma disparities work.
- Expand the mandate on housing developments, landlords, and any housing program that receives federal money to provide a smoke-free, pest-free, mold-free environment, especially for children with asthma or at risk of getting asthma.
- Stabilize CMS, NIH, HUD and other federal funding sources for home-based interventions in dealing with asthma triggers, like remediation services, and integrated pest management (IPM).

Federal priority 1.4 - In schools and child care settings, implement asthma care services and reduce environmental exposures, using existing federal programs in collaboration with private sector partners.

Community/ Local Stakeholder Recommendations

- Department of Education (DOE) must address disparities in resources within the educational system, which translates into some schools lacking nurses or lacking resources to implement best practices on asthma management within schools.
- Community and school-based asthma educa-

tion and prevention programs like those run by the American Lung Association are seen as very effective and should be expanded and partnered with federal agencies, who must be more proactive with engaging CBOs.

- DOE must require charter schools (which act as independent entities and don't fall under a unified system, and makes broad implementation of effective asthma interventions in schools challenging) to report educational metrics and the ancillary metrics surrounding child health; making it much easier to track effective asthma treatment.

Federal strategy two - Enhance capacity to deliver integrated, comprehensive asthma care to children in communities with racial and ethnic asthma disparities.

Federal priority 2.1 – Promote cross-sector partnerships among federally supported, community-based programs targeting children who experience a high burden of asthma.

Community / Local Stakeholder Recommendations

- Federal grant funding opportunities must require, not just promote, cross-sector and cross-agency collaboratives and coalition-based approaches specific to asthma disparities in communities of color and low income.
- Federal agencies, through their national and regional offices, must make improvements in capacity specific to collaboration, such as a lack of staffing dedicated to collaboration work, more effective follow-up from meetings, conferences and asthma summits, and greater collaboration with certain city agencies and CBOs, particularly the ones that deal with housing.

ASTHMA DISPARITIES

Federal priority 2.2 - In communities that experience a high burden of asthma, protect children from health risks caused by short- and long-term exposure to air pollutants.

Community / Local Stakeholder Recommendations

- Federal agencies must address asthma disparities, paying particular attention to those front line communities that are located adjacent to toxic polluting facilities, especially those highly concentrated in cities like Detroit, and New Orleans, and focus on their role in reducing the concentration of outdoor air pollution because it creates poor and unsafe environmental conditions for low-income populations, and it contributes to asthma disparities.
- Mapping of local air quality hazards - such as highways, bus depots, refineries and chemical plants in relation to communities and schools – must be conducted.

- Spatial information on air pollution as well as asthma prevalence is recognized as a foundational requirement for addressing asthma in all communities. However, efforts must be made in states like Mississippi where historically, there is little publicly available data on air pollution and its relation to asthma.

Federal priority 2.3 - Conduct research designed to evaluate models of partnerships that empower communities to identify and target disparate populations and provide comprehensive, integrated care at the community level.

Community / Local Stakeholder Recommendations

- Federal health and research efforts must leverage opportunities to support research capacity, community-academic partnerships, technical support and funding to support community-based organizations that are well poised to help with local research projects but are often



ASTHMA DISPARITIES

unfamiliar with and unengaged around the required rigors of federally-funded research requirements.

- Federal agencies must reinstate the Community-University Research Partnership grants program that helps to catalyze community-academic partnerships to foster community-level research
- Increase funding for integrated projects like asthma with diabetes, asthma with tobacco control, and asthma with lead prevention and education.
- Focus efforts towards cost-benefit analysis as opposed to continuing to evaluate models when many evidence-based models already exist.

Federal priority 2.4 - Examine the relative contribution and cost-effectiveness of different components of a system-wide partnership program.

- Many stakeholders expressed the notion that a cost-benefit analysis of different components of a system-wide partnership would be a redundant or unnecessary issue to focus on.
- Money spent on evaluating the cost-effectiveness of asthma interventions could be better spent on implementing the actual interventions.

Federal strategy three - Improve capacity to identify the children most impacted by asthma disparities.

Federal priority 3.1 - Investigate the added value of emerging technologies to enhance identification of target populations and risk factors.

Community/ Local Stakeholder Recommendations

- HHS and other federal, state, and local agencies should expand new testing technologies like nitric oxide, rather than spirometry - the gold standard for asthma testing. Not everyone is able to do this test and it is challenging for patients to self-test, while nitric oxide testing is much easier.
- Federal agencies should proactively disseminate information and education on asthma using cell phone alerts and other mobile technology resources.

Federal priority 3.2 - Standardize definitions, measures, outcomes and data/information collection methods, and maximize availability and use of collected data across federal asthma programs.

Community /Stakeholder Recommendations

- Asthma stakeholders must do more to track emergency department (ED) asthma admissions as a key indicator, noting that if a patient is visiting the ED, they most likely have poorly managed asthma or are not in compliance with their medication regimen.
- Monitoring prescription drug refills is also recommended to track whether patients are using their medication properly.
- Monitoring state and federal policies around asthma management, as well as asthma exposures by communities, is imperative.
- A recommended metric was asthma-related mortality. Although the numbers tend to be very small, it is one of the clearest and most "drastic" indicators of existing disparities, since asthma mortality is completely preventable.

ASTHMA DISPARITIES

Federal priority 3.3 - Promote the use of standard definitions, measures, outcomes and information/data collection methods in state, local and community settings.

Community Recommendations

- Publicly viewable state registries are being recommended that aggregate information from hospital admissions and electronic medical records around key asthma metrics.
- FQHC center-specific trainings for clinicians and staff can facilitate efforts towards standardizing language, definitions, measures, practices and guidelines on management and treatment of asthma. This can happen in all health centers receiving federal funding.

Federal strategy four - Accelerate efforts to identify and test interventions that may prevent the onset of asthma among ethnic and racial minority children.

Federal priority 4.1 - Reduce exposure to maternal smoking and environmental tobacco smoke (ETS; also known as secondhand smoke) among pregnant women and infants.

Community / Local Stakeholder Recommendations

- Programs like the “Tar Wars” for reducing parental smoking is an excellent model that federal agencies can learn from and / or partner with for help with creating smoke free environments. This is being suggested as a model for school-based asthma toolkits.
- Smoking cessation programs must be offered as part of all prenatal visits and implemented across all practices.

Federal priority 4.2 - Establish priorities and

collaborations for research across federal agencies to test interventions that may prevent the onset of asthma and reduce disparities in the incidence of asthma.

Community /Local Stakeholder Recommendations

- While federal agencies must work increasingly harder at cross collaborating with one another; increased collaborations across silos and within communities is the only true way to address and reverse the effects of disparities in asthma among children of color and low income.
- Federal agencies must turn their attention from testing interventions to implementing the interventions we already know are effective in vulnerable populations.

Federal priority 4.3 - Coordinate asthma research programs across federal agencies that support observational follow up of birth cohorts.

Community / Stakeholder Recommendations

- Opportunities for federal agencies to partner with state and academic institutions will allow access to students and researchers to further longitudinally test innovative interventions that may prevent the onset of asthma and reduce disparities.
- Federal health and research efforts must leverage opportunities to build research capacity, technical support and funding to support community based organizations, which are well poised to help conduct aspects of local research projects but are often unfamiliar and unengaged on the required rigors of research requirements for federal funding.

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ASTHMA DISPARITIES

Appendix

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Stakeholders Meet and Rally For Change



NYC Coalition Rallies For Asthma-Free Homes Bill



Jesus People Against Pollution, Jackson, MS



Green Door Initiative, Detroit



Deep South Center For EJ, New Orleans



Stakeholder Meeting in DC With Federal Task Force Members From EPA, HUD and NHLBI



WEACT and NYC Community Members Mobilize For Asthma-Free Housing at City Hall



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